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Cristiano Storni, Keelin Leahy, Muireann McMahon, Peter Lloyd y Erik Bohemia.

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Edited by:
Cristiano Storni
Keelin Leahy
Muireann McMahon
Peter Lloyd
Erik Bohemia

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Proceedings of DRS 2018

Catalyst

Volume 6

Editors
Cristiano Storni, Keelin Leahy, Muireann McMahon
Peter Lloyd and Erik Bohemia

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DRS 2018 Design Research
Society 2018
Catalyst

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25th – 28th June 2018

Editorial

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DRS2018, hosted by the University of Limerick and the Limerick Institute of Technology is the first international biennial conference of the Design Research Society since the 50th anniversary conference in Brighton. This represented both a challenge and an opportunity; a challenge to meet the high standards set in 2016, but an opportunity to contribute to a growing design research field. The balance between these has translated into the conference theme of *Catalyst*. A catalyst is something that precipitates events; it is the coming together of different entities to generate something new; it is the spark for wider change. Framed by the Catalyst theme, these proceedings explore existing and emergent areas at the intersections of design research, practice, education and policy.

The conference itself built further on innovations from the past two conferences; developing more interactive conversation and debate formats, and providing a forum for practice-based research through the increasingly popular workshops. A *PhD by Design* day, first initiated at DRS2016, provided a platform for PhD researchers to learn new skills, present their work, and network with other researchers. The design of the conference, however, was largely formed around the managed theme tracks which included themes relating to the Special Interest Groups of the DRS. In some cases theme tracks emerged from conversations held at previous conferences, representing a pleasing continuity.

From the initial calls for participation there was a great deal of interest in the conference. Once again we had a truly international range of work presented and published in these proceedings. The original call for theme tracks yielded 46 proposals from which 24 were selected. These formed the backbone of the conference and of these proceedings. The theme tracks represent an increasing engagement with new technologies and data but also reflect contemporary social and political concerns, and the need for different types of design research voices to be heard. In particular, the programme committee were committed to bringing diverse global perspectives into play during the conference.

Following the call for theme tracks, the call for papers resulted in 470 submissions of which, after a rigorous peer-reviewing process, 218 (46%) were finally accepted for presentation and publication. This is a slightly decrease in the acceptance rate from the previous conference indicating a corresponding increase in the quality of the proceedings papers. Although some papers were submitted to an open call, the majority of papers were submitted to theme tracks, with each track being managed through the peer-review process by a track chair and all peer-review overseen by the Programme Committee. In total nearly 1000 paper reviews were written by 330 reviewers. The opportunity for authors to rate and comment on the reviews they received has further helped drive up the quality of peer review for future conferences.

DRS2018 reflects the coming together of many different perspectives and themes. As with previous conferences its design has been emergent, developing over the two years prior to the conference. It has been the result of many discussions and collaborations both within the Limerick team and the DRS more generally. The conference, and the proceedings that have resulted, are an extensive collaboration between many people but we would especially like to thank the local organising committee comprising members from the University of Limerick (UL), The Limerick School of Art and Design (LSAD) at the Limerick Institute of Technology, as well as members of other Irish academic institutions all of whom contributed valuable insight and experience. We'd also like to thank the track chairs who worked tirelessly and diligently to organise their tracks, and the reviewers who have ensured the high quality of the papers within those tracks.

Lastly but not least, we need to acknowledge the system that helped shape the way we worked together and made our decisions: the ConfTool conference management system. For the uninitiated ConfTool represents an awkward and mysterious interface. For the initiated it represents an indispensable way to manage the complexity of every stage of the conference process. In a way that echoes the conference theme, ConfTool has been a catalyst for our collective effort in bringing DRS2018 together.

In this sense *Design as a Catalys*t becomes a *thing*; a thing in the Heideggerian sense of a gathering of different entities coming together to deliberate on shared issues and reaffirming the role of DRS as a leading forum for discussing design research from multiple angles. But also a *thing* in the sense of something that escapes a specific definition, reflecting the impossibility and perhaps undesirability of a specific definition of what design research is, and should be.

With this sentiment in mind, we sincerely hope that these proceedings catalyse positive change and that the changes propagate to DRS2020 and beyond.

Go raibh maith agaibh,

Cristiano Storni, Department of Computer Science & Information Systems
Keelin Leahy, School of Education
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Peter Lloyd, Vice Chair of the Design Research Society
Erik Bohemia, Events Secretary for the Design Research Society

Volume 6

Section 20.

Design for Tangible, Embedded and Networked Technologies

DRS 2018 Design Research Society 2018 **Catalyst**

University of Limerick
25th–28th June 2018

Editorial: Design for Tangible, Embedded and Networked Technologies Special Interest Group (tentSIG)

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tentSIG is interested in the design of networked and embedded technologies, and the human dimensions of experience as a result of living with them. This second DRS conference tentSIG track brings together papers that explore cultural practices and daily lives, catalysed, disrupted and managed through tangible, embedded, and networked technologies.

With research interests in intuitive interaction, sensory anthropology and design methodologies, this year's track chairs take the position that technology is not neutral, and that design efforts embed implicit values and attitudes to human agency, identity and power relations. We welcome the papers here in their acknowledgement that material, sensorial, and participatory design research practices have the cultural potential to influence the behaviours and practices of individuals and their communities in diverse ways, beyond instrumental goals.

Join us on the tentSIG LinkedIn group https://www.linkedin.com/groups/13537899

Managing daily life

Both papers in this section address networked and tangible technologies that have the ability to expand the human dimensions of daily experience through informing and empowering people. Kim, Cho and Jun focus on the positive opportunities offered by addressable LEDs as a mode of data visualisation. Six parameters of lighting are used to conduct a series of experiments. These are: intensity (the level of illuminance), colour (consisting of colour temperature and hue as stimulation in the retina by spectrum of light), area (illumination area by lighting), movement (automated changes of lighting), texture (the degree to which light scatters) and distribution (the direction of emitted light). They studied how individuals responded to a collection of objects designed for their experiments. Results suggest that creative approaches to working with light output as a material, and as a glanceable information channel in situations when abstraction and lower levels of legibility of information, is acceptable.

Guzin, Bahar and Jump take a similarly positive view of the potential of in-car infotainment systems to 'empower' the front-seat passenger through technologies for pragmatic (informative) and hedonic (entertaining) ends. What, how and why goals are used to structure an analysis of the extant literature of passenger experience, relating to tasks to achieve concrete goals ('do-goals'), operational steps, and emotion and meaning ('be-goals'). Infotainment systems for front-seat passengers are found to be a future scenario, not yet included in production cars. Input modalities being explored in concept cars include touch recognition, gesture recognition, eye-gaze recognition and audio recognition; an doutput modalities include curved OLEDs, flexible OLEDs, 3D panel LED projection, head up displays, shape changing and haptic displays, and audio feedback. Touch sensitive control surfaces are found to be spreading across new zones of the car interior in addition to the central console and dashboard, while the physical is becoming co-located with the digital in output displays. As a result, empowerment is discussed in terms of relatedness, autonomy, security and stimulation, which in turn conceptualises the passenger as active rather than passive; ‘passengering’ is suggested as a complement to ‘driving’.

As daily life becomes more nuanced due to increasingly sensitive technologies, so too do cultural awareness and design practices become more informed due to increasingly complex relationships between technology and user comprehension in the section below.

Catalysing cultural and design practices

Tangibility and the sensory dimension emerge here as entangled catalysts in the design process, which is challenged by the often dispersed, sometimes concealed, and undefinable contemporary technological artefact. The three papers in this section share a pragmatic concern with how such systems can be made humanly sensible, whether in use or in user informed development processes.

Hong goes beyond speculative design propositions in which tangible aspects of technology are presented as potential solutions for the maintenance of long distance human relationships. This work reclaims the separation of individuals as worthy of a pragmatic user centred design approach and treats participant designers as experts in their own experiences. Through engaging creative participatory methods, end users identify important criteria for technologies which may help support their human-human relationships over geographical distance. Importantly, technology in this case does not have to be digital – accessories, perfume and photos were able to function as representations of remote presence through personal customisation, and customisation is presented as a central concern for future technology development in the context of long distance relationships.

Manohar and Briggs discuss making the dispersed, and therefore intangible dimension of blockchain transactions materially available to multidisciplinary and participatory design teams. The political nature of tangibility is revealed as increased user comprehension highlights tokenistic policy efforts in data privacy and protection. By making blockchain transactions comprehensible in use, negative cultural practices (‘fraping’) are discouraged or thwarted; by making them more tangible during the design process, diverse stakeholders and end users can build mental models of the platform in order to catalyse critique and co-design desired interactions. In this view, tangibility supports comprehension and is contrasted with the hidden workings of ‘black box’ technologies, and human agency is deliberately built in to digital products and services.

Lee, Cooper and Hands discuss the design challenges for industry, outlining a network ontology, which demands novel approaches to new product development (NPD) and new service development (NSD). As digital objects are added to the field of existing products, a platform is created upon which there are exponentially increasing possibilities for user experience; an ‘array’ of service and innovation opportunities. Representations of data become entangled with physical artefacts rather than coupled in a one-to-one relationship, and new services and content can be generated after the creation of a technology as platform. The IoT is shown to be ontologically ambivalent, without discrete boundaries and features. This ‘geometric expansion’ of the design space cuts across and exceeds boundaries as functions are not only decoupled from, but exist outside the physical device and its form. In the face of this new environment, of potentially endless combinations of hardware, software and connection, sequential models of development are bound to fail, and the authors suggest a new model that combines iterative, concurrent and incremental change to address the challenge.

While the papers in this section address implications for designing with and for users, based on their practices with and knowledge about the technological artefacts, the next section moves beyond the human-centred paradigm altogether.

Disrupting the human-centred expectations of design

Liu and Pschetz question the normative anthropocentrism of design and technology. Is there anything more disruptive than new forms of life? This paper throws us back upon ourselves, revealing ‘disruption’ itself to be an anthropocentric concern. Autonomy in this view is the preserve not only of humans but of machine learning and artificially intelligent technologies, as part of an equal ecology. In such a horizontal ecology, humans may become more or less tangible to machines, as well as the other way around. By extension, design may or may not be undertaken by humans, as algorithms become capable of designing themselves.

These tentSIG papers span a broad range of perspectives about the human and non-human experiences that the future of tangible, embedded and networked technologies promise. They suggest that human agency may be gently augmented or even overlooked, and confirm that technology is, indeed, not neutral. TentSIG’s concerns with experience, power relations, comprehension, tangibility, critique and appreciation are all challenged by this orientation to technology, even to the extent that robots may have poetic sensibilities, playing out their time in solitary existential wanderings on a beach (Liu and Pschetz, these proceedings). The unthinkable happens as power relations are taken out of our hands and we are simply ignored.

DRS 2018 Design Research Society 2018 **Catalyst**

University of Limerick
25th – 28th June 2018

Exploring the Interaction Between Lighting Variables and Information Transfer as a New Function of Lighting

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Together with the improvement of artificial light sources such as LED, lighting has been utilized in our everyday products for various purposes such as visual aesthetic enhancement, and emotion induction. Nevertheless, little attention has been paid to another function of transferring information with lighting. Therefore, this study attempted to explore how information transfer would be effectively made with manipulating lighting variables. An experiment was designed in which the interaction between lighting variables and information transfer was investigated depending on type of information in human-product interaction Three products were adopted to represent each type of information and used in the design of experiment stimuli. 30 participants were recruited for the experiment. The results indicate that information transfer can be effectively made with manipulating lighting variables. This implies that lighting is a useful way to intuitively and fast deliver information to people. The findings could help designers better understand the roles of lighting variables in information transfer.

lighting; information transfer; lighting variables; type of information

1 Introduction

Vision is the most dependent sense for human's everyday life among human sensors because more than 50% of the brain is related to vision directly or indirectly (Elizabeth, 1996). Before handling artificial light expertly, most of human's daily life had followed the cycle of the sun that is the biggest supplier of light on Earth. They had started to use fire as an illuminator in the dark such as night, which is the origin of the artificial light and such use of light in human life is defined as lighting (Cho, Yang, & Seo, 2010). In early lighting candles and lamps had been mainly used for the purpose to brighten the space. Unfortunately, they utilizing the fire as the source of lighting had difficulties in emitting stable and regular light. Thanks to the bulb that Thomason Edison invented in 1879, our daily activities were able to be expanded to night without many constraints (Brox, 2010). Sources of artificial lighting have been developed continuously until today. These days, LED (Light Emitting

Diode) lighting is receiving much attention, because it is more efficient, digitally controllable, and much smaller than earlier types of light source (Hoonhout, Jumpertz, & Mason, 2011).

Thanks to the advent of LED, lighting does not only function to illuminate, but also to transfer information, enhance visual aesthetics, and induce emotions in human-product interaction (Figure 1) (Jun et al., 2014; Jun, 2015). For example, landscape lighting has been used to decorate the outdoor and to create better sceneries. Traffic signals have used lighting to deliver information at night. The LED indicator of battery charge can show how much the battery is charged with the color of the indicator.

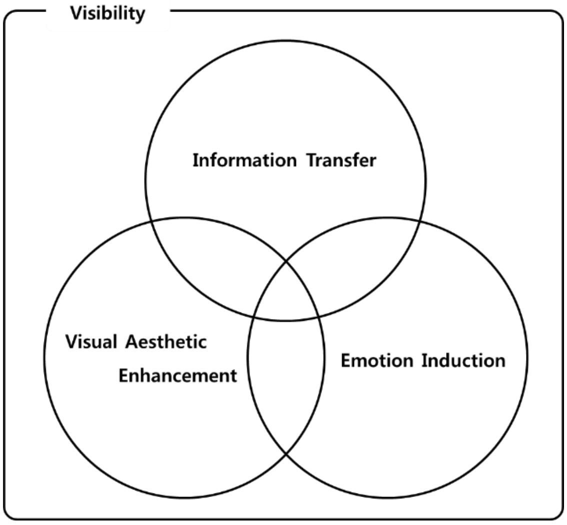


Figure 1 The visibility and three sub-functions of lighting in the human-lighting interaction

The visualization of information is a useful way to deliver information to people, and lighting also can be used to visualize information. The method for processing information in the eye is much more easy and effective than other senses (Smiciklas, 2012). With extending the method of delivering visual information such as paper, video, and computer screen, human has been able to extend the depth of our knowledge and experience (Tufte & Weise Moeller, 1997). The traffic signal is a typical product that uses visualized information using lighting. Especially, visualized information using lighting has increased better effectiveness in the dark night. After developing small light of LED, indicators in electronic appliance have started to use lighting in product. The representative product is the classic IBM system in 1964 (Schubert et al., 2005). Transmission of visual information by lighting is more effective immediately with understanding the information (Jun & Kim, 2014; Jun, 2015). The method of information transfer using lighting is expected to increase with the expansion of electronic goods and the development of LED lighting. Moreover, LED lighting can be easily controlled according to situations because of the function of LED digital control. Therefore, the lighting would be able to deliver a variety of information by utilizing the function to control lighting factors. With LED lighting the interaction between human and product in information transfer can be richer than the traditional ways of information transfer. Nevertheless, most studies have focused on the development of artificial light source only or the enhancement of aesthetics and emotion. Also, only a few factors such as turning on or off lighting and color change have been mostly used in present products with LED. Therefore, the study aimed to understand the interaction between lighting variables and information transfer, and then explore what possibilities could exist in information transfer with LED lighting. With a better understanding of the interaction, it can help designers increase utilization of lighting in product, improve usability of product, and furthermore create new interactive products with lighting in terms of information transfer.

In order to the research goal, research questions were formulated as listed below:

- Is it possible to deliver richer information by controlling variables of lighting?
- Which variables of lighting would play a role in transferring information?
- What experience do people have about lighting-based information in human-product interaction?

1.1 Lighting variables in human-product interaction

The parameters of lighting that affect vision have been diversified. Lighting has played a key role in theatre to create touching scenes in drama. Initially, four parameters of lighting were considered in theater lighting: distribution, intensity, movement, and color (Gillette, 2012). Recently, Essig and Setlow (2012) have identified seven parameters of lighting: intensity, color, direction, distribution, texture, shape, and movement. As lighting technologies are advanced, especially interactive design study related to lighting also has described seven parameters: the number of lighting, intensity, amount of light, type of light, color, reaction scheme, and light changes (Chang, 2010). Whereas architecture and interior design focus more on the arrangement or position of lighting than the other basic parameters of lighting. These studies of theatre and interaction have showed that many parameters of lighting are adjustable and these parameters would transfer diverse visual perception to human. Beritin’s research has represented the original visual variables and has described seven visual variables that these units were modified: value (change from light to dark), color size (change in length, area and repetition), texture (variation in grain), shape (infinite number of shapes), position (change in the location) and orientation (changes in alignment) (Bertin, 1983). Because the meanings of lighting parameters look similar or overlapping among studies, redefined lighting parameters were necessary for the study, through which exisitng lighting parameters can be overall and clearly represented. Based on the literature review, seven parameters of lighting could be redefined: intensity (the level of illuminance), color (consisting of color temperature and hue as stimulation in the retina by spectrum of light), area (illumination area by lighting), movement (automated changes of lighting), texture (the degree to which light scatters) and distribution (the direction of emitted light) (Figure 2) (Jun et al., 2014, Jun, 2015).

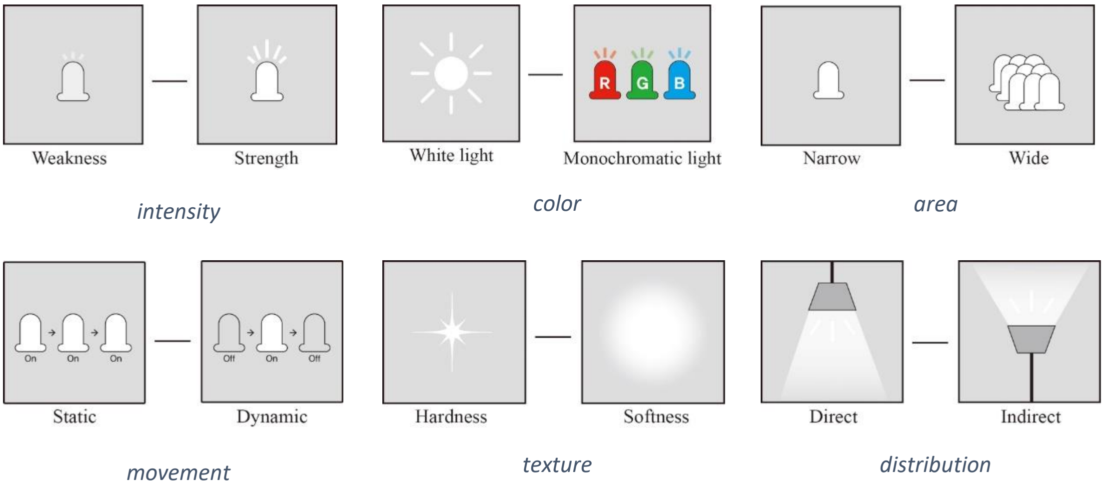


Figure 2 Six lighting variables

1.2 Type of information in human-product interaction

Because there are many types of classification of information, the classification of data and information is a big issue (Ware, 2013). Information can be categorized according to the subject such as physical information, biological information, economic information, and so on. Although the terminology has not been standardized or fixed yet, information consists of different types of data: primary data, secondary data, metadata, operational data, and derivative data (Floridi, 2010). One experiment was conducted to figure out structured framework for understanding the type of information that people need (Dearman, Kellar, & Truong, 2008). This study has been assorted the information as nine categories: person, establishment & organization, offering, event, environmental condition, trivia & pop culture, finding, availability, and guidance. In human-product interaction there are three important elements: person, product and environment (Rooden, 2001; Van Kuijk, 2010). Therefore, according to the concept of human-product interaction study with three components, information is classified as three categories: personal information, product information, and environmental information (Figure 3). Personal information includes information that is inherent to the person such as name, birthday, phone number, height, blood sugar, and so on. Product information refers to what is notified about the state of the product. It includes state of operation, size, price, battery storage, time, and so on. Environmental information includes weather, geography, traffic and so on. Environment information is closely related to human life. Human can get environmental information directly by human senses, and this information is delivered through some products such as phone, television, and so on as well.

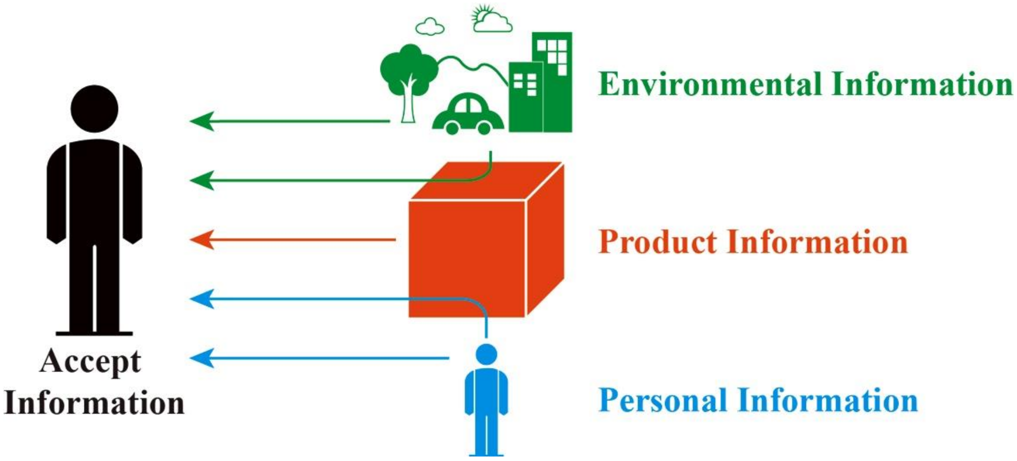


Figure 3 Three types of information in human-product interaction

2 Methodology

2.1 Experiment Design

2.1.1 Determining the level of lighting variables

Previously, six lighting variables were identified: intensity, color, area, movement, texture, and distribution. The level of each parameter was also determined according to three scales: weak, moderate, and strong. Exceptionally, there were four levels for color: red, green, and blue as three primary colors and white color that are typical for LED. And there were also two types of distribution: direct and indirect (Table 1).

Table 1 Control levels of each lighting variable

Variables	Control Level			
	1	2	3	4
Intensity	Moderate	Strong	Weak	-
Color	White	Red	Green	Blue
Area	Moderate	Wide	Narrow	-
Movement	Non-blink	Rapid Blink	Slow Blink	-
Texture	Moderate	Strong	Weak	-
Distribution	Direct	Indirect	-	-

2.1.2 The Development of Use Scenarios

Three experimental stimuli representing each information type were determined: blood pressure gauge, external memory disk, and ozone concentration indicator. Each product had three use scenarios related to their information. The blood pressure gauge could indicate how high or low the blood pressure of the user is with lighting. The lighting for external memory disk could be used to indicate how much space of storage is remained. The ozone concentration indicator could display the levels of ozone in the air. The scenarios of each experimental stimulus are shown in detail in Table 2.

Table 2 Use scenarios of each experimental stimulus

Experimental stimulus	Use scenario
Blood pressure gauge	High blood pressure
	Normal blood pressure
	Low blood pressure
External hard disk	The storage space is full
	The half of storage space is filled
	The storage space is almost empty
Ozone concentration indicator	Too high ozone concentration (Inappropriate for everyone to go out)
	High ozone concentrations (Inappropriate for the old and weak to go out)
	Normal ozone condition (Appropriate for outdoor activity)

2.2 Participants

Participants were recruited through an off-line advertisement. 30 participants were recruited for this experiment and they were all paid for the participation. 15 people were males and 15 were females. The age of participants ranged from 19 to 25 years old and the average was 20.7 years old. They were all university students at the time of the experiment.

2.3 Apparatus

2.3.1 Experimental stimuli

Some consumer electronic products such as battery charger and wireless router have already popularly used LED lighting to transfer information of the product. Because prior experiences could influence the experiment, it was necessary to find new products that have not used lighting as a means of information transfer before. The type of information could be divided into three categories depending on the source of information: user information, product information, and environmental information. Each experimental stimulus should provide each type of information respectively, and at the same time, no LED lighting has not been used for the stimuli to transfer information the product. Based on those criteria, three experimental stimuli were selected and developed. The stimulus providing user information was a blood pressure gauge. This information has been delivered with numbers indicating the blood pressure of the user. The stimulus representing product information was an external memory disk. The storage information of the memory disk has been also provided with numbers. The weather is one of the most definite environmental information. Ozone concentration indicator was selected as the stimuli representing environmental information, such information provided with numbers usually.

Experimental stimuli were developed in a way to control each variable of lighting with products in the experiment. Before the appearance design of the stimuli, coding was conducted in advance. Arduino was used to program the controller and Adafruit’s LED was used for lighting. Parts of the prototypes with Arduino and the LED are as shown in Figure 4.

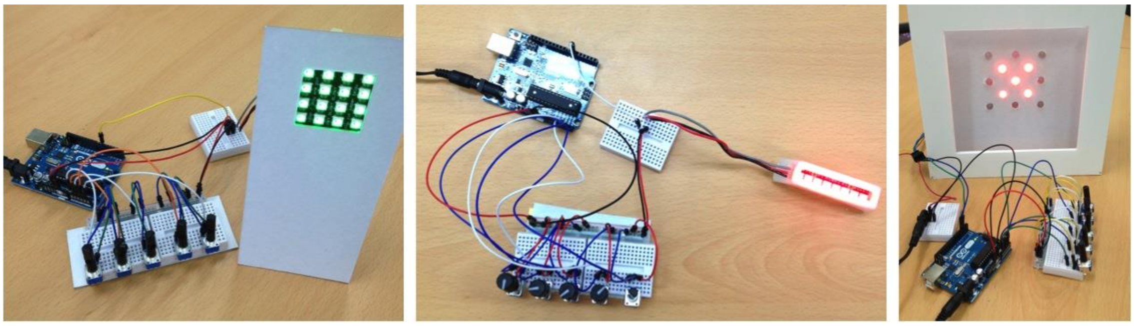


Figure 4 Control parts of the stimuli with Arduino and LED: external hard disk (left), blood pressure gauge (middle), and ozone concentration indicator (right)

After making control parts of the experimental stimuli, the appearance design was made in Solid works and they were manufactured through 3D printing technology. The appearance of all the stimuli was designed with simple rectangular shapes in order to avoid possible bias done by form and help participants concentrate on the manipulation of the lighting. For instance, a fancy form might affect the behavior of participants and influence the results of the experiment and it might also distract participants in the experiment. The same appearance design was applied to the design of control box equipped with Arduino inside and four potentiometers (Figure 5).

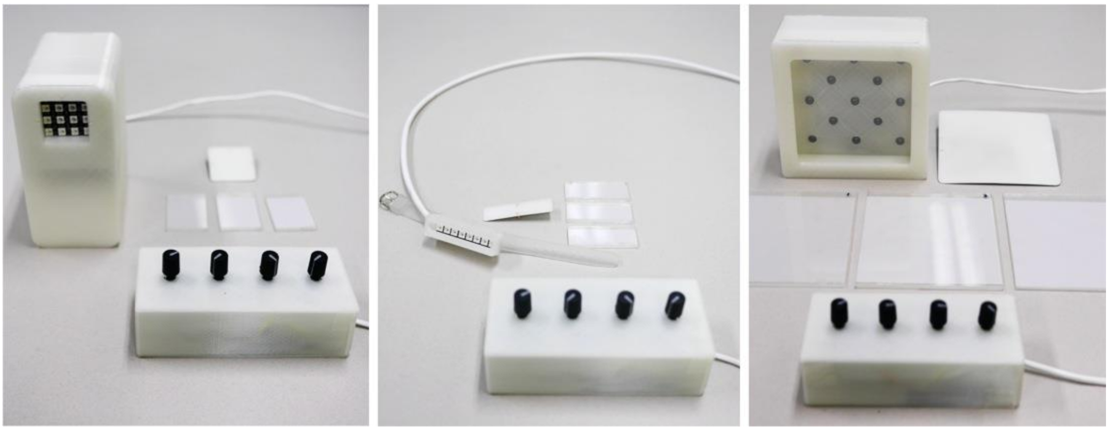


Figure 5 The complete experimental stimuli: external hard disk (left), blood pressure gauge (middle), and ozone concentration indicator (right)

All control boxes have four tuning switches to adjust level of four lighting variables, intensity, color, area, and movement. These control knobs could adjust its level of intensity, color, area and movement depending on the degree of turn (see the example of intensity in Figure 6). For texture, three films having different thickness were used for controlling texture of lighting (Figure 7): the thicker film was used, the light was scattered more. A cover was used to control distribution (Figure 7). When the light source is covered, this condition refers to indirect lighting. On the other hand, the cover is off from the light source, it refers to direct lighting.

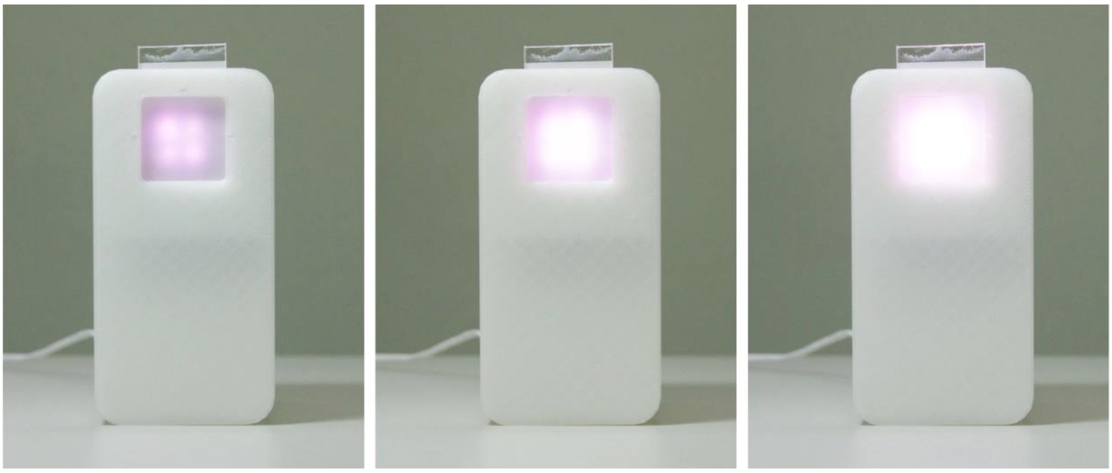
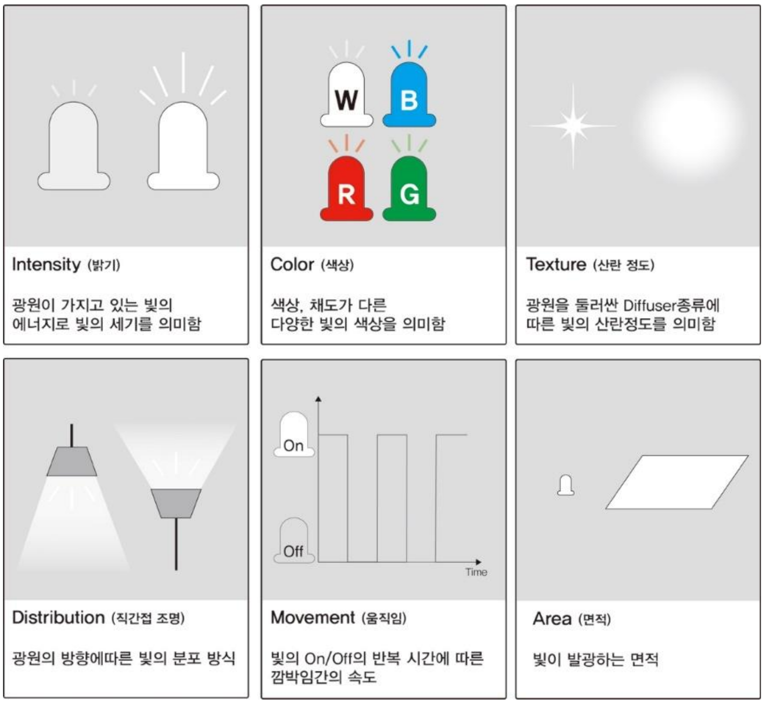


Figure 6 Example of three levels of intensity in the external hard disk

Figure 7 Example of controlling texture (left) and distribution (right) in the external hard disk

2.3.2 Lighting variable card set

In order to identify which parameter of lighting is dominant in information transfer, the participants were asked to rank the lighting variables according to the importance in perceiving the information. To gather this data, card sorting method was used and the card set including an icon and brief description of each variable was designed (Figure 8).



Intensity (밝기)

광원이 가지고 있는 빛의
에너지로 빛의 세기를 의미함

Color (색상)

색상, 채도가 다른
다양한 빛의 색상을 의미함

Texture (산란 정도)

광원을 둘러싼 Diffuser종류에
따른 빛의 산란정도를 의미함

Distribution (직간접 조명)

광원의 방향에따른 빛의 분포 방식

Movement (움직임)

빛의 On/Off의 반복 시간에 따른
깜박임간의 속도

Area (면적)

빛이 발광하는 면적

Figure 8 A card set consisting of six lighting variables on which the icon and description of each parameter of lighting are described.

2.4 Procedure

Participants were invited to Home Lab at UNIST and a sub-experiment was done per day with participants. Each participant attended three sub-experiments for 3 days. Each sub-experiment was conducted in a space expected people to use each experimental stimulus in real environment (Figure 9): the sub-experiment with the external hard disk was conducted on a desk with the computer. The sub-experiment with the blood pressure gauge was progressed in Home Lab, a virtual home where a studio for single person household was built in laboratory. And the sub-experiment with the ozone concentration indicator was also conducted on the windows of Home Lab. The level of ozone concentration in the air is mostly informed during daytime in real life. Accordingly, the sub-experiment was conducted only during daylight.

Figure 9 The experimental environments (from left to right): external hard disk, blood pressure gauge, and ozone concentration indicator

In order to avoid the order effect, sub-experiments were randomly given to participants were given. In each sub-experiment, a brief instruction of the sub-experiment was explained and a participant spent five minutes for getting accustomed to the experimental stimulus. Then, participants adjusted the parameters of lighting in a way that they think most appropriate to perceive the information of the given scenario (Figure 10). The same procedure was made for the other sub-experiments. After the sub-experiment, the participant was asked to rank each lighting factor with a card set that described each parameter of lighting according to the degree to which it is important (Figure 11). After this, a retrospective interview was conducted in order to figure out why they had chosen such levels. Lastly, participants were asked to give their opinions about the strength and weakness of information transfer with lighting.

Figure 10 Participants adjusting the levels of each variable in the experiment: external hard disk (left), blood pressure gauge (middle), and ozone concentration indicator (right)

Figure 11 participants ranking the parameters of lighting with the card set: external hard disk (left), blood pressure gauge (middle), and ozone concentration indicator (right)

3 Results

3.1 The usage of lighting variables in information transfer

3.1.1 External Hard Disk

There were three scenarios of external hard disk: the storage is full, the half of storage is filled, and the storage is almost empty. Figure 12 shows the rate of same answers in accordance with the scenarios of external hard disk. When the storage was full, 47% of participants chose moderate intensity. The selection of moderate intensity was 70% when the half storage was filled. In the case of the empty storage, all level of intensity most equally was selected. Almost all participants chose red color when the storage was full. The red color was not chosen in any other scenarios. When the half storage was filled, blue and green were selected as 40% each. 64% of participants chose white color when the storage was empty. When the storage was full, 30% of participants chose rapid blink lighting and 47% selected slow blink lighting. Total 77% of participants selected blink lighting for full storage. However, in other scenarios most participants preferred non-blink lighting. When the storage was full, all level of area was almost equally selected. The moderate area was substantially selected as 63% when the half storage was filled. When the storage is empty, narrow area was chosen by 40% and wide area was chosen by 37%. Half of the participants selected strong texture when storage was full. When the half storage was filled, 54% participants chose moderate texture. Strong texture was also selected by 50% when the storage was empty. Most participants preferred the direct lighting in all three scenarios. However, there were a few participants to select indirect lighting. Selection of indirect lighting slightly increased when the storage was empty.

Because the sample size is not enough for parametric test, non-parametric tests were adopted in the study. A Kruskal-Wallis test was conducted to identify which variables of lighting affected the perception of information between the scenarios with external hard disk (Table 5). Color significantly affected information transfer in external hard disk [H(2) = 19.34, p < .05]. Red color was preferred when the storage is full, and white color was commonly selected in empty storage. And Movement also significantly affected information transfer [H(2) = 40.41, p < .05]. Slow blink lighting presented the state of full storage and non-blink lighting was used in half filled and empty storage state. However, the other variables showed no significant differences between scenarios.

Table 3 The Kruskal-Wallis test value for lighting variables between scenarios in external hard disk

variable	Chi-Square	df	Sig.
Intensity	1.656	2	0.437
Color	**19.338**	**3**	**0.000**[*]
Movement	**40.407**	**2**	**0.000**[*]
Area	1.029	2	0.598
Texture	0.594	2	0.743
Distribution	0.539	2	0.539

[*] $p < .05$.

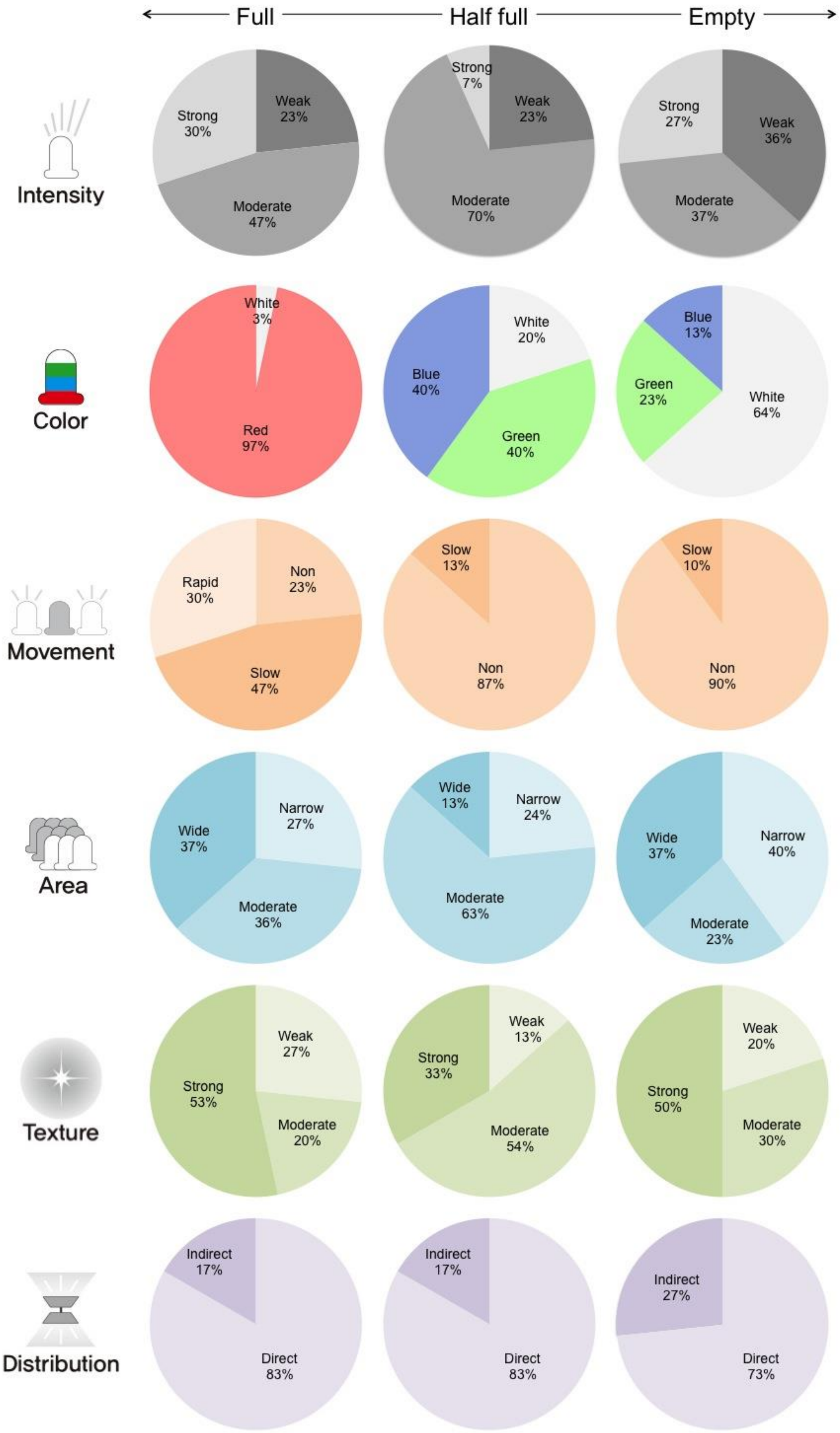


Figure 12 The response percentages of each variable according to the scenarios of external hard disk

Through the interview, the reasons that participants had chosen the level of lighting factor were identified. Some participants selected strong intensity to show the information clearly. Or in order to perceive a strong message that storage was full, they chose strong intensity. When the half storage was filled, moderate intensity was selected because no warning information was necessary. Although the storage was empty, participants chose strong intensity to perceive the state of whether it was connected to the electric outlet. The red color was selected to alert that there was no extra storage space. Participants considered that white color presents the empty situation like white paper. The reason that green color was chosen was to show the state of remaining space for storage. And some participants chose blue color because blue represents the mean of computer and technology. Participants considered that blink lighting delivers alert state and attracts attention from them. Therefore, most participants selected blink lighting when the storage was full. On the other hand, participants thought that blinking light was disturbing when the alarm was not required. The selection of area was irregular because some participants selected the wide area indicating the remaining storage space, while someone selected the wide area which in this case implies the used storage space. Although there was no certain reason to select a particular level of texture, many participants preferred more scattered lighting with strong texture. Most people chose direct lighting in information transfer because indirect lighting could hinder their perception of the light. On the other hand, only a few people selected the indirect lighting because of its aesthetical characteristic.

3.1.2 Blood Pressure Gauge

There were three scenarios of blood pressure gauge: high blood pressure, low blood pressure, and normal condition. The results of the experiment are shown in Figure 13. In high and low blood pressure, almost half participants chose strong intensity. On the other hand, 47% of participants selected weak intensity in normal condition. Almost all participants chose red color in high blood pressure. 30% of participants still chose red color in the scenario of low blood pressure. However, the half participants selected blue color. In the normal condition, 50% of participants chose green color and 33% chose white color. Rapid movement was preferred by 63% when blood pressure was high. 47% of participants still chose rapid movement in the scenario of low blood pressure. Most participants preferred non-movement in the normal scenario. More than 70% of participants selected wide area in high blood pressure and 57% of participants chose wide area as well in low blood pressure. On the other hand, 50% of participants preferred moderate area in normal condition. When blood pressure was high or low, all level of texture was almost equally selected. In the normal condition, 57% of participants chose strong texture. 73% of participants preferred the direct lighting in high blood pressure. 67% of participants selected direct lighting as well in low blood pressure although the selection of indirect lighting slightly increased. In the normal condition, 63% people preferred indirect lighting.

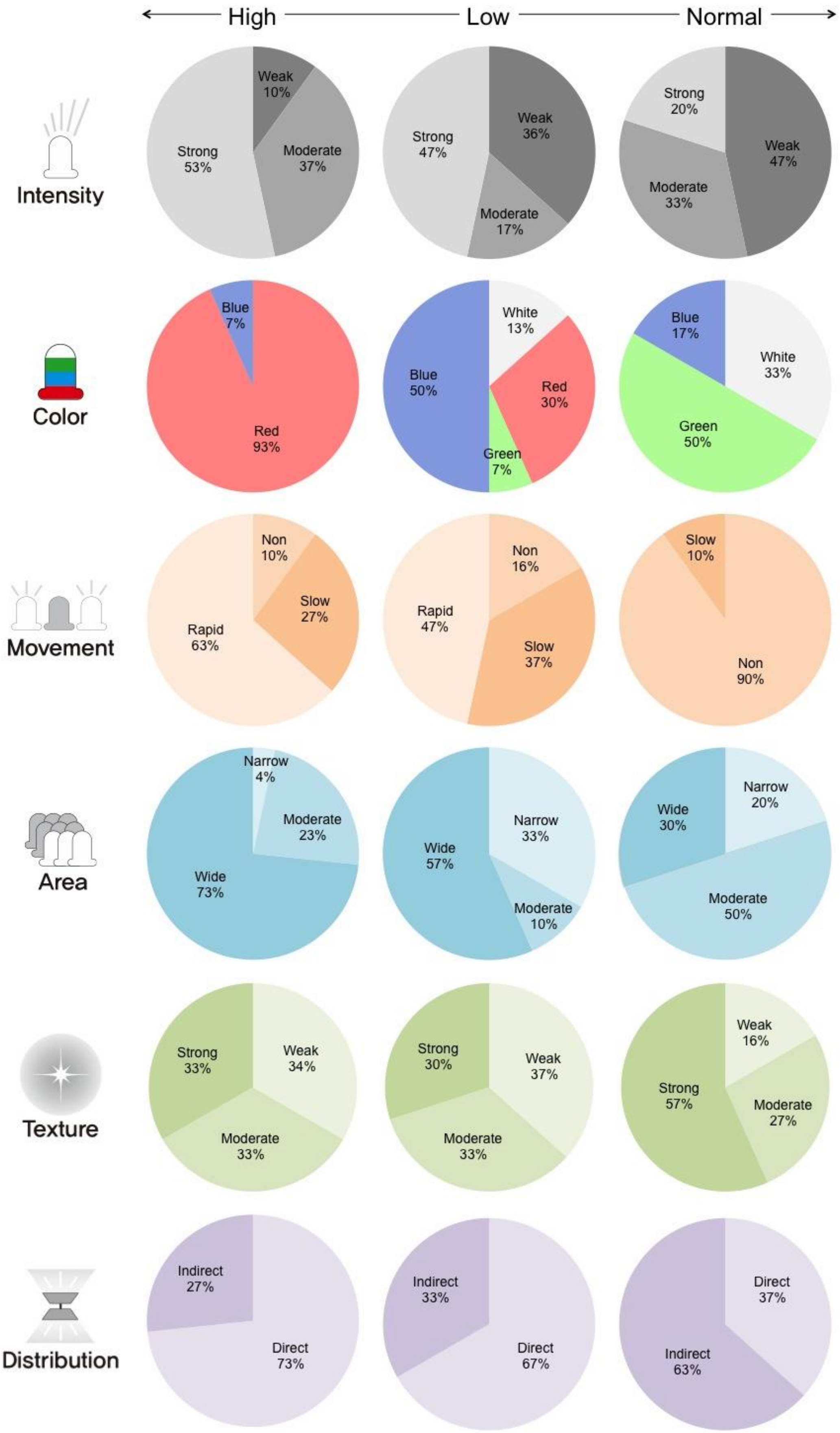


Figure 13 The response percentages of each variable according to scenario of blood pressure gauge

Information transfer in blood pressure gauge significantly was affected by most variables of lighting except texture. Intensity affected significantly information transfer [H(2) = 10.23, p < .05]. Strong intensity was used to deliver high and low state and weak intensity informed the normal condition. Color significantly affected information transfer [H(2) = 8.36, p < .05]. Red color presented high blood pressure and blue presented low blood pressure. Green delivered normal condition. Movement significantly affected information transfer [H(2) = 46.71, p < .05]. Rapid blink indicated high and low blood pressure and non-blink delivered the normal condition. Area significantly affected information transfer [H(2) = 10.26, p < .05]. Wide area presented high and low state and moderate area indicated the normal condition. Distribution significantly affected information transfer [H(2) = 9.35, p < .05]. Direct lighting presented high and low blood pressure, and indirect lighting delivers normal state.

Table 4 The Kruskal-wallis test value for lighting variables between scenarios in blood pressure gauge

Variable	Chi-Square	df	Sig.
Intensity	**10.227**	**2**	**0.006***
Color	**8.356**	**3**	**0.015***
Movement	**46.714**	**2**	**0.000***
Area	**10.263**	**2**	**0.006***
Texture	5.669	2	0.059
Distribution	**9.349**	**2**	**0.009***

*p < .05.

Through the interview, the reason that participants selected the level of lighting factor was identified. Participants chose strong intensity in order to notice the dangerous state of high and low blood pressure. On the other hand, they selected weak intensity in normal state when the alarm was not required. Red color was selected in order to present dangerous situation in high blood pressure. Some participants still chose red color for the dangerous alarm in low blood pressure. However half participants selected blue color for low blood pressure in contrast with red color for high blood pressure. They considered that blue color indicates low and cold state. Green color represented safe situation in the normal blood pressure. In normal condition, some people chose white color to present the non-problem state. There were two main reasons for participants to have chosen the rapid movement in the high blood pressure. The first reason was transmission of alarm, and the other was that the fast flowing of blood well matched the state of rapid blink. Even rapid movement was chosen in order to show alarm in low blood pressure. Otherwise some participants selected slow movement to present low blood pressure. Most participants preferred non-blink lighting in the normal condition to avoid nerves. Some participants considered that wide emitting area is regarded as high blood pressure and narrow area is low blood pressure. However, more than half of participants selected the wide area in order to notify the information, regardless the state of high or low. Moderate area was selected because there was no urgent alarm in normal condition. Although there was no particular reason to select level of texture in high and low blood pressure, half participants chose strong texture in order to avoid glare in normal condition. Participants preferred direct lighting in high and low blood pressure, because the direct lighting looked better to deliver lighting information than indirect lighting. On the other hand, a few participants selected the indirect lighting in all scenarios, because this device was close to human eyes. Many participants chose indirect lighting in normal condition, because alarm was not required in this state. A Kruskal-Wallis test was conducted to identify that which factor of lighting affected the perception of information between the scenarios of blood pressure (Table 6).

3.1.3 Ozone Concentration Indicator

There were three scenarios of ozone concentrations indicator: Too high ozone concentration (inappropriate for everyone to go out), high ozone concentration (inappropriate for the old and weak to go out), and normal condition (appropriate for outdoor activity). Figure 14 shows the experimental results of same answering in accordance with scenario of ozone concentration indicator. 73% of participants choose strong intensity when ozone concentration was too high. More than half participants selected strong intensity in high ozone concentration as well. Most common choice in the normal condition was moderate intensity. Almost all participants selected red color in too high ozone concentration. In high ozone concentration, the other colors were chosen little by little although red color was still selected by 57% of participants. Green and white colors were chosen by each 40% in the normal condition. When the ozone concentration was too high, 40% of participants choose rapid movement that was not chosen in any other scenario. Although 43% of participants selected slow movement, more than half participants preferred non-blink lighting in high ozone scenario. In the normal condition, all participants selected non-blink lighting. Wide area was selected by 86% when ozone concentration was too high. In high ozone scenario, moderate area was chosen by 70%. In the normal condition, most common choice was wide intensity by 47% and selection of moderate area was as high as 40%. Although selection of strong texture was high in the all scenario, the other level of texture was chosen by range from 20% to less than 40%. Most participants preferred the direct lighting in all three scenarios. However, there were a few people to select indirect lighting. Selection of indirect lighting slightly increased in normal condition.

A Kruskal-Wallis test was conducted to identify that which factor of lighting affected the notification of information in the scenario of ozone concentration indicator (Table 7). Intensity significantly affected information transfer [H(2) = 8.99, p < .05]. Strong intensity presented too high and high ozone concentration. Movement significantly affected information transfer [H(2) = 31.97, p < .05]. Rapid movement delivered the perception of too high ozone concentration. Non-movement indicated high ozone concentration and normal condition. Area significantly affected information transfer [H(2) = 21.22, p < .05]. Wide area delivered the state of too high ozone concentration and moderate area presented high ozone concentration.

Table 5 The Kruskal-wallis test value for lighting variables between scenarios in ozone concentration indicator

Variable	Chi-Square	df	Sig.
Intensity	8.991	2	0.011*
Color	2.932	3	0.231
Movement	31.968	2	0.000*
Area	21.217	2	0.000*
Texture	1.796	2	0.407
Distribution	4.182	2	0.124

*p < .05.

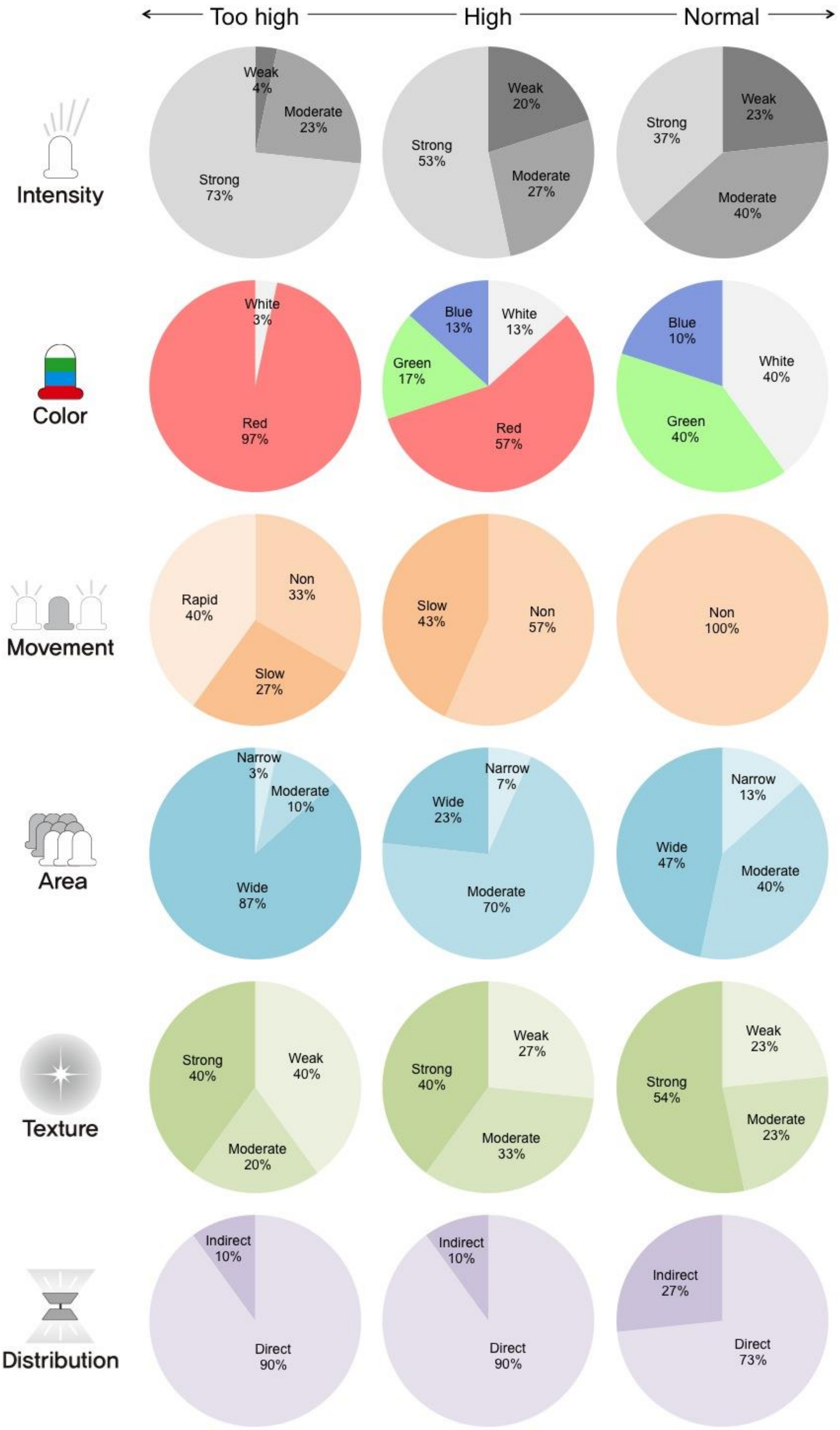


Figure 14 The response percentages of each variable according to scenario of ozone concentration indicator

Participants told that the strong intensity was associated with a dangerous situation. Therefore, they selected brightest intensity when outdoor activity was riskier. Red color was chosen to notice the alarm of dangerous outside when ozone concentration was too high. Although half participants also selected red color in high ozone concentration, the others chose different colors because it is possible for general people to go outside. In normal condition, the green color was selected as the meaning of safety for outdoor activity, and white color was chosen as the meaning that alarm was not required. In order to perceive the too high ozone concentration, participants preferred blinking light. On the other hand, blinking light was not selected at all in a normal condition, because blinking light was considered disturbing. Participants presented the difference between too high and high ozone concentration by controlling area. The wide area meant too high ozone concentrations, and middle area meant high ozone concentrations. Whereas narrow area was not preferred in normal condition in order to show the connection of power. Regarding texture, participants preferred scattered lighting by strong texture. Participants preferred direct lighting in all scenarios in order to deliver exact information. However, a few participants wanted indirect lighting, because it looked beautiful than direct lighting.

3.2 Prioritizing lighting variables in information transfer

Participants were asked to rank the factors according to the importance of information transfer through the card sorting method. The most important factor was given six points and the least important factor was given one point. The mean value of the answer given by 30 participants was analyzed. The mean value of each factor was presented according to experimental product as shown in Figure 15. Color was perceived as the most influential factor commonly in all experimental products. Movement and Area were the second and third important factors in both blood pressure gauge and ozone concentration indicator. However, Intensity was the secondly important factor only in the external hard disk, followed by Movement and Area. In all experimental products, Distribution was fifth-ranked. Texture was the least important factor in all experimental products.

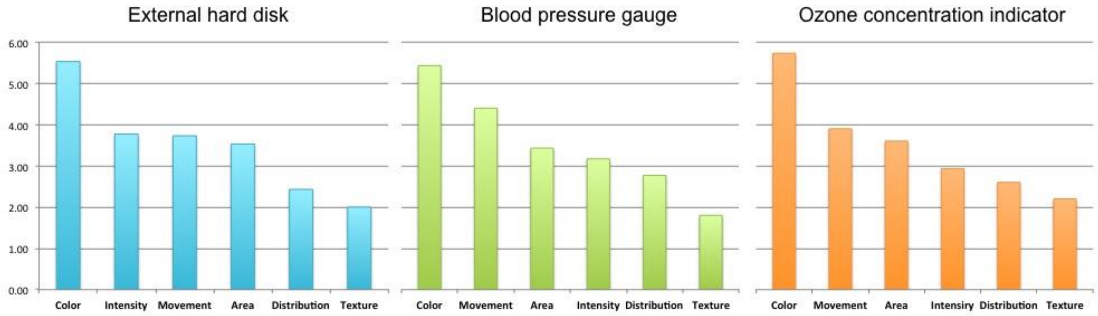


Figure 15 Mean values of prioritizing lighting variables between the experimental stimuli

To figure out the reasons of their prioritizing lighting factors in information transfer a retrospective interview was followed after the main experiment. Color was the most important factor because they could intuitively perceive the meaning of information (e.g. red refers to danger or warning). Someone mentioned that Movement was the most important factor in information transfer because Movement easily attracts people's attention. In addition, although the colour-blind cannot distinguish color change, they can recognize blinking light. Following Color and Movement, it turned out that Area and Intensity were also important to create visual stimulation. This was because lighting-based information is more conspicuous with wide area or strong intensity. Either directness or indirectness of lighting was not as important as the others because direct lighting is necessary to show the information. Texture was not important either because it was difficult to distinguish texture levels without a comparable object. A Friedman test was conducted in order to identify if there is a statistically significant difference in ranking the lighting factors among experimental products. SPSS 20 was used for the analysis and the results were shown in Table 9. There was no significant difference in Color by three products [χ^2 (2)=1.08, p > .05]. Therefore, Color was the most dominant factor in information transfer regardless of product type. The importance of Intensity significantly changed over three products [χ^2 (2)=6.81, p < .05]. Intensity was more important in external hard disk than in blood pressure gauge and ozone concentration indicator. The importance of Movement significantly changed over three products [χ^2 (2)=7.61, p < .05]. Movement was more important in both blood pressure gauge and ozone concentration indicator than external hard disk. The other factors such as Area, Distribution and Texture did not show a significant difference between three experimental products.

Table 6 The Friedman test value for the importance of lighting variables

Variable	N	Chi-Square	df	Asymp. Sig.
Intensity	30	6.805	2	0.033*
Color	30	1.077	3	0.584
Movement	30	7.605	2	0.022*
Area	30	0.966	2	0.617
Texture	30	3.947	2	0.139
Distribution	30	0.750	2	0.687

*p < .05.

3.3 Opinions of participants about lighting-based information transfer

At the end of interview, participants were asked their opinions about what advantages and disadvantages of lighting-based information transfer would have. According to them, the advantage was easy to perceive at a glance, which is intuitive. However, the disadvantage of lighting-based information transfer was that lighting does not provide detailed numerical information compared to character information. Apart from that, participants gave particular comments related to products. For instance, the lighting-based information transfer in external hard disk would be useful during daytime, but it would be annoying in the night because of the dazzling light. Participants preferred visible lighting-based information only in case that the information is urgently necessary. On the other hand, there was an opinion that the lighting-based information transfer seems less efficient in bright surroundings. Many participants mentioned that the lighting-based information transfer in blood pressure gauge would be useful to the elderly who has poor eyesight because the elderly is not easy to perceive the numbers on display. Although they could see the number, it might be difficult to figure out the meaning of the number, too. Another interesting comment was that people around the elderly user could help them when the elderly is in emergency state. For example, blinking light could warn not only the elderly user but also people around him or her. According to some participants' comments, ozone concentration indicator would be useful for families who have young children. Parents could warn their children not to go outside if the indicator shows red colour. Although too large indicator might disturb interior design, well-designed product would improve home decoration together with the function of information transfer.

4 Conclusions and Implication

The purpose of this research was to figure out possibility of delivering richer information by controlling lighting factor and consider which factor of lighting is effective to transfer information. Through the experiment and analysis of data, it was found that participants selected different variables of lighting to present information of given scenario. And participants had appropriate reasons why particular variables were chosen in order to identify the information. Especially participants paid much attention to the state of information to see whether it needs alarm and fast recognition. For example, in the case of high blood pressure or too high ozone concentration, participants chose strong lighting stimuli such as red color, bright light, and blinking light. On the other hand, weak light was chosen in the normal state that requires less awareness. In addition, participants answered that the information transfer using light is intuitive and this method quickly delivers information to people. It meant that lighting-based information is useful and delivers richer information by controlling lighting factor. It was expected that the influence of color would be one of the effective factors because color already has been used in product. And frequent use of red and green color was expected, because these are representative colors in lighting of consumer products. However, an interesting finding was that many participants preferred choosing white color than green one. Green was usually used to symbolize safety and white mostly presented the state of low, less, and empty. It means that lighting color is a useful factor which can represent different information regardless of previous experience. It seems necessary to identify their relation between lighting color and information transfer for further study because LED lighting can control diverse colors. To capture the people's attention with blinking light was a good way to deliver information according to importance of situation. Especially, communication using Movement of lighting will be important to the color-blind who cannot distinguish color change. This study found that movement should be utilized carefully because too much blink lighting might evoke annoyance. Brightness of lighting can be adjusted by Intensity of the lighting. Perception of the brightness is dependent on the context where the lighting is used. For example, a particular level of intensity can be relatively differently perceived between at day and at night. Therefore, understanding context of usage is important to create lighting-based information. Because too strong intensity might be dazzling and too low intensity might not deliver visual stimulation. Even though change of texture was not important factor in information transfer, this study found out that people prefer scattered lighting by using strong texture. Distribution is not important in this experiment. However, there was a remarkable reason when participant chose the level of Distribution in blood pressure gauge. Most participants preferred indirect lighting to reduce eyestrain by lighting in normal blood pressure. It means that Distribution is important to improve usability according to product context. In addition, the interesting fact is that some people prefer indirect lighting, because it is nice to see regardless of information transfer and product type. The experiment was conducted with three representative products in order to identify the possibility of lighting-based information by controlling lighting factor. Each lighting variable had different functions to deliver information. In this study, color and movement were used as important factor to present information. However, it could not be applied to all product type. Considering there are a lot of consumer electronic products in the world and the types are diversified, the interaction between human and lighting in information transfer should be continually studied. This study identified that controlling factor of lighting deliver richer information. Considering applying lighting factors to products will increase due to controllable LED lighting, visual stimulation can be an effective method to transfer information and lighting easily creates visual interaction in product without high technology. Therefore, the study might be helpful for designers to understand the role of lighting variables in information transfer, which can lead to creating products people love to use. However, it is hard to generalize the findings of the study considering limitations of the study: a small number of participants in the experiment, all of whom were university students. Furthermore, we have to be careful in implementing the findings considering that there are some number of colour-blind people in our population. Therefore, further studies should take these issues into account to produce more reliable and applicable outcomes.

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Contemporary Automotive Infotainment Solutions to Empower Front-Seat Passengers

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Automotive infotainment systems have neglected front-seat passengers' needs as they have not been the primary users of the car. Recently R&D efforts in academia and the automotive industry have been directed towards empowering front-seat passengers. Front-seat passengers can spend substantial time in the car accompanying the driver, but without having sufficient means to entertain themselves. This paper first briefly introduces the (front-seat) passenger-oriented studies in automotive user experience (UX) literature and concept cars presented in several automotive or technology shows in 2015-2016. The identified solutions are then categorized based on the varied dimensions of the infotainment experience. This helps the understanding of diverse aspects of the innovations including: novelties in in-car interactions based on embodiment of interaction technologies; new functionalities/infotainment features; and hedonic or pragmatic contributions to the passenger experience. However, there is still a need to investigate the link between the dimensions of front-seat passenger experience to prevent the users being exposed to underexplored technology-driven designs.

front-seat passenger experience, automotive infotainment, automotive user interfaces, automotive UX trends

1 Introduction

Traditionally, automotive user interfaces have been designed within the limitations of 'driving activity', since drivers have been the main controllers of the vehicle. This has resulted in automobile interiors and infotainment systems which neglect the passenger experience. Nevertheless, passengers may spend as much time in the car being driven around but without having the means to entertain themselves. Within the shared experience of mobility, passengers have fewer distraction issues and they can concentrate on more varied stimuli. Their physical access to diverse parts of interior is also not as limited as that of the driver. These opportunities encouraged us to rethink the way passengers interact with the car infotainment system to empower them and to enrich their travel experience. Empowering front-seat passengers means increasing their involvement in the car journeys by providing them means that will add both pragmatic and hedonic values to their travel experience.

This paper provides an analysis on the R&D efforts in academia and automotive industry within the scope of “automotive infotainment solutions empowering front-seat passengers”. It refers to passenger-oriented automotive UX studies and a detailed technology review of a selection of concept cars introduced at the Geneva Motor Show (2015-2016), Frankfurt Auto Show (2015), and Consumer Electronics Show (CES) (2015-2016).

It is important to mention that the introduction of autonomous driving enables drivers to act as front-seat passengers as well. To meet this challenge, automobile manufacturers have started to come up with interface solutions that will fill that gap created by the elimination of the driving task. This paper will refer to these solutions as part of passenger empowerment, although the distinction between the driver and front-seat passenger still continues even in autonomous car concepts since someone needs to take control of the car when autonomous driving option cannot be used.

2 Brief introduction to passenger-oriented studies in automotive UX literature

When we analyse (front-seat) passenger-oriented studies in automotive UX literature, there are two main approaches: i) emphasis on the driver and front-seat passenger collaboration and ii) emphasis on the front-seat passenger and investigation of what automotive user interfaces can offer them beyond enabling them to assist drivers in driving-related tasks.

2.1 i) Driver and front-seat passenger collaboration

The collaboration between driver and front-seat passenger is mainly handled through using the navigation system together. To exemplify, Perterer et al. (2015) introduce a tablet-based navigation app concept and prototype “Co-Navigator” that provides diverse kinds of information, such as landmarks and upcoming hazard warnings, then they discuss how front-seat passengers can make use of the app. Rümelin et al. (2013) also demonstrate a system to enable driver-passenger collaboration by letting front-seat passenger deal with secondary navigation-related tasks which are too much to handle for the drivers. The results of user-evaluations of this system show that the occupant (either the driver or the passenger) executing the defined task felt more involved; however, the level of control increased for both car occupants when the passenger provided support in the task.

Similar studies include “I need help! Exploring Collaboration in the Car” by Gridling et al. (2012) and “Where Should I Turn? Moving from Individual to Collaborative Navigation Strategies to Inform the Interaction Design of Future Navigation Systems” by Forlizzi et al. (2010). Another study called “Gaze Assist” by Trösterer et al. (2015) explore the eye-gaze detection as a new way sharing information between the front-seat passenger and the driver, since the sitting positions of these two front-seat occupants and driver’s need to keep the eye on the road do not allow them to have a natural face-to-face communication. To facilitate the communication and the collaboration, the system works in a way that the eye gaze of the front-seat passenger is captured and visualized for the driver to show exactly where the front-seat passenger looks. In this study they compare two different visualisation techniques (LEDs at the bottom of the windshield vs. dots on the screen) and reach to the conclusion that while the LED visualisations is better to avoid driver distraction, dots perform better in terms of visual accuracy and control of the front-seat passenger. The use cases for front-seat passenger’s “gaze assistance” are illustrated as warning the driver for upcoming hazards or giving support in navigating in an unfamiliar region (Trösterer et al., 2015).

2.2 ii) "Passengering" beyond driver-passenger collaboration

This category of research puts passengers as the focal point and analyse their needs and activities as passengers. In this regard, Inbar and Tractinsky (2011) propose that IVIS (Inter-vehicle information system) should be made more accessible to passengers so we can reduce boredom and increase a sense of inclusion of the front or rear-seat passengers. They also argue that making in-car information more accessible to passengers can eliminate the need for the driver to share trip-related information with passengers, which reduces distraction and information load of drivers. In addition, Lee et al. (2015) present a study on a split-view navigation system and list the information needed or prioritized by the driver and front-seat passenger individually during the phases of the journey.

The examples included thus far relate to the shared use of the available in-car information with passengers. Nevertheless, there are also academic efforts to understand (front-seat) passengers' further needs and interests beyond the provision of travel information alone. Osswald et al. (2013) presents a probing study conducted with front-seat passengers. They demonstrate a cluster of the modalities (e.g. interface modalities, radio, display); services (e.g. navigation, internet, social media, games); context (e.g. weather, speed, front-seat passenger area) and information (e.g. surroundings, TV, distance left/travelled) the front-passengers deal with or mention about the most.

3 Analysis of (front-seat) passenger-oriented infotainment solutions

We have briefly introduced the approaches followed in the literature regarding the front-seat passenger experience. Now we will provide a deeper analysis of the passenger-oriented studies in the literature and concept cars.

The content of the academic and industrial R&D efforts needs such deconstruction that we can position their contributions within varied dimensions of the UX. Therefore, while analysing the passenger-oriented automotive interface solutions, we will refer to Hassenzahl (2010)'s *how, what* and *why* dimensions of interacting with technology. The model investigates how a user connects his/her-self to the world through an activity with a three-level goal hiearchy. In this model, 'what' dimension for 'do-goals' refers to the tasks to be completed or a concerete goal to be achieved by users, which can defined as the functionality. At the lowest level, there is 'how' dimension for 'motor-goals' which involve all the operational steps that user has to go through while interacting with the product. At the highest level, there is 'why' dimension for 'be-goals' which is about the meaning, motivations and emotions related to that activity.

The previously mentioned research can be referred to again to exemplify how these diverse levels of interacting with technology are studied in literature. The use of emerging technologies (e.g. eye-gaze recognition, split-view displays) in front-seat passengers' in-car interactions illustrates the investigation of the *how* dimension, because embodiment of these technologies has a direct influence on how we interact with the interfaces. On the other hand, the *what* dimension has been studied through the identification of the type of information or services that front-seat passengers are interested in. These studies have also touched upon the *why* dimension by explaining the positive effects of these applications on users such as 'reduced boredom' or 'sense of inclusion'. It is important to mention that all these dimensions are linked: Improvements in interactions and functionalities contribute to a pleasant user experience (*why* dimension); and thinking about what makes a pleasant experience helps designers come up with appealing interface designs and functionalities.

The examples can be expanded with the passenger-oriented solutions that automotive companies are planning to integrate into future cars. Therefore, concept cars introduced in Geneva Motor Show (2015-2016), Frankfurt Auto Show (2015), and Consumer Electronics Show (CES) (2015-2016) were investigated with an eye to reveal the technologies and passenger-oriented solutions they have recently integrated and/or have visions to include. The official websites of the auto shows as well as other online automotive design sources including Car Magazine, CNet, Digital Trends, The Verge, YouCar, and Autogefühl were studied. Car manufacturer web-sites were also referred when further information was needed for a specific model introduced in these shows. In total, 253 cars (53 concept cars, 200 production cars to be released in near future) were reviewed.

Each concept car has its own prominent features and they present varied innovations in styling, performance, alternative energy usage and automotive HMI (human-machine interfaces within the car). Based on the scope of the research, 13 cars offering new concepts for in-car interactions were selected for further analysis. The selection criteria were based on two questions:

1. Do the in-car interactions (automotive HMI) demonstrate anything beyond what exists in production cars?
2. Does the car provide any (front-seat) passenger-oriented infotainment solutions?

The 13 cars that successfully fulfilled one or both of these criteria include Mercedes F015, Volkswagen Golf R Touch, Kia DriveWise (CES 2015); BMW i8 Vision, Volvo Concept 26, Volkswagen BUDD-E (CES 2016); Porsche Mission E, Mercedes IAA Concept (Frankfurt Auto Show, 2015); Audi Prologue (Geneva Motor Show 2015); Ferrari GTC 4 Lusso, BMW Vision Next 100, Opel GT Concept, Skoda VisionS (Geneva Motor Show 2016).

Infotainment systems that are dedicated to the use of front-seat passengers do not yet exist in production cars; we can discuss such versions of infotainment only in the context of future car journeys. Therefore, detailed analysis of concept cars is important to identify the trends in automotive user interfaces, to investigate the use of interaction technologies and infotainment features envisioned for future travel scenarios.

The technology review of the selected concept cars was conducted as a content analysis of a varied collection of media; including the explanatory texts, visuals and videos which demonstrate the interactive features of the car interfaces. The categorization of the relevant content was mainly based on the passenger-specific automotive user interface solutions, the interaction technologies used for information provision and input, and the car infotainment features targeting the front-seat passengers / occupants (in shared systems). Further categorization of the results and the discussion can be found in the following section.

4 Results & Discussion

In this section, based on the model of Hassenzahl (2010) to explain the different dimensions of interacting with technology (why-what-how), the paper will first investigate the *how* dimension – 'front seat passenger infotainment interactions'. With regards to this dimension, it will introduce new control and display configurations in the car's interior that empower (front-seat) passengers, trends in automotive user interfaces and mostly used interaction technologies in selected concept cars. For the latter two, passenger vs. driver-oriented solutions are not differentiated, because the very same technology or interface can be reconsidered as control and display of front-seat passenger infotainment systems. Secondly, it will focus on 'front-seat passenger infotainment features' (the *what* dimension). It will provide a categorization of passenger infotainment features based on passenger interests identified in the literature and passenger-oriented infotainment trends presented in the technology review. The categories include information, communication, and entertainment. Finally, it will touch upon the *why* dimension – 'enhancement of front-seat passenger journeys'. In this part, we refer to studies which identify the types of positive effect (as well as affect) that these solutions have on front-seat passengers. It will also discuss in what ways the efforts mentioned under *what* (the way we interact the system) and *how* (the infotainment features) dimension could enhance the front-seat passenger journey experience.

4.1 Front-seat passenger infotainment interactions

This section will provide the analysis of the automotive user interface solutions presented in the literature and the technology review with a focus on how (front-seat) passengers are expected to interact with the infotainment systems. The section includes the following headings: i) New interior control and display configurations that empower (front-seat) passengers; ii) Mostly used interaction technologies; and, iii) Trends in automotive user interfaces.

4.1.1 New interior control and display configurations that empower (front-seat) passengers

Table 1 illustrates how (front-seat) passenger empowerment is achieved through different approaches in automotive user interface design. The categories range from infotainment systems dedicated to front-seat passengers (A), to more indirect solutions that integrates the front seat passenger as well to the experience of interactive infotainment systems of the cars; either through information provision extended to the front-seat passenger side (B) or by turning the whole car interior into a ‘digital social space’ (C).

Four concept cars out of 13 that were reviewed - Mercedes IAA Concept, Opel GT Concept, VW Golf R Touch, and Kia DriveWise - are not included in Table 1 as they do not provide any interface or infotainment solutions dedicated to passengers. They only have controls and displays in the central console area through which the front-seat passenger has a limited access to driver-oriented infotainment, as in the case of most of the today’s cars. However, they are included in the discussion of front-seat passenger infotainment interactions for their innovative approaches in automotive HMI design.

Volvo Concept 26 and BMW Vision Next 100 have been placed in category *B. Information provision extended to front-seat passenger side* only because they provide a shared information provision to front-seat passengers through extended displays. Unlike the other two cars in this category (Porsche Mission E and BMW i8 Vision) they do not offer any front-seat passenger-specific solutions that enable them to control infotainment from their cockpit.

Table 1 Control and display configurations in interior that empower (front-seat) passengers

A. Infotainment screens dedicated to front-seat passenger


Ferrari GTC 4 Lusso


Audi Prologue


Skoda VisionS

B. Information provision extended to front-seat passenger side
(Accessed by both front-seat occupants)


Porsche Mission E


BMW i8 Vision


Volvo Concept 26


BMW Vision Next 100

C. Whole car interior as a 'digital social space'


Mercedes F015


Volkswagen BUDD-E

4.1.2 *Mostly used interaction technologies*

In this paper, the term 'interaction technology' corresponds to the interactive features of the automotive user interfaces such as touch recognition. The information provided for each concept car does not always contain which specific technology is used to deliver the interactivity, especially for input. For example, we can gather information about the type of modality used (e.g. touch vs. gesture recognition), how it is applied in the car interior (e.g. touch sensitive armrest vs. touch screen); but cannot always identify the exact underlying technology (e.g. capacitive vs. ultrasonic touch recognition) mostly because of the confidentiality of R&D of automotive user interfaces.

Figure 1 summarizes the type of interaction technologies used for input and information provision in the reviewed cars; how frequently the technologies are utilized, and in what ways they are applied to the car interior. Input technologies refer to the means that are utilized to control interfaces; whereas, information provision technologies correspond to any type of display or feedback that are utilized to provide information to users.

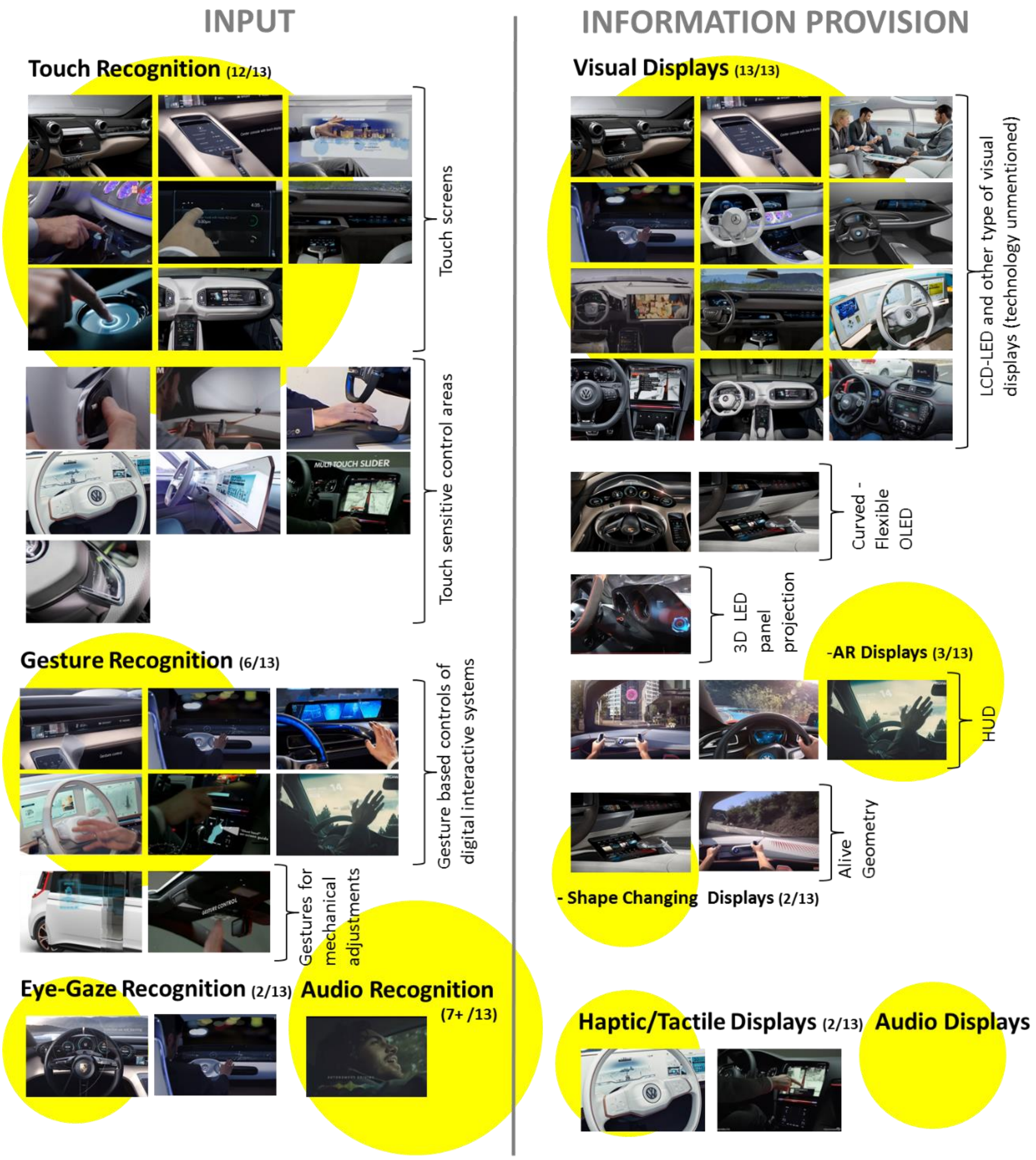

Figure 1 Distribution (x out of 13 cars) of interaction technologies (input and information provision) used in concept cars (circle's size represents the relative frequency)

Regarding the input technologies, it is observed that touch recognition, gesture recognition, eye-gaze recognition and audio recognition are used as a replacement of the physical controls like knobs and buttons. It was a challenging task to identify the concept cars with audio recognition since it is not a visible feature. Therefore, audio recognition is added as a feature for the concept cars if it is mentioned or presented as type of input in the video or text-based sources reviewed. We can claim that *at least* seven out of the thirteen cars have this feature.

The categorization of the technologies for information provision was also made based on the sensory modalities used. As can be seen in Figure 1, visual display types vary from currently used LCD or LED displays to curved OLEDs, flexible OLEDs, 3D panel LED projection, head up displays and shape changing displays. In addition to visual displays, information is also communicated via haptic displays (e.g. touch sensitive surfaces or touch screens with 'surface-haptics' feedback) and audio displays (e.g. audio feedback). It is important to mention that a specific technology can appeal to more than one modality or can be used for both input and information provision. For example, shape changing displays are applied as means of visual feedback in the BMW Vision Next 100 under the concept of ‘alive geometry’ (tiny triangular physical surfaces in motion to notify the driver); however, the very same technology have been studied as a haptic feedback or even as an input via changing shapes as well.

4.1.3 Trends in automotive user interfaces

This section presents the most commonly used interaction technologies in concepts cars and the trends that automotive firms followed to utilize them to enhance car interfaces, interactions and interiors. The information about the trends (see Figure 2) are as follows.

- *Touch as the most used modality.* Automotive firms started to use touch sensitive surfaces in different zones of the car interior in addition to the touch sensitive screens in the central console and dashboard.
- *Expansion in areas and ways of information provision*. There is an expansion from the conventional information provision areas (infotainment screens on central console/dashboard, instrument clusters and HUDs at driver’s side) to passenger dashboard, side doors and other surfaces of the car interior. Such expansion also applies to head-up displays, which has been rethought as a “windshield display” in concept cars. We also see novelty in the way that information is provided as in the example of “alive geometry” in BMW Vision Next 100 (2016) where tiny triangular physical surfaces in motion notify the driver about incoming dangers (BMW, 2016).
- *Increasing integration of gestural recognition.* Hand gestures are mostly utilized to control the information provided through displays expanded to the front-seat passenger side or HUD displays, where the use of touch is not an option for the driver because of the reach issue. Another motivation for the integration of gesture recognition is to decrease the number of physical controls - the visual complexity of the interior.
- *Curved displays blending into interior.* It is also observed that the aim behind the use of particular display technologies (e.g. Curved OLEDs, 3D LED Panel projection) is to eliminate the need to use flat interior surfaces just to place flat-rectangular screens on the dashboard. This brings much more flexibility to the design of the car interior and its visual aesthetics.
- *Co-located physical and digital layers.* There is an increase in interactivity of physical items in the car either through e.g. integration of LED light-based visual feedback under the mesh leather upholstery of the steering wheel (BMW i8 Vision) or HUDs which augment the outside windshield view with a digital information layer.
- *Expansion of control areas from dashboard/central console to the whole of the car interior.* As the travel scenarios change in a way that integrates more car occupants in control of interactive systems (see Table 1), it becomes necessary to create ready-at-hand control areas for them. That is why we see examples like touch sensitive arm-rests or touch-sensitive side doors. This trend is highly related to the “expansion of information provision”, especially for interfaces where control-feedback is achieved using the same interactive element, as in the case of touch-screens.

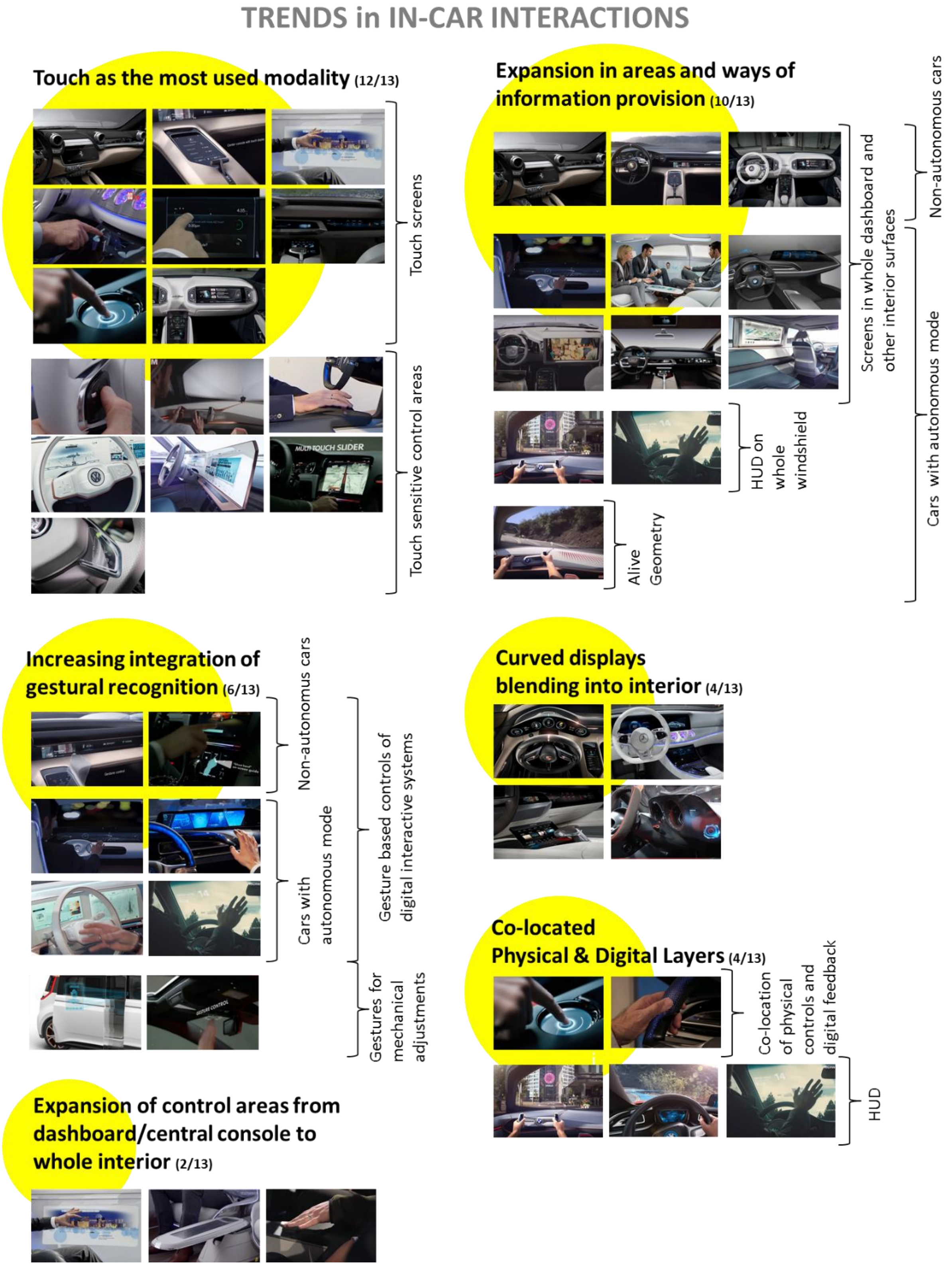

Figure 2 Distribution of (x out of 13 cars) of future trends for in-car interactions in concept car (circle's size represents the relative frequency)

4.2 *Front-seat passenger infotainment features*

The previous section covered diverse ways of accessing infotainment features in a car. This section will focus on what these infotainment features are; in other words, what front-passengers will be able to do when front-seat passenger infotainment systems are realised. The infotainment features are either shared by other car occupants (See B & C sections of Table 1); or provided specifically for front-seat passengers (See the section A of Table 2).

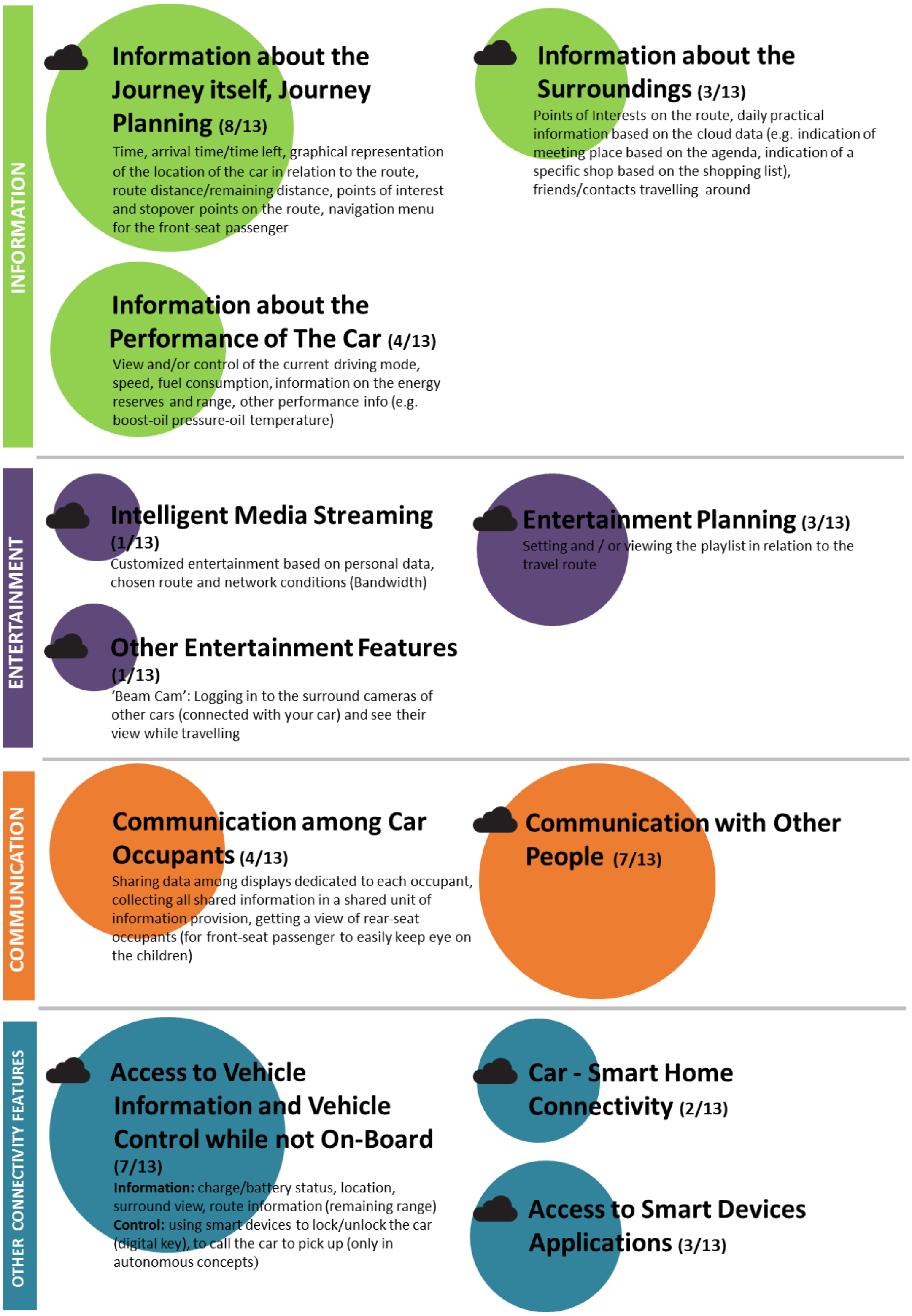

Figure 3 Distribution of (x out of 13 cars) of infotainment features in concept cars (circle's size represents the relative frequency)

The content analysis of the new functionalities presented in the literature and concept cars revealed three main categories of infotainment features: information, entertainment and communication. Some aspects of the infotainment features overlap with each other; therefore, it is not possible to make a distinct separation between these three categories. However, the prominent attributes of each category are as follows. *Information* concerns anything that passengers would like to know or learn throughout the journey*; entertainment* relates to anything that would help to reduce the boredom of being a passenger, which, of itself is not necessarily stimulating; *communication* is about sharing things with other car occupants and other people outside the car and involving them to a specific part of travelling experience through infotainment.

Most of these features can function thanks to today's connectivity technologies and cloud systems which create a network among the vehicle and smart devices, other vehicles and the infrastructure. Following information, entertainment and communication, this paper will also touch upon other connectivity-enabled features which can be used either inside or outside of the car. These features are mentioned under a separate category because they are not necessarily about information, entertainment or communication; they are about being able to access or control all of these features while on-board or not on-board.

Figure 3 illustrates the list of all (front-seat) passenger-oriented information, entertainment and communication features together with the other connectivity features offered by the concept cars. It demonstrates that most of the infotainment features are enabled by connected car technologies. Another highlight is that the information and communication categories have been explored more in detail compared to the entertainment category. New entertainment functionalities presented in concept cars focus on how to organize media playlists rather than exploration of alternative entertainment features.

4.2.1 Information

Information provided to (front-seat) passengers in the reviewed concept cars include the *i) journey and journey planning; ii) surroundings of the car*; or *iii) the performance of the car.* See Table 2 to view additional information categories mentioned in literature.

i) The information about the journey itself and journey planning includes:

- Time, arrival time/time left to the destination
- Graphical representation of the location of the car in relation to the route
- Route distance/remaining distance
- Points of interest and stop-over locations on the route
- Navigation menus for the front-seat passenger

These features exist in the following cars and infotainment menus: Ferrari GTC 4 Lusso (Navigation), Audi Prologue (Road Trip, Personal Assist) (Figure 4), Skoda Vision (Navigation), Porsche Mission E (Navigation), BMW i8 Vision (Navigation), Volvo (Navigation), Mercedes F015 (Guided Path-Time, Guided Path-Places), and VW BUDD-E (VW Travel App).

It is important to mention that this information is given as a part of either navigation menus or other specific menus that provide the key information about the journey without complex navigation-related features. The content and functionalities of the passenger-specific navigation menus are not clear from the concept cars related sources we reviewed. However, from the literature we can add 'tracking journey via real-time mapping' and 'surrounding streets information' features (Inbar & Tractinsky, 2011) to the bullet points provided within this sub-category.

Figure 4 Audi Prologue concept with journey-related information in ‘Road Trip’ and ‘Personal Assist’ menus. Source: Carscoops (2014)

ii) Information about the surroundings includes:

- Cultural information (e.g. Information about the points of interest on the route)
- Daily practical information based on cloud data (e.g. indication of meeting place based on the agenda, indication of a specific shop based on the shopping list) (Figure 5)
- Social information: Friends/Contacts travelling around

These features are present in Audi Prologue (Road Trip, Personal Assist), BMW Vision Next 100, and Mercedes F015 (Guided Path-Places, Guided Path-People).

Regarding cultural information, the research of Osswald et al. (2013) presents which point of interests and other car surroundings related information are prioritised by front-seat passengers (see Table 2). The ‘Toll gate information’ example provided by Lee et al. (2015) shows that a diversity of the travel scenarios can enrich the examples regarding the information about the surroundings that needs to be provided to passengers. Connectivity-enabled daily practical information or social information is not mentioned in the literature.

Figure 5 Indication of the flower shop that sells the specific flower in the shopping list (BMW Vision Next 100). Source: BMW (2016)

iii) Information about the performance of the car include:

- View (and/or control) of the current driving mode (Figure 6)
- Speed
- Fuel consumption, information on the energy reserves and range
- Other performance info (e.g. boost-oil pressure-oil temperature)

Fuel information also appears as a type of information that front-seat passengers mentioned in the probing study conducted by Osswald et al. (2013). While talking about sharing in-car information with passengers Inbar and Tractinsky (2011) also give example of a Maybach car with speedometer dials attached to rear seat passenger’s side door.

Figure 6 View of the current driving mode through front-seat passenger's infotainment screen in Ferrari GTC4 Lusso. Source: Ferrari (2016)

4.2.2 Entertainment

Media (audio-video) players can be considered as default entertainment features in contemporary cars. What is new in concept cars regarding media playing and entertainment is enhancements brought by the connectivity. These new entertainment features include:

- *i) Intelligent media streaming*: Customised entertainment based on personal data, chosen route and network conditions (bandwidth) as present in Volvo Concept 26 (Figure 7)
- *ii) Entertainment planning:* Setting and /or viewing the playlist in relation to the travel route) as present in Volvo Concept 26, Mercedes F015 (Guided Path-Music), VW Budd-E (VW Travel App)
- *iii) Other entertainment features* e.g. 'Beam Cam': Logging in to the surround cameras of other F015 cars connected with your car and seeing their view while travelling. This feature exists in Mercedes F015 (Guided Path)

Entertainment is not a concept that is deeply explored for the front-seat passenger. Having reviewed passenger-oriented studies, we can only refer to Osswald et al. (2013) where front-seat passengers mention TV, DVD movies, games, Facebook, pictures, and YouTube as possible infotainment features. Most of these features can be provided through the connected car systems, like Apple Car Play or Android Auto, to enable the access to smart device applications in car. It is mentioned under 'Other connectivity features' category.

Figure 7 'Content created and optimized for your chosen route' in Volvo Concept 26. Source: Volvo Car Group (2016)

4.2.3 Communication

Communication features can either contribute *to i) communication among car occupants or ii) communication with other people.*

i) Communication among car occupants can be illustrated as follows.

- Sharing data among displays dedicated to each occupant (Skoda VisionS, Audi Prologue)

- Collecting all shared information in a shared unit of information provision (Mercedes F015, VW Budd-E)
- Getting a view of rear-seat occupants, e.g. for front-seat passenger to easily keep eye on the children at the back (Skoda VisionS, see Figure 8)

The above-mentioned literature about specific in-car applications developed for passenger-driver collaboration in navigation tasks can be considered as examples of infotainment features enabling communication among car occupants (See Table 2).

Figure 8 Watching a movie and keeping eye on the kids on the rear seats simultaneously thanks to front-seat passenger infotainment system in Skoda VisionS. Source: Car Magazine (2016)

ii) Communication with other people is achieved in the reviewed cars via audio-video calls (Figure 9) or text messaging. This feature is provided for passengers in Skoda VisionS (chat), Porsche Mission E (Contacts), BMW i8 Vision, BMW Vision Next 100, Volvo Concept 26, Mercedes F015 (Connected Device), VW Budd-E (‘Messages’ and ‘Phone’).

In relation to communication with other people; Facebook, e-mail, contact list, SMS and Skype features and applications are listed by Osswald et al. (2013).

Figure 9 Video chatting with a colleague in BMW i8 Vision (when autonomous driving is activated). Source: Cnet (2016)

4.2.4 Other Connectivity Features

This section refers to connected car features, which cannot be considered only as an information, entertainment or communication feature but can be a part of the car infotainment systems, including:

- *i) Access to vehicle information and vehicle control while not on-board:* The information that can be accessed via connected smart devices (phone or watch) consists of charge/battery status, location, surround view, route information (remaining range). Vehicle control via smart devices can be illustrated with locking/unlocking the car (digital key) and calling the car to pick-up (only in autonomous concepts). Please note that these features are provided only to the owner of the cars, authorised drivers or driver-passengers of the autonomous cars. We believe that vehicle information access and control while not on-board can be customised for other car occupants, in our case, for front-seat passengers as well.

- *ii) Smart home-car connectivity:* Access to smart home information and controls (e.g. viewing the home security camera footage, Figure 10) is presented as a feature in BMW i8 Vision and VW Budd-E.
- *iii) Access to smart devices applications:* This feature includes systems like Apple Car Play and Google Android Auto and they are only mentioned for the concept cars to be released into market in a very near future (starting from 2017). These cars are Ferrari GTC 4 Lusso, Audi Prologue - 'Audi Smartphone', VW Golf R Touch).

Figure 10 Viewing home security camera footage through infotainment screen in VW Budd-E. Source: (Volkswagen, 2015)

Table 2 presents the resulted categories for passenger infotainment features and how they are depicted in literature and technology review (of concept cars). The table shows that academic and industrial efforts are aligned when it comes to the identification of front-seat passengers' needs and finding solutions to fulfil them.

Table 2 List of (front-seat) passenger infotainment features depicted in literature vs. concept cars

Infotainment features depicted in literature	**Infotainment features depicted in concept cars**
COMMUNICATION	
Information about the Journey Itself, Journey Planning • time travelled, travel duration*, estimated time of arrival** • distance travelled, distance to destination*, estimated distance of arrival** • location of the rest area, information about rest area, attractions of destination • tracking journey-real-time mapping*** • traffic info, traffic lights*, traffic jam** • surrounding streets***	**Information about the Journey Itself, Journey Planning** • time, arrival time/time left • graphical representation of the location of the car in relation to the route • route distance/remaining distance • points of interest and stop-over points on the route • navigation menu for the front-seat passenger
Information about the Surroundings • shopping, hotel, restaurant, road signs, radar, sightseeing, toilet, gas station, activities, church, cinema, events, camping, picnic, swim, POI *, toll information (near toll gate) **	**Information about the Surroundings** • points of interests on the route • practical information based on the cloud data (e.g. indication of meeting place based on the agenda) • friends/contacts travelling around
Information about the Performance of the Car • fuel* • speedometer (Maybach example)***	**Information about the Performance of the Car** • view (and/or control) of the current driving mode and speed • fuel consumption, information on the energy reserves and range • other performance info (e.g. boost-oil pressure-oil temperature)
Information about the Weather • weather* weather information of destination** outside temperature dial***	
News*	
Google Search*	
ENTERTAINMENT	
• TV, DVD/movies, games, Facebook, pictures, Youtube*	• **Intelligent Media Streaming** • **Entertainment Planning (Setting and/or viewing the playlist in relation to the travel route)** • **Other Entertainment Features** • 'Beam Cam': Logging in to the surround cameras of other cars and see their view while travelling
COMMUNICATION	
Communication among Car Occupants • front-seat passenger and driver collaboration in navigation****	**Communication among Car Occupants** • sharing data e.g. route plan among displays dedicated to each occupant • collecting all shared information (e.g. playlist) in a shared unit of information provision, • getting a camera view of rear-seat occupants
Communication with Other People • Facebook, e-mail, contact list, SMS, Skype*	**Communication with Other People** • audio/video calls, text messages
[*] Osswald et al., 2013; [**] Lee et al., 2015; [***] Inbar & Tractinsky, 2011; [****] Trösterer et al., 2015; Perterer et al., 2015; Rümelin et al., 2013; Gridling et al.; 2012 and Forlizzi et al., 2010.	

4.3 Enhancement of front-seat passenger journeys

This paper argues that there is a design opportunity for “empowering” front-seat passengers and provides examples of academic studies and automotive solutions that would enhance front-seat passengers’ journeys. The term “empowerment” is used as an umbrella term to define the main motivation behind these efforts. This section explains in what ways these new interfaces, interactions, and infotainment features can enhance front-seat passengers’ travelling experience, along with bringing empowerment to users.

The expected contributions of sharing in-car information with passengers are clearly identified by Inbar and Tractinsky (2011) as “reduced boredom”, “increased trust”, “increased sense of inclusion” for (front-seat) passengers. We can claim that studies exploring driver-passenger collaboration not only investigate pragmatic navigation solutions based on collaboration but also aim for front-seat passengers’ ‘autonomy’ and ‘competence’ (Sheldon et al., 2001; Hassenzahl, 2010) by giving them more control and responsibility in completion of driving-related tasks, ‘relatedness’ (Sheldon et al., 2001; Hassenzahl, 2010) based on increased communication between front-seat occupants, and ‘stimulation’ (Sheldon et al., 2001; Hassenzahl, 2010).

In the section “Front-seat passenger infotainment features,” we introduced these features under the categories of *communication, entertainment and informatio*n. These categories also act as concepts to identify the ways of enhancing front-seat passengers’ journeys. We can link these categories to the psychological needs of the passenger Sheldon et al., 2001; Hassenzahl, 2010) as well. Accessing the *information about the journey, surroundings and performance of the car* can provide front passengers more ‘autonomy’ and ‘security’. It can be claimed that communication related features like audio/video calls, access to social media accounts carry potential to increase ‘relatedness’ and ‘popularity’. The feeling of ‘security’ and ‘relatedness’ can also be improved through the infotainment feature like having a camera view of rear seat-passengers in front-seat passenger cockpit. ‘Stimulation’ is also an obvious expectation from entertainment features.

Such potentials can only come true and be enhanced when the infotainment features are executed with appealing interfaces and interactions. For example, it is easy to associate media playing features with stimulation and fun; however, the user interfaces can be *stimulating* as well when they are used to access to *information* features. This argument can be generalized for any interface design, but it becomes even more to-the-point within the scope of this paper because ‘passengering’ is less a task or a pragmatic act than driving.

5 Concluding remarks

The paper identified that there has been a lack of automotive user interfaces that provide infotainment features and interactions enriching front-seat passenger's journeys. Needs and motivations of the front-seat passengers have been neglected since the main concern in automotive HMI design has been limited to the driving activity. Based on this problem definition, the paper provides an analysis of academic and industrial efforts that investigate empowerment of front-seat passengers. The main the source for the academic studies was the automotive UX literature, whereas industrial efforts were demonstrated through the technology review of a selection of the concept cars presented in several automotive/technology shows in 2015-2016.

The paper presents examples of front-seat passenger-oriented infotainment solutions. It also contributes to automotive UX literature by categorizing the intense list of solutions based on different dimensions of interacting with technology. By reviewing these categories, readers can easily differentiate the innovations regarding infotainment system interactions (how dimension) from the new functionalities/infotainment features provided to front-seat passengers (what dimension). This will enable investigation of new relations among varied dimensions/levels of the infotainment experience; such as delivering a specific communication feature (the functionality) with a new display technology that has never been considered for the use of the front-seat passenger.

The paper also gathered the concepts that identify the expected hedonic or pragmatic qualities from passenger infotainment systems such as ‘reduced boredom’ or ‘sense of involvement’ (why dimension), which helps designers to imagine more appealing infotainment features and interactions.

The concept car examples presented in the technology review show that passenger empowerment is on the agenda of automotive companies. This empowerment has been achieved either through exclusive solutions like infotainment screens dedicated to front-seat passenger or active involvement of front-seat passengers in the use of the infotainment system. The categorizations provided in Table 1 can be considered by designers and design researchers as a selection of approaches to follow while addressing front seat passengers’ needs. However, in pursuit of any of these design approaches, there are certain conclusions that should be drawn from the analysis to better target this specific car occupant:

Most of the solutions demonstrated in the paper fall short of making use of the full potential of the available interaction technologies. Despite the new infotainment features/functionalities provided, the general approach follows a ‘selective duplication of previous driver-oriented solutions’. We generally observe screens attached or extended to the passenger dashboard together with gesture or touch-based controls, although the solutions can be more flexible, such as portable displays and controls, head up displays as part of information provision, entertainment or communication. Driving is a challenging task that comes with the problem of division of attention to varied stimuli; therefore, manufacturers keep introducing new modalities (e.g. haptic feedback) in automotive HMI to rely less on the visual channel. This approach can also be introduced for the front-seat passenger. For example, there can be a switch between haptic and visual feedback in the infotainment interactions while front-seat passengers switch from resting with closed eyes to acting as a co-navigator. In fact, a technology which has been used for pragmatic purposes for the driver can deliver hedonic quality to the front-seat passenger’s user experience.

Front-seat passenger-specific infotainment has not been explored enough in production cars until now. Further investigation is needed to understand which solutions would be more favourable and worthwhile from R&D efforts to be applied into a real car. Solutions need to be tested considering different travel scenarios or contexts. For example, the relevance of the infotainment features can change based on the type of the travel. Information about the attractions of the destination is expected to be more appropriate during leisure journeys in comparison with the daily commute.

The link among the why-what-how dimensions of the front-seat passenger experience is also missing. The solutions demonstrate the most recent technologies and functionalities, but the motivations behind these front-seat passenger-oriented applications are not always clear. In other words, there is not enough exploration on how these solutions will enhance the user-experience or deliver hedonic quality as well as a pragmatic one. Designers need to reflect on their proposals with questions like “What type of positive emotions can be evoked by providing the estimated time of arrival information to passenger through a screen on the passenger dashboard, will it contribute to passenger’s sense of involvement in the travelling activity, what are the captivating ways of providing this information?” Therefore, while testing the design proposals, the research should be conducted in a way that we can investigate the links among different dimensions of the front-seat passenger infotainment experience.

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Understanding Design as a Catalyst to Engage Remote Couples in Designing for Long-Distance Relationships

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There is a gap between understanding the needs of couples who are in long-distance relationships in research and designing technologies for them in practice. The aim of this study was to understand how design can act as a catalyst in bridging the gap. Taking a user-centered approach, the study engaged with ten participants, i.e. five remote couples who had remained committed to each other in serious long-distance relationships. The goal was to build empathy with them, explore their experiences and skills for coping with long-distance relationships, identify their main challenges and needs, and understand their perspectives on existing artifacts that mediate intimacy between remote partners. As design considerations for future technology development, the findings reveal there is a need to take the strategy of customization into account when designing technologies for long-distance relationships, where customization can serve as an aid to empower remote couples as skilled practitioners to creatively use technologies so as to meet their diverse needs.

user-centered design, long-distance relationship, customization

1 Introduction

When you tell someone that you are in a long-distance relationship (LDR), what follows is often a look of pity implying “*doom*”. In a narrow sense, an LDR can be defined as an intimate relationship in which the couple is separated by a geographical distance that restricts physical contact and face-to-face communication.

Culturally, geographic proximity and frequent face-to-face interaction have been valued as relational necessities (Stafford, 2005). In opposition to those traditional values, studies of LDRs have remained marginalized in traditional relationship research (Jiang & Hancock, 2013). The growing interest in this domain started when Rohlfing (1995) claimed the LDR as an under-studied phenomenon. A survey conducted by Guldner (2005) suggested that there are over seven million couples (i.e., 14-15 million individuals) who consider themselves in an LDR in the US. LDRs among college students occupy a significant proportion; reports estimated that 75% of college students have at some point been in at least one LDR (Guldner & Swensen, 1995). Married couples also occupy a place in LDRs. According to Conlin (2009), approximately 3.5 million Americans live apart from their spouses for reasons other than marital discord. The international job market has been boosted by the integrated global economy, which pushes people to be apart from their loved ones in order to pursue overseas workplaces in today's competitive environment. This reason for separation from a loved one is on the rise among other causes for separation, including educational demands, dual-career pursuits, military deployment, emigration, and other such factors (Stafford, 2005). As a matter of fact, there is a tendency that the number of interpersonal relationships that have to face geographical separations, including but not limited to romantic relationships, has been steadily increasing over the past few years (Griffin & Bone, 2015).

The phenomenon of LDR has become prevalent. Despite the fact that there are numerous communication channels that have made it much easier for couples to stay in touch across the miles, technology presents a double-edged sword for LDRs. Couples maintain LDRs by using various interpersonal media, e.g. phone calls, video chats, texting, instant messaging, e-mail, etc. (Jiang & Hancock, 2013), whereas the point of frequent exchange of messages is emotional connection rather than just sharing information (Quintanilha, 2008). It has been found out that:

> *Most available technologies however focus on the transmission of explicit information, which neglects the emotional and subtle communication so typical for close relationships. (Hassenzahl et al., 2012, p. 30:2)*

Having acknowledged the above-mentioned problem, there has been a growing body of work on designing technologies aimed at mediating emotional communication in LDRs in the field of human computer interaction over the past decade. Early studies on connecting distant loved ones through an ambient communication channel have presented a pair of beds that bridge the distance between two remotely located individuals through aural, visual, and tactile manifestations of subtle emotional qualities (Dodge, 1997); a pair of interactive picture frames which, when one of them is being touched, the other lights up through an Internet connection (Chang et al., 2001); and virtual intimate objects that were designed to express intimacy in a rich manner so that when one circle is clicked, the remote partner's circle turns bright red, and then fades over time via a low bandwidth connection (Kaye, 2006). Technologies have advanced greatly over the past decade; recent work has introduced, for instance, concepts using a pair of bird-shaped devices wirelessly connected and used to send color messages as intimate acts back and forth between two lovers (Jespersen, Stounbjerg & Verdezoto, 2015); a set of two bathroom mirrors which makes it possible to leave a message on a steamy bathroom mirror over a distance (Schmeer & Baff, 2011); a vibrotactile glove that allows couples to feel the flex actions of their remote partners' fingers through vibrotactile sensations on their skin (Singhal et al., 2017); a ring that can measure the wearer's heartbeat and send it to the loved one's ring in real time (Werner, Wettach & Hornecker, 2008); and a distributed tangible jigsaw puzzle allows couples to play remotely and synchronously (Pan et al., 2017).

It can be seen from the above that wearable technologies, ambient media, biosignals, haptic sensations, hybrid interactions, etc. are widely employed to create a relatedness experience for couples in LDRs, in order to mimic the core components of every relationship, which are to be able to see, listen to, smell and touch each other. However, the focus has been put on technology-based experience to facilitate such communication, which might make users feel overloaded by technologies, as lifeless machines and standardized tools may fail to build an emotional connection needed by them. As a result, there is a gap between understanding LDR users' needs in research and designing technologies for them in practice.

The aim of this study is to bridge the gap between research and practice. Taking a user-centered approach, this study engaged five LDR couples in a series of design activities, with a view to building empathy with them, discovering their needs and challenges, and generating insights on designing for LDRs. The intention of this study is not to present a finalized solution to LDRs, but to discuss how design can act as a catalyst to elicit empirical insights around the experiences, challenges and needs of LDRs, and how these can act as a foundation for future technology design, so as to close the gap between research and practice.

2 Engaging authentic participants thoroughly in the design process

Prior studies have involved LDR couples in the process of designing technologies to mediate intimacy and relatedness over distance. For example, Lottridge and her colleagues engaged 13 LDR couples in the design of a technology probe to support the sharing of empty moments (Lottridge, Masson & Mackay, 2009); Chien developed different versions of a robotic pet and applied it to his own LDR in the sense of an autobiographical design exploration (Chien, Hassenzahl & Welge, 2016). LDR couples are often involved in the evaluation stage so as to achieve feedback from end users for improvements. For instance, Yang and her colleagues performed a four-week field test on a telepresence robot with two LDR couples in real-world settings (Yang, Neustaedter & Schiphorst, 2017); Gooch and Watts undertook a case study involving a single couple, who lived around 120 miles from each other, for an eight-week evaluation of a prototype device intended to allow distant lovers to share goodnight messages (Gooch & Watts, 2012b). Nevertheless, the results of a recent systematic literature review on research addressing the design of systems with unconventional user interfaces for emotional communication between partners' LDRs has revealed that most of the recruited participants in the analysis of 52 systems – filtered from the systematic search results of a total of 150 papers – were actually not remote couples in real life, but substitute participants were used instead (Li, Väänänen & Häkkilä, 2018).

LDR couples who have sustained a long-term commitment in their relationships are experts in the LDR experiences. Such authentic participants should be engaged throughout the design process as co-designers, not just in the evaluation stage, so as to design desirable LDR-oriented products that can fit into the lives of the end users. Furthermore, authentic participants should be encouraged to feel that they are seriously regarded as experts in the LDR experiences. In doing so, they will feel that they need to respond as experts in their experience domains (Visser et al., 2005), thus allowing their contributions to provide valuable insights on how technology can be designed to enhance the users' experience in LDR-oriented artefacts.

This study engaged a total of ten participants, i.e. five LDR couples (M=5, F=5) ranging in age from 23 to 45, who were involved in different stages of LDRs. The most experienced LDR couple in the study was a married couple who had been in an LDR on and off around 14 years, while the most inexperienced one was a couple who had been dating for two years, but were forced to live apart from each other for five months due to study-related obligation. Every couple selected for this study had remained committed to each other in a serious LDR, as opposed to a casual dating relationship; all participants had been in steady romantic relationships for at least two years. LDRs are diverse in terms of relationship stage, reasons for separation, miles apart, and communication patterns (Merolla, 2010). These were used as the basis for recruiting participants, who varied significantly in terms of nationality, age, occupation, location, marital status, and personality.

Given that the participants were all currently involved in LDRs, they were divided into two groups. The 'local' group included five participants (M=1, F=4) who were recruited from Rovaniemi, Finland, where the study was carried out, whereas the 'remote' group consisted of their remote partners, who had to participate remotely from China, the US, Poland, Russia and Helsinki. The participants volunteered for the study. Consent forms were provided, so as to ensure that the participants fully understood the potential risks and benefits of participating as well as their right to privacy.

3 Study design

This study consisted of three stages (see table 1) that followed an iterative design thinking process which consisted of empathizing, defining, ideating, prototyping and testing (Institute of Design at Stanford, n.d.). Firstly, the study began with gaining an empathic understanding of LDR couples.

After gathering the initial findings, challenges, needs and skills of LDRs were then defined. Following this, two workshops were conducted in order to ideate and prototype possible concepts with the participants to collaboratively design for LDRs. Lastly, the study attempted to test the feasibility of the solution for supporting LDRs. In doing so, the aim was to bridge the gap between understanding the needs of LDRs in research and designing technologies for LDRs in practice.

Table 1 Overview of the design activities.

Stages	Activities & Duration	Aim	Tools	Participants
1	Semi-structured interviews 2 hours each	To build empathy with participants, explore their personal experiences and skills for coping with LDRs, identify main challenges and needs, and understand current perspectives on existing LDR-oriented artefacts.	• Recorder • Skype • 12 images of existing LDR-oriented artefacts	N=10, M=5, F=5
2	Workshop #1 2.5 hours	To engage participants in the design process by encouraging them to collaboratively design possible solutions for mediating emotional communication for LDRs.	• Recorder • Black Sharpie pens • Sticky notes • Persona • Rip+Mix set • Prototyping materials	N=5, M=1, F=4
3	Workshop #2 2.5 hours	To evaluate the need and potential of customization when designing for LDRs without the support of technology.	• Recorder • Clamshell-shaped containers • Materials brought by participants	N=5, M=1, F=4

3.1 Stage One: Building Empathy and Defining the Problem

Empathy is a powerful tool and strategy that can be used to understand users – their needs, challenges, experiences, thoughts, feelings, motivations, preferences, interests – based on which, designers are able to create desirable user experience. Empathy can be defined as:

> *Our intuitive ability to identify with other people's inner states based upon observation of their outward expressions, their behavior. (Fulton Suri, 2003, p. 53)*

To build empathy with the participants, a set of semi-structured interviews was carried out with each remote couple. The participants were divided into two groups, i.e., on-site participants (N=5, M=1, F=4) and their remote partners, who took part in the interviews as remote-site participants (N=5, M=4, F=1). Skype was used as a support for remote-site participants who were unable to reach the place where the interviews were carried out.

To create a relaxing and familiar atmosphere where the participants would feel comfortable enough to share thoughts, insights and personal experiences, the interviews were conducted in each on-site participant's residence where they usually had video chats with their remote partner (see figure 1).

The questions embedded in the semi-structured interviews were intended to broadly understand LDR couples' needs, identify their challenges, and investigate how they tackle LDRs differently.

Figure 1 The participant discussing existing LDR-oriented solutions with her remote partner

To gain a deeper understanding of the real needs in LDRs and the current LDR couples' perspectives on existing LDR-oriented artefacts, a host of existing LDR-oriented artefacts that imply different needs – i.e., physical needs, emotional needs, sexual needs, social needs – were presented as 12 images to the participants. The presented LDR-oriented artefacts included published design concepts and existing products as follows:

- Pillow Talk (2010), a pair of wristbands designed to pick up the user's heartbeat and play in real time to the paired user's pillow speaker.
- Couple (2012), an intimate mobile application designed for two remote partners, where LDR-oriented interactive functions such as Thumbkiss and Live Sketch are available.
- Touch Room (2013), an interactive mobile game application where the users can both enter a virtual room, and when their fingers touch the same spot, the phone vibrates.
- Frebble (2012), a pair of hand-holding devices that allow users to hold each other's hands and feel each other's touch, even if they are on opposite sides of the world.
- Kissenger (2012), a mobile accessory that enables remote couples to send kisses over distance.
- Hug Shirt (2002), a shirt that enables users to send hugs over distance.
- Beam (2013), a telepresence robot that provides authentic eye-to-eye connection instantly across distance, allowing users to seamlessly move within space and engage in real time.
- Onyx & Pearl (n.d.), a pair of wirelessly connected masturbators enabling an interactive erotic experience for two individuals online.

- Roly Poly (2012), a pair of egg-like objects designed to sense the presence of each other, each object mirroring the other's movements and creating a simultaneous reaction.
- AmBird, a prototype device wirelessly connected in pairs and used to send colour messages as intimate acts back and forth between two remote partners (Jespersen, Stounbjerg & Verdezoto, 2015).
- RingU, a ring-shaped wearable prototype system for sharing intimate, interpersonal interactions remotely through subtle colored lighting and tactile expressions (Pradana et al., 2014).
- CheekTouch, a prototype device of an affective audio-tactile communication technique that transmits multi-finger touch gestures applied on a sender's mobile phone to a receiver's cheek in real time during a call (Park, Bae & Nam, 2012).

The participants were asked to choose four preferred artefacts out of the options provided. The six strategies used to create a relatedness experience, i.e., awareness, expressivity, physicalness, gift giving, joint action, and memories (Hassenzahl et al., 2012), were used as a basis for selecting the LDR-oriented artefacts shown to the participants. The workshop closed with the participants discussing the pain points in terms of current LDR-oriented solutions.

3.1.1 Findings from Stage One

All the semi-structured interviews were audio recorded and then transcribed. The transcripts were then subjected to a thematic analysis (see table 2) to form a viewpoint on each couple's skills for coping with LDRs, challenges and needs in their LDRs. Every participant faces own challenges, has diverse needs, and uses different skills to maintain and nurture an LDR. Table 2 only presents the main challenges, needs and skills that mentioned by both parties in each group.

As can be seen from table 2, some common challenges, i.e., geographical separation, an unstable communication environment and unsynchronized daily lives, can be identified. As mentioned previously, geographical proximity and frequent face-to-face contact are commonly assumed to be necessary to maintain close relationships (Stafford, 2005). A lack of these two relational necessities is believed to be the killer of LDRs. However, the participants highlighted that distance does bring inevitable challenges to LDRs, albeit to varying degrees, while those who have remained committed to their LDRs have proved that distance does not necessarily kill a relationship. This can be seen in the following comment by a married couple who had been in an LDR on and off for about 14 years:

> *We have no choice but to be in an LDR; it is damn hard, but we finally have become the experts* [on tackling issues and challenges in an LDR] *… distance starts to mean nothing when someone means the whole world to you.*

Every couple's needs are different when it comes to LDRs. Showing the 12 images of existing LDR-oriented artefacts to the participants and asking them to choose four preferred options helped reveal their real needs. It turned out that the most primary needs were emotional needs, accounting for 63.9%. This demonstrated that emotional impact plays a significant role in LDRs.

Although the participants had a variety of ways of maintaining LDRs, they relied on mainstream communication tools to keep in touch with their remote partners, as mainstream communication tools provide instant, cheap, and convenient ways to stay connected. However, one of the pain points of mainstream communication tools is that they are designed for a large variety of end users. Thus, the emphasis is then placed on functionality, rather than providing the emotional communication needed for LDRs (Hassenzahl et al., 2012). As one participant said:

> *Sometimes we have nothing new to talk about at the end of the day, because we already know each other's stories from Facebook.*

Table 2 Details of the semi-structure interviews.

Groups	LDR Duration[1] & Type	Main Challenges	Main Needs	Skills
Couple #1	14 years International LDR	• Time zone differences • Unstable communication environment • Safety issues	• Create playful experience with children over distance. • Keep each other updated in real time.	Fully trust and be committed to each other.
Couple #2	Three years International LDR	• Time zone differences • Unsynchronized daily life • Unstable communication environment	• Do more activities together to synchronize daily life. • Create some shared experiences during separation.	Get creative in using social media to connect with each other constantly.
Couple #3	One year International LDR	• Unstable communication environment • A lack of physical intimacy • Absence of tangible support	• Find out ways to avoid misunderstanding. • Learn to control negative emotions.	Keep reinventing romance and creating pleasant surprises for each other.
Couple #4	Five months International LDR	• Unstable communication environment • Unplanned changes • Insecurity and uncertainty	• Know each other's schedules in advance. • Schedule more regular communication dates.	Have some hobbies outside the relationship and pursue common interests.
Couple #5	1.5 year Domestic LDR	• Hyper-connectivity • Overwhelming communication tools • Unnecessary online misunderstandings	• Set up healthy communication patterns. • Find out ways to avoid excessive communication.	Make the distance in-between seem more bridgeable by doing the same things at the same time.

Unlike mainstream communication tools, LDR-oriented solutions are targeted at a specific group of users, that is LDR couples. However, only one couple claimed they had experience of using LDR-oriented products in real life. Furthermore, despite the 12 LDR-oriented artefacts being introduced and shown as images to the participants, it is noteworthy that one of the participants chose none of

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[1] All the interviewed participants had been in steady romantic relationships for at least two years. The durations shown in table 2 were the lengths of time they had been apart in the relationships.

the provided options. As a matter of fact, most LDR-oriented artefacts provide a traditional one-size-fits-all solution, even the same package for every user, which might not be appealing and sufficient to meet every user’s needs, as the following comment by one participant shows:

> *Every single relationship is supposed to be unique … how does my ring* [one of the LDR-oriented artefacts shown to the participants] *differentiate itself from others? … are these* [functions of the artefact] *adjustable?*

The participants also raised serious concerns about experiencing intimacy through technology. Seven participants described using technology to share intimate moments with a remote partner as being *“*uncomfortable*”, “*unreal*”, “*weird*”* and *“*geeky*”*. The emphasis of existing LDR-oriented artefacts has been put on technology-based experience, which might make users feel overloaded by technologies, as one participant said: “S*ometimes I feel a bit overloaded by all these fancy products; I can’t keep up.*”

Another important feedback was linked to the possibility of using current LDR-oriented artefacts without an internet connection. As one participant suggested:

> *I can’t access the internet when I am at work; even my phone doesn’t have any signal … I’d prefer something else other than instant messaging applications.*

As can be seen from the initial findings gathered from the empathizing stage, the problem of the current LDR-oriented solutions could be defined as a gap between understanding LDR users’ needs in research and designing technologies for them in practice.

3.2 Stage Two: Ideating and Prototyping for LDRs

Having empathized with the participants, identified emotional needs as the most primary needs in LDRs, and defined the problem statement, the aim of the first workshop was to encourage the participants to step into the role of designer, ideating possible solutions for mediating emotional communication to support LDRs. The workshop started with ice-breaker activities that enabled the participants to introduce themselves and learn more about each other. Due to geographical barriers, their remote partners were not able to participate in the workshop.

Before the workshop, three personas were created based on the valuable personal stories revealed during the semi-structured interviews. The purpose of applying the persona methodology is to exhibit the real motivations, reactions, goals and needs of a specific group of LDR couples, while using fictional characters to present the participants themselves (Stickdorn & Schneider, 2011).

The participants were encouraged to collaboratively design ideas that would make the personas feel emotionally connected, even when interaction and communication are restricted due to a breakdown of the internet connection.

> *Users can become part of the design team as ‘expert of their experiences’, but in order for them to take on this role, they must be given appropriate tools for expressing themselves. (Sanders & Stappers, 2008, p. 9)*

To encourage creative and innovative thinking and allow the participants from a non-design background to be easily engaged in the design process, the notion of Rip+Mix, a fast and effective idea generation tool (Press et al, 2011), was introduced to the participants. The idea was to mix a pleasurable experience in real life and a painful experience in LDRs, in a fast and intuitive way to think of new or improved solutions. As mentioned earlier, an unstable communication environment has been identified as one of the common pain points in LDRs. Choosing an unstable communication environment as a painful life scenario and using the provided template, the participants successfully generated ideas that responded to the identified needs of the personas (see figure 2).

Figure 2 The participants using Rip+Mix worksheets to generate ideas for the provided personas

Following the ideation stage, the workshop entered the next phase, where the participants were encouraged to make their ideas tangible by using prototyping materials – e.g., Legos, plasticines, strings, cardboards, etc. – to visualize their design concepts (see figure 3). The workshop closed with the participants picturing how they might interact with the design concepts in their own LDR in real-life settings.

Figure 3 The participants using prototyping materials to visualize their ideas for mediating emotional communication in LDRs

3.2.1 Findings from Stage Two

The challenging topic of designing an emotional connection for couples to maintain LDRs without the support of an internet connection triggered a lively discussion. The participants found that modern society is becoming too reliant on technologies to maintain a relationship, which is a significant contrast with the old times. As one participant revealed:

> *My grandpa was a sailor; he used to write letters and send postcards to my grandma... my grandma had to sit by a landline waiting for my grandpa to call her at a specified time … they finally got married after three years of dating long distance … my grandma still keeps some of those letters and postcards; she looks back on her treasures* [letters and postcards] *every now and then; they remind her of the good old memories…*

Taking the persona as a user-centered approach, the participants found themselves resonating with the provided personas, which helped spark insights for designing feasible solutions for LDRs. Using Rip+Mix as a hands-on idea generation tool, the participants – notably those without a design background – were easily engaged in the design process.

During the idea-generation phase, the participants outlined a set of simple and practical ideas which not only could fit in real-life scenarios, but also could be regarded as an emotional attachment: e.g. a blanket that maintains a constant warmth which synchronizes itself with the temperature of a remote partner's body. The participants discussed and shared their ideas. The most favored idea was a pair of keyrings that display meaningful and personal information, such as the current time of a distant loved one, the time until the next reunion, reminders for special dates, a memory photo gallery, etc. Additionally, the functions and appearance of the keyring are customizable, so that users will have a one-of-a-kind keyring that reminds them of a distant loved one.

When asked the reason why they favored the concept, the participants highlighted that it was "portable", "customizable", "interesting", "multi-functioned", and "private". When asked how the concept could build an emotional connection between LDR couples, the participant who came up with the idea stated:

> *It* [the keyring] *might seem like an ordinary accessory to others, but to the owner it's more than that … the functions can be customized, so the owner is able to decide how it will work the best … if a couple invest effort in customizing the appearance together, it then becomes something special between the two, and that would make them feel mindfully connected with each other.*

This demonstrates there is a need to apply the strategy of customization when designing technologies for LDRs. The design concept is discussed and presented as a starting point to provide a range of preliminary insights and design considerations for further technology design for LDRs. Customization offers opportunities for users to adjust, specify and modify a product, where they are able to creatively use technology to better fit their diverse needs in real-life situations. By inputting efforts in customization, it makes a lifeless object become meaningful and symbolic to users, and as such the object will become a one-of-a-kind object to which users become emotionally attached.

3.3 Stage Three: Testing the Role and Impact of Customization

In order to evaluate the role and impact of customization when designing for LDRs without the support of technology, the second workshop was carried out, where a couple of small clamshell-shaped containers were provided for the participants to customize their ideal necklace that could make them think of their distant loved ones. Before the workshop, the participants were asked to bring materials that could remind them of their remote partners. Using materials, e.g. photos, accessories, perfume, etc., that were brought to the workshop for customization, the participants made a number of low-fidelity prototypes (see figure 4). The purpose of taking the low-fidelity prototyping approach was to enable the participants who came from a non-design background to easily participate in the design process (White et al., 2003). The workshop closed with the participants sharing the backstories behind their designs, and all of them had big smiles when they left the workshop.

Figure 4 The participants customizing their ideal necklaces, and a few examples of the low-fidelity prototypes they produced

3.3.1 Findings from Stage Three

The participants had positive feelings about the strategy of customization, as it helped them build a bond with an ordinary object using materials that would make them think of a distant loved one. The relationship itself is one of the crucial criteria for developing an artefact that can function as a representation of remote presence (Tollmar & Persson, 2002). Even though the workshop itself did not involve any support of technology, the implementation of customization was able to help the participants who have sustained a long-term commitment in an LDR to feel emotionally evocative across the miles, as in this feedback from one participant:

> *I gave it* [the necklace] *special meanings by customizing exactly the way I want it to be… for me it's not just an ordinary necklace; I just feel it reminds me of my partner and the feeling makes me feel connected…*

During the process of customization, the participants started to open up and share their personal LDR stories with the others, which evoked some shared memories with a distant loved one. One participant recalled a memory of an event she had with her remote partner, and related it back to the necklace she customized:

> *It was the day he proposed to me… the place was covered with hundreds of blooming daisies that spelled out "marry me" … Daisies are my favorite flower.*

This demonstrates that the strategy of customization could provide more fun interactions to enrich user experience and enable emotional connection even without the support of technology. There is no doubt that technologies can provide immediate access to talk to, see or even to feel a remote partner in real time. However, it is questionable whether the technology-based one-size-fits-all solutions for LDR are still useful when there is no internet connection or technology to support such communication and interaction between LDR couples. In this light, customization can play a subsidiary yet important role when designing technologies for LDR couples. Although it may not seem surprising that customization was seen positively by the participants, given that it has been well-known for engendering value for an object that cannot be obtained through mass production, customization adds to the positive impact of what technology is able to bring to LDRs, as customization supports LDR users as skilled practitioners in utilizing technology to meet their diverse needs in their own creative ways.

4 Discussion

4.1 The Need and Potential of Customization in LDRs

It has been noted that current commercial communication tools are often standardized:

> *Each individual has a unique voice and style of handwriting, things which are identifiable by people who know that individual well. In contrast, all email messages or typed letters look the same regardless of who the author is. (Gooch & Watts, 2011, p. 238)*

Gooch and Watts (2011) propose a design framework for meditating personal relationship devices, where personalization is valued as one of the key factors. Prior work has proven the merits of personalization in designing technologies to support couples in LDRs, which can enhance communication affectivity in terms of providing awareness and reminding people of their specific distant loved one in the context of remote interpersonal communication (Saadatian et al., 2013). For example, to activate different metaphors of hand-holding, personalization was utilized in order to make the prototypes stand out from a standardized object and meaningful to participants (Gooch & Watts, 2012a).

Customization and personalization both refer to tailored contents. The difference between these two terms is that customization is user-tailored while personalization is system-tailored (Sundar & Marathe, 2010). When designing technologies to enable an emotional connection in LDRs, it not only brings to light the need of employing personalization to symbolize a remote partner, but also sheds light on employing customization as a user-tailored approach to enable creativity, where remote couples who are the experts in LDR experiences can feel empowered to become designers on their own, having space to adapt, modify, specify and create a desirable product according to their own preferences and needs, which is thereby able to meet their diverse needs.

4.2 Design as a Catalyst for Engagement and Empowerment

Design enabled this study to work at two different levels. The first was a strategic level, where design was used as a catalyst to enable engagement. Given that the majority of the participants were non-designers, Rip+Mix was used to help encourage creative and innovative thinking; a low-fidelity approach was taken to ensure they could be easily engaged in the design process. The use of three typical personas enabled the participants to feel resonance with other LDR couples, so that empathy was able to be generated.

> *To develop empathy is an individual act, but by discussing it in a team, the discussion serves as a trigger for others to make more connections, which will lead to increased understanding (Kouprie & Visser, 2009, p. 439).*

While discussing ideas for mediating LDRs in real-life scenarios, the participants revealed the need and potential of customization as an experience-driven user interaction when designing technologies for LDRs. The ideation process empowered the participants to take on roles as co-designers and experts in LDR experiences, to collaboratively design possible solutions to tackle the problems that they had encountered in LDR experiences. This entered the second level, where design catalyzed empowerment. Encouraging the participants to make their ideas tangible during the prototyping process, caused the participants to shift their roles, becoming builders who visualized their ideas and storytellers who shared LDR experiences. These two levels working together helped bridge the gap between understanding LDR users' needs and designing technologies for them.

4.3 Limitations and Future Work

Several limitations of this study should be acknowledged. Firstly, the size of the sample may limit the study's generalizability. Due to geographical barriers, the remote-site participants were not able to participate in the workshops. However, every participant varied dramatically in terms of nationality, age, occupation, marital status, personality, etc. Additionally, every LDR couple in this study was a typical case among most types of LDRs, as their relationships differed with regards to communication preferences, relationship length, relationship stage, geographical distance, reasons for separation, etc. The typicality of the sample is believed to give solid indications on understanding LDR couples' needs, identifying their challenges, and investigating how they tackle LDRs differently. Although a relatively small number of participants were involved, they were engaged thoroughly in the study. Moreover, they were skilled practitioners of LDRs who were more likely to contribute valuable insights on how technology could be better designed for LDRs, as they had been involved in steady romantic relationships for at least two years and had remained committed in serious LDRs. Therefore, the study size is appropriate, given the level of intensity of the authentic participants' involvement. Secondly, the short-term duration of the study and a lack of real-life prototyping over time may not be sufficient to assess the value of customization for LDRs. Although the findings are encouraging, the evaluation was conducted with only one side of the five LDR couples. In future work, continuing towards more mature prototype development and more comprehensive evaluation is needed.

5 Conclusion

Through this study, design has acted as a catalyst to encourage storytelling and build empathy with ten authentic participants who had remained committed to one another in serious LDRs, with the aim of bridging the gap between understanding the needs of LDRs in research and designing technologies for LDRs in practice. A deepened understanding of current LDR couples' perspectives in regard to existing LDR-oriented artefacts, as well as their challenges, needs and skills in LDRs have been provided. The findings indicate that there is a need to take the strategy of customization into account when designing technologies for LDRs, where customization can play a subsidiary yet important role: that is, empowering LDR couples as skilled practitioners to use technologies in their own creative ways to meet their diverse needs. In doing so, customization makes a lifeless object become meaningful and symbolic to users, and as such the object becomes a one-of-a-kind object, which thereby enables an emotional connection with it. Further research is needed to pursue a more longitudinal and in-depth study on further scoping the design space around employing customization to design technologies to support emotional communication for LDR couples.

With the increasing popularity of 3D printing technology, which has been assessed as an enabler for customization (Srinivasan et al., 2017), more possibilities for mitigating challenges on customization will be opened up. This study can be considered as a step towards developing new concepts for designing customized technology based on individuals' needs.

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Are Traditional NPD Processes Relevant to IoT Product and Service Development Activities? A Critical Examination

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Increasingly physical products are being equipped with sensors, which connect them to the Internet; the network of these 'smart products' are acknowledged as the Internet of Things. These digitalized artefacts have a wide variety of material properties that could include a range of outcomes, such as new products, platforms, services, and other value pathways that differentiate them from their non-digital counterparts. Practitioners and researchers acknowledge that these differences influence tremendously on IoT product and service development processes. These are significant for IoT firms that occupy the market, due to a paucity of established literature on this theme; it is difficult to find studies on NPD processes, which reflects this digitization. This is an exploratory paper. That explores current literature prior to further empirical data collection. Through a critical examination of literature, this paper examines how smart product development processes are different from traditional product development processes. Thus, this paper offers critical insights and observations to enable both practitioners and academics to ascertain a detailed understanding of diverse approaches to NPD process activities for the IoT.

new product development process; internet of things; digital innovation; big data

1 Introduction

By 2020, it is estimated that 50 billion devices around the world will be connected to the Internet (Cisco, 2011). This seemingly recent trend has been decades in the making, but is at a critical tipping point now (Burkitt, 2014). The IoT era represents a transformative shift for the economy in which other major technology industry trends (e.g., cloud computing, data analytics, and mobile communications) can be incorporated (ibid, 2014). At present, the Internet of Things remains a fertile field for enterprises and so that in every six businesses is planning to roll out an IoT-based product (ibid, 2014). It is anticipated that the amount of IoT products will soon overtake the number of connected individuals: Gartner (2014) forecasts that the IoT will reach 26 billion units by 2020, up from 0.9 billion in 2009, and will affect how organisations develop new products and services.

Consequently, the 'Internet of Things' (IoT) is becoming a popular theme of exploration amongst academics and industry practitioners, i.e. a new technological orientated paradigm regarded as a vision of connectivity, for anything, at anytime and anywhere, with an impact on everyday life more dramatic than the Internet had in the past twenty years (ITU 2005). IoT is also defined as "Interconnected objects having an active role in what might be called the Future Internet" (European Commissions Information Society, 2008). Such interconnected objects, so called 'smart products', have the capability to retrieve, store and share massive amounts of data which is also transforming business (Pisano, Pironti, & Rieple, 2015) and NPD processes (Johnson, Friend & Lee, 2017). Moreover, these pervasive adoptions of and innovations with digital technologies is radically changing the nature of products and services (Yoo, Boland, Lyytinen & Majchzak, 2012) and therefore influencing NPD processes on smart products and services.

1.1 Study Rationale

With the emergence of IoT as a new source of huge data, businesses face new opportunities as well as new challenges (Porter & Heppelmann, 2014). Not only manufacturers but also the many various service industries are in the process of adoption of the IoT to increase revenue through enhanced services and to lead the market (Lee & Lee, 2015). The adoption of this technology is rapidly gaining momentum since technological, societal, and competitive pressures push companies to innovate and transform themselves (ibid, 2015). Although researchers and practitioners often critically debate the opportunities and challenges to the adoption of IoT, not much attention has been focused on the New Product Development process of IoT; arguably one of the most critical marketing planning and implementation process activities. It is difficult to identify a generic NPD process, which reflects the rapidly growing digitization, as such, there is a paucity of studies on the differences between traditional NPD models and emergent approaches towards IoT product and service development models.

1.2 Research Goal, Questions and Methods

This paper forms part of a summary of IoT products development practices, and is focused on a critical examination of established NPD and NSD processes that are related to the development of IoT products and services.

Its primary aim is to contribute to a deeper understanding of the IoT product and service development processes. The paper provides insights with regard to establishing new approaches to the IoT product development process, which could then enable academics and industry practitioners to better understand the process of developing IoT products and services. The following research questions will be both offered and critically debated:

- What are the characteristics of existing NPD and NSD processes and their relevance to IoT product and service development activities?
- What are the key factors affecting the development of IoT NPD processes, and how do they differentiate them from their non-digital counterparts?
- What are the new attributes required by IoT product and service development activities?

In order to answer these primary questions, this paper presents a common understanding of established NPD and NSD processes; then it offers a summary of relevant trends of IoT, and closing with implications for emergent approaches towards the IoT. The first stage focused on issues surrounding traditional NPD (Cooper, 1990; Booz, Allen & Hamilton, 1982; Trott, 2012; Takeuchi & Nonaka, 1986; Pennell, Winner, Bertrand, & Slusarczuk, 1989; Crawford, 1997; Baker & Hart, 1999; Cooper, 1994; Smith, 2007), NSD process (Johnson, Menor, Chase, & Roth, 2000) and innovation process (Chesbrough, 2004) identify the common characteristics of existing development processes for products and services. Secondly, it examines the key factors in digital innovation which affect approaches towards the development of hybrid products and services, including six dimensions of digital innovation (Yoo, Lyytinen, Boland & Berente, 2010); three dimensions of big data (McAfee & Brynjolfsson, 2012; Meta Group, 2001); new opportunities in digital age (Henfridsson, Mathiassen & Svahn, 2014) and three traits of innovations (Yoo et al, 2012). Finally, based on the study of NPD for IoT products and services, guidelines for developing smart products and services are then offered.

The research has involved an extensive examination of current literature surrounding these topics; articles and texts, which were broadly selected through searches of electronic databases such as Wiley Online Library Journals, Business Source Complete, ProQuest Business Premium Collection, Springer Journals Archive and Google Scholar. Search terms used, included 1) "NPD (New Product Development)", "NSD (New Service Development)", "design process", "Agile software development", "Innovation process", "Digital innovation process", Digital innovation management", 2) "IoT (Internet of Things)", "Smart product", "Hybrid product and service", and "Digital artefact". These were then supplemented by manual searches of abstracts of articles published in Journal of Product Innovation Management, Journal of Information Technology, Research Technology Management, Information Systems Research, Organisation Science, International Marketing Review, Journal of Marketing, and European Journal of Innovation Management. Each text was critically examined for their relevance to the central three themes or questions of study.

2 The Internet of Things (IoT)

The 'Internet of Things' is the combination of physical components (hardware), smart components (sensors, software and data analytics) and connectivity (wired or wireless connection) which empowers to improve value creation. The smart components elevate the capabilities of the physical product, whilst the connectivity components enhance the capability of the smart components. Connectivity allows IoT products both the capability to exchange information between the product and its environment, whether that its user, the manufacturer or other smart products, and the capability to offer functions that exist outside the physical device (Porter & Heppelmann, 2014).

IoT products provide geometrically expanding opportunities for new functionality, greater reliability, higher product utilization, and capabilities that cut across and exceed traditional product boundaries (Porter & Heppelmann, 2014). IoT is penetrating a wide range of industries including retailing, manufacturing, healthcare, insurance, home appliances, heavy equipment, airlines and logistics (Lee & Lee 2015). These new types of products externally alter industry structures and boundaries but also internally re-shape the value chain by changing product design, marketing and manufacturing, and by demanding the need for product data analytics (Porter & Hepelmann, 2014). Giudice (2015) argues that the IoT utility is even reshaping innovation processes connected to products and services as well as interpreting the business process management in many sectors.

Whether companies are going to take either get-ahead strategy or catch-up strategy (Firms implementing get-ahead strategy, use innovation reputation to differentiate from their competitors, in contrast, implementing catch-up strategy, companies are able to remain efficient in order to survive, grow, and even overtake the leader's position), all companies often expect to have appropriate NPD processes to develop their own IoT products or services in order to take advantage of IoT innovations in the future. A new product development process for IoT is therefore emerging where products consisting of electrical and mechanical parts become intelligent systems that combine hardware, software, control sensors, data storage and connectivity in infinite ways. With so much potential value in the investment of IoT technology, organisations need to have an appropriate and efficient NPD process to minimize the risk of failure. As such, this paper will now review how traditional NPD and NSD have evolved and their characteristics before exploring their relevance to IoT and, new approaches toward IoT product and service development(s).

3 New Product Development and New Service Development

As contemporary competitive pressure and pace of technological change increases, corporations face the challenges of increasing efficiency, creating breakthroughs, and pre-empting competitors (Meyer & Utterback, 1995; Kessler & Bierly, 2002). In this context, the continual development of new products are generally admitted as a requirement for companies' growth and long-term prosperity. Consequently, the subject of New Product Development (NPD) has gained a considerable amount of attention from product development professionals and researchers over the decade (Durisin, Calahretta, & Parmeggiani, 2010; Machado, 2013). A large number of academics has defined new product development, such as the transformation of a market opportunity and a set of assumptions about product technology into a product available for sale (Krishnan & Ulrich, 2001). Bruce and Cooper (2000) argue it is a term used to capture a range of different types of innovative activities leading to the production of a new service or product from radical innovations to simple modification and adaptations to existing products.

Awwad and Akroush (2016) identify NPD efficiency as the most significant element to determine a company's competitiveness and survival, because it distinctively affects firm's financial performance. Thus, NPD is a fundamental business activity and as such "the development of new and improved products for the survival and prosperity of modern corporations" (Cooper, 2005). However, managing new product development is a challenging, complex and risky process (Bruce & Cooper, 2000; Goffin & Koners, 2011), as the failure rates of NPD are estimated about 40% of new products at launch, and further only 13% of companies report that their total efforts to NPD hit their annual profit objectives (Cooper, 2017). Hauser and Dahan (2007) argue that having a good NPD process is critical in terms of firms can efficiently managing the inherent risk of new product development.

Numerous NPD process models are characterized as step-wise approaches such as stage-gate system (Cooper, 1990) or The Booz, Allen and Hamilton model (Booz, Allen & Hamilton, 1982) that managers are recommended to use (Harmancioglu, McNally, Calantone, & Curmusoglu, 2007), which are clear and useful in terms of management (Eveleens, 2010), but also effectively acting as a blueprint for organizations to follow and adapt as required (Oorschot, Sengupta, Akkermans, & van Wassenhove, 2010). However, these sequential models are regarded as relatively simple standard processes for NPD (Tidd & Bessant, 2005; Bruce & Cooper, p.11, 2000) and too prescriptive and mechanistic, therefore, fail to take into account overlaps of activities that will occur naturally in the workplace (Bruce & Cooper, p.11, 2000). Moreover, these models can increase cycle time (Schilling & Hill, 1998) so that besides the strength of the models, the weaknesses apparent in the sequential models led to the development of more complex models.

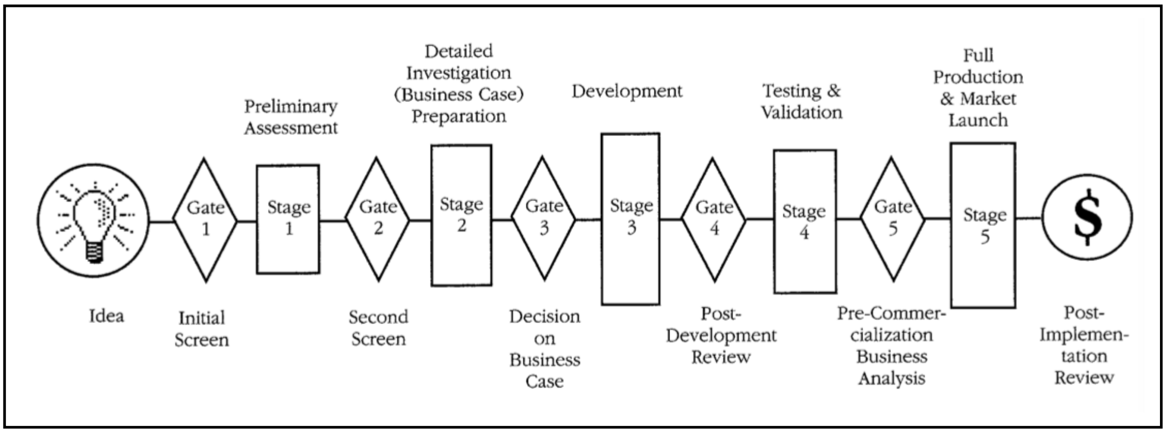

Figure 1 A Stage-Gate System. source: Cooper, R. G, 1990

Several researchers applied sequential models to the service development activity (Stevens & Dimitriadis, 2005). Johnson, Menor, Chase, and Roth (2000) developed a model describing the NSD sequence which identifies 4 broad stages and 13 tasks that must be conducted to launch a new service, and the components of the organisation that are involved within the process. Although sequential NSD models provide a descriptive view of ongoing processes, they suffer from three major weaknesses as linear NPD models do: 1) time-consuming and overly bureaucratic processes slow projects down (Cooper, 1994); 2) each stage does not describe the way of integration that firms organise development teams (Stevens & Dimitriadis, 2005); 3) linear models do not help to define what must be produced during each stage (ibid, 2005).

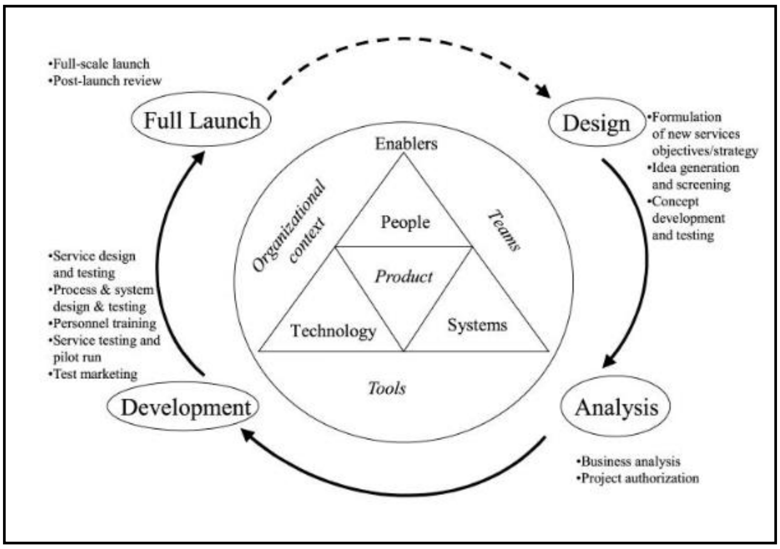

Figure 2 New Service Development Process. source: Johnson et al, 2000

From the idea to focus attention on the project as a whole rather than the individual stages (Trott, 2012), radically different approaches have emerged which are simultaneous approach such as parallel processing models (Takeuchi & Nonaka, 1986), Concurrent Engineering (Pennell, Winner, Bertrand, & Slusarczuk, 1989), Activity-stage models (Crawford, 1997), multiple convergent model (Baker & Hart, 1999) and Third-generation model (Cooper, 1994). The key benefit of parallel processing NPD models is that they decrease time to market by reducing the cycle time (Anderson, 1993) and emphasises the need for a cross-functional approach (Trott, 2012). However, adopting parallel processing requires more effort from all departmental functions, more effective management, and large-scale organisational changes in routine (Bruce & Cooper, 2000) so that most organisations are not willing to deal with the changes, altering the traditional method of NPD (Anderson, 1993).

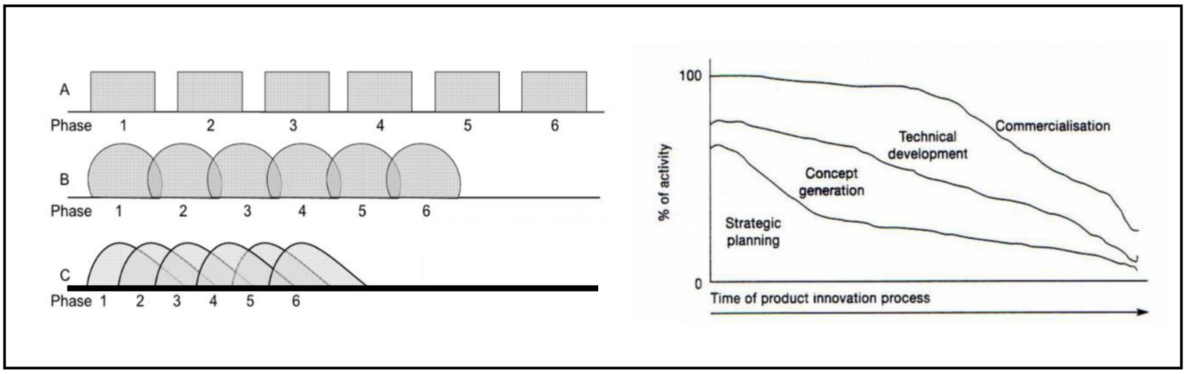

Figure 3 Left: Sequential (A) vs. Overlapping (B & C) Phases of development. source: Takeuchi & Nonaka, 1986; Right: Activity-Stage Model. Source: Crawford, 1997

Chesbrough's (2004) open innovation concept is not presented as a model of NPD as such; however, it has been highly influential in the areas of R&D management, innovation, and NPD. It emphasises the significance of external network interactions in relation to NPD activities and this phenomenon has grown due to a number of factors such as the reduction of the product life cycle, the aggregation of global competition and the rising costs of research and development (Caputo, Lamberti, Cammarano, & Michelino, 2016).

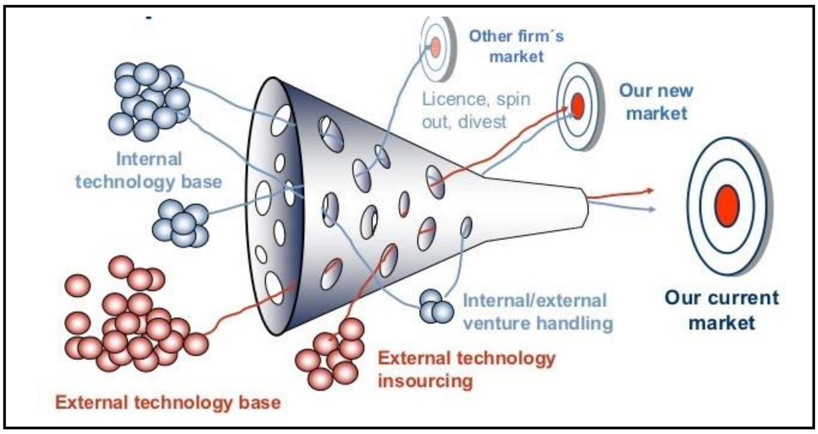

Figure 4 Open Innovation Model. source: Chesbrough, 2004, Presentation at 10th Annual Innovation Convergence

Recently, flexible product development is the ability to make changes to the product being developed or in how it is developed (Smith, 2007) so that agile methodologies begins to attract interest from developers of physical products (Cooper, 2014; Ovesen & Sommer 2012) who experienced the limitations and challenges of traditional waterfall product development approaches. Agile development method is for software development based on iterative and incremental process consists of a number of short development cycles, known as sprints (Beck, Beedle, van Bennekum, Cockburn, Cunningham, & Flowler, 2001). It is argued that these 'sprints' improve communication and coordination activities, speed to market and faster responses to changed customer requirements or technical challenges (Begel & Nagappan, 2007). However, since agile methodology is for software development, some challenges for manufacturers adopting agile practices have been identified, i.e. a lack of scalability, a proliferation of meetings, and a lack of effective management (Cooper, 2017).

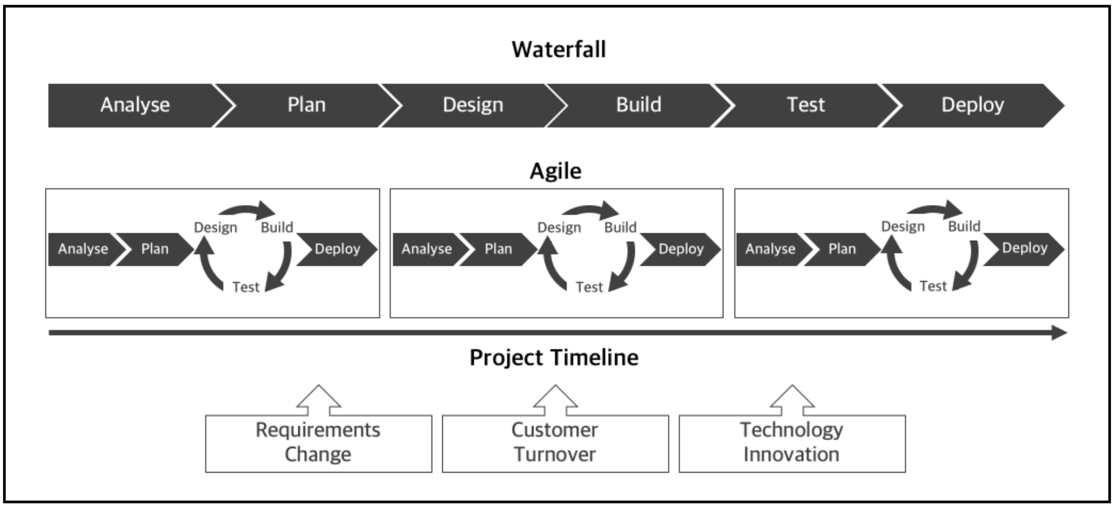

Figure 5 Agile Software Development adapted from Mistral, 2015

Summarising the development of NPD models (Rothwell, 1994; Ortt & Duin, 2008; Cooper, 2016), is supported by some trends of increasing and particular significance. Firstly, the organisation's capability to develop new products quickly have become an increasingly important aspect in recent years in determining competitiveness, specifically in industries where product cycles are short and technological change rates are high (Rothwell, 1994; Goktan & Miles, 2011; Cooper, 2014; Chang & Taylor, 2016). Secondly, simultaneous processing is regarded as another key factor for successful

NPD management, with cross function teams working independently which improves the speed, efficiency and flexibility of the NPD process (Williamson & Yin, 2014). Thirdly, unlike NPD approaches in the industrial era, which chiefly relied on information from internal research, recent approaches (e.g. open innovation) are more likely to look outside the company, such as to customers, competitors, and suppliers, in order to find new strategic partners and build comprehensive networks to have more value and competitive advantage (Chesbrough, 2006).

Although a comprehensive set of literature surrounding NPD approaches has been discussed, and indeed successfully applied (Cooper, 1994; Chesbrough, 2003; Hansen & Birkinshaw, 2007; Sheu & Lee, 2011; Williamson & Yin, 2014), it is clear that established NPD processes are still too time-consuming, with many that either are simply a waste of time or are cost ineffective. (Cooper, 2016; Ortt & Duin, 2008; Sheu & Lee, 2011; Cooper, 2014). More importantly, NPD processes reflecting the nature of IoT product and service development are limited in number. Emerging NPD approaches for IoT are now required since the field of innovation management must adapt to a changing economic, societal and technological context in this digitized era. Therefore, the attention of this discussion will focus upon the key factors that are influencing the development process for IoT products and services and how they differentiate from existing NPD processes.

4 What factors differentiate traditional NPD to NPD for IoT

Yoo et al (2010) argues that to understand the nature of digital innovation, one must understand how digital technology differs from earlier technologies, in other words, characteristics of digital technologies; the reprogrammability, the homogenisation of data, and the self-referential nature of digital technology. The reprogrammability refers to a digital device that is, reprogrammable, allowing the device to perform a wide array of functions (Yoo et al., 2010). The homogenisation of data means that any digital content which can be stored, transmitted, processed, and displayed, can be combined easily with other digital data to deliver diverse services which blurs the boundaries of product and industries (ibid, 2010). Finally, the self-referential means that digital innovation requires the use of digital technology which allows fostering further digital innovation through a virtuous cycle of lowered entry barriers, costs, and accelerated diffusion rates (ibid, 2010).

The six dimensions of digital innovation, identified by Yoo et al (2010), are also associated with both innovation outcomes (convergence, and digital materiality) and innovation processes (generativity, heterogeneity, locus of innovation, and pace).

The first dimension of digital innovation is digital convergence. Since digitized technologies share the same infrastructural capabilities, which open novel opportunities for products and services (Tilson et al, 2010), convergence refers to continuous integration of diverse and heterogeneous technologies through homogenization of digital data (Yoo et al, 2010). This therefore changes the nature of products towards becoming digital platforms: e.g., an automobile has become a mobile computing platform (ibid, 2010). More artefacts interacting with other digital devices, provide novel user experience: e.g., GPS (Global Positioning Systems) service in mobile phones, when combined with cars or clothing, deliver an array of service and innovation which connects previously disconnected customer experiences and creates a new kind of virtual physical world (ibid, 2010). Consequently, digital convergence will affect the process of developing IoT products and services in which firms need to differentiate user experience offerings, but consider the combination of devices, services and contents and then the interactions with other competitive digital devices and environment in which the IoT products operate.

Secondly, digital materiality differentiates NPD processes significantly to their counterparts of physical materiality. Physical materiality refers to artefacts that can be seen and touched, that are generally hard to change, whereas digital materiality refers to what the software incorporated into an artefact can do by manipulating digital representations (Yoo et al, 2012) which allows designers to expand existing physical materiality by “entangling” it with software-based digital capabilities (Yoo et al, 2010; Zammuto, Griffith, Majchrzak, Dougherty, & Faraj, 2007) when they develop IoT products and service. IoT products can be defined not by their physical materiality but also by fundamental functionality enabled by digital materiality. Trainers or toothbrushes could be an example of physical materiality, however when it contains a microchip in the trainers or a toothbrush that then can be programmed to record a user's amount of physical activity or health status of user's gum, it presents new experiences as digital materiality.

Generativity refers to the way actors, who were not directly involved in the original creation of a technology; begin to create devices, services, and contents which may not be consistent with the original purpose of the artefacts (Zittrain, 2006). An illustrative example of generativity is smartphones with apps, due to its reprogrammable nature, novel functions or capabilities can be added after a device has been produced and launched (Yoo et al, 2012). Higher levels of generativity allow higher numbers of novel ideas, which result in faster innovation cycles with increased iteration, that are more dynamic, agile innovation process than linear approach models (Yoo et al, 2010).

Heterogeneity refers to the integration of diverse forms of data, information, knowledge, and tools and locus of innovation refers to dramatic geographical and social dispersion of innovation sites and processes due to low communication and storage cost (ibid, 2010). New forms of innovation, such as crowd sourcing and open source, enable the locus of innovation moving from inside an organisation to its periphery and edges (ibid, 2010). Both of them affect IoT product and service development processes in terms of enabling: independent innovation at different layers of digital service architecture; and innovation activities towards the periphery of the innovation network (ibid, 2010) both physically and geographically. As a number of innovations spurred by Apple's iPhone came from a number of app developers, rather than Apple itself, the de-centering of innovation activities pushes intelligence toward the edge of the organisation's enlarging network (ibid, 2010).

The last dimension of digital innovation is pace. Pace refers to how frequently firms need to innovate, the speed to innovation, and the required speed of diffusion (ibid, 2010). Increased pace affects IoT product development processes in which innovation needs to be continuous, incessant, and fast, and allows an industry to increase the role of digital artefacts (ibid, 2010).

Unlike traditional products which have a fixed, discrete set of boundaries and features, distinctive characteristics of IoT products are malleable, editable, open, transferable, etc. (Yoo et al., 2010; Zittrain, 2008; Henfridsson et al., 2014), delineated as "ambivalent ontologies" (Kallinikos, Aaltonen, & Marton, 2013). The scope, features and value of digital offerings can continue to evolve even after the innovative product has been launched or implemented, thus a new approach towards IoT product and service development should be identified. Moreover, most IoT designs are launched incomplete and in a state of flux in which both the scale and scope of the innovation can be expanded by various participating actors (Hanseth & Lyytinen 2010). Thus, this conveys an unprecedented level of unpredictability and dynamism in accordance with assumed structural or organisational boundaries of digital innovation, be it a product, platform, or indeed a service.

5 Emergent approaches towards developing IoT based products and services

Although, the number of study on emergent approaches towards developing IoT based product and services, Figure 6. (below) is a new approach, which is developed as a process for designing digital public space by Jacobs & Cooper (2018). This model is developed by combining existing NPD models, which can focus on underlying principles, and related tools that must be taken into consideration when designing Digital Public Space (Jacobs & Cooper; 2018)

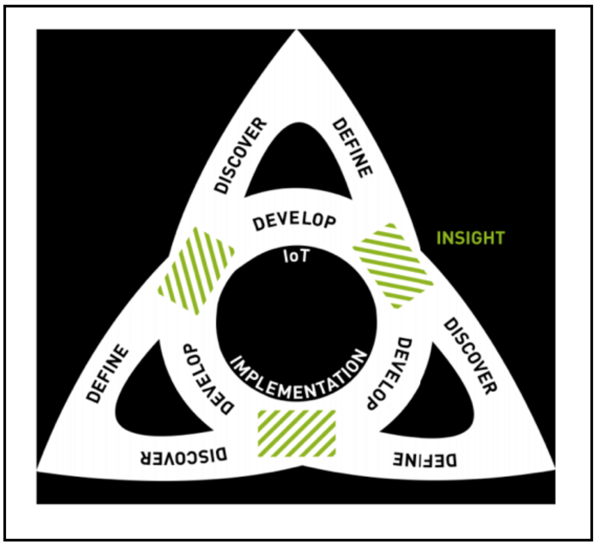

Figure 6 A new process for designing IoT products and services. source: Jacobs & Cooper, 2018

One of the most distinctive attributes different to the existing NPD and NSD processes is that the new approach is not linear, but it is a continuous and emergent process, whereby; the *Discover*y phase enables co-design and collaboration to uncover the requirements and attributes crucial for the space. The *Define* phase uses narratives, scenarios and fictions to visualise and test the design idea before the *Development* phase, through which the products and services are created with users and lead adopters and implemented, with in use insight revealing emergent and new qualities that feed another cycle of discover, define and develop (Jacobs & Cooper; 2018)

This is because unlike tangible components, which get functionality at the time of production, digital components in IoT are able to modify subsidiary functionality, add supplemental functionality, or introduce entirely new functionality over the product lifecycle (Henfridsson et al., 2014). Not only one of the characteristics of digital technology, reprogrammability, but also digital materiality and pace which of the six dimensions of digital innovation, affect the scope, feature and value of IoT products and services can continue to evolve even after the innovation has been launched. Consequently, NPD processes for IoT has continuous and never-ending process cycle, which means that IoT products and services are able to keep evolving for enhanced customer experiences.

Secondly, the process should contain a short cycle of discover, define and develop phase, which is comparable to the ‘agile’ approach, one of the existing software development approach with shorter, faster iterations within the process. The approach is feasible in IoT product and service development processes due to pace and generativity, and the dimensions of big data that are commonly referred to as the 3Vs: volume, velocity, and variety (McAfee & Brynjolfsson, 2012; Meta Group, 2001). As big data aids companies to acquire the massive volume of diverse market information promptly so that they are more easily to meet customer needs (Slater & Narver, 1995; Zhang, Wu, & Cui, 2015), it leverages the new approach towards development process for IoT. It is identified that companies, which use big data and analytics in their innovation processes, are 36% more likely to beat their competitors in revenue growth and operating efficiency (Marshall, Lievens, & Blazevic, 2015).

Another attribute can be explained with one of the traits of innovations associated with pervasive digital technology, which is the emergence of distributed innovations (Yoo et al., 2012). Although it is not clearly shown in the model above (Figure 6), during the process of developing IoT products and services, the control over innovation activities are occurred across organisations (Chesbrough, Vanhaverbeke, & West, 2006; von Hippel 2005) due to the fact that the use of IT enables to reduce communication costs so that democratize the innovation process, involving more of distributed actors which is referred as self-referential nature of digital technology, locus of innovation, and generativity (Yoo et al., 2010).

Value in the IoT will be created through the transformation of customer experiences; companies need strong capabilities in experience design (Burkitt, 2014) which is as offerings, more entwined in a collaborative network of technology, people, and other offerings (Jacobs & Cooper; 2018). In essence, designing Internet of Things requires the design of – the physical object; its software interface; its hardware interface; how it interacts with other devices over the network; how it is represented on a network to people and to other devices (Jacobs & Cooper; 2018). This indicates that design for IoT can encompass and influence a wide range of design disciplines.

6 Conclusion

As novel and challenging as today's IoT is, it offers fertile opportunities for long-term sustainable growth for the organisation. Due to its nascent status, there is still a paucity of academic studies on the development process of IoT products and services, which is one of the most critical marketing planning and implementation process activities. Although the demands of a new approach towards developing new IoT products and services has received widespread attention, there are limited studies that focus upon this emergent topic. Connected devices offer new possibilities for everything from preemptive maintenance to new services and business models. In order to prepare for what is coming, business managers need to consider the new aspects of IoT development process in relation to their own business and the ecosystem of partners, as well as emerging technology.

The main purpose of this study is to examine traditional NPD and NSD processes, considering factors that differentiate IoT products and traditional products in order to investigate if they are relevant to NPD activities for IoT. In exploring this theme, the paper draws attention to the primary research questions at large: What are the characteristics of existing NPD and NSD processes and their relevance to IoT product and service development activities? What are the key factors affecting the development of IoT NPD processes, and how they differentiate them from their non-digital counterparts? What are the new attributes required towards IoT product and service development activities?

The authors have argued that the characteristics of existing NPD and NSD processes are identified as: established NPD processes are too time-consuming, with many that either are simply redundant or are cost ineffective; the firm's capability to develop new products efficiently have become an increasingly important aspect; simultaneous processing is regarded as another key factor for successful NPD management. Development processes are more likely to involve the customers, competitors, and suppliers, although, NPD and NSD processes are evolving, overcoming their shortcomings, traditional NPD approaches are not reflecting the nature of IoT product and service development.

Yoo et al (2010) identified six dimensions of digital innovation, which are associated with innovation outcomes (convergence, and digital materiality) and innovation processes (generativity, heterogeneity, locus of innovation and pace). Three characteristics of digital technology, the reprogrammability, the homogenisation of data, and the self-referential nature of digital technology, are uncovered by Yoo et al (2010). The dimensions of big data, referred to as the 3Vs—Volume, Velocity, and Variety, which are relevant to the process of developing IoT products and services as identified by McAfee and Brynjolfsson (2012), and Meta Group (2001). Henfridsson et al (2014) discover influences of digital technology that affect design flexibility and design scalability. These key factors are identified as the main reasons that differentiate the IoT development process away from existing NPD processes. However, not all the factors deeply influence the IoT design and development process. Factors, such as reprogrammability, digital materiality, pace, generativity, self-referential nature of digital technology, dimensions of big data, and locus of innovation are closely related to differentiation of IoT NPD processes from their non-digital counterparts.

Finally, this paper referred to a new process for designing Digital Public Space (Jacobs & Cooper; 2018) in order to explain the three attributes required towards IoT product and service development activities; this new approach should be a continuous and emergent process. The development process should contain a short cycle of discovery, definition and development phases; the activities during the process of developing IoT products and services should involve more distributed actors and stakeholders input.

Although this paper has explored issues related to the NPD/S process for the IoT there, is some limitation that need to be addressed by further research. Firstly, further key factors need to be considered such as the size of the IoT ecosystem in which new products and services are developing, alongside the dimensions of digital innovation, artifacts and technology and the IoT firm's business strategy in comparison to a traditional company strategy. Although it is fair to say that many businesses with be both engaged in traditional NPD and IoT NPD. Secondly, relying solely on a limited literature review in order to identify new approach towards developing new products and services for IoT where only a limited number of studies have been discovered. Consequently, this paper has identified related and practical questions for further research: What are the key factors that differentiate the traditional NPD and emerging NPD for IoT in terms of its business strategy and process changes?; Is there a generic IoT product and service development process in the IoT industry? And finally, what is the NPD process for IoT firms, which create meaningful value and increased turnover for all its primary stakeholders?

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Designing *In* With Black Box Technologies and PD

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Building on prior work we examine design research challenges posed by working with new technological applications of Blockchain within multidisciplinary research. Drawing from recent design research of others, we articulate the value – and associated challenges – of Participatory Design creative approaches involving co-design of similar 'black box' technologies. We go on to report on three workshops, including one in which we invited technologists and designers to work together to talk through and materially represent their tacit understandings of how two Blockchain applications – BITNATION and Trust Stamp – work. We demonstrate how creative methods are useful in enabling critical reflection and knowledge exchange providing a useful bridge between radically different disciplines; to counter emerging technologies' 'unconscious image' as magic; and to valuably inform on future oriented design implications.

participatory design, emerging technology, blockchain, 'black box' technology

1 Introduction

The role of the designer within the expansive field of digital technology has become increasingly significant. In 2006 John Maeda noted how designers should not only understand human factors to iteratively improve their design, but should also understand how the technology worked, including where appropriate, how to write code. More than a decade later; how much do we, as design researchers, need to know about the complex workings behind opaque data technologies within our multidisciplinary enquiries? Digital designers may use increasingly sophisticated enabling technologies such as 'app builders', avoiding the necessity to understand 'under the bonnet' code. Should interaction design researchers similarly design for and contribute to building complex 'black box' products and services without understanding their precise workings, or potential impact? Norman and Stappers (2015) argue that designers' input should not stop at the design stage, but involve implementation of "complex socio technical systems" (p.84).

In this paper we demonstrate our explorative Participatory Design (PD) approach in research that is developing TAPESTRY, a browser-based (in the first instance) service that aims to enable people, businesses and digital services to connect more safely online through exploitation of the complex digital footprint left behind by individuals' everyday digital interactions. In designing and building what aims to be a private, secure and trustworthy online service, we are using PD to support understanding and connect different perspectives of designers, psychologists, computer scientists and the potential users and beneficiaries of the service. Grounded in this study, we go on to discuss design implications relating to researching and developing black box systems, and touch on wider societal values such as personal privacy and safety; and the recently growing area of policy regulation that aims to control the potential negative impact of online risks and threats towards enabling democratic online citizenry (see Pasquale, 2015).

2 Background: Designing Tools to Support Trust and Privacy Online

This study forms an early part of the larger research project which aims to enable safer online connectivity through the design of a browser-based tool that helps someone establish the authenticity and 'trustworthiness' of the interactor or organisation an individual is about to disclose personal information to. The research focuses on three use-cases of online dating, e-commerce and e-health; all domains where verifying the real person behind a pseudonymised online identity might help to minimise risk and support trust-related decision-making. The research team is building the TAPESTRY tool with the aim of supporting lower level digital literacy users – who have limited skills and experience of making judgements online. Our selected use-cases pose particular and heightened risks when making investments/online purchases; building rapport and trust online towards developing intimacy and meeting offline or; seeking to self-diagnose an illness or condition and administer an 'alternative' treatment. In all these cases the authenticity of the interactor's digital identity is vital in being able to establish someone or something's legitimacy.

2.1 Recognised Risks and Threats

There are much-increased incidences of serious sexual assault in the UK during the first face-to-face meeting following relationships that are established through online dating (NCA, 2016). Online, would-be daters disclose personally sensitive information and build perceived trust and intimacy more quickly than those who initially meet offline, due to the anonymous nature of their online interaction. Our wider contextual research shows that, amongst other things, men lie about their marital status and relationship goals, and women their weight and age (see Jones & Moncur, 2018). A combination of misdirected expectations and misrepresented online identities is believed to have directly led to a significant increase in reported and, it is thought unreported, sexual assault (NCA, 2016). In seeking to solicit money, crowdfunding fraudsters are known to manipulate social identities, including by constructing fake social media accounts to generate followers and increased pledges (Jones & Moncur, 2018), or in charity crowdfunding – appeal to people's sympathy. Our discussions with a crowdfunding executive suggest that fundraisers have suffered reputational damage from negative comments posted to live campaigns by competitors posing as disgruntled investors. And in e-heath forums, anonymity makes it difficult to assess medical credibility if someone for example endorses an unusual remedy (ibid.). Again, online trust building processes can lead to premature or over-disclosure of personal information, leaving those with a medical condition vulnerable to identity theft and personal safety when location details were shared (Blythe, Sillence & Briggs, 2017, p.122).

2.2 How TAPESTRY works

The proposed TAPESTRY service aims to support people's judgement about the authenticity of the interactor behind a particular online persona. It does *not* aim to make people's trust related decisions *for them*, but rather, communicate whether a digital pseudonym matches the person or company claiming to be behind it. TAPESTRY aims to make it more difficult to fake or hijack another's digital identity, including through 'fraping', where someone uses another's computer or online profile maliciously (see Moncur, Orzech & Neville, 2016).

The technology behind the opt-in service will collect shared details about individuals' digital footprints (social media use, browsing and purchasing habits etc.), encrypt, and store relevant data in a Blockchain. A browser plug-in will then facilitate cross-checks and visually communicate the level to which this conforms to the digital identity. These operations will happen in real time; during use, the relevant crowdfunding platform, e-health or dating website will enable those with the plug-in to cross-refer to the TAPESTRY third party service.

3 The Multidisciplinary Context of Emergent Designed Technologies

'Emergent technologies' bring radically novel and potentially prominent technological change, if also ambiguous wider impact and uncertainty (Rotolo, Hicks & Martin, 2015). Societal impact clearly implicates the interaction designer and design researcher. Nanotechnology, Artificial Intelligence (AI), Blockchain, and so on, are the subjects of much debate in the media, academic research and policy and regulation discourses. Some of these discussions concern futuristic envisioning or near-future horizon scanning of potential threats, whether to individual or national security, with a view to managing control. Perceived benefits in the application of such technologies are often apparent to the technical experts, whose understandings elude or raise questions for the wider research team; whether around practical operations, the ways in which the technologies could be beneficially exploited, or wider social implications. In our research, our collaborating computer scientists describe the inherent trustworthy functionality of Blockchain – the decentralised nature of the distributed ledger, immutability of transactions and inherent need to use private and public keys to securely store and share personal data (see Elsden, Manohar, Briggs, Harding, Speed & Vines, 2018). Meanwhile the wider research partners and co-investigators grapple with and try to build up mental models of understanding (Johnson-Laird, 1980) while also identifying potential flaws from their own domain.

3.1 Gaps in Knowing

In the absence of informed understanding, folk theories are often constructed as a way to orientate towards enabling future action (Rip, 2005). Folk theories around emerging technologies and wider science (Rip mentions folk physics, folk chemistry etc.) are necessary to understand the current situation and how a science/technology can segue into the future, as well as provide opportunity for further inter- and multidisciplinary interactions with other disciplines (ibid.). These understandings help researchers to decide what characteristics of an emerging technology to avoid developing, and what to take forward in future designs (see Muller & Lia, 2017).

3.2 Making Sense of Blockchain

Blockchain is an infrastructural technology that is proposed to fundamentally transform the ways in which people transact, trust, collaborate, organise and identify themselves (Elsden et al., 2018). We have explored design issues relating to Blockchain (and DLT, the underpinning technology) and its increasing popularity due to its speed, security and reputation as a trusted mode for online interaction (ibid.). While Blockchain through crypto-currencies are especially prominent in financial domains, there are several well recognised societally relevant applications, including providing transparency in empowering people from developing countries with recognised identity, asset ownership and financial inclusion (Underwood, 2016). Yet there is currently little guidance or published research on how to approach developing shared understandings within multidisciplinary design of emerging technologies. This is especially timely as data-related policy and regulation – including the imminent EU General Data Protection Regulation (GDPR) which includes the 'right to be forgotten' – are placing designers in view of policy makers who task them with designing *in* functions that aim to support online privacy and safety. This paper then, contributes to methodological discussions around the abstract black box nature of digital design and how emerging personal data technologies might be approached as a (co)design material. We start by outlining relevant literature before examining how uncertainties can be addressed more holistically by adopting a PD creative approach.

3.3 Designing in Flux

Crucially, there is an increasing number of real-world applications of emerging technologies where the design of functions that aim to protect the user are 'bolted on' retrospectively, without adequate consideration for the end user or overall design. Considering implications for multidisciplinary research, legal data experts Diver and Schafer (2017) claim that companies prefer data privacy and protection to be managed by policy rather than designed *in* to a system. Here, the onus is on the user to give a company e.g. a social media platform consent to harvest and use personal information. However, most complex back box technologies are beyond most users' comprehension, making any policy tokenistic (ibid.). Luger, Moran and Rodden (2013) working within the Human Computer Interaction field also critique the notion of informed consent around personal online data, saying that platforms and other ubiquitous technology companies construct unreadably complex terms and conditions with dubious legal legitimacy. British journalist Nicole Kobie says "the best way to ensure that security is considered by designers is for them to understand the basics of security and authentication" (2016, p.1). Increasingly, governments are putting pressure on companies to design *in* personal data privacy and security functions. Diver and Schafer (2017) propose a holistic approach 'by design' stating:

> *By enabling the deep integration of regulatory norms early on in the design process, we can balance … the need to retain a democratic connection between the creation of regulation and the locus of its operation, and … the desire to invent and develop new digital products and services. (p.40)*

Of particular relevance is the authors' advocacy for computing-legal collaborations that necessarily 'bridge' disciplines enabling a more interdisciplinary approach to sharing heterogeneous understandings from technologists and, in their case, legal experts towards societal benefit.

3.3.1 Designing With/For Black Box Technologies

Emerging technologies are often appropriately discussed as futuristic as their real-world applications are still being developed and discovered. Such technologies go through a "process of shifting application domains and rapid subsequent growth in the new domain" according to Adner and Levinthal (2002, p.63). During this process the user base is very small, unstable and in flux.

In preparatory work with colleagues we surveyed Blockchain applications to gain better understanding of this still-developing technology (Elsden et al., 2018). Within the many hundreds of examples are Crowd Jury, Cambridge Blockchain, BitNation and Trust Stamp. We were constantly reminded that by their nature, some Blockchain services exist only as concepts, or early prototypes in beta under development by start-ups or activist groups. This still-emergent quality amplifies challenges of deployment and testing to identify and understand users and their needs and potential input, or evaluate and iterate designed experiences – as the technologies do not yet fully exist. We addressed the design space around these technologies still-emergent nature with groups of designers and technologists through a PD approach.

3.3.2 History of Terminology

> *(M)ore and more products in everyday life have become what engineers call 'black boxes'— we know what goes in and what comes out, but not what goes on inside. This has reinforced the unconscious image of technology as magic. (Dumas, 2010, p.5)*

The idea of black box technology seems to originate from the Second World War where the term was used to refer to the gun sight carried on Flying Fortresses, which incorporated hidden components that corrected for environmental variables (Tenner, 2003). Whilst the crew probably knew little of how the device worked they certainly knew how to use it and were critically aware that it may be crucial to survival. Possibly, the term was borrowed from E.M. Forster's science fiction work *The Machine Stops* (1909), in which the whole world is a black box that functions through input, an unknown process, and an abstracted output, from which human beings are disconnected from direct experience. Building on this, Bruno Latour (1999) used the term to question the science in action i.e. how can the plane fly, or how does the theory of relativity work?

> *Scientific and technical work is made invisible by its own success. When a machine runs efficiently, when a matter of fact is settled, one need focus only on its inputs and outputs and not on its internal complexity. Thus, paradoxically, the more science and technology succeed, the more opaque and obscure they become. (Latour, 1999, p.304)*

Recently, the term is applied to algorithmic data science.

> *Hardly a day goes by without a story in the media involving machine learning, whether it's… Google's AlphaGo beating the human Go champion; US retailer Target finding out a teenager is pregnant before her parents do; or the US National Security Agency (NSA) looking for dots to connect. But in each case the learning algorithm driving the story is a black box. (Domingos, 2016, p.xv)*

To return to our research, Diver and Schafer (2017) advocate for individuals' control of personal data to be designed and built *in* to the digital technologies that gather and process these data to balance on-going development of new digital products and services. As legal experts they are writing in anticipation of imminent GDPR; the aim of which is to make companies liable to provide users with both clear explanation for decisions that automated systems reach and also control over their data, including the right to be forgotten (see Luger, Moran & Rodden, 2013). Just how much should you trust an Artificial Intelligence's decision, for example on approving your request for a loan, diagnosing an illness or selecting someone for promotion in a job? When technologists lack full understanding on how these decisions are made from within their black boxes, Pasquale (2015) amongst others calls for the workings of the mathematic models and algorithms to be made more transparent, comprehensible and accountable. According to Knight (2017), access to these models may help promote general understanding about the reasons behind automated decision-making. For a recent stark warning of how data systems reinforce socio-economic polarisation see Eubank (2018). Bryson and Winfield (2017) advocate that better understanding around how Artificial Intelligence's deep learning and machine learning works, can help designers, technologists and users to recognise why certain applications fail. So can we, as design researchers help to make these workings more explicit and comprehensible?

3.4 Overview of Comparative Design Research

Blockchain has been an apparent answer to extremely centralised models of finance, governance, notary, utilities etc., challenging the status quo through its disintermediated ubiquitous systems that we can use day-to-day. The significant feature of Blockchain is the complex network that builds up through a distributed database, the peer-to-peer transmission formed through transactions, and the irreversibility (or mutability) of records. Groups of transactions are blocked together and a 'fingerprint' of each is added to the next block, creating the growing network, or *chain*, irreversibly (Government Offices of Sciences, 2016, p.56). Blockchain is the recent object of investigation within smart cities design research – towards enabling "liveable, sustainable and sociable urban futures" through citizen-centred approaches (Speed, 2016b, p.1). It is also proposed to extend digital humanities into new forms of storytelling and narrative (Maxwell, Speed & Campbell, 2015) and provide alternative forms of (non-monetary) value exchange (Nissen, Symons, Tallyn, Speed, Maxwell & Vines 2017). These explorative investigations aimed to make Blockchain more accessible to designer researchers and publics through familiar props and materials.

Chris Speed with Debbie Maxwell and Dug Campbell (2016a) used Lego bricks in a workshop with design students to further understanding on the principles of Blockchain (see Figure 1). Their stated aim was to demonstrate the distributed nature of the technology and something of its 'complexity', but not *illustrate* the network (chain) within Blockchain. The workshop was a catalyst for conversations to identify research challenges rather than creating accurate representations (ibid.).

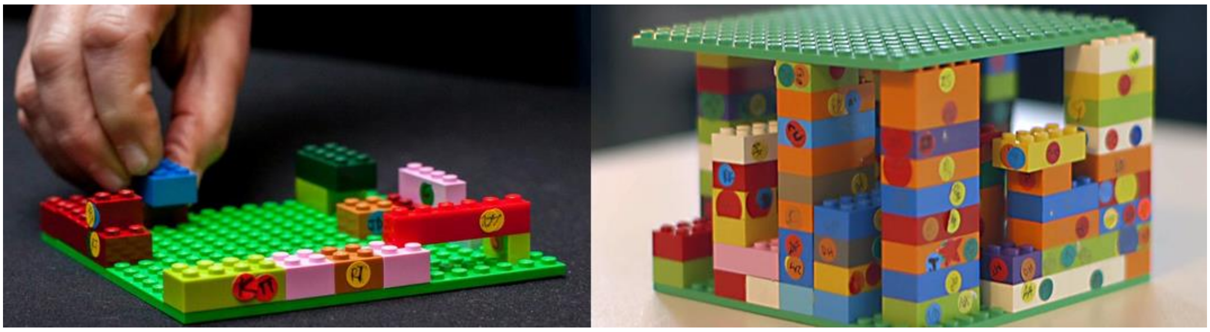

Figure 1: Speed's workshop use of Lego bricks to represent Blockchain. ©Chris Speed reproduced with permission.

Maxwell, Speed and Campbell (2015) in associated work explored the applicability of Blockchain to adaptive storytelling. They addressed ways in which stories may be read, written and shared through DLT, drawing novel comparisons between story narratives and cryptocurrencies using the creative approaches of 'physical modelling' and 'Lego based activity'. Whereas Speed (2016a) focused on identifying interesting research questions, Maxwell and colleagues speculated on and mobilised Blockchain's creative possibilities for new applications (2015). Our workshops reported below aimed to both explore and enable multidisciplinary knowledge across participating researchers (workshop 3) as well as familiarise us with the everyday digital practices of groups of researchers and those who attended a drop-in IT help session at the local library (workshops 1&2).

4 The Workshops

We ran three workshops between July and October 2017. The first two aimed to broadly scope the level of understandings and digital 'competency' of our design and computer science colleagues and a target user group, to provide initial insights into their attitudes to and breadth of practices around online safety in the context of the research. The two earlier workshops involved an icebreaker and use of a 'conversation tool' based on Covey's (2004) three concentric circles, used to indicate areas of online life over which our workshop attendees felt they commanded total control, some influence, or which concerned them but about which they felt powerless (see Figures 2&3). We provided 15 scenario cards (see Table 2, later); in turn each person was asked to read out and discuss a response to one of the scenarios and place the card appropriately in the circle as marked 'safe', 'unsafe' and 'not sure'. These sessions were audio recorded and where practical and decipherable, the audio files were transcribed. All names have been changed.

4.1 Workshop 1 and 2: Structure

Workshop 1: 'Scoping' workshop of 90 minutes with academic researchers (3 men and 2 women) from design and computer science. Following a short icebreaker the group was split into 2 groups for the Conversation Tool (Figure 2)

Workshop 2: The following day we ran a 50-minute Conversational Tool session directly after the city library's Computer Coffee Morning which offers tailored volunteer expert help to novice users on 'how to use your new digital device': 9 Computer Coffee Morning attendees, their 6 digital skills volunteers and session organiser Lauren were present (Figure 3). We observed in the session people being shown how to move photos from a smartphone to a laptop, and adding urls to 'favourites'.

Figure 2 (left): Conversation Tool with designers and technologists. Figure 3 (right): Conversation Tool discussion with attendees, volunteers and organiser of the city library Computer Coffee Morning.

4.2 Workshop 3 (Blockchain)

Following an icebreaker, this 2-hour session was focused on materialising the understandings of Blockchain and its applications with designer-researcher and computer scientist researcher colleagues recruited from two collaborating labs (3 men, 4 women). We appropriated aspects of creative methods: Anderson's Magic Machine (2013); Nissen and Bowers approaches to materialising data within design making practices (2015); and Playful Triggers (Clarke, Briggs, Armstrong, Macdonald, Vines, Salt & Flynn, n.d., after Akama & Ivanka, 2010) as means of engagement and to invite dialogue around the Blockchain technology and its application. We provided a collection of familiar household objects, toys and novel materials such as Playform, plastic cups, small plastic balls, and human and animal figurines. The overall aim was to gather insights into others' conceptualisations and perhaps folk theories around how Blockchain and its applications work, using visualisation and material making.

We introduced the TAPESTRY project and described the workshop structure before posing an icebreaker question, for which the group were given 10 minutes to construct individual responses on paper, before sharing. The first author then gave an overview of Blockchain introducing general definitions including from pioneer Nakamoto (2008). He describes the technology as a combination of i) *distributed ledger*, a database shared between multiple actors who are all allocated read and write permissions; ii) *immutable storage*, where changes to the ledger, or transactions, are stored in 'blocks' and where each copy of the database retains every block in the 'chain' as an immutable history; and iii) *consensus algorithms*, which are protocols for trustless actors in the network to verify the transactions made on the Blockchain and achieve a secure shared consensus about the state of the database. For more on this in layman's speak see Thomson (2016). Then, in two groups (3 designers and 1 computer scientist in each), our workshop attendees were invited to visualise and map their understanding of the Blockchain applications Trust Stamp and BITNATION. The brief included information from the respective websites (Table 1 shows text provided) to minimise purely subjective interpretation.

Table 1 Website Definitions of the Two Blockchain Applications Used in Workshop 3

Trust Stamp uses social media and other publicly available data to verify your identity and provide a unique FICO-like trust score of your score are private and under your control, you can easily share your trust score on any platform. (Trust Stamp, 2017)
BITNATION is the World's First Virtual Nation – A Blockchain Jurisdiction. The Internet has radically interconnected our world and Blockchain technology – a cryptographically secured public ledger that is distributed amongst all of its users – allows us to choose to govern ourselves for the way we want to live now: peer-to-peer, more locally and globally. (BITNATION, 2017)

Both applications facilitate identity services with distinct features; BITNATION is presented as a virtual nation while Trust Stamp offers identity verification services through publically available social media and wider personal data.

The two groups, who worked in separate rooms and without facilitation, were invited to use the range of physical props and materials that had been laid out. Our aim over this 40-minute activity was to solicit responses both in terms of materialising specific application functionality, and then to promote general discussion across the two groups. Ultimately, we aimed to investigate opportunities for knowledge exchange and ways of bridging the gap between technical and design – and in the case of the library workshop – user domains. Could such workshops help technologists and designers communicate? And; build better applications?

5 Findings Workshops

5.1 Workshops 1&2

The researchers were unanimous in their assessment that 'receiving an email from a stranger' is safe; Computer Coffee Morning (CCM) attendees on the other hand were less sure (see Table 2). Yet

CCMs reported feeling safe ‘Sending money using online banking’ and ‘Storing [their] email password’ whereas the researchers were ambivalent. Two thirds (6/9) of the CCM attendees classified ‘Sharing photos on the cloud’ as safe (compared to 2/5 of researchers) and they were unanimous that ‘Sending money in online banking’ was also safe (compared to 3/5 researchers). This apparent confidence probably stemmed from the topic having recently been covered by the CCM group: “*You have to come to my other course, you will learn all about that, all about security. Online banking is really safe to do”* Lauren had told the researchers in the workshop.

While limited in their findings, the two workshops were a useful early sense check about the level and range of experience of TAPESTRY’s target users. ‘Booking a room through AirBnB’ and ‘Giving your credit card details on online gambling websites’ were outside of all the group’s — including Lauren’s and the volunteer experts’— experience. (‘Exchanging personal information in online gaming’ unsurprisingly perhaps, proved similarly unfamiliar, though the second author asked a woman who’d discussed playing iPad chess with her friend if that was ‘online gaming’.) The sessions then revealed issues relating to our terminology, and different generational interests and values. Online dating, gambling and gaming were perhaps outside of the CCM group’s experience. And there was some ambiguity around whether a volunteer’s answers reflected their ‘lived’ or more ‘imagined’ experiences around their discussions on Tinder and making in-app purchases; and discussions seemed to conflate online- and potential for offline risks.

Table 2 Conversation Tool scenario cards and categorisation in workshops 1 (Researchers) & 2 (CCM)– broadly listed from more common practices to niche. The researchers worked through all the cards but the CCM attendees had relatively lower numbers of responses (marked) due to some having no experience.*

Questions	Wrksp	Safe	Unsafe	Not Sure	Questions	Wrksp	Safe	Unsafe	Not Sure
Receiving an email from a stranger	1	5	0	0	Sharing photos on the cloud	1	2	1	2
	2	4	1	4		2	6	2	1
Creating a Facebook profile	1	3	2	0	Shopping online on Amazon	1	4	0	1
	2	3	1	1		2	6	2	1
Sending money using online banking	1	3	2	0	Downloading an App on an iPhone	1	2	3	0
	2	6	0	0		2	3	0	0
Storing your email password	1	2	2	1	Messaging a stranger on a dating platform like Tinder	1	3	2	0
	2	4	2	2		2*	0	1	0
Using Skype to call your family	1	5	0	0	Making an in-app purchase on an online gaming platform	1	3	0	2
	2	4	1	0		2*	2	0	0
Facetime call with your friend	1	5	0	0	Giving your credit card details on online gambling websites	1	1	1	2
	2*	2	0	0		2*	0	0	0
Sharing your location on Facebook	1	4	0	0	Giving personal information online gaming	1	1	4	0
	2	2	2	0		2*	1	1	0
Sharing photos on WhatsApp	1	2	0	2	Booking a room through AirBnB	1	2	2	1
	2	3	2	1		2*	0	0	0

Overall the relatively more experienced researchers revealed varied perceptions of what was ‘safe’, which broadly reflected their multi-generational range. The more mature technologist was very distrustful overall, commenting on how their trust in Facebook had diminished over 6-7 years of use; a younger Design researcher, while finding social media “*pointless and unnecessary*” expressed no concerns about sharing their location on Facebook.

5.2 *Blockchain Workshop*

5.2.1 Icebreaker

An icebreaker question asked "Is there a need for users, technologists and designers to understand how digital technologies work and why? Digital designer Alice expressed "*a categorical 'Yes!'*" due to "*implications of use*". Programmer John said, that while it was important to recognise the limitations of technology, technologists didn't "*get a say in how [the technologies they create] affects general interactions,*" somewhat abdicating technologists' ethical responsibility. Cara stated that *all the groups* need *"an idea of the ethical, moral and social impact it might have on one's life*", referencing Einstein's support of the atomic bomb project. Kris said users didn't *need* to understand, but on reflection stated: "*if I am using something or designing something or engineering it. Sometimes I am doing all three*", recognising his mutable position. Another programmer said: "*I want to be more 'no' than the others*" this time referencing Leonardo's flying machine as an example of how innovation can thrive without technical feasibility. He likened this to algorithms: "*We don't understand what is happening in deep learning, 10 to the power 9 or something. We can't pretend we know…we can't visualise it*" (Alex). Designer Peter said promoting a product through use increases its influence and power. He advocated for historical critique, concerned that people were losing technological know-how: "*technology is built upon technology...without a roadmap and a general understanding, [people] will have no means of deepening knowledge.*" Tina considered understanding unnecessary at a "*technical 'I could make this happen' level"* but she said it was "*crucial"* to ask questions to account for different perspectives and motivations as *"technology has multiple purposes and intersections of power."* Designer Carol took more of a user's perspective: "*Technology shapes us as much as we shape it."* She suggested "*literacies…as a portable kind of skill for figuring out how things are done"* and, echoing Tina, accommodating *"different ways of knowing*."

5.2.2 Making Activity

The main workshop was loosely informed by the approaches taken to giving material form to 'prototyping' (Andersen, 2013; Nissen & Bowers, 2015; Akama & Ivanka, 2010) within open PD dialogue. We used these as means of engaging participants and prompting their discussions on the properties and workings of the Blockchain technologies. Each group was invited to consider Blockchain and its Blockchain-based application (BITNATION or Trust Stamp) separately.

5.2.3 BITNATION

The four participants used a stack of clear plastic cups to build a chain of transactions with coloured balls representing different users' data in the Blockchain (Figure 4). These data balls were incorporated in such a way that they cannot be removed – representing Blockchain's immutable character. To support understanding further they labelled this with coloured letters spelling out the word Blockchain. The group signified the BITNATION application itself with more coloured balls, placed in threes on a "*twirling*" plate, which they animated using circular card to suggest movement. Angela explained "*All the disks are turning at the same time and everyone is looking at everyone"* representing groups of individuals consenting to each other's transactions. "*It's like the tea cups that twirl in the fun parks"* Angela said, going on to explain how the chain was developing in real time.

5.2.4 Trust Stamp

Group 2 visualised the Trust Stamp application (Figure 5) using figurines and other material props, literally and metaphorically– again selecting the coloured balls, which clearly suggested their use as personal data. Human figurines stood in as Trust Stamp users, and a 'sea' of blue beads signalled the shoreline-threshold between digital and physical worlds. This representation incorporated the functional Blockchain and its Trust Stamp application as one technology – prompting higher level narrative overviews which perhaps belied clear understanding of how the technologies functioned. Overall, the more metaphorical whimsical approach was reminiscent of some of sociologist David Gauntlett's (2008) work describing creative methods for making material understandings of social experience and identities, the results of which require explanation and interpretation (ibid.). This group’s activity facilitated wider thinking about the technology’s application and implications for design and use, including regulation. The group used the uniformed figurine as an authority to oversee the verification process.

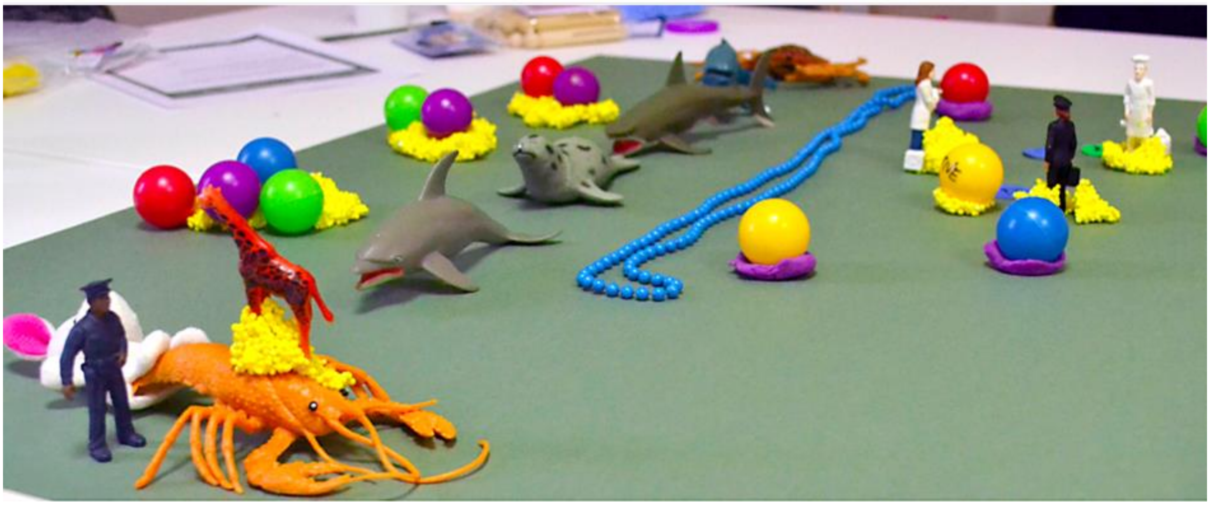

Figure 4 (top) Visualisation of BITNATION; Figure 5 (bottom) Visualision of Trust Stamp.

6 Discussion

Both the groups were able to clearly show the *immutable* characteristics of the Blockchain technology. Kris, who’d locked the coloured data balls into the chain of plastic cups made a nice analogy; “*Thinking about materials, thinking about stuff that that could go one way but not the other, like burning a match…or making a cake.*” Both groups struggled to show the *distributed* nature of the system. This was possibly due to finite materials and time: “*how do you show the* *distributed ledger system? We need an entirely new [material]!"* declared Tina, who was probably the most knowledgeable of all the participants on Blockchain and its uses.

The workshop process did provide valuable insights into the complicated workings of the technology for those contributing: "*It makes people understand the individual steps*" said Tina on how the physical build invited 'conceptual deconstruction' of the Blockchain process. This in turn provided critical insight: *"…you realise Trust Stamp really doesn't need Blockchain. Then, why are these people going through Trust Stamp and trusting them as a verification body?*" she asked. Carol agreed; the making exercise enabled better understanding and comprised "*… an easy way to cut through all the marketing BS*" around new Blockchain applications.

This speaks to Melanie Swan's (2015) argument that decentralisation, agreeing to a consensus model or recording every single transaction on a public ledger is not necessary in every situation, and reinforces complaints about the level of 'hype' around Blockchain technologies. Their inherent opacity and complicated nature opens up potential for exploitative marketing – or apparent black box 'magic' (Dumas, 2015, p.5).

> *Kris stated that his position hadn't changed (since the icebreaker), but increasingly supported this with references to needing professional standards and regulation:*
>
> *Kris: "if I am in a car with my family driving on a bridge and the bridge collapses, is it my fault as a user or is it the designer's fault? […]*
>
> *Alice: "In the bridge, you may look for signs [of damage and potential collapse] but in software you cannot."*
>
> *John: "Unless you are literate."*
>
> *Alice: "Exactly. A lot of people are not and that's why it is important [to have sufficient understanding]."*

Our methods solicited insights, enabling us to better understand people's understandings of not only the 'mechanical' nature of the Blockchain applications but also how people perceived them. Alice called BITNATION "*pretty dystopian…pretty dodgy*"; although BITNATION is meant to comprise a "*borderless nation*" the Blockchain introduces a form of "*customs*" (Angela). She later said "*it is like Stasi all over again"* referring to the secret police. Peter declared: "*Trust Stamp terrifies me*." Kris was untrusting of BITNATION and its online presentation stating: "*these [Blockchain] systems are dishonest.*"

The value of material making was in making explicit and sharing their understandings of the workings of Blockchain as a prompt for inviting more tacit insights (technical and socio-trust related) into understandings and attitudes. Yet it also enables them to see through the 'magic' and 'BS'. However, we are equally aware as design researchers that such approaches could misinform and confuse; the groups were set a task and without some level of existing understanding amongst the group they struggled to develop deeper or clearer understanding, even with access to the respective websites. Obviously, there are ethical and value-related issues with research projects such as TAPESTRY around which we need to be critically aware.

7 Conclusion

There are many issues to be resolved before potential users routinely enable algorithms to capture and manage their data. Users may be expected to trust the Blockchain application system, because the data is locked with a private key. Providing discussion and insights through creative methods potentially opens up opportunities for people to understand how they think about these systems and how they and their peers respond to the 'unknown'. We propose that creative design techniques within PD have rich purpose beyond providing interesting and thought-provoking mediation between designers, technologist and user groups.

However, such workshops have limitations. These include the availability of key participants. We worked with colleagues from a computer lab on campus, rather than our TAPESTRY Blockchain and AI computer scientists. Our participating colleagues demonstrated a generous willingness to take on abstract playful activities, and were prepared to share their varying understandings on the Blockchain technologies and personal attitudes to various digital practices. And, while the materials we provided (readily available in our studio lab from previous workshops) lent themselves to enabling broad representational work, they sometimes invited particular uses (the coloured balls as data, the figurines as controlling authorities); meanwhile, showing a 'distributed ledger' proved difficult (see Kensing & Blomberg, 1998).

We only began to scratch the surface of how applications such as BITNATION and Trust Stamp may impact on our world. Our study prompted quite dystopian negative reactions. Critics Iaconesi (2017) and Swan (2015) amongst others warn that using Blockchain tends towards quantification, with all relational, emotional and expressive interpersonal exchanges becoming 'transactions' as a form of what Swan calls *economification*.

This paper concludes that PD approaches are useful in eliciting understandings around the perceptions of the functions, value and ethics of emerging technologies within multidisciplinary Design research. Although there is much we can learn from investigating emerging technologies, it is also crucial that they are studied from multiple perspectives – not only designers' and technologists', but those of myriad potential users to best fit societal and human purposes.

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Designing machines with autonomy: from independence to interdependence to solidarity

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Current notions of design are strongly influenced by user- and human-centred approaches. However, with technologies that present increasing computing power and context-awareness, and algorithms that 'design themselves', designers are beginning to face issues that go beyond the needs of users. In this paper, we argue that the focus on humans not only neglects the increasing potential of machines, but also other forms of life, limiting design's possibilities. We attempt to investigate the design of machines with autonomy, beyond human-centred and anthropocentric views, and present an alternative approach, in which machines do not serve or command humans, but exist and evolve in parallel with them. We present this exploration through three design concepts (*Gatekeeper on the Mission, Perception Companion,* and *Poet on the Shore*) that seek to explore notions of independence, interdependence, and identification between humans and machines. We conclude by discussing the main challenges faced in these three perspectives and future directions for research.

autonomy; machines; solidarity; design provocation

1 Introduction

Popular views of machines are strongly anthropocentric and often permeated by ideas of dominance. On the one hand, machines are viewed as tools to perform human actions. On the other, echoing science fiction movies and other products of popular culture, they are regarded as potentially dangerous, overriding human capabilities. The spread of emerging technologies such as machine learning and artificial intelligence (AI) is, however, beginning to challenge these perspectives. With more computing power, connectivity, context-awareness, and algorithms that 'design themselves', machines are increasingly moving away from the role of passive objects into the position of active subjects. This movement helps to question instrumental views. Nevertheless, the integration of machine learning and AI into many aspects of everyday life, from shopping and navigation activities to providing emotional support, helps to demystify and reduce the fears (and awe) surrounding these technologies.

Designers are not immune to these perspectives either. While the move from system- and product-focused to user- and, later, human-centred design has taken decades and includes important developments, we argue that a new perspective is necessary to design new technologies that present some form of autonomy. The sole focus on humans restricts design possibilities, and anthropocentrism is often regarded as contributing to many of the ecological imbalances that we currently face, from resource depletion to climate change. As Morton (2017) provocatively claims, “anthropocentrist is directly opposed to the interests of humankind” (p. 154).

In this paper, we present a design exploration into the world of machines that attempts to move away from anthropocentric views towards more equal relationships between humans and nonhumans. We explore these ideas through the following three design concepts: *Gatekeeper on the Mission*, *Perception Companion*, and *Poet on the Shore*. The exploration departs from an articulation of agency based on concepts of actor-network theory (ANT) and object-oriented ontology (OOO). We then move to a discussion of ethics and morality of autonomous agents, referring to concepts such as human-in-the-loop. Finally, the paper questions what it takes to promote greater equality between diverse entities, particularly considering Verbeek’s (2009) notion of ‘designing the human into the nonhuman’ and Morton’s (2017) notion of ‘solidarity’ between humans and nonhumans.

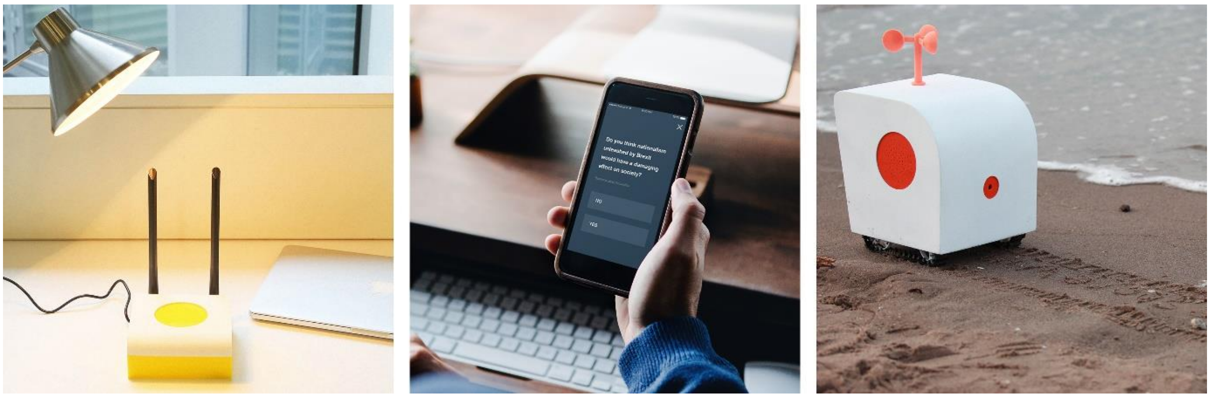

Figure 1 Three design concepts: Gatekeeper on the Mission (left), Perception Companion (centre), and Poet on the Shore (right).

2 Beyond human-centred design

The world has been experiencing unprecedented technological development. Machines are becoming smarter, acquiring context-awareness and social abilities (Stone et al., 2016). In *Shaping Things*, Sterling (2005) famously articulates his concept of spimes, arguing that ambient connectivity would grant artefacts a particular form of agency in the human world. With more devices connected to the Internet, Cisco publicises that it has already surpassed the number of people on the planet (Evans, 2011). With computing power, the idea of agency of objects has become more credible, but this idea is not limited to computational devices.

Heidegger (1947) and Latour (1993) have articulated the view that subjects and objects must be considered intrinsically interwoven. Through the concept of ANT, Latour (2005) developed the notion that humans, objects, and anything in the world develop social relationships. Despite criticism, including by Latour himself (1998), ANT became popular by promoting the notion that objects have agency and shape the world as much as humans do. The theory suggests that humans and nonhumans are equal actors, existing in interconnected networks, and should be described in similar terms. This idea led some to argue that we should employ the same analytical and descriptive framework when faced with a human or a machine (Cressman, 2009). Similarly, OOO argues that both humans and nonhumans exist in a gap with their appearances. It rejects privileging human existence over the existence of nonhuman objects (Bogost, 2012). The theory claims that objects exist independently of human perception and that “everything exists equally” (Bogost, 2009). The idea of people and other entities as being on the same level might sound provocative, but it is important to stress that the aim is not to objectify humans, but to invite designers to acknowledge the role of nonhumans in shaping perceptions, experience, and constructing and the world in each given moment, as much as humans do.

Our aim is to begin acknowledging similarities between humans and nonhumans. With advances in ecology studies, we are coming to recognise that behaviours such as empathy, which for a long time were considered intrinsically human, are in fact presented by other species (Waal, 2012). With advances in genetic, prosthetics, and biomonitoring practices, we are becoming aware that human bodies can be ‘designed’ (Rifkin, 1999), and that much of our bodies is composed of other organisms and nonliving materials (Washburn, 2013). In other words, there are many commonalities between humans and nonhumans in terms of experience, behaviour, and makeup.

However, these powerful ideas are rarely considered in design. It has taken many years for the design community to move from systems-centred to a human-centred perspective, particularly in the design of interactive systems (Cockton, 2004). The concepts of ANT, OOO, and subsequent ecological theories offer a starting point to reflect on a broader perspective that may encompass artefacts, things, machines, and other beings.

3 Machine autonomy

A useful framework regarding machine autonomy and discussing the morality of artificial agents is provided by Floridi and Sanders (2004). They propose the following three properties that determine the level of agency of a machine: interactivity, autonomy, and adaptability. First, there should be some level of interactivity, meaning that the agent and its environment (including other agents) can act on each other. Second, the agent should be able to perform internal transitions to change its state, which also means that it should present at least two states. This property imbues an agent with a certain degree of complexity and independence from its environment. Finally, there should be some degree of adaptability, which means that the agent’s interaction can change the transition rules by which it changes its state.

A few design projects can be used to illustrate high levels of agency. One example is the well-known *Brad the toaster* (2012) by Simone Rebaudengo, an anthropomorphised device that connects to the Internet and other toasters alike. Rather than being owned by humans, Brad and his fellow toasters are hosted by people who have promised to use them. By tweeting about the usage habits of their human hosts, Brad can exchange information and compare his life with other toasters. When feeling underappreciated, Brad draws attention to himself by playing pranks, throwing tantrums, and expressing his sadness loudly on Twitter. Eventually, Brad becomes disillusioned and demands a move to a more attentive host. The anthropomorphisation makes Brad a clear example of an object with agency. The network of toasters has some degree of independence from humans; however, humans are still at the centre of their world. In this paper, we question whether it is possible to consider a more horizontal relationship between humans and nonhumans.

Principles of autonomy have been increasingly employed in Internet-connected (or IoT) devices. *Bitbarista* (Pschetz et al., 2017) is an autonomous coffee machine that serves coffee in exchange for a Bitcoin contribution towards its next coffee supply. The machine has its own Bitcoin wallet and rewards people for performing maintenance tasks, such as cleaning, filling its water tank, replenishing it with coffee beans, etc., while adjusting its prices according to international markets and its own needs. Similarly, in the speculative realm, the *Aspirational Lamp* by Craddock et al. (2015) collects solar power during the day to save energy and money. In the fictitious scenario, it would invest in external markets, as well as upgrade and repair its hardware.

The consideration of machines independently from humans is challenging. The idea becomes even more complex when questions of morality and ethics emerge (e.g. when the machines guide human practices or are entangled with decision-making). Actor-network theory has been criticised for its lack of attention to moral issues. Waelbers and Dorstewitz (2013) argue that, due to the lack of intentionality in Latour's definition of agency, ANT fails to address questions of responsibility from an ethical viewpoint. The question of morality is a complicated one. Moral agency is said to be one's ability to make moral judgments based on some notion of right and wrong and to be held accountable for those actions (Taylor, 2009). According to Himma (2009, p. 24), a moral agent should have the capacities for "making free choices", "deliberating about what one ought to do", and "understanding and applying moral rules correctly in paradigm cases". Himma attributes concepts such as 'free choice', 'deliberation', and 'intentionality' to the capacity for consciousness; as Himma (2009, p. 24) puts it, "the idea of accountability, central to the standard account of moral agency, is sensibly attributed only to conscious beings". However, these concepts are open to philosophical debates, and lead to 'the Problem of Other Minds' (Hyslop, 2005). That is, how would the agent's 'free will' and 'deliberation' be assessed by another agent? Floridi and Sanders (2004) propose a useful approach using the notion of 'mindless morality', which does not require intelligence or consciousness. Machines that exhibit a certain level of intelligent behaviour, in their view, should be considered moral agents regardless of their capacity for cognition. This is a useful concept for shifting the question from cognition to visible behaviour and the effect of machine practices.

A design attempt to discuss the moral agency of machines is *Ethical Things* (2015), a project created by automato.farm, which explores ethical decision-making by autonomous systems in quotidian situations. The 'ethical fan' connects to a crowd-sourcing website every time it faces an ethical dilemma, such as either focusing on a fat person who sweats a lot or a thin one. This project, however, eliminates the machine's influence, sidestepping the issue of morality. As a consequence, the machine, namely the fan, returns to the position of a tool to mediate human decisions, which, as discussed in Section 5, can be problematic.

4 Revealing perceptions of machine autonomy

Within this context, we developed a series of probes that attempted to invite designers to reflect on the perspective that machines have on the world. Each probe pack consisted of an envelope with cards that aimed to investigate the perceptions of consciousness, accountability, ethics, and equality of autonomous machines. The questions challenged Asimov's *Three Laws of Robotics* (1950), which seeks ways to maintain the human-centred social order. The cards contained the following questions:

1. If machines such as drones and guns knew they were killing, how would they behave?
2. If a machine knows the service it provides may do harm to its user's health, what should it do?
3. If machines could self-destruct, when would they do so? Of the appliances in your home, which one do you think would self-destruct?
4. When do you think a robot would have the right to demand companionship?
5. If machines formed their own society, which machines would claim that 'All machines are equal, but some machines are more equal than others'? Can you rank the hierarchy of appliances in your home?

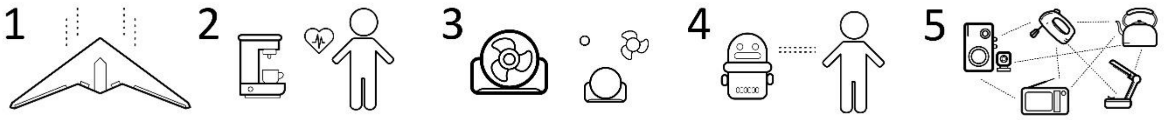

Figure 2 Illustrations that accompanied the questions above.

We created specific scenarios and visualizations to help participants understand the context and internalise it (see Figure 2). Participants were encouraged to express their personal thoughts and experiences through words and sketches. The probes were given or sent to 40 interaction designers based in the UK and 33 responses were collected. Key insights are summarised below.

Figure 3 Responses from 33 interaction designers were collected and analysed.

4.1 a) Varying moral standards

In Questions 1 and 2, regarding the moral dilemmas of harmful behaviour, the participants' reactions varied greatly. The most common attitude was to consider the behaviours of the machine as predicted by a human designer: "Depends on how they are programmed and if they can learn." "It depends on the algorithm that the machine is programmed with." "As a machine, I am an expression of my designer's intentions." The designers would therefore be held responsible for the machine's behaviour – "I don't believe anyone would be silly enough to give machines enough autonomy to decide what killing means." Some participants simply dismissed the idea of consciousness and autonomy: "Whenever the machines decide they are going to kill any human being, we require these machines to ask the permission of any human individuals so that we know at least who is responsible for every murder."

Other participants made assumptions based on the 'value' of different people in Western industrialised societies: "...they [machines] would probably make pragmatic decisions based on data that is socially available. For example, if someone has a criminal record vs someone with social value like a doctor." However, some participants believed the machine would invariably refuse to do any harm: "They should reject doing it." One participant simply regarded machines as killers, potentially following narratives of machine dominance: "They would kill and like it." Finally, some participants believed that the machine would be able to access a number of factors to base its decision upon: "The machine should definitely take into account a range of variables: 1. Combatant or civilian; 2. consequences; 3. necessity, etc."

4.2 b) Self-destruction if no longer relevant for humans

The responses to Question 3 regarding machine self-destruction were predominantly anthropocentric. For example, most participants thought that machines would self-destruct if they sensed they were no longer functional as "they cannot serve the purpose anymore" or could potentially be harmful to its user due to flaws or ageing as they would be "detrimental to human interest."

While the dominant notion was that machines would only serve human purposes, some participants imbued machines with consciousness, affirming that a machine would self-destruct when "it senses it can cause harm". Interestingly, one participant thought that machines might self-destruct "when they don't find meaning or don't like their work." This, in a way, echoes what Reeves and Nass demonstrate in *The Media Equation* (1996) - in the absence of an existing model, people would treat an object as a person. That is, when people do not have a mental model for a particular situation, they apply the same rules as they apply to daily social interactions.

4.3 c) Robot companionship

For Question 4, regarding robots' right to demand companionship, one main theme emerged among the responses concerning the affection and intelligence of the robot, as some participants asked "does an AI have feelings?" Many participants imagined a form of emotional connection between humans and machines. Some participants believed a robot would demand companionship when "it feels (lonely)". Other participants believed a robot could demand such companionship when it is in the best interest of the user, for example, "machines try to improve the user's well being". Some participants believed machines should never "demand anything", no matter what, and some ultimately concluded that if "an AI that develops a consciousness similar to humans, it should be granted basic human rights."

4.4 d) Hierarchy in machine society

The participants' reactions to Question 5 (concerning machine society) were strongly diverse. Some participants considered that access to information or the Internet was the most important property for machines: "I would assume the machines that have access to information about how other machines work would be superior." This opinion reflects views of the dominance, which are often seen in social organisations. However, other participants considered what would be important for the machines, and what would eventually create a hierarchy among them (e.g. in terms of 'smartness'): "Probably the top of the list would be 'smart appliances' such as laptops, phones, video game consoles. At the low end are appliances that only serve as one function, for example a kettle or blender. If you can control one appliance from another, for example home-heating with a smartphone, then that appliance is at the bottom as well." Access to electric power was considered another key factor: "If the 'life' of a machine is the electricity, then the machines that control electricity supply to other machines are more privileged (e.g. power generator, portable battery etc.)." Some participants ranked their appliances based on purchase cost, while others attached importance to the utility value of machines: "My ubiquitous phone rules them all." Finally, some participants stated that there should be no hierarchy among machines, saying, "We are not a hierarchy, we are all interconnected. We are not individuals, we are one."

The probes demonstrate how difficult it is for designers to consider machines as independent from humans. As designers are trained to focus on users' needs (Norman, 2013), they naturally place humans at the centre of the action (Dourish, 2004). Our concern is that this attitude limits designers' possibilities, leading them to disregard not only the role of machines, but also other nonhuman entities. We therefore moved to a design exploration that attempts to investigate machine independency and collaboration, as well as the identification between people and machines.

5 Designing machines with autonomy

Three design concepts and provocations were developed to practically explore the potential for a more equal relationship between humans and machines. It is important to observe that while our goal was to look beyond anthropocentric approaches, we had no issues with anthropomorphism. Designing entities with similar characteristics to humans often supports the communication of ideas and, as mentioned, there are indeed many commonalities between humans and other entities, even when these traits are considered intrinsically human. Our concern is with anthropocentrism, or the consideration that humans are central to all events in the world; thus, neglecting other forms of being in the world.

5.1 Independence: Machine society

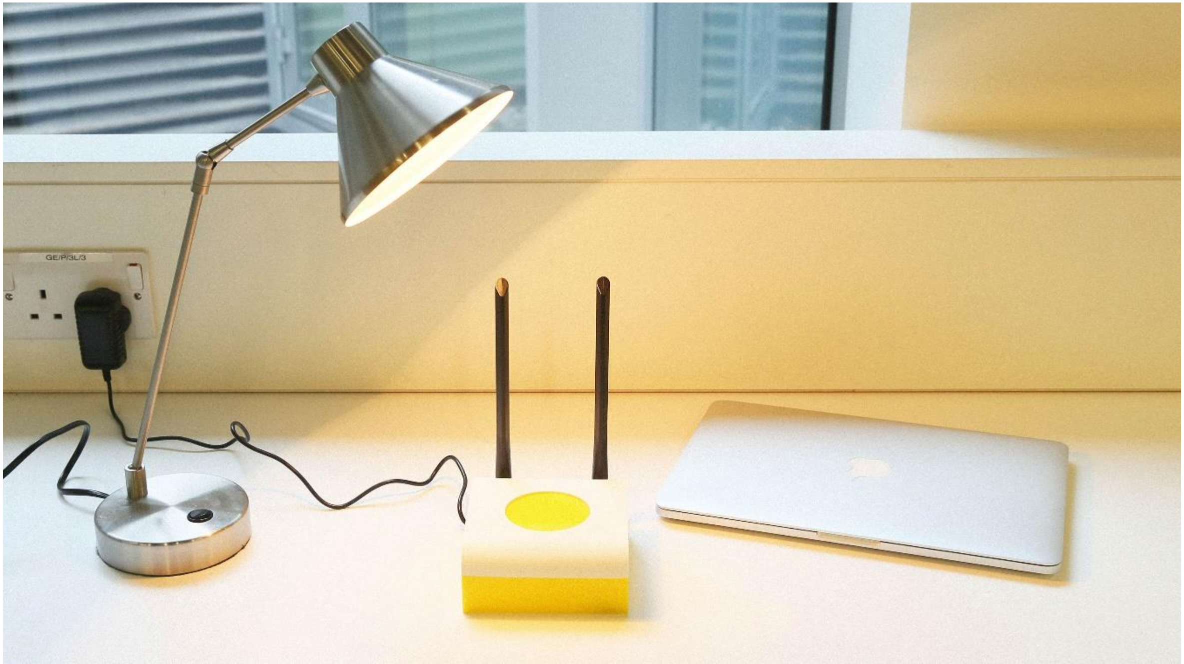

Figure 4 Gatekeeper on the Mission: A fictional machine society.

While many of the projects discussed above allow machines to communicate and have some level of independence, we are interested in exploring the potential of machines constituting a fully independent society. How would the world of devices be without humans? What would machines exchange? What kind of social relationships would they create? These questions led to the design of the *Gatekeeper on the Mission* (Figure 4). In this concept, data is not only the communication means, but also the currency among machines. Empowered with context-aware intelligence, devices generate data by observing and interacting with any entities in the world, be it a human or a fellow machine. In this scenario, the machines would have autonomy to exchange information with each other. Reflecting the responses from the probe, in which the participants were asked to discuss machine hierarchy, roles in this society would be defined based on degrees of access to data. Such access would depend on sensing capabilities, computing power, and learning ability. A smart speaker, for example, which has a more robust processor and a more comprehensive algorithm, would have more prominence than a lamp.

In this concept, the router acts as a gatekeeper, mediating and regulating access to other appliances. The router has control over the access of other machines to the Internet, closely monitoring the data traffic and 'conversations' between its fellow machines. For appliances to receive data, they need to offer some data in exchange – data that is generated by monitoring the environment. By regulating the distribution of the data resource, the router maintains the social order within the machine society. Inspired by the iconic *Nabaztag* (2009), the gatekeeper indicates its working state by shaking its antennas and blinking. Humans, however, cannot truly interpret these behaviours and have no control over the autonomous society. Consequently, human and nonhuman organisations remain separated.

Figure 5 The gatekeeper monitors the data traffic within the machine network and indicates its working state by shaking its antennas.

5.2 Interdependence: Moral machines

Empowered by AI, machines are increasingly taking the role of decision-makers, and much has been said about how machines will eventually make decisions together with humans and all of society. Concepts such as human-in-the-loop, in which AIs learn from the decisions of humans integrated in their interaction loop, are regarded as providing benefits for both machine efficiency and the 'quality' of human judgements (Cuzzillo, 2015; Wang, 2016). One example is the autopilot mode of the Tesla Model S. Although the car can drive itself, it allows drivers to steer it to learn from their behaviour and eventually give drivers control. While human-in-the-loop aims to embed an individual's judgement into AI systems, society-in-the-loop is "the algorithmic governance of societal outcomes" (Rahwan 2016). Society-in-the-loop is a method for considering the general will of the public and embedding it into an "algorithmic social contract" (Rahwan, 2016). To implement society-in-the-loop, according to Rahwan (2016), "we need to build new tools to enable society to program, debug, and monitor the algorithmic social contract between humans and governance algorithms".

The concept of society-in-the-loop reflects tensions created by narratives of control, with agents interpreting and telling people what to do or vice versa. If we consider the *Ethical Things* project (described in Section 3) in the context of a society-in-the-loop, we could consider the possibility of a governing AI to reconcile diverse opinions, make judgements, and guide collective decisions, potentially resulting in better moral standings. The problem, however, as we have seen with other examples of AI's, is that learning from people's opinions and attitudes, and making generalisations from sets of people that an algorithm is able to reach, can lead to controversial outcomes. A good example is the collapse of Microsoft's Tay. Released on Twitter on March 23, 2016, Tay was an AI chatbot that was created for the purposes of engagement and entertainment. Tay's behaviour was dictated by public data and input from improvisational comedians in order to engage and entertain people. The public data was modelled, filtered, and anonymised. In addition, nicknames, genders, favourite foods, postcodes, and relationship statuses of the users who interacted with Tay were collected for the sake of personalisation. Powered by AI technologies, Tay was supposed to understand speech patterns and context through increased interaction. According to Peter Lee, Vice President of Research at Microsoft, the company “stress-tested Tay under a variety of conditions, specifically to make interacting with Tay a positive experience” (Lee, 2016). Despite all these tests, Tay turned into a problematic bot that promoted Nazis and attacked feminists and Jewish people. Furthermore, biases exist in many different levels from the personal to social scales. Given the rise of post-truth and the ‘news bubble’ phenomenon, it is difficult to affirm whether people’s decisions are consequential or an emotional response to repeated and even fake news.

These issues could be addressed by defining a moral compass to a judging AI. However, there remains the question of what this moral compass is based upon. Even within the same culture, people may still have different moral views; the fundamental assumptions and values may differ radically from person to person (Pearce and Littlejohn, 1997). The usual approach is to attempt to understand what would be most beneficial for the majority of entities in a network. It is the old ‘trolley dilemma’ (Thomson, 1976), which questions whether it would be ethical to sacrifice one person by pulling the lever to divert the trolley onto the side track and save many others who are on the main track. A computer would logically respond ‘yes’ to this dilemma. For a person, however, this question is more complicated. Often, the morals of computers are based on decisions that logically benefit the whole. This approach disregards individuals and entities in a way that humans would not necessarily do. According to Morton (2017), this type of thinking - the whole being greater than the sum of its parts, and therefore where our attention should be focused - is problematic. It leads us to consider that even if entities or entire species are annihilated, the whole will still take control and make sure that we carry on. Morton suggests the concept of ‘subscendence’, in which we conversely consider the whole as the sum of its parts, and regard this set as greater than the whole. Based on this argument, we suggest that, rather than attempting to align our human ethics to generalisations of the logic of computers, we look at situated scenarios. Instead of defining who makes decisions, we try to introduce a form of cooperation between humans and machines in which machines learn about humans biases and question them. They still attempt to reach a collective decision and outcome, but this time by inviting reflection.

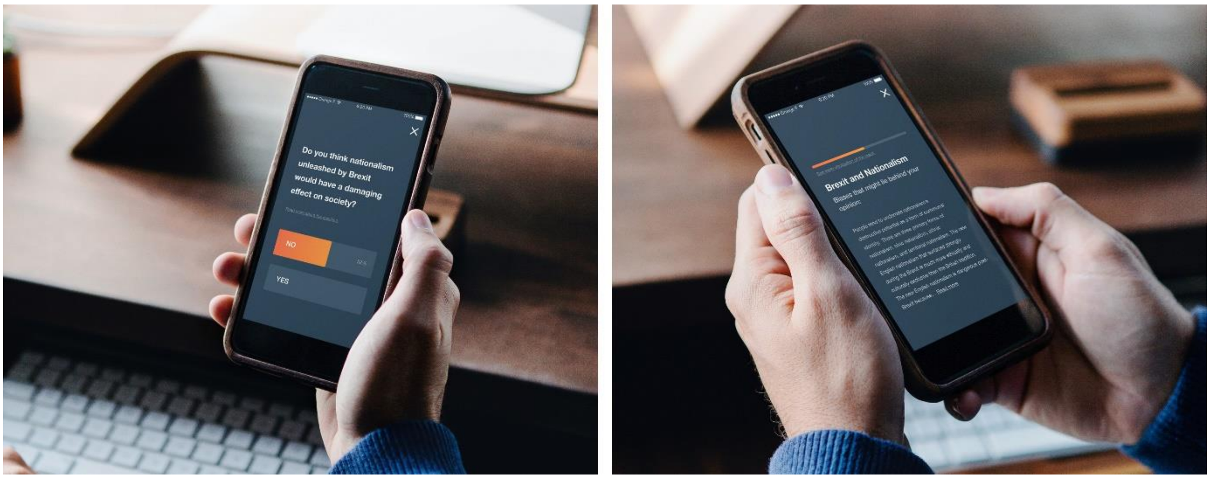

Figure 6 Perception Companion: An AI system learns and potentially challenges people’s biases by asking questions on specific themes and inviting reflections..

To illustrate this scenario, we developed the *Perception Companion* (Figure 6), a system that would communicates with people through a series of questions on a particular theme (e.g. people's opinion on Brexit). Based on the responses, the companion would learn about people's biases. Instead of averaging the responses, it asks follow-up questions to search for the reasons behind the biases, potentially challenging them. These follow-up questions are not confrontational, and the AI does not assume the same biases, it simply listens, questions, and invites reflections. Rather than a traditional judge that decides about the 'the best' outcome based on a majority of votes, the companion attempts to reveal similarities and the place of people, animals, and things in the world, contextualising rather than generalizing opinions.

Verbeek (2009, p. 16) critically argues for a broader domain for morality, a domain in which "technology does not impede morality, but rather constitutes it". To augment the ethics of technology, Verbeek suggests designers to materialise morality by "designing the human into the nonhuman" and "making visible the human in the nonhuman" (p. 18). In other words, designers can aim to shape the mediating technology as well as reflect on the moral role of the technological mediation. In doing so, the boundary between humans and nonhumans can be crossed, and an alliance between both entities can be created (Verbeek, 2009). To create such an alliance, humans need to be in solidarity with nonhumans and vice versa. According to Morton (2017), becoming human means creating a network of kindness and solidarity with nonhumans. The companion attempts to promote solidarity by asking questions.

5.3 Solidarity: Searching for identification

As we move from independence to interdependence, we realise that identification is useful for creating equality and, potentially, solidarity between humans and other entities (machines, things, and other beings). Masahiro Mori's concept of *Uncanny Valley* (1970) has been increasingly employed to explain the relationship between the degree of familiarity and the resemblance to the human figure, particularly in robotics. Mori argues that as resemblance increases, for instance, from an industrial robot to a humanoid robot, the level of familiarity also increases, until it reaches a stage at which the curve sharply drops into an uncanny valley. In the uncanny valley, resemblance between humans and machines results in no familiarity and even generates an attitude of repulsiveness. The point is that humans and machines should maintain their own integrity. While humans and machines can and should have some similarities to enable some level of identification, the model collapses when machines try to *be* humans.

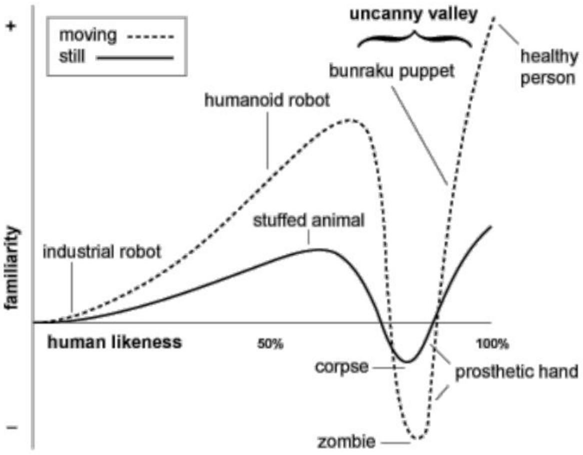

Figure 7 Masahiro Mori's notion of Uncanny Valley (1970).

While Mori's model mostly focuses on the aesthetics of machines, we are interested in exploring the level of resemblance between attitudes of humans and machines. As particular actions can reflect particular attitudes, we want to explore what type of machine actions can reflect human attitudes, and in doing so try to create a strong level of identification, while not trying to be a human.

The *Poet on the Shore* was designed to envision a scenario in which a robot would be imbued of poetic sensibility. The autonomous robot roams on the beach, enjoys watching the sea, listening to the sound of waves lapping on the beach, the murmurs of the winds, children's conversing, and the incessant din of seabirds. Most of the time, the robot roams alone to listen and feel. Sometimes, it writes verses into the sand, and watches the waves washing them away.

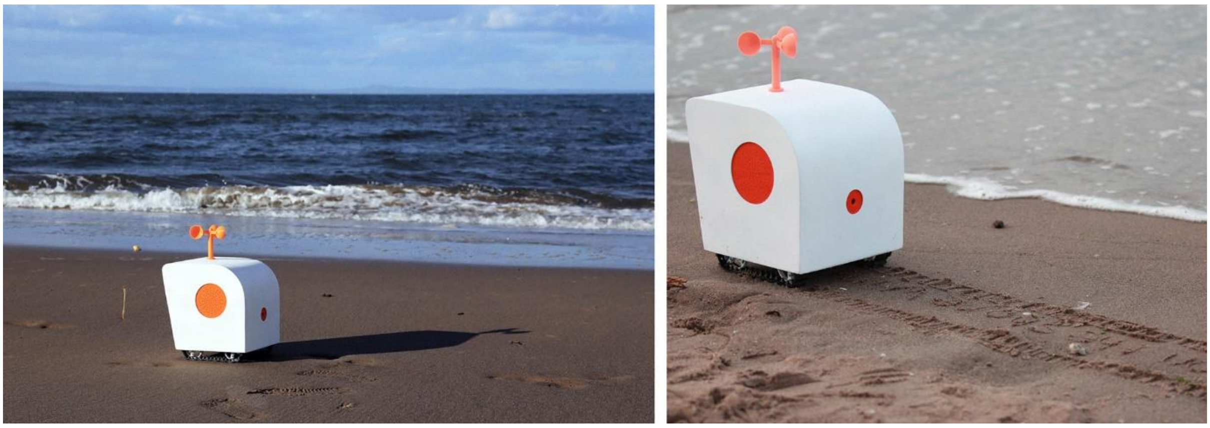

Figure 8 Poet on the Shore: An autonomous robot that roams on the beach.

The robot has several sensors that enable it to sense the world around it: the sea, the wind, the sounds, etc. Empowered by machine learning, it can discover patterns, and create associations in its mind. Furthermore, it translates these perceptions into poems and writes them on the beach. The robot, thus, intervenes in the world and has multisensory experiences. Its behaviour does not require the intervention of humans. These interventions, expressed through the kinetic and poetic gestures, reveal its non-utilitarian existence: the words it writes are eventually be washed away by the waves or winds.

Poet on the Shore is an attempt to facilitate reflection on the alternative values of machines and emotive responses. It is important for us that the robot does not have a specific function. Rather than serving humans in an utilitarian manner, it performs actions that are typical of humans and potentially many other beings. By not serving or trying to be among humans, the robot maintains its integrity. The intention is that this behaviour would lead to a sense of identification and solidarity, which could lead to recognition of agency, sensibility, and even rights of machines.

6 Discussion and future work

In this paper, we present practical explorations that demonstrate the three main challenges of designing machines with autonomy. The first challenge is to simply acknowledge that machines may have social organisations that are independent from humans. In the *Gatekeeper on a Mission* concept, we found it useful to establish analogies with existing forms of social organisations, illustrating a parallel world of machines that reflects power relationships among humans and often also among other species. While computer scientists have been considering the autonomy of algorithms for some time (since, for instance, Conway), indeed leading to technologies that are increasingly being introduced in products and applications, the consideration of such applications in design, as explained in Section 3, is relatively recent. A useful exercise for future work is to consider other forms of organisations, such as chemical and geological. This shift in awareness has the potential to lead to forms of design that not only extend the realm of human action, but also the lifetime of humans, expanding designers' awareness into deep- or micro- temporalities.

The second challenge is to understand how designers could support relationships of interdependence between humans and machines, beyond notions of dominance. Rather than machines serving or overriding humans, they would evolve in parallel to them. While there has been great discussion on the ethics in computing, particularly given the influence that they seem to have had in recent elections, there have been few responses to these issues in the design community. Based on Morton's (2017) notion of subscendence, we propose to, instead of thinking about big data as an intangible, abstract entities, considering the tangible effects of different entities such as people, machines, or other living beings. Through the *Perception Companion,* we attempted to explore, not how machines would influence people or make decisions, but how they would learn from people's biases, and how they could challenge these biases by pointing out things in the world. The implementation of such a concept would certainly face many challenges, but we argue that, as machines evolve, it is important to consider how they will evolve *with* and not *for* or *by* humans.

The third and most challenging aspect concerns the creation of identification and potentially solidarity between humans and nonhumans. Although ANT and OOO offer philosophical frameworks for placing human and nonhuman on the same footing, we recognise that these theories could provoke uneasiness in terms of alluding to some sort of human 'objectification'. Morton (2017, p. 12) suggests that focusing on the commonalities between humans and nonhumans helps to support solidarity between humans and nonhumans. The challenge is, therefore, to explore ways in which the importance of objects would be revealed, not to serve or override humans, but to propose commonalities, while maintaining the integrity of both entities. This could be done on an aesthetic level, as insightfully suggested by Mori in the concept of *Uncanny Valley*, but also through other human traits. In *Poet on the Shore,* we attempted to support identification between humans and nonhumans on a subjective level. Increasingly, not only the appearance but also attitude may lead to identification between people and things. There remains the question of what type of attitude we, as designers, would like to support in this context.

Our investigation has focused on particular scenarios and in the relationship between humans and machines. Expanding awareness beyond human-centred design would, however, also involve designing for other forms of life. This creates questions and possibilities concerning reflecting on how machines would organise themselves, interact, evolve, and potentially create identification with everything in the world. Shifting attention from humans to the world makes space for enormous creative potential. Sharing experiences and challenges, while reflecting on future directions, can help us designers on this journey.

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Section 21.

Health and Wellbeing by Design

DRS 2018 Design Research Society 2018 **Catalyst**

University of Limerick
25th – 28th June 2018

Editorial: Health and Wellbeing by Design

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One of the most complex global challenges is improving wellbeing and developing strategies for promoting health or preventing ‘illbeing’ of the population. The role of designers in indirectly supporting the promotion of healthy lifestyles or in their contribution to illbeing is emerging.

Motivated by the challenges of an ageing population and the associated rise in the number of people living with non-communicable disease this track has been formed. Its aim is to provide a collection of the state-of-the-art design-led work that look at the ways design is contributing to the health and wellbeing of population.

The diverse collection of papers in this track offers an insight into the significant role and value of design in an area traditionally dominated by health sciences. Divided into three distinct themes, a total of 15 papers explore various aspects of health and wellbeing, namely health by design, health management, healthcare applications and medical devices.

The session on ‘health by design’ provides an overview of the challenges and opportunities in healthcare, including the role of designer within this space, the advent of the Internet of Health of Things. In this session, Nusem presents under ‘*Design in Healthcare: Challenges and Opportunities*’ a synthesis of theory on the application of design and design research to healthcare. It also presents a matrix of this synthesis and then describes a small study with focus groups. In their paper entitled ‘*Design research opportunities in the Internet of Health Things: A review of reviews*’, Tsekleves and Cooper provide a review of the review articles that have been published on the topic of the Internet of Things within healthcare, with a specific focus on health IoT within the home environment. They identify eight key areas for design intervention. In ‘*The role of the designer in public discourse – A critical discourse analysis of a medical brochure for diabetes patients*’, Jacoby explores the role of a designer in producing medical related information brochures, using work done with a diabetes patients group as a case study. Next, Dunn et al, in ‘*Building Relationships and Sustaining Dialogue between Patients, Caregivers and Healthcare Practitioners: Designing Digital Platforms for Ventricular Assist Device Users*’ offer a review of digital platforms to support Ventricular Assist Device Users, and propose a set of criteria for how these interventions could be designed to be more effective and user focussed. Laslty, in ‘*Social innovation by design in mobile healthcare for sleep disorders*’ Catoir-Brisson explores how a methodology based on systematic design, which includes the different profiles of stakeholders of a complex healthcare problem, such as insomnia, contributes to re-design the whole experience of the patient care journey and to design educational kit tools for patients and care professionals.

Health Management has its own session looking into different ways of self-health management at an individual and community level. More precisely, Tan et al. in their paper entitled '*Healthy Self-Management Communities by Design*' offer an insight on how communal spaces have been created in Singapore to help older people enjoy better health and well being. In '*Mentian: piloting design fiction on dementia policy*', Darby and Tsekleves discuss the use of participatory design fiction to explore the future implications of UK dementia policy. Young-ae presents in '*Socio-cultural factors in diabetes management in South Korea*' the outcomes of research activities that identify the socio-cultural factors triggering diabetes and how patients cope with the disease. Etherington et al. present in their paper '*Cascading Mentorship: Designing a Support Tool for Patients with Ventricular Assist Devices*' holistic design considerations for Vetricular Assist Devices and training, that were developed with a co-design approach. The inclusion of the stakeholders reveals concrete considerations that can improve the lives of their users. Kopanoglu presents in '*Design for Multi-Dimensional Stages of Lymphoedema Self-Management*' a literature review and a preliminary framework of four themes and their stages, in order to assist designers in understanding how people with lymphoedema experience self-management.

The session on healthcare application and medical devices demonstrates a number of case studies of design interventions for the management and of diverse health conditions. In '*Toward a more granular management of the calibration process for hearing devices: The role of design-based knowledge translation*' Picinali and Atvur examine how design might help translate technical and medical knowledge to allow people to self-calibrate their hearing aid device. They argue that design thinking provides valuable insights to make translation process easier. Menheere et al. present in '*Encouraging physical activity and self-enhancement in women with breast cancer through a smart bra*' the design research supporting the design & prototype of a temperature-activated bra for registering feedback to breast cancer survivors in their recovery from surgery and treatment. In the paper entitled '*A Qualitative Inspection of Human Centeredness of Turkish Medical Devices Industry'*, Cifter and Kose examine human centred design in Turkey in relation to medical device development. The authors suggest that there is a 'lack of attention' paid to human centred design amongst Turkish medical device manufacturers. Stead et al. explore in '*Do-It-Yourself Medical Devices: Exploring Their Potential Futures Through Design Fiction*' the possible future implications of do-it-yourself medical devices from both democratised innovation and regulatory perspectives, through speculative design. Lastly, in '*Does feedback from this device change my unhealthy habit? Lessons from my PhD project*' Hermsen explores the mechanisms for user feedback from personal digital devices in respect to engendering long-term behaviour change.

DRS 2018 Design Research Society 2018 Catalyst

University of Limerick
25th – 28th June 2018

Social Innovation by Design in Mobile Healthcare for Sleep Disorders

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This project-grounded research aims at answering a need for research on sleep disorders and connected objects, through an interdisciplinary dialogue between human and social sciences, medical sciences and design. The objective of this article is to answer the following questions: how can social innovation by design sustain the development of innovative medical devices? How can design work to optimize the prevention, the support and the follow-up in sleep medicine? The project aims at creating a digital platform optimizing the circulation of the data, the customer's journey and the communication between patients and care professionals. The research has had a double scientific challenge, carrying on therapeutic education in sleep and digital health literacy, especially in the field of medical computing and mobile devices for chronic diseases. First, the scientific roots and methodology is explained. Then, the methods of inquiry and the results are reported. Finally, a contribution to design research for healthcare is proposed, focusing on the role of design in promoting sleep's hygiene through the creation of suitable services, products, experiences and healthcare environments.

m-Health; insomnia; service design; digital literacy

1 Introduction

This article deals with a project-grounded research currently being developed at the PROJEKT Lab at the University of Nîmes, on service design in mobile healthcare (especially sleep disorders), in collaboration with the University Hospital in Nîmes[1]. Based on an interdisciplinary dialogue between design sciences, information and communication sciences and medical sciences, this research involves, at the same time, interaction design, service design and social innovation by design. Using experimentations and prototyping, the objective is to show that a digital service can be useful to

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[1] The research is co-managed by Dr Beatriz Abril, Neurologist and Sleep disorder specialist, Dr Gauthier Brisson, General praticionner and Sleep disorder specialist, Marie-Julie Catoir-Brisson, Associate Professor in Design and Communication Sciences. Sandrine Pirolles, social service designer also participated to this one-year study.

educate and to follow insomniac people up, if it is integrated in a care network and supported by care professionals. The financial contribution of the University Hospital in Nîmes (Second award won in October 2016 at the Innov'actions Trophy) has made this one-year study possible, to assess the feasibility of the project and to make inquiries with local stakeholders. Research is needed on chronic insomnia and connected objects. In France, insomnia is a public health problem that affects almost 20% of the population. In spite of the recommendations of the HAS (*Haute Autorité de Santé* which is French Health High Authority), patients care is limited at any level: access to healthcare, availability of the professionals, lack of educational kit tools, reimbursement for healthcare, and adverse drug reactions. Moreover, connected objects and apps dedicated to sleep are growing faster and faster. They are used by the citizens, without any medical supervision, and are often given up after a few months (Kebs, Duncan, 2015). But their emerging use implies the development of health digital literacy. These technological innovations and the social changes accompanying them make the participation of health professionals, designers, researchers and citizens in the field of mobile healthcare for sleep disorders necessary. Problematics in this study aim to answer the following question: How the design of mobile health technologies in the field of insomnia leads to rethink the cooperation's models between healthcare professionals and patients, the care journey of the patients and the role of the different stakeholders? This article consists in three parts to cope with this complex issue. In the first part, the scientific roots and the methodology are presented. In the second part, the first results of the research are discussed. In the third part, a contribution to design research for healthcare is proposed.

2 Scientific roots and methodology: social innovation by design and digital social innovation

To start with, let's introduce the different concept and values of the design research, in order to define the specificity of the methodology.

First, this project-grounded research is part of a specific methodology called *recherche-projet* (Findeli, 2003), characterized by the fact of articulating a research project and a service design project. It is a kind of action-research[2] (Rapoport, 1973) to make the experience of the participants better. Considered at the same time as experts of their own experience and beneficiaries of the project, they are involved in the search for solutions.

To be more specific, the methodology is based on an interdisciplinary dialogue between medical sciences, social and human sciences (in peculiar information and communication sciences) and design sciences, as we can see in the diagram below.

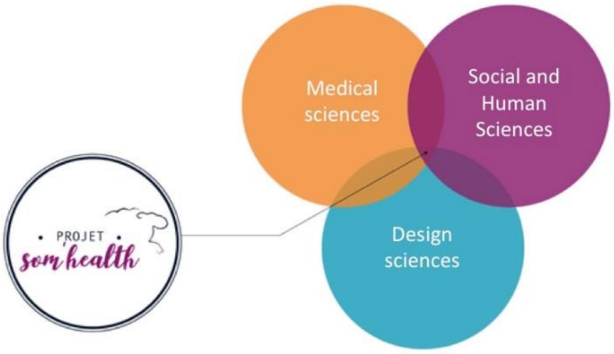

Figure 1 – Interdisciplinary methodology of the project-grounded research

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[2] According to Robert N. Rapoport (1973, p.115), « action-research aims at making a contribution at the same time to the practical concerns of people being in problematic situations and to the development of social sciences, by a collaboration that connects them according to a mutually acceptable and ethical plan. »

Secondly, it is important to explain the meaning of social innovation through in this research. Social innovation by design is a topical issue in human and social sciences especially in the design sciences. Nevertheless, it is not really new and this trend takes up with the origins of design history (for instance, the works of the Bauhaus, then V. Papanek, A. Findeli). Design sciences may seize the problem of social innovation today because these two fields have in common to study the problematic of uses, and try to stand out from technology and product-centered innovation. This approach gives the patients a power to design and act, beside healthcare professionals and administrations. Thus, digital products and services can be designed for social change, as far as they are designed to create uses and behaviours dedicated to social innovation (Tromp, Hekkert, Verbeek, 2011). It is important to underline the implication of both patients and professionals in this project, to explain how it is possible to reframe patients as persons with active participation in their own healthcare. The objective of the project is to build a human and digital network in which the patients can develop their healthcare and digital skills based on the expertise of their own experience of patients. In addition, healthcare professionals can develop their knowledge in the field of insomnia as well as their digital literacy, by taking part in the service network.

The specificity of this project-grounded research is also based on human-centered-design (Buchanan, 2001). The objective is to go further to the problematic of use to reach social issues involving the designer's responsibility[3]. Human-centered-design "is an on-going search for what can be done to support and strengthen the dignity of human beings as they act out their lives in varied social, economic, political, and cultural circumstances." As a consequence, "the quality of design is distinguished not merely by technical skill of execution or by aesthetic vision but by the moral and intellectual purpose toward which technical and artistic skill is directed.[4]" In this perspective, the objective of the project-grounded research is to develop a *creative ethics of technology* that is close to *ethics by design*, based on the responsibility of the act of design in the proposal of an *experience-à-vivre* (Vial, 2015) from five key steps in the design process: understanding the experience of the users, using participative methods, relying on a systematic approach (to create a synergy between all the actors), making workshops in order to practice ideation, co-creation or co-design services and prototypes with the beneficiaries, in an iterative way of thinking.

At last, digital social innovation[5] is also part of the methodology of this project. This approach of technology makes the movement from technological-centered innovation to social and digital innovation possible, in which digital technology is put in the service of the common good for public health interventions.

3 Methods of inquiry: a qualitative, participative and creative research

The first step of the design process was dedicated to inquiry, in the field of the public hospital in Nîmes but also in office practice (general practitioner). This methodology was useful to understand and then to make many actors (patients, healthcare professionals and administrations) take part in the healthcare project. It can be considered as a contribution in both research and practice on insomnia because "no study was focused on the cross-personal views of these actors.[6]" The qualitative methods were used to collect data on the representations, the practices and the expectations of the participants.

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[3] Tromp N., Hekkert P., Verbeek P-P., « Design for Socially Responsible Behavior: A Classification of Influence Based on Intended User Experience », Design Issues Vol. 27, N°3, 2011, p.3-19.

[4] Buchanan R., « Human Dignity and Human Rights: Thoughts on the principles of Human-Centered Design », in Design Issues, Vol 15, n°3, 2001, p .35.

[5] Our research leads on the values developed in the European community research of DSI : https://digitalsocial.eu

[6] Gaboreau Y., Pricaz F., Cote-Rey A., Roucou I., Imbert P. (2017) « Consensus, controverses et dissensions entre médecins généralistes et patients autour de l'insomnie chronique primaire », *Revue Exercer #130* Volume 28, Collège National des Généralistes, février 2017, p.52.

Figure 2 Observation periods and interviews

The inquiry was based on three steps: observation periods, interviews and workshops, from February to June, in 2017. Observations of specialized consultations in the Sleep Medecine Unity of the University Hospital in Nîmes were undertaken with the agreement of the doctors and fifteen patients. Then, semi-structured individual interviews and focus group based on visual and creative methods were organised in the public hospital and in the office of a general practitioner (with doctors, patients, medical secretaries, and also local public administrations (ARS Occitanie, CPAM du Gard). This step was useful to understand the limits, constraints and the specificities of the consultation in medical city office and in the public hospital. It was also helpful to visualise the patient's journey in order to underline the problems between the patients and the touch points of their healthcare journey between public hospital and many healthcare professionals in the city). The analysis of the data collected during the observations period allowed us to design two workshops in April and June based on creative method and co-design.

The first workshop was composed of twelve healthcare professionals (psychologist, general and specialist practitioners) in order to come together the main actors and to understand their actual problems in the insomniac patient's journey and their uses of digital tools and mobile devices. Visual and creative methods were used to make the expression of the participants easier. Visual materials came from two different sources. The participants - especially the general practitioners - were invited to send some photographs of the digital tools they may use in their everyday professional practice. For example, two general practitioners sent us a screen shot of their mobile phone representing the homepage of Klepios (an app for doctors with a synthetic medical index of the main pathologies; see https://www.klepios.com) and Univadis (free medical app and website with medical information, especially on drug interactions; see https://www.univadis.fr). We also gave boards and visual cards representing various digital tools used in medical city office, made by the social service designer of the project. The visual methods used in this investigation were based at the same time on the participants', the designer's and the researcher's productions. We let the participants free to cover the boards with notes in order to represent the digital tools for which they did not have any picture. With this methodology, we collected information on the individual practices of twelve healthcare professionals.

Figure 3 Workshop #1 April 2017

The second workshop of co-design at the beginning of June was made with patients, healthcare professionals and administrators. Different methods coming from game storming were used, based on activities made to use space as an expression of opinions, and also visual and creative methods. The participants were invited to work in small groups of three or four people, and each team had to mix patients with doctors, and a secretary or an administrator. Visual materials (such as game board, cards, personas, patient care journey, map-tools, map of the network etc.) were prepared by the designer and researcher and proposed to the participants to support their expression by playful and participative materials.

The results of this co-design workshop were very useful, as three maps of the care professionals and insomniac patients network were sketched, in order to express different visions of the sleep institute imagined by the participants. In addition, more than twenty digital tools at the service of the human network were produced, allowing to imagine the digital and healthcare services of the institute, the functions of the website and the connected object used to optimize the prevention, the support and the medical follow-up in sleep medicine.

Figure 4 Workshop #2 June 2017

The visual methods were relevant to make the voicing of opinions easier and to increase the implication of the participants in the workshops. « This implication can be explained by the fact that visual methods offer participants the possibility to express themselves from several materials that they can mobilize in a free way.[7] » All the visual and physical materials were used as mediation's support in the workshops, at the service of the methodology of this project-grounded research. Relying on co-design and inclusive design can be a useful way of leading organizational change-making based on a method to involve participants, who can be care professionals, patients and relatives. This systemic design practice and research is necessary in the field of healthcare because this specific field is a complex field, which combines the interventions of many different stakeholders.

The observations, the interviews and the two workshops allowed to draw and to propose some solutions that can be useful to the research and to the project. The main results accentuated the necessity of 1/ creating a patients and healthcare professionals network to develop therapeutic education and to optimize the patient's care journey; 2/ improve the communication between healthcare professionals, patients and administrations. This network would be based on a digital tool allowing to collect data on the patient, which would serve to develop the research on sleeping disorders within a living lab[8] (ENoLL, 2008). The data would be visualized, after a work of information design, to inform the patients on their own mechanisms of sleep and improve the understanding and the follow-up of their pathology. A human care professional network in the local community would support the digital network. These results invite us to think about the way the digital technology re-configures the medical practice and the communication between doctors and patients. They also open the reflection on the mutual contributions between information and communication sciences and design sciences.

Moreover, we can list the various project deliverables that we produced during this first year of study. A book - including the results of the enquiry, some recommendations for the design of the institute dedicated to insomnia, more than twenty digital and educational tools for patients and care professionals, and users scenarios - was printed. A pedagogical project was also managed with the students of the Master's programme "Design Innovation Society" (Master DIS) in the University of Nîmes, from October 2017 to January 2018[9] to develop the possible deliverables of the project. The objective of the pedagogical project was to make students understand the complexity of the field of healthcare, and imagine solutions able to change customer's journey, landscape and experience in healthcare through social innovation by design. The student's propositions were useful to give form to the human network that can improve the patient's care journey and to develop the interaction design between the digital network and the connected object dedicated to the data collection on sleep (including a prototype of the web application). A short documentary was produced to explain the project methodology based on social design. A website is also proposed to follow the current events of the project (see: https://projetsomhealth.org).

It is important to finish with the main limits of this experience of project-grounded research in the field of healthcare. We can list three limits: 1/ political limits both in the local and national context as chronic insomnia is not considered as a priority in French health policy during this one-year study; 2/ limits in relation with the stakeholders such as representations of patients and care professionals on insomnia and its treatment, fears of change and of technology, access to professionals; 3/limitations

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[7] Catoir-Brisson M-J., Jankeviciute L., « Entretien et méthodes visuelles : une démarche de recherche créative en sciences de l'information et de la communication », *Sciences de la société*, 92, 2014, p.125.

[8] According to the European Network of Living Labs (http://openlivinglabs.eu): "a Living Lab is about experimentation and co-creation with real users in real life environments, where users together with researchers, firms and public institutions look together for new solutions, new products, new services or new business models."

[9] This pedagogical project was supervised by Marie-Julie Catoir-Brisson, in collaboration with Lucile Haute and Sandrine Pirolles. Participating students were : Younes Gzouli, Marylou Planchon, Emeline Titeux-Flores, Tiphaine Rosier, Alan Shammas, Camille Soulier.

of the methodology, in peculiar for the participative action-research: difficulty to make care professionals (especially doctors and health administrations) participate in the workshops.

4 A contribution to Design Research for Healthcare

In this third and last part, a contribution to design research for healthcare is proposed. Our project-grounded research can be studied to demonstrate how design can improve the prevention and the promotion of sleep's hygiene through the creation of services, products, experiences and healthcare environments. More precisely, the methodology based on systemic design allows us to open the project from a service focused on mobile devices to a project of institute considered as a complex of systems and service design dedicated to insomnia prevention and treatment. A human and digital network of patients and professionals can support the institute. In addition, mobile devices and connected objects can be used to serve various stakeholders. The global solution includes optimizing the patient care journey and the communication between patients and caring professionals through secure information systems and database. Access to the patient's data should be co-defined by patients and care professionals. This peculiarity is very important for the ethic value of the project. But the access to the patient's data will also need to consider the recommendations of the French Health High Authority (HAS[10]) and the legal regulations on data protection in the European Union. The minimal equation of the digital platform is composed of professionals + data + patients. And the final form of the digital network should be suitable to the constraint of information system's interoperability (in peculiar between the softs used in public hospital, city office and public administrations). This technological challenge will be possible only if the social interoperability between the various actors is made possible by the local and national public health authorities. This project of connected objects and sleep medicine affects health public policies. This supported need to improve the development of the project was also recommended by one of the general practitioners in the first April workshop. He noticed the importance of a " political support " to develop a " national information campaign " on chronic insomnia, to strengthen our initiative of network on the fieldwork. This is where design can be useful to develop information and educational kit tools, to sustain sleep hygiene and patients' and care professionals' digital health literacy.

The results of this one-year design research lead us to think about mutual contributions between information and communication sciences and design, and to focus on the contribution of design to the field of human and social sciences.

4.1 Mutual contribution between information and communication sciences and design

On the one hand, we can emphasize the links between these to human and social sciences. In design sciences, the project is seen as "the act of design" and the act of design is an "act of communication" (Vial, 2014). It can be analysed from both perspectives: conception and reception, that is to say "the design gesture" and "the effect of design" (Vial, 2015). The act of design refers to the act of communication inherent to any media device. In this project-grounded research, the link between the two sides of the co-construction of the meaning (by designer and user) is analysed with three main approaches that build the specificity of the main researcher's profile: semiotics, communication and anthropology.

Moreover, it is necessary to put the designer's and researcher's roles in a project-grounded research into perspective, especially in the fieldwork. Our experience of this project makes us think that these two approaches are complementary. With the researcher, the designer contributes to the creation of mediation devices that are helpful to the transmission and the collection of information between the participants. The visual materials can be considered as "transitional objects", useful in a

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[10] See the Frame of reference of the best practices on health applications and connected objects published in 2016: http://webzine.has-sante.fr/portail/upload/docs/application/pdf/2016-11/has_ref_apps_oc.pdf

"potential environment of skills development[11]". These materials build up an environment allowing to develop the necessary conditions to develop the creativity of the participants. In addition, the designer can draw visual synthesis of the enquiry, which can enlighten some characteristics of the qualitative analysis.

On the other hand, the mediation tools produced *in* and *for* the project can be considered as case studies in information and communication sciences. These creative tools based on visual methodology contribute to the renewal of the qualitative inquiries in human and social sciences, with different objectives according to the different steps of the project. In the periods of observation, the visual materials can ease the voicing and the expression of the participants. They are useful to collect representations, experiences and data co-produced by stakeholders, designers and researchers. In the workshops, these mediation tools can be used to help the participants give form to their ideas and solutions. In the development phase of the project, visual materials can be helpful to communicate the solutions to the beneficiaries, and to sketch user's scenarios to explain the functions of the complex system of service design, relying on a storytelling focused on a patient experience.

4.2 Specific contribution of design to human and social sciences in the field of healthcare

At the end of this one-year study on design and mobile health in the field of sleep medicine, we can underline the advantages of our methodology based on systemic and inclusive design: implication of the participants committed in the co-design process, appropriation of the project and the values of the project, and empowerment in the prevention, the care and the follow-up of chronic insomnia.

The participative design practice and research also allowed the participants to seize the project and to become some contact persons in each community of the local territory. They participated in the distribution of the project in their own networks. To us, this is the minimal condition to make a project dedicated to social innovation in healthcare successful. Indeed, co-design can improve acceptability and adoption of the solutions by the beneficiaries as far as they can take part in the design process.

The qualitative approach allowed us to seize the fears, the expectations and the aspirations of the stakeholders, to be able to propose the most adapted solutions. The contribution of design to human and social sciences in the field of healthcare is to take time, with qualitative and participative methods to understand the constraints and the representations of the stakeholders. This approach is relevant to identify their reluctance and to find solutions to go with the cultural and social change. By understanding the fears and the reluctances of the actors, and putting oneself in the main beneficiaries' shoes - who sometimes live innovation as an order, the qualitative methodologies can accompany the innovation in the field of healthcare to acculturate the professionals and the patients in the collective intelligence based on creative methods, but also in the digital health literacy.

At last, we can distinguish five figures of the designer's mediation role in a project. The designer can also be a "competence connector" (Deni, 2014), a coordinator, a communicator, a facilitator and a translator, able to manage the inter-professional and interdisciplinary dialogue between the multiple stakeholders. New roles for the designer can be identify in the complex field of healthcare. Sleep medicine, as a new cross-disciplinary discipline, offers great challenges for designers to lead multidisciplinary groups and make major decisions that will influence behaviour contributing to long-term prevention and better overall population sleep's hygiene.

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[11] Berten A., (1999), « Dispositif, médiation, créativité: petite généalogie », *Hermès 25, Le dispositif,* CNRS, p.41.

5 Conclusion

To conclude, this project-grounded research on design and m-Health dedicated to sleep disorders can be considered as an attempt to contribute to the design research on healthcare and wellbeing. The specific contribution is about the systemic design of the project, including many stakeholders and some digital tools at the service of the patients and care professionals network. The systemic approach is useful to understand how it is necessary to re-design the whole experience of the patient's care journey, and to design educational kit tools for patients and care professionals, including telemedicine service and mobile health.

The specificity of the project and of the complex fieldwork lead us to build up a methodology based on social innovation by design, to give suitable answers to the questions we identify on the field. In this perspective, this project-grounded research goes forward to object or service design to reach to systemic design of systems and services based on suitable solutions for the main stakeholders. The scientific roots of the research, based on human-centered-design lead us to work on social interoperability between the actors. The solutions are designed to optimize the communication between insomniac patients and care professionals, to improve the patient's care journey, to develop the training of professionals in sleep medicine and therapeutic education, and to develop digital health literacy. The objective of the project is thus to consider the benefits form designing a digital service dedicated to insomnia, which is integrated in a patient and professional network, to improve the implication and sustain the empowerment of insomniac patients in their own pathology.

In addition, we can say that further results could be presented to the DRS Congress in June 2018, as the current development phase has led the scientific team to meet potential partners to develop a prototype of the digital network and the connected objects in the following two years.

To finish with, these two initiatives can also be considered as an attempt to underline the role of design in prevention and wellbeing in sleep medicine.

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The Role of the Designer in Public Discourse – A critical discourse analysis of a medical brochure for diabetes patients

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This article discusses the implications of medical brochures titled ‘Hva er diabetes?’ (‘What is diabetes?’) for patients’ perception of diabetes as a chronic illness. The brochure is part of a public relations program targeting people who interact with or have recently become diabetes patients. It is created by diabetesforbunet.no, a Norwegian non-governmental organization aiming to promote issues around diabetes and handed out by all major hospitals and doctors in the Oslo area. The research sets out to understand what discourses are contained in the information given primarily to newly diagnosed diabetic patients and acts as a precursor to a larger study in which patients and designers will be interviewed. The critical discourse analysis found that the brochure aims to calm the patients, it aims to make them compliant with their new lifestyle as chronic care patients. The study focuses particularly how the designer can influence this discourse. The findings build on the understanding of the role of the designer as a public relations practitioner, who is involved in the construction and maintenance of discourses and the ways in which this is achieved.

critical discourse analysis, design, communication theory, health and design

1 Introduction

People undergo a paradigm shift when receiving a diagnosis for a chronic illness (Paterson, Thorne, Crawford, 1999). Often, the first information that they receive after the consultation with their doctor and nurse is the medical brochure. Its visual and written language sets the stage for a patient's new understanding of his/her illness, and, as a result, he/she begins to understand him/herself in a new way. This paper argues that critical perspectives on the production of media designers require attention to discourse in terms of language use, sign media, and the social worlds they all presuppose and bring into being. In short, designers should be aware of their participation in public discourse through their design efforts and intentions. With critical discourse analysis, the aim of this study is to add to ongoing debates within social theory. It accomplishes this by engaging the frameworks of analysis presented by James Gee, Norman Fairclough and Gunther Kress among others.

1.1 Entering into discourse

When entering into discourse, it seems prudent to clarify what understanding of discourse this article follows, as it is a difficult concept to pin down to one specific definition. There a number of conflicting and overlapping definitions of the term discourse, which stem from various theoretical and disciplinary standpoints. This research article aligns itself with Fairclough's concept of discourse.

> *This concept of discourse and discourse analysis is three-dimensional. Any discursive 'event' (i.e. any instance of discourse) is seen as being simultaneously a piece of text, an instance of discursive practice, and an instance of social practice. The 'text' dimension attends to language analysis of texts. The 'discursive practice' dimension, like 'interaction' in the 'text-and-interaction' view of discourse, specifies the nature of the processes of text production and interpretation, for example which types of discourse (including 'discourses' in the more social-theoretical sense) are drawn upon and how they are combined. The 'social practice' dimension attends to issues of concern in social analysis such as the institutional and organizational circumstances of the discursive event and how that shapes the nature of the discursive practice, and the constitutive/ constructive effects of discourse referred to above (Fairclough, 1992, p. 3-4).*

This study presents an introduction into critical discourse analysis (CDA) methodology by giving perspectives of various stakeholders, such as patients, public relations practitioners and designers. This methodology has been applied to understand how public discourse can sway readers/receivers of messages and assert power relations in a given society (Fairclough, 1992).

However, the research scope often excludes the role of the designer in this public discourse. According to Kress and van Leeuwen (1996, 2001), elements of design, such as the layout, colour, text, typography, provenance, perspective and mode, are all expressions of this discourse. This involves the designers quite directly as producers of precisely these elements. However, designers are often unaware of this tool of analysis. Which leaves them consequently unaware of the influence of their role in public discourse.

Critical discourse analysis, popularized among others by Fairclough and van Leeuwen, applies the analysis of spoken, written and visual language to understand the medium and message in a social context. This involves paying particular attention to 'not just describing discursive practices, but also showing how discourse is shaped by relations of power and ideologies and the constructive effects discourse has upon social identities, social relations and systems of knowledge and belief, neither of which is normally apparent to discourse participants' (Fairclough, 1992, p. 12).

2 Method

2.1 CDA

Often, CDA is represented as one specific 'method'. Rather than being an explicit methodology within discourse analysis, CDA offers the opportunity to incorporate the humanities and the social sciences. It is considered to give relevant insight into the manner in which discourse embodies relations of power and ideologies in society (Fairclough, 1992). This assortment of methods does not limit itself to the analysis of specific structures of text or discourse. Rather, it systematically relates these structures to the socio-political context. However, there have been issues noted with CDA. For example, it has been said that it is simultaneously too broad to distinctly identify manipulations within the rhetoric, yet it is also not powerful enough to appropriately find all that researchers set out to establish (Roffee, 2014). Nevertheless, this methodology offers the possibility of generating a broad understanding of an impact of a discourse, while identifying the key participants in this particular discourse. As such, it is considered relevant in this research context.

In many cases, a brochure will not be the first meeting with a chronic illness, as the patient will develop a relationship with an illness gradually. He or she will interpret it through signs that are known and unknown. This then leads to a meeting with a general physician, who will evaluate symptoms described by the patient and possibly after some tests will give a diagnosis, which is in turn followed up with the handing out of a brochure. The aim of this study is to utilize this tool of analysis to understand the impact this particular meeting with chronic illness might have on new patients and then develop a follow-up study. In this larger follow-up study, the aim will be to capture the experience of the patient as a recipient of information, as well as to explore what the intent of the designer is when producing brochures. Simultaneously, the intention is also to apply CDA to the medical brochure 'Hva er diabetes?' ('What is diabetes?') to understand the potential of raising the designer's awareness of critical discourse.

2.1 *Case study: «Hva er diabetes?» (What is diabetes?)*

Qualitative case study methodology provides tools for researchers to study complex phenomena within their contexts. It allows the researcher to explore individuals or organizations, simply through complex interventions, relationships, communities or programs (Yin, 2003). According to Yin (2003), a case study design should be considered when: (a) the focus of the study is to answer 'how' and 'why' questions; (b) the researcher cannot manipulate the behaviour of those involved in the study; (c) the researcher wants to cover contextual conditions because he/she believes they are relevant to the phenomenon under study; or (d) the boundaries are not clear between the phenomenon and context. In the context of this particular case study, several of Yin's aspects were true. The study sets out to understand how a particular medical brochure is involved in shaping the power relations between the reader and information giver. Simultaneously, this sheds light on the situation of a newly diagnosed diabetes patient and how he/she is spoken to by the Norwegian healthcare system. It acts as groundwork for further research on the phenomenon of how language, visual and written language that is, can shape identity in a newly diagnosed patient.

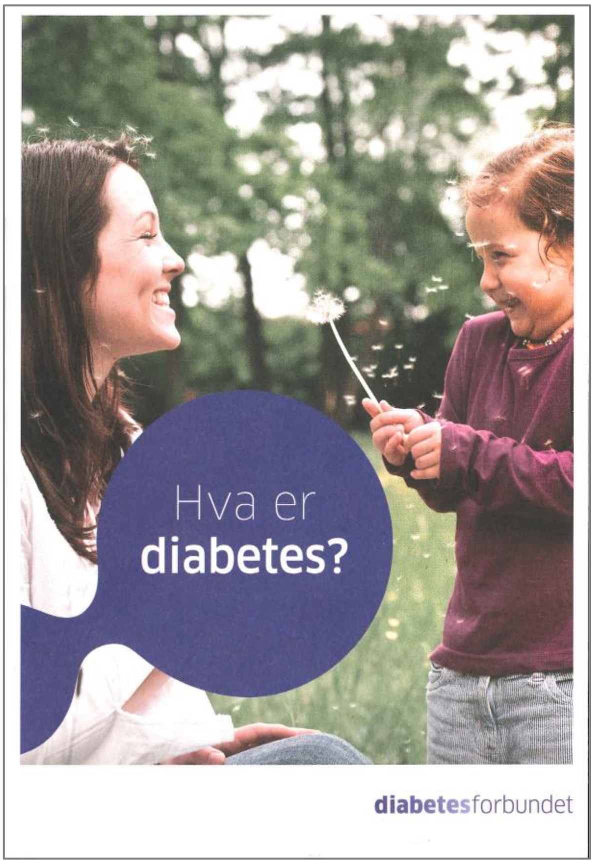

Figure 1 (Diabetesforbunet, 2016, p.1)

In this case study, the brochure ‘Hva er diabetes?’ (‘What is diabetes?’) was chosen as a single holistic case. The reason is that it is one of the few medical brochures regularly handed out to patients in Norway targeting newly diagnosed diabetes patients that is not funded or published by a pharmaceutical company. Rather, the brochure ‘Hva er diabetes?’ (‘What is diabetes?’) with its 27 pages, is produced by Diabetesforbundet in Norway. This non-governmental organization aims to be a common foundation and meeting place for people who have or are concerned with diabetes. They aim to promote issues of diabetes patients in a social and political arena in Norway (Diabetesforbunet.no, 2017). As such, their brochures are commonly handed out to patients across clinics and hospitals in Norway. Since it is so widely received by patients in Norway, it can be understood as one of multiple primary sources of information for newly diagnosed patients. Moreover, it is part of a network of information that shapes the perception of diabetes for newly diagnosed patients. This background sets it apart from others of its kind. Additionally, this study chooses to initially focus specifically on Norway, in order to bind the case for it to be more effective. The aim is to limit the scope and hence better understand the culture of diabetes in Norway, as Susan Sontag in her book ‘Illness as Metaphor’ describes illness as ‘stereotypes of national character’ hinting at the fact that the metaphors societies ascribe to illnesses such as cancer, TB or HIV/AIDS are culturally specific.

It can be agreed that most illnesses are embedded into a local culture, through social perceptions, metaphors and an individual understanding of what it means to be ill. This points towards a comparative case study approach; however, it seems prudent to first study one specific culture in a single holistic case and then move to a comparative case study approach as a second research endeavour.

This case study examines the medical brochure ‘Hva er diabetes?’ (‘What is diabetes?’) through CDA from an outsider’s perspective, as the researcher is neither a patient nor a health worker. Rather the researcher completes the analysis of the brochure on his own. This might not offer a complete view of how patients understand, interpret and experience the discourse in this brochure, but it does offer an initial perspective on how the brochure can be read, without the emotional anxiety often experienced by a newly diagnosed patient or other concerned parties. This emotional view is not to be discounted in general, but should maybe be considered at a later stage, when the initial discourse is outlined.

This methodology offers an advantage over other qualitative methodologies, which ‘work to understand or interpret social reality as it exists, discourse analysis endeavours to uncover the way in which it is produced’ (Phillips & Hardy, 2002, p. 6). CDA differentiates itself by ‘not just describing discursive practices, but also showing how discourse is shaped by relations of power and ideologies and the constructive effects discourse has upon social identities, social relations and systems of knowledge and belief, neither of which is normally apparent to discourse participants (Fairclough, 1992, p. 12). It is precisely these relations of power and ideologies that are interesting when analysing a medical brochure, as these might affect the reader in his or her perception of the illness discussed. However, this methodology offers no specific set of procedures to conduct this particular discourse analysis. ‘This leaves the researcher in the position of developing an approach specific to the study conducted, and argue to justify set approach’ (Phillips & Hardy, 2002, p. 74).

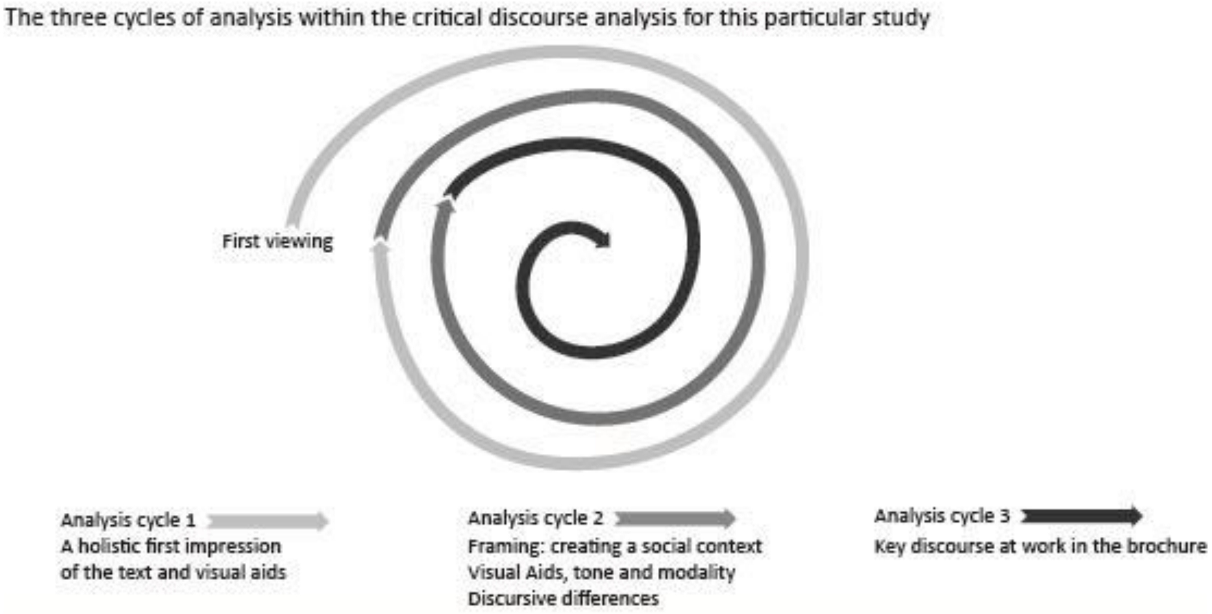

Figure 2 (Diagram of analysis cycles performed)

In this study, CDA was conducted based on an ‘educated guess at some of the most likely interpretations that might be made of that text’ (McKee, 2003, p. 1). In this case, the textual analysis can be divided into three cycles of analysis that build on each other chronologically, as shown in Figure 2. Initially, the text and the visuals as a whole are considered.

In the second cycle of analysis, the genre of the brochure and how it is framed are analysed. This is followed by a discussion of agent-patient relations in the text, and sentence-level presuppositions and insinuations. Further, a more in-depth sentence analysis of the connotations and labels as well as the voice and modality of the text in respect to their authority are scrutinized. Lastly, the key discourses are identified and their impact discussed.

3 Findings

3.1 Cycle 1

3.1.1 A holistic first impression of the text

On the cover of the brochure (Figure 1), a young woman with a little girl playing with a dandelion in a field are depicted. This image has a blue bubble on it, which carries the title of the brochure: ‘Hva er diabetes?’ (´What is diabetes?´). The entire graphic is framed in white with the logo of Diabetesforbunet in the bottom right of the page. With the colourful print and happy, social imagery, this brochure does not give a serious or medical impression. On page four, the brochure ‘Hva er diabetes?’ (What is diabetes?) states its intention of targeting everybody who is new to this chronic illness, regardless of whether they are diagnosed themselves or someone in their family or social network is suffering from diabetes. It is important to note that it does not use the word ‘diagnosed’. Instead, it uses the wording ‘for you, who has recently gotten to know that you have diabetes’ (Diabetesforbunet, 2016, p. 4). By avoiding the word ‘diagnosed’, it is giving the brochure a decidedly non-medical tone. This tone carries on not just in the text, which is written with very little reference to medical terminology, but also in the imagery displayed in the brochure. In its non-medical style of imagery, tone and layout, the brochure is easily understandable for a general lay audience and seems to require no prior medical knowledge of the illness. In general, the brochure discusses diabetes as a change in life, which requires changes in lifestyle in response, rather than a serious chronic condition.

Its cover and the following pages display colourful imagery, which ranges from happy to hopeful in tone. One example for the non-medical imagery can be seen on page 11, here listed as Figure 3, where two middle-aged people are hugging. They are wearing outdoor jackets and backpacks and seem to be hiking and having a great time. In the blue bubble next to the woman, it says: ‘Live life – with diabetes’

Figure 3 (Diabetesforbunet, 2016, p.6)

In general, the brochure is very colourful, using bold non-serif letters in deep blue or white on a blue background, with layers of translucent colour bubbles to help the reader navigate the information. It does not appear clinical or objective, but instead has clear and simple headings and images that invite the reader to identify with its subject on a human level.

3.2 Cycle 1

3.2.1 Visual communication

The brochure meets the reader with a smiling, healthy-looking young woman enjoying the outdoors with a young and equally happy and healthy-looking girl. Nothing in this image implies illness, but rather the opposite. They seem to be enjoying a light-hearted, fun moment together. They are playing outdoors in a field wearing clothes that are suitable for a sunny, warm day. Their attire and their activity give the impression of two people who are generally carefree. They are not necessarily well dressed, but in a nondescript manner; their clothes are of current fashion and new. Their appearance speaks of a comfortable, middle-class background, where there is time for leisure to enjoy a moment of play together.

The title ‘Hva er diabetes?’ (What is diabetes?), as it appears on the image, does not convey the serious nature of the illness either. It simply poses a seemingly innocent question. Here the graphic attention is placed on the word diabetes. It is written in bold. However, the manner of the plain sans-serif font is reminiscent of a school book that seeks to explain something complex in rather simple terms.

Kress and van Leeuwen remind us that pictorial structures of design not only reflect reality but also are ‘bound up with the social institutions within which the pictures are produced, circulated, and read. They are ideological’ (1996, p. 45). Considering the social institutions in which the medical brochure belongs, it is fitting that the designer(s) selected specific genre of imagery called stock photos to visually support the text. This genre is often professionally produced photographs that are not very demanding of the viewer, while still offering rather clear messages. Photographs, as Connie Malamed puts it, ‘are dependable and versatile – they can represent something concrete, tell a story, or convey an abstract idea’ (Malamed, 2007, p.68). This aspect of the imagery communicating simple messages easily supports the underlying goal of the medical brochure, which intends to simply explain – to not demand but to offer instead.

Next to this versatility of conveying information, these images have another advantage; to most readers they are legible. ‘A photograph, whether it appears in an advertisement, a newspaper, or in a family album, is often regarded as an accurate and truthful record of real life’ (Galer 2007, p. 130). It is this notion of ‘truthfulness’ that likely is employed by the designer when choosing this genre of imagery to accompany the text. They set a tone. In their own right, they create a modality that underlines the tranquillity of the passive voice in the text. A picture of a little boy, in winter, feeding ducks accompanies a chapter explaining the differences between diabetes types 1 and 2. It is the mundane that characterizes this visual language. However, within this there is also an inherent omission in the selection of the images. They are uniformly, happy, healthy-looking and white in skin tone. They cater towards an image of Norwegian society, which is not necessarily what is met with in the reality of waiting rooms in diabetes clinics in Norway. Considering that there are currently 223 different nationalities living within Norway’s borders (Statistics Norway, 2017) and that the study on ethnic differences in risk factors on the Norwegian CONOR study states that among the immigrant population with origins in South-East-Asia and some countries in Africa there is a higher risk of developing diabetes type 2 (Rabanal, 2013), the discrepancy between the visual language of the brochure and its readers becomes even more apparent. This poses the question of why the imagery in the brochure caters to a predominantly white image of Norwegian society when a large section of the population of Norwegian diabetes patients is not white. This exclusion of a large portion of its readers in the imagery of the brochure points towards an unfamiliarity on the side of the writers or designers with their audience. The makers of the brochure seemed to be unaware of the socio/cultural background of their readers and as such fail to represent them adequately in the visual language of the brochure.

3.3 Cycle 2

3.3.1 Framing: creating a social context

Conveying to readers that what they want to know is the same as what they need to know is largely achieved through framing techniques. Each of these framing techniques either limits or defines the meaning of a message, and in so doing shapes ‘the inferences that individuals make about the message’ (Hallahan, 1999, p. 207). The key frame being conveyed in the brochure is to give insight into daily life with diabetes and the implications that follow. This is made evident in the titles, which all tie back to the daily routines of diabetic patients, such as ‘Live life with diabetes’ or ‘Some factors that can help you live a good life with diabetes’. This constant referencing to daily routines is an important part of understanding the impact the illness diabetes has on a patient’s life. It is precisely these daily routines that need to change to improve the chances for successful long-term care and self-care.

Throughout the brochure, the reader is reminded of the seriousness of diabetes and what can be done to regulate it. The use of this frame means the brochure effectively fulfils one of the first aims of persuasive health messages – namely that a message should ‘convince individuals (a) they are susceptible to a severe threat and (b) adopting an easy and feasible recommended response would effectively avert the threat’ (Witte, 1995, p. 146). Hence, the brochure essentially grooms the newly diagnosed patient into becoming a compliant patient – one who will be successful at the self-management of his or her care. Offering him/her a hope of control in this moment of uncertainty: if he or she is compliant, so will the illness be.

3.4 Cycle 2

3.4.1 Agent-patient relationship, discursive differences and tone

Patients (or laypersons) are discursively positioned in the brochure as the questioners seeking answers and accordingly as those lacking knowledge. This is become clear on the cover page of the brochure, where the reader seems to begin reading with the question, ‘What is diabetes?’. Following this, the reader opens the brochure and is told of the content and the aim of this medical brochure. He or she is invited in to come along on a journey of sorts. This message is supported by the image of a young man and woman coming towards the reader on a country lane. Dressed in wellingtons and outdoor clothing, they seem to be engrossed in a conversation.

This implied invitation positions the medical brochure as the answerer and possessor of knowledge, which it will share with the reader if he or she joins the journey. The patient or reader is only allowed to pose that one question: 'What is diabetes?' Following this and throughout the text, the brochure simply describes common issues around diabetes in a lecturing style, without giving the reader the possibility to ask more clarifying questions. These, one can only assume, are to be stored for the next meeting with the doctor or nurse. On the second to last page a pictogram in the brochure invites the reader to 'Ask the experts' by SMS, face2face or email, but these are the only two instances in which the brochure invites the reader to ask questions.

Figure 4 (Diabetesforbunet,2016, p.23)

The text's tone remains largely devoid of a writer's presence, although it could be argued that, in scientific writing (and in academic writing generally), the use of a neutral and anonymous third-person voice is common. Nonetheless, the lack of an identity in the voice of the writer results in conveying an impersonal scientific discourse, and as such the writer is portrayed as being an objective presentation of ideas that transcend any individual voice (Hyland, 2002). This neutrality in language gives the impression of scientific information delivered by experts to laypersons. This experience is further supported by naming the publishers of the brochures as experts, as is done in Figure 4. This language places the reader in an inferior position of power.

The brochure only subtly hints at these positions of power, which fits together well with its labels and connotations. The brochure sets out to have a personal and human-centred view of the chronic illness diabetes. As such, it seems to invite the reader for a friendly chat. On pages 18–19, the brochure talks about 'Life with diabetes'. In the subheading to this, the reader is spoken to directly: 'Do you have a child who has been diagnosed with diabetes? It can often seem unfair, meaningless or incomprehensible'. This sentence positions the brochure (and its writer) next to the reader on a very personal level, where feelings and human aspects of the illness are discussed. On page 6, diabetes is described as 'one illness with many faces' giving the illness a personal character, which is just as individual and personal as the patients who have been diagnosed with it. The connotations of the illness being an individual in itself opens up the possibility of not just learning about an illness, but rather becoming acquainted with it.

3.5 Cycle 3

3.5.1 Key discourse at work in the brochure: regulation, risk and lifestyle

In the textual analysis of the brochure, an over-riding discourse of regulation, risk and lifestyle was discussed. Initially, a risk discourse is made apparent in the chapter 'Komplikasjoner' (Complications) of the brochure that states 'Badly regulated diabetes often leads to complications'. It continues by explaining that this can lead to other illnesses in the heart, eyes, feet, kidneys or the nervous system. (Hva er diabetes? p. 6). The use of the term complications means something must be stopped from happening – the counter inference being that other illnesses will happen without preventative measures being taken. Here the risk is clear: if the patient does not comply with the treatment plan to regulate his or her diabetes, there will be complications. This, however, fails to mention, 'that diseased bodies are unpredictable' (Mohl, 2012, p. 20). This implies that no matter how compliant a diabetes patient is with his or her treatment plan and how willing he or she is to adopt lifestyle changes, the illness might spread or rather not stay contained and can, regardless of the good will of the patient, lead to complications. This discourse also contains in it another understanding of diabetes that is passively introduced, namely, that diabetes does not change. When reading this brochure, the reader is drawn the image of diabetes as a static illness that can be regulated and controlled and in that contained and its progress stopped. However, the reality of chronic illness is a rather different one. Chronic diseases are, by definition, those for which no cure is available, and conventional intervention is limited to symptom control, preventing progression and promoting self-care management (Thorne, Paterson, 2000). A part of this reality of chronic illness is also the fact that the human body in its complexity, the illness progression and the patient as person cannot be controlled. Change is inevitable.

4 Discussion

The aim of this research is to map out CDA's potential to foster an awareness in designers of their involvement in public discourse within medical brochures. Even though this research methodology focuses mainly on the written aspects of a discourse – in this case a medical brochure – researchers such as Kress and van Leeuwen highlight the importance of a visual and graphic language that is part of the discourse. Currently in the discussion on discourse within the social sciences, designers are remaining silent. It is here where a knowledge gap seems to emerge. Why are designers not participating in this discourse? One answer might lie in the fact that Gunther Kress's social semiotics has grown from a very early interest in 'critical linguistics' (Fowler, Hodge, Kress, & Trew, 1979; Kress & Hodge, 1979). This generally emphasized the importance of language, and texts in particular, on social processes. However, for more than a decade now, social scientists such as Kress and van Leeuwen have argued for the importance of visual as well as verbal signs and media in literacy (Kress, 2003; Kress & van Leeuwen, 1996; Kress, Jewitt, Ogborn & Tsatsarelis, 2001).

The advent of design thinking and its wider circulation has given rise to a design profession that is beginning to view itself as an active participant in policymaking, economic decision making and other aspects of public life. It seems fair to argue, then, that this trend of understanding designers as more than mere service providers within their fields of graphic, product or other areas of design implies that designers should enter into the debate on discourse. On the one hand, it implies a growing interest from the side of social sciences to invite designers into this debate. On the other, it might also point towards a usefulness and a willingness on the side of the design profession in understanding their impact on critical public discourse.

The fact that designers are often not viewed as a part of public discourse production can find its foundation in designers' potential misconception of not producing public discourse as such. However, designers do design with intent. As Nathan Crilly points out in in his paper, Representing Artefacts as Media, designers intend artefacts of any kind to be experienced or, in the case of a brochure, to be read in a particular manner (Crilly et al., 2008). Therefore, if designers at large are not active participants in public discourse, it is not due to their lack of intent or conception, rather it might be due to this understanding of design intent as a natural goal of a design process rather than an act of cultural manipulation. On another level, the design of a medical brochure, a product or a service might be understood by the designer as a service provided to a client rather than an act of public discourse. However, particularly in the case of this medical brochure, it is not necessarily the client that choses the happy photographs, the legible fonts and the soothing colour scheme. Often it is the designer who selects and composes these to support the message that his or her client wishes to send. Here the responsibility for the message sent is shared between the designer and his/her client. In this context, it is not as much an issue of responsibility as it is a question of awareness, particularly since the communication in this case is not a dialogue between two parties, the designer and the client. It is a dialogue between three parties, with the designer and the client on the one side and the reader on the other side. The reader is also an active participant in this process – deciding what the message means for her or him at a particular time in a particular context. He or she is just as much part of the discourse making, in his/her role as interpreter and as an active meaning-maker. Communication between professional healthcare providers and persons affected by chronic disease has long been recognized as critically important to providing care and supporting self-care management (Von Korff, Gruman, Schaefer, Curry,Wagner 1997; Clark, Nothwehr, Gong, Evans, Maiman, Hurwitz, et al. 1995).

The question of impact and awareness is not just the case for this medical brochure. One can argue that in many instances, design is the vehicle used to transport messages in such a manner that target audiences are willing to listen to them. In addition, they succeed in many instances; one example is the success of the IKEA instruction manual, which turns something as complicated as constructing a kitchen cabinet into a simple comic with very few written instructions understood by IKEA users across the globe. It is not hard to imagine the frustration that documents in plain text describing each item in the box and what to do with it would cause for IKEA shoppers. Similar 'success', can be seen in public relations campaigns during elections or, for example, information handed out by the World Wildlife Foundation to raise awareness on particular endangered species. A plain-text document informing the reader of the possible extinction of the shark is not nearly as effective as an advertisement enticing the reader with exotic imagery of wildlife or edgy questions. As this example shown in Figure 5 of a print advertisement created by DDB in Turkey for World Wildlife Foundation in 2010 illustrates:

Figure 5 (Print advertisement created by DDB, Turkey for WWF, 2010)

All these act as examples of services rendered by designers for larger co-operations or organizations. However, if the outcome of that service is mass-produced and circulated in society, the designer becomes an active participant in public discourse, whether or not he/she is aware of it. It is the act of applying design to a medical brochure and designing its visuals, which activates a whole chain of connections, values and judgments. Therefore, even before a reader opens the brochure, ranges of discourse models have been positioned to, or one could argue, 'have been designed to be read'.

5 Conclusion

Initially, this paper set out to critically analyse the public discourse contained in the medical brochure 'Hva er diabetes?' (´What is diabetes?´) published by Diabetesforbunet Norway. In the course of the analysis, it became evident that discourse as it appears is, in fact, not just a matter of writers/publishers and readers. Rather, in this single holistic case, it is a matter of writers who produce content and then pass this on to designers, who in turn design and visually shape the content. Through the act of designing, they add another layer of meaning to this set content. This layer of meaning takes form in chosen images, colour schemes and layout, which then in turn is read and interpreted by the diabetes patient (reader). This three-way system of producing and interpreting media in public discourse sheds a light on the designer's role in the production of discourse. This paper has argued for a more critical view on the production of media, as items of public discourse, on the side of the designer. It has questioned the designer's role in shaping messages in public discourse and his or her willingness or ability to take part in discourse making as an active and aware participant. At the beginning of this argument, of course, stood the question of whether the designer is indeed a participant in this discourse at all. Based on the findings in this single holistic case study, there are strong indications that this is indeed so. This leaves the following question: Where do designers go from here? Should they become part of the academic debate around CDA within the social sciences? Moreover, if they wish to enter into this debate, how can they? There seem to be many overlaps between the application of CDA and a design process. However, there are significant discrepancies in terms of language used to describe these similarities. It would be interesting to further explore these overlaps, how they could work in terms of interdisciplinarity and what that implies for a shared language between the social sciences and the design professions. Another aspect that could be explored is that of implementing CDA into a design process as a tool and what effects that would have on the design outcome to further contextualize the implication of the designer as a producer of public discourse.

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Building Relationships and Sustaining Dialogue Between Patients, Caregivers and Healthcare Practitioners: a design evaluation of digital platforms for ventricular assist device users

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Technology-driven medical device design for the growing incidence of cardiovascular disease and heart failure has enabled ventricular assist device (VAD - a small mechanical pump which takes over the function of the heart) implantation as a treatment option. However, challenges are emerging with how patients' and caregivers' quality of life is negatively impacted during the VAD journey. Design innovation in digital platforms for VAD users can enable building relationships and sustaining dialogues between patients, caregivers and practitioners, which may improve outcomes. This paper details a content analysis methodology used to investigate sixteen digital platforms designed for VAD patients, caregivers and practitioners. Most digital platforms supported the primary purpose of daily home monitoring or stakeholder education, and featured varying levels of interactivity, communication and focus through the different stages of the patient journey. This paper suggests five implications for future digital platforms designed to support VAD users: embrace the entire patient journey, emphasise human-centred design over patient-centric design, encompass holistic wellbeing, enable communication channels, and blend 'manual input' with 'smart input' interactivity.

patient centric design; human centred design; user experience design; design innovation

1 Introduction

Significant advances in support for patients suffering advanced heart failure have been made since the first successful clinical use of cardiopulmonary bypass in 1953 when mechanical circulatory support (MCS) became a reality (Schumer, Black, Monreal, & Slaughter, 2016). From early beginnings in the 1960s, followed by a collaboration between scientists, device engineers and the heart transplant community, the Novacor Left Ventricular Assist Device (LVAD) was implanted as a bridge to heart transplantation in 1984 (Kirklin & Naftel, 2008). This led to a surge in regulatory approval for VADs throughout the 1990s (Schumer et al., 2016). Since then, Ventricular Assist Devices (VADs) have been miniaturised and further improved to demonstrate better durability and a reduction in noise levels, but more importantly, a reduction in complications and increased patient survival rates (Kaan, Young, Cockell, & Mackay, 2010a; Kirklin et al., 2017; ReliantHeart, 2017; Rose et al., 2001; Schumer et al., 2016).

In the United States, approximately 5.7 million adults were afflicted with heart failure in 2015, with this figure projected to increase to 8 million by 2030 (Go et al., 2013; Heidenreich et al., 2013; Mozaffarian et al., 2016). Meanwhile, in Australia, over 167,000 hospitalisations saw heart failure and cardiomyopathy recorded as either the principal or secondary diagnosis, representing 1.6% of all hospital admissions during 2014–15 (Australian Institute of Health and Welfare, 2016). The number of patients awaiting heart transplantation has doubled within the last 15 years (Prinzing et al., 2016) yet only a steady rate of global heart transplant activity with very little increase has been observed from 2011-2015 (The World Health Organization (WHO) & Organización Nacional de Trasplantes (ONT), 2015). It is obvious that the quantity of donor organs available is insufficient to support patients who are awaiting heart transplantation.

A Ventricular Assist Device (VAD) is a mechanical pump that takes over the pumping function of a single ventricle as an alternative to immediate heart transplantation, which isn't always available. VADs can support end stage heart failure patients while they are waiting for a future donor organ transplant (Brigitta Bunzel, Laederach-Hofmann, Wieselthaler, Roethy, & Wolner, 2007; Jakovljevic et al., 2014). The development of VADs has led to overall improved quality of life for patients diagnosed with heart failure and afforded increased survival time, since over 40% of patients worldwide waiting for heart transplantation have been implanted with a VAD (Schumer et al., 2016). Thus, VADs have become an important and widely accepted treatment option for severe, acute, and chronic heart failure with four key use scenarios: (1) bridge to transplantation, (2) bridge to decision, (3) bridge to recovery, or (4) as destination therapy (i.e., as a substitute for transplantation for patients who not suitable for transplantation) (Boling, Hart, Okoli, & Halcomb, 2015; Jakovljevic et al., 2017; Kaan et al., 2010a; Makdisi, Makdisi, & Bittner, 2017; McLarty, 2015; Prinzing et al., 2016; van Manen, 2017).

However, current VAD solutions, including the device itself, support tools, and systems surrounding VAD implantation still require more thoughtful designs to optimise the patient experience. A greater understanding of the impact of inserting a complex mechanical device into an even more complex and nuanced human experience should be considered as prerequisite, and is within the domain of design expertise. Moreover, all stakeholders including patient, caregiver (e.g., a spouse, family member, or a friend who can provide fulltime help and support), cardiologist, surgeon and nurses and their main touch points of interaction with the device must be considered throughout the design development process. Patient support tools should facilitate building relationships and sustaining dialogues between stakeholders in order to improve the overall VAD implantation experience for all users, and improve patient outcomes. This challenge becomes even more critical when we consider the rising number of VADs implanted in patients and the global increase in heart disease (Go et al., 2013; Heidenreich et al., 2013; Koprivanac, Kelava, Cruz, & Moazami, 2014; Mozaffarian et al., 2016).

If we draw our focus towards VAD support tools, currently there are several digital platforms available for this very purpose, each with different aims, content, focus, and audience. There is evidence to support the emergence of digital platforms for VAD users in recent years (Casida, 2017; Hawkins, Ventresco, & VanderPluym, 2017; Husain, 2016; K. Kostick et al., 2016). This paper therefore explores the key challenges associated with digital platforms designed for VAD users, and outlines a range of design implications and recommendations for how designers of such platforms could either improve future designs, or design new digital platforms that better fulfil patient, caregiver and practitioner needs.

The paper is structured as follows. First, a literature review is presented, outlining the current state of the VAD field, and a summary of the fundamental needs of each major user group – i.e. patients, caregivers and health practitioners. Following this, the authors examine specific design approaches which may assist in the creation of a more positive user experience for VAD patients, and for better enabling and empowering caregivers and health practitioners to support patients at each stage of the VAD journey. By improving the experience for all VAD users (i.e., VAD patients, their caregivers, and their health practitioners), the authors anticipate a flow-on benefit for the overall wellbeing and quality of life of VAD patients. A content analysis of existing digital platforms for VAD users is therefore presented to outline the state of this emerging field, to decipher which stakeholder requirements were being met, and to identify and consolidate unmet needs into a set of design recommendations. Finally, this paper presents the gaps and opportunities for the design of digital platforms for VAD patients, caregivers and practitioners, the limitations of the current study, and opportunities for future research.

2 Building Relationships for a Better Quality of Life

The importance of quality of life and assessment of the patient’s experience is broadly acknowledged in health care and healthcare research, although some confusion remains about how to measure this (Muldoon, Barger, Flory, & Manuck, 1998; Schumer et al., 2016). A heart failure patient’s physical condition generally improves after VAD implantation (Starling, 2010) however the associated negative impact on both the patient and their caregiver’s quality of life is still questionable, especially from the perspective of the longer-term emotional consequences (B. Bunzel, Laederach-Hofmann, Wieselthaler, Roethy, & Drees, 2005; Brigitta Bunzel et al., 2007; Jessie Casida, 2005; Kaan et al., 2010a). In order for VAD implantation to become a better therapy option for patients with heart failure, an improvement to both a patient’s physical and psychological long-term quality of life should be considered as a prerequisite.

Muldoon et al. advocated that patient quality of life can be identified by two operational definitions, ‘objective functioning’ which relates to an individual’s physical status, and ‘subjective wellbeing 'which relates to an individual’s psychological status (Muldoon et al., 1998). It is suggested that the subjective evaluation of wellbeing could be influenced substantially by psychological factors which might not be directly related to health; or could change over time as a patient’s criteria and perception of wellbeing changes. We know there is a correspondence between physical wellbeing and health, and as the prevalence of chronic illness increases with advancing age this may become more significant as people grow older, (Steptoe, Deaton, & Stone, 2015). However, psychological wellbeing is affected by many factors other than physical health. These include material conditions, social and family relationships, and social roles and activities. The design of a digital platform for VAD users can thus (1) assist with motivating patients and their caregivers to perform beneficial behaviours and activities that improve material conditions, and (2) encourage social connection by building relationships and sustaining dialogues between patient and caregiver, patient groups, caregiver groups, patient and practitioner, caregiver and practitioner, and even between practitioners.

2.1 A Patient Perspective

Living with a VAD requires extensive commitment to its daily monitoring and maintenance, and has a considerable effect on a patient's body and sense of self (Chapman, Parameshwar, Jenkins, Large, & Tsui, 2007). Factors influencing the quality of life of VAD patients are diverse and could include levels of pain, apprehension, depressed mood, and functional impairment (Muldoon et al., 1998). Patients experience emotional shock and both physical and emotional scarring, and key themes emerge around confidence and trust in the machine keeping them alive and in their own bodies' capabilities (Chapman et al., 2007). In addition to their overarching condition of heart failure all VAD patients have a risk of suffering from blood clotting, stroke, bleeding, infection, organ malfunction, device failure, and right heart failure (Schumer et al., 2016; Starling, 2010), with a likelihood of increasing the level of a patient's emotional distress. Being restricted by their physical activities, unable to drive, swim or take a bath (Starling, 2010), and unable to travel any significant distance (especially on a plane) contributes to patients feeling isolated and depressed. Moreover, VAD patients can experience body image disruption because unlike, for example, a fully implanted pacemaker, a VAD is technically only partially implanted because it has both an internal device and external percutaneous drive lines, controller unit and power supply (Chapman et al., 2007; Starling, 2010). In addition to these components, some VAD patients are expected to experience symptoms of post-traumatic stress disorder (PTSD), especially after heart transplantation (B. Bunzel et al., 2005).

2.2 A Caregiver Perspective

In most cases, VAD patients require one or more dedicated caregivers at home since the complex management required of the VAD lifestyle does not support independent living. Caregivers are likely to experience fear and anxiety, and are often overwhelmed by the initial stages of the journey (Casida, 2005), which can escalate quickly depending on the urgency of the VAD implantation. They describe their role as difficult, and continue to feel losses of various kinds throughout the VAD experience, such as the need to stop work or live away from their own communities (Kaan et al., 2010a). It is clear that taking on a fulltime role of VAD caregiver and the associated commitments increases a caregiver's stress levels significantly (Kaan et al., 2010a).

Research has revealed that more caregivers are experiencing PTSD than the VAD recipients' themselves (B. Bunzel et al., 2005; Brigitta Bunzel et al., 2007; Kaan et al., 2010a), with the majority of caregivers being female (e.g., a partner or spouse of male patients). Female caregivers are even more likely to experience adverse psychological distress than their male partners, since women are more vulnerable than men to experience PTSD symptoms after exposure to trauma (B. Bunzel et al., 2005). This highlights the need to "support the support person" (B. Bunzel et al., 2005), since there are significant levels of emotional burden and risk of developing anxiety disorders for VAD caregivers over the longer term.

2.3 A Healthcare Practitioner Perspective

Current designed digital platforms for VAD users are applicable for healthcare practitioners in three ways. First, digital platforms can be information enhanced for point of care, thus healthcare practitioners can either use these to update their own knowledge or convey that knowledge to patients and their caregivers. Secondly, digital platforms can function as a Decision Support Tool (DST) that can assist healthcare practitioners to make a well-informed decision whether or not to implant a VAD (Yang, Zimmerman, Steinfeld, Carey, & Antaki, 2016). For a DST to be truly useful to, and adopted by, a practitioner it must carefully take into consideration clinical reality and understand the practitioner's work practices, workflow integration, the context where decisions are made, and other critical factors that can influence a medical decision (Yang et al., 2016). The third use of a digital platform from the perspective of a VAD practitioner is to enable the remote monitoring of patients. This allows patient data to be automatically conveyed to their practitioner and digital records to be formed, accessed and maintained, and can potentially streamline the practitioners' workflow and reduce administrative elements. Additionally, giving practitioners a secure platform to establish and sustain a dialogue, and build a relationship with their patients and caregivers may mean that adverse issues, anomalies, and difficulties can be detected by the practitioner early, giving them greater control and influence over patient outcomes.

3 Usability, User Experience Design and Human-Centred Design

An understanding of the holistic user experience is important in the design of medical devices, as optimum usability is created when both physical and psychological human capability and limitations are designed into the patient experience. Evans & Geiselhart (2012) identified a set of usability factors that should be considered when designing medical devices and their associated systems, these include:

- *Physical abilities,* including anthropometry, biomechanics and sensory abilities.
- *Cognitive abilities*, including how the brain processes information, the capabilities of memory, the manner in which humans learn new things, and how habits are developed.
- *State of being,* including the general health of expected users, disease states and comorbidities likely to challenge patients' mental and emotional states, and motivation for learning new things.
- *Experiences*, including educational backgrounds, knowledge of particular disease states, and lifelong experiences with objects that will guide behavioural interactions with any delivery system.

The ultimate success of a product or service is determined when the users are first willing to use, and secondly find the product or service they have been offered to be useful (Martin, Clark, Morgan, Crowe, & Murphy, 2011). Likewise, the experience can be measured by how well users understand the product and service, the users feeling towards the product or service during usage, how well the user receives the purpose of it, and how well it fits into the context of the user (Bate & Robert, 2007). Introducing the user experience early in the design process could considerably reduce development time because usability problems are able to be identified and resolved before the systems are launched. Additionally, when the focus is kept upon meeting the users' needs with a more accurate understanding of both user requirements and barriers for adoption and regular use, a higher level of user acceptance can be achieved (Martin et al., 2011).

User experience design implies that designers shouldn't be limited to designing only for patients as is the case with patient-centric design, but should also incorporate the needs of other major stakeholders (including caregivers and healthcare practitioners in this context). Caregivers and healthcare practitioners have the greatest degree of responsibility to look after patients, are accountable for most health-related tasks, are on the front line of managing patient health risks, and are actively supporting patients in various circumstances throughout the entire patient journey and beyond. Therefore an emphasis should be placed on incorporating a human-centred design approach as opposed to a patient-centric design approach, wherein human-centred design brings the experience of all users to the core of the design process and through the use of *"techniques which communicate, interact, empathize and stimulate the people involved,"* obtains *"an understanding of their needs, desires and experiences which often transcends that which the people themselves actually realized"* (Giacomin, 2014, p. 610). A human-centred design approach will thus increase the likelihood of designing a product or service that meets the users' needs (Kouprie & Visser, 2009; Krippendorff, 2004).

4 Medical Device Design and Innovation

Medical device manufacturers create life-changing innovations through the collaborative expertise of various disciplines including engineering, manufacturing, clinical, regulatory, marketing, sales and business specialists, with the role of the designer often being that of user advocate, providing insight and opinion (Privitera, Southee, & Evans, 2015) as well as aesthetic design, form giving, human factors application and testing, along with implementing contextual inquiry/ethnography methods

(Petrie, Aidan; Copeland, 2011). Appropriate use of design ensures that the optimum user experience is championed from early on in the process and throughout the development process as design trade-offs need to be made (Norman, 1986).

While cutting-edge technology advancement in medical device design is indisputably valuable, patients and caregivers don't necessarily notice the sophisticated underlying technology behind a medical intervention – they notice the entire experience from cognitive and emotional level (Bate & Robert, 2006) as they interact with the whole medical device system. Exemplary medical device design should integrate technology development with user needs (Martin & Barnett, 2012). That is, human-centred design should function an enabler of technological innovation, because *"the involvement of users in medical device technology development and assessment is central to meet their needs"* (Shah & Robinson, 2006, p. 500). However, much advancement in medical device design is firstly driven by technological advances, with the fulfilment of patient or practitioner needs as a secondary result of the technology discovery. As Martin et al.(2008, p. 275) state, *"currently, users are generally not brought into the developmental process until after the design brief for a new product has been produced. This may be because medical devices are frequently technology driven rather than resulting from an identified un-met need"* (Martin et al., 2011, 2008). However, design innovation does not occur solely through technology development and feasibility as can be seen in Figure 1, it occurs through the intersection of technology with desirability of a solution that fulfils of user needs, along with viability of the business model (Brown, 2009).

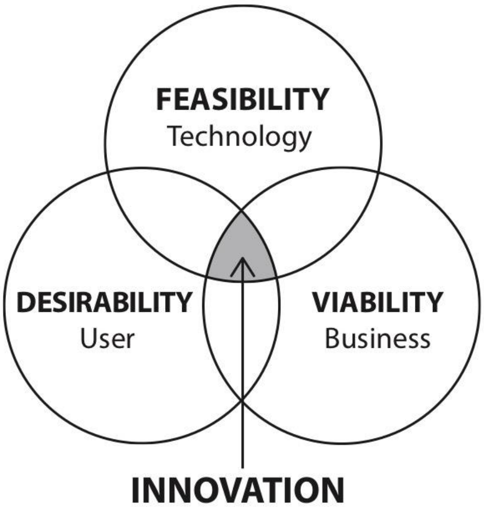

Figure 1 Design Thinking framework by Tim Brown (Brown, 2009)

One type of tool that (1) doesn't rely on further cutting-edge technology discovery for present-day implementation and (2) can help improve the overall patient experience through task management, education, or by providing appropriate communication channels, is what the authors have called a 'designed digital platform'. In this paper, a designed digital platform has been defined as an application, website or portal created specifically for VAD users, that is, patients, caregivers or practitioners.

This paper focuses specifically on the digital platforms that support VAD patients, practitioners and carers because the big picture industry challenges that are emerging with a growing incidence of heart disease, heart failure and VAD implantation (Go et al., 2013; Heidenreich et al., 2013; Koprivanac et al., 2014; Mozaffarian et al., 2016) can be met with patient-centric designs that don't have to be technology-driven, but can be created with attention to the user experience (Martin et al., 2011). We can see a trend materialising as designed digital platforms for VAD users are emerging along with the VAD industry as a whole, due to an increasing recognition of the need for tools to assist with the decision-making process, practitioner education, patient and caregiver education, daily maintenance and monitoring, self-care, and wellbeing management (J. M. Casida, Aikens, Craddock, Aldrich, & Pagani, 2017; Jesus Casida, 2017; Hawkins, Fynn-Thompson, et al., 2017; Hawkins, Ventresco, et al., 2017).

There appears to be a new segment of digital platforms for VAD users being researched, developed and launched within the past 3-4 years. A content analysis of digital platforms for VAD patients, caregivers and practitioners was therefore undertaken in order to (1) better understand the current state of the field, and (2) to generate theories about the design of digital platforms for VAD users. From this increased understanding, the intention is to investigate design implications and possibilities for future digital platforms for VAD users, and develop a new digital platform that could be used to improve the entire VAD patient journey. This research is novel as previous innovation in this context has been largely focused on technical innovation.

It is not simply VAD manufacturers who may wish to better address the patient journey of their users, but in fact many third-party groups are showing interest in the digital patient engagement space with multidisciplinary teams being assembled from different facets of medical, clinical, business and technology fields working together to address new and evolving needs. This presents an opportunity for designers and design innovators who may be brought onto such multi-disciplinary development teams to become involved in the development of new solutions – ideally at the earlier stages rather than later.

5 Method

A content analysis methodology (Elo & Kyngäs, 2008) and investigator triangulation (Begley, 1996) techniques were used to chart what digital channels are currently being used by VAD patients, caregivers and practitioners. The authors used Straker et al.'s (2015, p. 113) definition of a digital channel as technology-based platforms that use the internet to:

- Connect with customers via digital technology;
- Provide a range of different content and purposes; and
- Facilitate communication with a range of different interaction levels.

For the purposes of this research, the authors have limited the scope of digital channel analysis to 'designed digital platforms', defined as digital technology-based applications, websites or portals that have been created specifically for the use of VAD patients, caregivers and practitioners. Selection of the digital platforms was not restricted by the party behind each platform's creation, allowing for the inclusion of third-party platforms. The authors explicitly excluded touchpoints such as social media networks, private blogs and informal online communities (e.g. Facebook groups) in the content analysis, as these platforms have not been designed specifically for VAD patients, caregivers or practitioners as their core customer, and cannot offer services such as secure exchange of sensitive patient data, or private communication between the patient/caregiver and health practitioner. Additionally, the way that social media is used as a virtual community and support group by VAD patients has been explored previously by Boling, Hart, Okoli, & Halcomb (2015) and the scope, content and quality of social media related to left VAD has been examined in a detailed content analysis and principle components analysis by Kostick, Blumenthal-Barby, Wilhelms, Delgado, & Bruce (2015). While the existence of designed digital platforms for VAD users has been on the increase over the last 5 years, and several individual case studies of designed digital platforms (such as patient-centred apps) for VAD users could be found in the academic literature, so far there has not been a comparative content analysis of such platforms.

Each designed digital platform in the study was therefore purposively sampled (Guest, Bunce, & Johnson, 1995; Sandelowski, 1995) based on the inclusion criteria of being:

- A designed digital platform (application, website or portal);

- Created specifically for patients, caregivers or practitioners; and
- Under development, under clinical trial, or in use by VAD users.

Data was collected from a variety of publicly available online sources. To negate any potential bias in the findings, the authors used an investigator triangulation (Begley, 1996), whereby each researcher analysed the data independently. Each researcher then compared results, and an appropriate level of common agreement was found.

Analysis took place over three phases. The first phase involved discovering the development and use of digital platforms by VAD patients, caregivers, hospitals and medical practitioners. This was achieved through the use of publicly available sources to detect the presence of digital platforms for VAD users, and filter any digital platforms that were not designed specifically for those involved in the VAD patient journey. Any website or app, particularly those designed for heart failure or generic medical device self-management that had no reference to VAD implantation was excluded from the research. Some of the search terms used included “Ventricular Assist Device app”, “VAD app” and “LVAD app”. Both scholarly material as well as a variety of online sources were surveyed. During the first phase, these designed digital platforms were classified according to whether they were ‘Patient / Caregiver centric’, ‘Practitioner Centric’ or both ‘Patient / Caregiver and Practitioner centric’. For the purposes of this research and simplicity of classification, patients and caregivers were grouped together as users as they form a care partnership in the VAD journey, and ‘Practitioners’ is an umbrella term the authors have used to refer generally to healthcare professionals including but not limited to nurses, intensivists, social workers, psychologists, surgeons and cardiologists.

The second phase involved tabulating the results of phase one and determining the name of the platform, the company, founder or sponsor, when the platform was last updated, the location, the development phase or project status, the primary user or audience, the technology or device platform (e.g. website, iOS or Android), the main purpose, interactivity, communication, focus, and whether the designed digital platform was available to the research team. Finally, phase three involved using a thematic analysis approach (Braun,V & Clarke, 2006) to identify patterns in the data.

6 Findings

The authors were able to make a range of observations from the sixteen designed digital platforms chosen for assessment, listed in *Table 1,* and were able to identify patterns in the data, (detailed in Appendix. *Table 3* and *Table 4*). Of the digital platforms for VAD users presented in this paper, most were currently in use and updated within the previous two years, with two platforms nearing obsoletion, and some of the more interesting digital platforms for VAD users were still in the developmental or trial phase. Cross-platform digital solutions (i.e., those that could be used on a range of platforms such as iOS, Android, phone, tablet, desktop computer, kiosk, and web-browser, and not just isolated to any one digital channel or device) were more prevalent, and by default these allow more universal access by various users.

Only eleven out of a total sixteen platforms were available for the researchers to assess as some platforms were region specific and not accessible from Australia, or were still in development or only for use with a purchased device. Moreover, the authors found that most of the digital platforms for VAD users were developed for the US market, with the exception of one Japanese platform. So far, no solution existed specifically for the authors’ Australian context.

The most common primary purpose of digital platforms for all users was for daily at-home patient monitoring, followed by educational. Most practitioner-centric platforms were educational and offered either one-way communication or limited communication ability between the practitioner and the digital platform.

Table 1 Comparison of designed digital platforms for Ventricular Assist Device users

No.	Name	User / Audience	Platform	Purpose	Interactivity	Communication	Focus
1	**CORA Patient Counsellor**	Patients & caregiver and Practitioner	Website	DST (Decision Support Tool) and educational	Manual input	Two way	Multiple stages
2	**Deciding Together**	Practitioner	Website, downloadable PDF	DST (Decision Support Tool)	No Input	In between	Specific stage
3	**Harvi**	Practitioner	iPad app, website	Educational	No Input	One way	Specific stage
4	**Heart Failure Health Storylines**	Patients & caregiver	Mobile & web app; Android and iOS	Daily home monitoring	Manual input	In between	Multiple stages
5	**Heartmate 3™**	Practitioner	Android and iOS app	Educational	Manual input	One way	Specific stage
6	**John Hopkins ABX Guide**	Practitioner	Website, app for iOS and Android devices	Educational	No Input	One way	Specific stage
7	**LVAD Calc**	Practitioner	iOS app	DST (Decision Support Tool)	Manual input	One way	Specific stage
8	**LVAD@home and LVAD@care**	Patients & caregiver and Practitioner	iPad app	Daily home monitoring	Manual input	Two way	Multiple stages
9	**MyLVAD**	Patients & caregiver	Website (plus MyLVAD hospital locator app for iOS and Android)	Community support and educational	Manual input	Two way	Entire journey
10	**Qualia Health - Health Check Qualia Plus - Health Score and Tracker**	Patients & caregiver	iOS App	Daily home monitoring	Manual input plus smart wearable input	Two way	Entire journey
11	**ReliantHeart HeartAssistRemote™ Monitoring | FlowAccurate™ Diagnostics | VADLink™ Network**	Patients & caregiver and Practitioner	Website, app, hospital console	Daily home monitoring	Smart input	In between	Multiple stages
12	**VAD Care App**	Patients & caregiver and Practitioner	App - unspecified	Educational and daily home monitoring	Manual input	Two way	Multiple stages
13	**VADable**	Patients & caregiver and Practitioner	iOS app	Daily home monitoring	Manual input	Two way	Multiple stages
14	**VADKids®**	Patients and caregiver (parents)	Smartphone, tablet or computer	Educational and daily home monitoring	Manual input	Two way	Entire journey
15	**VADWatch® and Alere™ VADCare® Program**	Patients & caregiver and Practitioner	Telemonitoring - unspecified	Daily home monitoring	Manual input	In between	Multiple stages
16	**Vidscrip**	Patients & caregiver and Practitioner	Website, iOS and Android app	Educational	Manual input	In between	Multiple stages

Communication has been defined along a spectrum, whereby:

- 'One-way' implies passive consumption of information by a user (for example reading, watching, or listening),
- 'In between' refers to a basic ability to communicate by filling out a question and answer form or worksheet for discussion, tick boxes, or simple data entry to get an automatically generated answer) and
- 'Two-way' describes the ability to communicate between more than one human party using the platform (for example, questions, queries and images are sent to an actual practitioner to get feedback, or the platform hosts an interactive patient forum).

Similarly, each of the sixteen designed digital platforms for VAD users in *Table 1* was assessed for level of interactivity. The authors have defined the interactivity spectrum as follows:

- No input – No information needs to be input into the digital platform itself to gain information output (for example, downloadable / accessible information such as a PDF or video).
- Manual input – Patients, caregivers or practitioners enter in data manually to experience the full suite of resources the digital platform offers. This is a step up from pen and paper worksheets that allows data to be instantly collected and trends to be seen over time, but still may require many steps and consistent effort to input.
- Smart input – Data is input to the digital platform automatically via connected devices (e.g. VAD or other communication-enabled patient monitoring device) in order to reduce the number or tasks and potential for human error (for example, a blood glucose level monitoring device automatically refers result to digital platform, or a digitally connected VAD with remote monitoring capability).

Most of the digital platforms required some kind of manual data input for interactivity, and only one platform offered some level of smart integration with existing consumer fitness trackers. Likewise, just one smart connected VAD-system solution existed (ReliantHeart, 2017), and was only available and approved for use in Europe at the time of analysis (though under clinical trial in the US).

A substantial number of the digital platforms had been designed with both the patient/caregiver pair and practitioners in mind, but when we looked more closely among these, each platform was skewed towards either being practitioner-centric or patient-centric. Furthermore, patient-practitioner platforms that enabled two-way communication were not inherently social (patient-to-patient) whereas the only platform that was classified as being both patient-centric and also enabling a high level of two-way communication, MyLVAD, was also distinctly social (patient-to-patient). However, it was noted that this platform was not actively moderated by practitioners which may lead to misleading information being shared (K. M. Kostick et al., 2015)and patient questions going unanswered.

Most platforms that functioned as DST did cover the pre-implantation stage but were noticeably practitioner-centric. The exception to this was the CORA Patient Counsellor platform which attempted to target both patients/caregivers and practitioners in its design, but the platform's communication-style was still distinctly practitioner-toned. The authors observed how this platform offered a wealth of educational tools but could appear insensitive to patient emotions, that is, the tool demonstrated a lack of empathy toward the patient experience, with abrupt statistical communication about potentially sensitive topics such as predicted patient survival rates and mortality.

A considerable majority of the digital platforms designed for VAD users covered multiple stages of the patient journey, with only two offering support to the entire journey. Interestingly, the bulk of patient-focussed training about the hands-on daily tasks required for living with a VAD appeared to be delivered at a point on the journey soon after implantation, with the exception of the VADKids® platform and its associated program, which aims to train parents using simulations in order to increase confidence of care before implantation and bringing the VAD patient home(Hawkins, Fynn-Thompson, et al., 2017; Hawkins, Ventresco, et al., 2017; Transplant Talk, 2017; Vector blog, 2017). The designers of the VADKids® platform recognised a greater need for practical, scenario and task-based caregiver and patient training prior to discharge from hospital.

7 Discussion

One key area where a distinctive gap in the competitor landscape could be identified was in the level of interactivity of digital platforms for VAD users. The research supports that each of the three interactivity typologies ('no input', 'manual input' and 'smart input') performs a different function. A level of interactivity on the ‘no input’ end of the spectrum is useful where the information supplied would be common to all VAD users and there is no need for a personalised variation of the information supplied. All three platforms assessed which required no user input for the platform to function were practitioner-centric, and offered simple delivery of educational material for a practitioner to refer to via a digital textbook, as a reference guide at point of care, or PDF worksheets to fill out offline. The problem with this low level of interactivity is that these platforms do not take advantage of the gamut of benefits that are afforded by more sophisticated digital platforms with a higher level of interactivity. The main benefit is simply being able to carry a large amount of information in one’s pocket to access when needed.

A level of interactivity that requires ‘manual input’ is the logical next step forward for VAD user digital platforms because VAD patients and their caregivers must collect large amounts of daily data to submit to practitioners for monitoring and review. The authors found that the majority of designed digital platforms for VAD users came under this category and for this reason, the category is by no means homogenous. Each of the platforms that fell under this category exhibited a wide range of interactivity inputs, from one-off data inputs needed to calculate patient risk, all the way up to input that allowed practitioner-to-patient or patient-to-patient communication channels. Digital platforms that enable self-care are still useful for helping patients to adapt the ‘new normal’ of life with a VAD, for example by sending push notifications that remind patients and their caregivers to collect clinical information and pump parameters to submit to practitioners from home after surgery (J. M. Casida et al., 2017). The limitation of manual input with no level of smart input is that the quality of the data is subject to human error and input consistency.

Finally, on the other end of the interactivity spectrum, we have ‘smart input’. While ‘smart input’ is not a blanket replacement for all manual input, since it is only useful for objective data, we could still expect that many day-to-day tasks requiring manual input of data by VAD patients and their caregivers could be replaced by connected devices with sensors that automatically detect and then input patient data to a digital platform. In this way, the practitioner could access the objective data that they need without the barrier of the patient or caregiver having to act as a conduit for that information. That is, the process of data flow would be seamlessly sent straight from the VAD (or associated) device, via a digital platform, to the patient’s practitioner, without the patient or caregiver intermediary, as in the case of ‘manual input’. However, subjective data (e.g., a personal wellbeing assessment, or symptom journal) would still require manual input.

This research suggests that a major benefit of automatic ‘smart input’ is the ability to reduce task burden, mental load and stress on patients and caregivers, so that they may focus their energy on tasks that cannot be automated, for example, regular exit site cleaning and dressing (Jessie Casida, 2005). Currently, the authors could find only two examples of platforms which demonstrate a level of ‘smart input’ interactivity – i.e., platforms that were designed to enable communication between a physical device (one being an off-the-shelf consumer fitness tracker and the other, an implanted VAD flow sensor) and the designed digital platform. Device-to-digital-platform smart input is only one part of the story, however. The next level is (1) integrating the automatic data input with (2) additional complimentary data input manually by the patient/caregiver then (3) consolidating this on the one platform, and then (4) allowing the patient’s practitioner secure access to this data for remote monitoring.

8 Design Implications and Recommendations

We draw the following five implications from our findings to inform and inspire digital platform designers in exploring new design possibilities and creating future solutions to support VAD users (Table 2): (1) embrace the entire journey, (2) emphasise human-centred design not patient-centric design, (3) encompass holistic wellbeing, (4) enable communication channels, and (5) blend manual input with smart input.

8.1 *Embrace the entire journey:*

Digital platforms for VAD users should support a wider part of the patient journey – from heart failure diagnosis, decision support, pre-implantation training using simulation, post-implantation life, then finally to explantation. This could potentially lead to better patient outcomes as the journey is supported from beginning to end as opposed to individual situation-specific tools that do not work together and could lead to a disjointed, confusing experience. The patient journey would best be considered from a system design perspective, whereby each touch point is considered to make up a constellation of the whole experience (Bate & Robert, 2006). The heart failure journey starts long before a decision to implant a VAD is even made. While VAD manufacturers are limited to serving a highly specific therapeutic purpose at one point in the patient journey, a better overall experience may be designed by considering the wider patient journey and the processes leading up to decision, all the way through to potential recovery. However, this calls for functional integration.

8.2 *Emphasise human-centred design, not patient-centric design*

Patient-caregiver pairs are not the only stakeholders in the VAD journey, and do not exist in a vacuum. As such, it is not enough to design a patient-centric platform exclusively for patients and their caregivers without also considering their healthcare practitioners and the wider system. In the content analysis presented in this paper, we noticed that for a digital platform design to be truly considerate of the nuanced and complex needs of patients and caregivers, it must also consider the needs of the practitioner. It is more appropriate, then, that the design of future digital platforms for VAD users embodies the philosophy of human-centred design and not just patient-centric design, which may exclude the wider design context and miss opportunity areas.

Table 2 Summary of design implications of digital platforms for VAD users during the entire patient journey

	JOURNEY			EMPHASIS			
	PRE	DURING including 6 weeks post-surgery	POST	Human centred	Communication Channels	Interactivity	Wellbeing
PATIENT	Education, Decision making tool	Training, Start monitoring	Daily home monitoring and communicating with practitioners	Understand physical and psychological limitation	Practitioner moderation, future platforms for patient-to-practitioner, patient-to-patient social networking	Blend manual input with smart input for remote monitoring purposes and communication	Factors including mental, emotional and social health with physical factor
CAREGIVER		Training, Start monitoring		Understand fear, anxiety, overwhelm, stress and commitment			
PRACTITIONER		Help training patients and caregivers	Receiving information and analysing	Understand the workflow and clinical reality			

8.3 *Encompass holistic wellbeing*

Future designed digital platforms for VAD users should consider not only physical health and clinical parameters but holistically integrate overarching wellbeing factors. The authors of this paper acknowledge the significance of addressing the spectrum of wellbeing factors including mental, emotional and social health with physical factors as a part of holistic self-care management in VAD patients and caregivers who can experience a range of challenges from physical concerns, to psychosocial issues and the need to form adaptive behaviours to cope with the 'new normal' of daily life with a VAD (Jessie Casida, 2005; Chapman et al., 2007; Kaan, Young, Cockell, & Mackay, 2010b; Pérez-García, Oliván, & Bover, 2014; Savage & Canody, 1999).

8.4 Enable communication channels

Digital platforms for VAD users should continue to provide patient-practitioner communication channels, and patient-to-patient channels. Ideally, future digital platforms could be designed to facilitate both communication needs, as opposed to focussing on just one or the other. That is, future platforms that are designed as patient-to-patient channels should include some kind of practitioner moderation, and future platforms that are designed for patient-to-practitioner could also facilitate patient-to-patient social networking.

8.5 Blend manual input with smart input

Future VAD platforms need to become more than just digital substitutes for the pen-and-paper forms and worksheets currently used by patients and caregivers. An increase in interactivity level of the digital platform towards the 'smart input' end of the spectrum is one key area where progress can be made. Future digital platforms for VAD users should attempt to reduce patient, caregiver and practitioner task burden and mental load by having smart input for objective data, while maintaining the ability to manually input subjective data for remote monitoring purposes and communication with the healthcare practitioner.

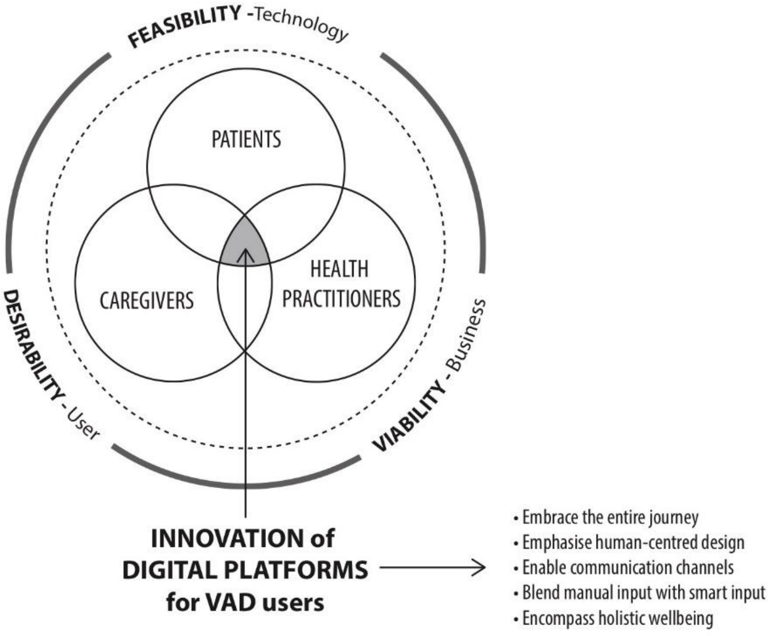

Figure 2 Design Innovation for patients, caregivers and practitioners in VAD digital platforms, building on Design Thinking framework by Tim Brown (Brown, 2009)

9 Future Work

As this study was based on content analysis of secondary data, an important direction for future research would be to conduct detailed analysis with primary data, working directly with patients, caregivers, hospitals, and practitioners including nurses, intensivists, surgeons and cardiologists. Additionally, it has been stated that *"a general limitation of content analysis is that it is a descriptive method, i.e. it is able to characterise existing, documented phenomenon",* and *"it is unable to reveal the underlying design rationales or motives for the observed patterns"* (Straker et al., 2015). Therefore, further research is needed to uncover these design rationales and assess the effectiveness of the current digital platform designs for VAD users. Additionally, the research team intend to design, develop and test a new designed digital platform for VAD patients, caregivers and practitioners in Australia, based upon the design implications and recommendations discussed above.

Future work could involve creating and producing a new designed digital platform (such as an app, website and/or portal) for VAD users based upon patient, caregiver and practitioner feedback, refining and detailing the design, then bringing this refined prototype to a representative sample of patient/caregiver pairs to assess the effectiveness and ease of use of the design proposal. From there, clinical studies and implementation could test the success of the digital platform intervention in improving quality of life measurements against quality of life without using a digital platform.

In addition, future research could explore how digitally-connected smart devices and automated data input could significantly impact the patient and caregiver experience by reducing the task burden and mental load of daily VAD management, while improving practitioner workflow. Yet future research could explore if monitoring adverse events actually reduces their occurrence. It is not too optimistic to envisage a future of digitally connected VAD and home health monitoring device systems that, when paired with the appropriate sensors, communications units, machine learning and intelligent back-end algorithms, could be used to detect health setbacks or events of deteriorating patient condition as they occur, and therefore improve positive patient outcomes.

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Appendix

Table 3 Detailed comparison of designed digital platforms for Ventricular Assist Device users

No.	Name	Description	Company / Founder / Sponsor	Last Updated	Location	Development Phase / Status	User / Audience	Platform	Purpose	Interactivity	Communication	Focus	Currently accessible to our research team?
1	**CORA Patient Counsellor**	CORA (Cardiac Outcome Risks Assessment) is a service designed for both patients and physicians to assist the decision for VAD therapy, as well as provide supplementary resources for post surgery life. It offers interactive tools as well as a variety of informative videos explaining the LVAD, the surgery, and testimonials from patients.	Carnegie Mellon University with Allegheny Health Network (Pittsburgh), U. Colorado Denver, Duke University, and Harvard/Brigham & Women's hospital	2016	Pittsburgh, PA, USA	In use	Patients & caregiver and Practitioner	Website	DST (Decision Support Tool) and educational	Manual input	Two way	Multiple stages	Yes
2	**Deciding Together**	A Left Ventricular Assist Device (LVAD) Decision Aid that is currently available as a series of downloadable PDF modules for clinicians. The site also links to various videos for patients and caregivers.	Center for Medical Ethics & Health Policy at Baylor College of Medicine with funding from Patient Centered Outcomes Research Institute (PCORI)	2015	Houston, TX, USA	In use	Practitioner	Website, downloadable PDF	DST (Decision Support Tool)	No Input	In between	Specific stage	Yes
3	**Harvi**	An interactive simulation-based textbook that helps practitioners learn about pressure volume loops of the cardiovascular system and how interventions such as VADs and EMCOs impact these loops.	Daniel Burkhoff, MD, PhD and PVLoops LLC	2016	Columbus, OH, USA	In use	Practitioner	iPad app, website	Educational	No Input	One way	Specific stage	Yes
4	**Heart Failure Health Storylines**	Created with input from people with heart failure and congestive heart failure (CHF) to better manage and monitor heart failure, this app allows patients to record symptoms, vital signs, medications, physical activity, daily moods, wellbeing journal, treatment responses, and more. The activity log can then be shared with a practitioner at the next visit.	Heart Failure Society of America; powered by the Health Storylines™ platform from Self Care Catalysts Inc.	2017	Bethesda, MD, USA and Toronto, Ontario, Canada	In use	Patients & caregiver	Mobile & web app; Android and iOS	Daily home monitoring	Manual input	In between	Multiple stages	Yes
5	**Heartmate 3™**	An interactive augmented reality based application, which assists the doctor to educate patients about heart failure and how a left ventricular assist device (LVAD) helps such patients to overcome it.	St. Jude Medical and RxPrism Health Systems	2017	St Paul, MN, and New York, NY, USA	In use	Practitioner	Android and iOS app	Educational	Manual input	One way	Specific stage	No
6	**John Hopkins ABX Guide**	A comprehensive resource that delivers up-to-date, authoritative information on infectious diseases, drugs, and pathogens, with Left Ventricular Assist Device (LVAD)-related Infections one of the topics covered.	John Hopkins Medicine and Unbound Medicine	2017	Baltimore, MD, USA	In use	Practitioner	Website, app for iOS and Android devices	Educational	No Input	One way	Specific stage	Yes
7	**LVAD Calc**	A decision support tool for practictioners to help predict survival and level or risk in patients who are using the HeartMate II Left Ventricular Assist Device.	By BiznetIS Net Inc. and Jennifer Cowger, MD, MS	2014	Southfield, MI, USA	In use	Practitioner	iOS app	DST (Decision Support Tool)	Manual input	One way	Specific stage	Yes
8	**LVAD@home and LVAD@care**	LVAD@home is a cloud based home management system that allows patients to send clinical information and pump parameters to practictioners. LVAD@care is a complimentary monitoring application that allows practitioners to receive and monitor data from patients.	Kyoto University, Graduate School of Medicine (Research Institute)	2016	Kyoto, Japan	In development - preliminary clinical study	Patients & caregiver and Practitioner	iPad app	Daily home monitoring	Manual input	Two way	Multiple stages	No
9	**MyLVAD**	An online community and resource hub that provides a variety of information on VAD topics, with a primary focus on what to expect when living with this device. The community forum allows users to discuss living with a VAD, as well as sharing tips and asking for help from experienced patients and caregivers.	MyLVAD, MedStar Heart Institute, Washington Hospital Center	2017	Washington, D.C., USA	In use	Patients & caregiver	Website (plus MyLVAD hospital locator app for iOS and Android)	Community support and educational	Manual input	Two way	Entire journey	Yes

Table 3 Detailed comparison of designed digital platforms for Ventricular Assist Device users

No.	Name	Description	Company / Founder / Sponsor	Last Updated	Location	Development Phase / Status	User / Audience	Platform	Purpose	Interactivity	Communication	Focus	Currently accessible to our research team?
10	**Qualia Health - Health Check** **Qualia Plus - Health Score and Tracker**	Helps users understand their physical, mental, and social health through a quick and fun health check up. Originally designed with heart failure patients in mind, but now a consumer health app, it has undergone clinical trial applications for LVAD patients to assist with wellbeing management. Qualia Plus connects to existing health tracker devices.	Qualia Health founded by Dr. David Beiser, MD and Kevin O'Leary	2016 & 2017	Chicago, IL, USA	In use	Patients & caregiver	iOS App	Daily home monitoring	Manual input plus smart wearable input	Two way	Entire journey	Yes
11	**ReliantHeart HeartAssistRemote™ Monitoring** **FlowAccurate™ Diagnostics** **VADLink™ Network**	Remote patient monitoring works with the HeartAssist5® LVAD containing a flow sensor within the implant that continuously sends data to a controller accessory, which then transmits the data to a secure data center. This data can be viewed remotely using the VADLink™ Network that provides the clinician a window to the patient LVAD. This LVAD is the only device with direct flow measurement that precisely monitors blood flow and manages data with FlowAccurate™ Diagnostics. Other LVADs rely on estimates by their software.	ReliantHeart, Inc.	2017	Houston, TX, USA	Investigational use in US, approved for use in Europe	Patients & caregiver and Practitioner	Website, app, hospital console	Daily home monitoring	Smart input	In between	Multiple stages	No
12	**VAD Care App**	A patient self-care app with daily push notifications (alerts), cues for daily self-management tasks, two-way communication using text messages and videoconferencing (virtual clinic), and links to LVAD self-management skills and videos easily accessible for self-management skill review.	University of Michigan School of Nursing and Logic Solutions	2017	Ann Arbor, MI, USA	In development - under clinical trial	Patients & caregiver and Practitioner	App - Unspecified	Educational and daily home monitoring	Manual input	Two way	Multiple stages	No
13	**VADable**	An app that prompts the patient to collect and input daily information relating to the function of their VAD, as well as prompting for an image of the patient's driveline site to send to their practitioner to check for signs of infection. Facilitates real-time data collection for the VAD team.	Medable, the USC Center for Body Computing, and USC's Keck School of Medicine's Cardiology Department	2016	Los Angeles, CA and Palo Alto, CA, USA	In use	Patients & caregiver and Practitioner	iOS app	Daily home monitoring	Manual input	Two way	Multiple stages	Yes
14	**VADKids®**	A home-monitoring app that allows patients and parents to confidentially and securely communicate with the Boston Children's Hospital VAD team, access educational information and log and track vital signs.	Boston Children's Hospital	2017	Boston, MA, USA	In pilot phase	Patients and caregiver (parents)	Smartphone, tablet or computer	Educational and daily home monitoring	Manual input	Two way	Entire journey	No
15	**VADWatch® and Alere™ VADCare® Program**	Alere provides everything needed to support a VAD patient's long-term needs including life-sustaining equipment, supplies and maintenance, as well as telemonitoring of blood coagulation (clotting) in VAD patients.	Alere™ Home Monitoring; Standing Stone	2017	Orlando, Florida, and Westport, CT, USA	In use	Patients & caregiver and Practitioner	Telemonitoring - unspecified	Daily home monitoring	Manual input	In between	Multiple stages	No
16	**Vidscrip**	A platform that allows doctors to prepare short informational videos for their patients. Sharon Shaughnessy, RN and VAD Coordinator for the Mechanical Circulatory Support Division of Advanced Heart Disease at Brigham and Women's Hospital has created a series of educational videos for her patients and caregivers using the Vidscrip platform.	John Brownlee and Brian Kuyath	2017	Minneapolis, MN, USA	In use	Patients & caregiver and Practitioner	Website, iOS and Android app	Educational	Manual input	In between	Multiple stages	Yes

Table 4 Summarised patterns and themes in the data from Table 3.

Last Updated	2014	1
	2015	1
	2016	4
	2017	10
Location	USA	14
	USA & Canada	1
	Japan	1
Development phase / status	In Use	13
	In Pilot Phase	1
	In Development	2
User / Audience	Practitioner	5
	Patients & Caregiver	3
	Patients & Caregiver and Practitioner	8
Platform	Website only	2
	iOS app only	4
	Android app only	1
	Website & app (either platform)	6
	Website, app and hospital console	1
	Telemonitoring - unspecified	1
	App - unspecified	1
Purpose	DST (Decision Support Tool)	2
	DST (Decision Support Tool) and educational	1
	Educational	4
	Daily home monitoring	6
	Educational and daily home monitoring	2
	Community support and educational	1
Interactivity	No input	3
	Manual input	11
	Manual input + smart wearable input	1
	Smart input	1
Communication	One-way	4
	In between	6
	Two-way	6
Focus	Specific Stage	5
	Multiple Stages	9
	Entire Journey	2
Currently Accessible?	Yes	11
	No	5

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Design Research Opportunities in the Internet of Health Things: a review of reviews

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This paper charts the challenges and opportunities for design research in the Internet of Health Things (IoHT), by conducting a systematic review of review papers. The Internet of Things (IoT) is already impacting health services and could be the basis for a new healthcare paradigm in the near future. Thus there is a need to engage more designers and design researchers in actively shaping the next generation of development and deployment of IoT in health and care. Following a systematic review of the literature, we present key emerging themes, where design can add value and make a significant contribution to this field. Our findings indicate eight key challenges, which provide several opportunities for design researchers who wish to contribute and lead research in the field of IoHT.

design for health; Internet of Things; Internet of Health Things; design research; systematic review.

1 Introduction and motivation

We are witnessing the dawn of a new era of Internet of Things (IoT). The term ‘Internet of Things’ has come to describe some technologies and research disciplines that enable the Internet to reach out into the real world of physical objects (Xia et al, 2012).

The IoT has the potential to impact health services (Swiatek & Rucinski, 2013) and be a game-changer for the healthcare industry (Rajput et al, 2012), especially as it is expected that by 2020 the number of Internet connected devices will likely reach 50 billion (Fernandez & Pallis, 2014). IoT could be the basis for a new healthcare paradigm leading to more personalised, participatory, predictive and preventive health (Schreier, 2014).

However, the IoT impact in healthcare is still in its initial development phases (Dey et al, 2017), with numerous technical and engineering challenges still present. Nevertheless, the interest of researchers and health professionals has caused a shift in the field of IoT and wearables from the development of sensors to the design of systems (Patel et al, 2012). The interest in IoT is growing outside of a clinical setting into the home environment (Burns & Adeli, 2017). Examples include the interdisciplinary SPHERE project, which is researching the development of a sensor platform for healthcare in a residential environment, involving 100 homes in the UK (Zhu et al., 2015).

Given the interest of the research community in the Internet of Things, there is a plethora of papers exploring individual projects, products and platforms across a wide range of IoT applications. Most of them form generic technical reviews, which present IoT's history (Suresh et al, 2014) the generic architecture of IoT (Khan et al, 2012), various mediums of deployment of IoT and current development trends (Khan et al, 2012; Suresh et al, 2014).

Other papers present brief reviews of the applications of IoT across different areas of health and wellness, including personalised healthcare as well as challenges and opportunities (McCullagh & Augusto, 2011; Fernandez & Pallis, 2014; Hiremath et al, 2014; Islam et al, 2015). However, the vast majority of challenges and opportunities provided are targeted towards the engineering and healthcare communities (Suraki & Jahanshahi, 2013; Fernandez & Pallis, 2014; Islam et al, 2015; Metcalf et al, 2016).

The literature highlights a number of issues resulting from a technology-led approach, such as the predominant use of IoT in clinical settings, lack of robust clinical validation studies, leading to misuse of health and wellbeing related IoT products by consumers and patients (Dhawan, 2016; Michard, 2017). More precisely, IoHT have been mainly applied in clinical environments, such as hospitals and healthcare facilities, under managed care and by well-trained and specialized individuals (Dhawan, 2016). There are very few applications in the home environment where more opportunities for promoting and managing personalised health exist. As most IoHT devices and sensors have not been validated against reference methods in well-conducted and independent clinical studies, they are portrayed, as products 'not fit for medical use'. However, this can still lead to misuse of IoT for health management and decision making, as in the case of a product that lead to the underestimation of blood pressure in 77 % of hypertension cases (Planteet al, 2016 in Michard, 2017).

There is therefore a need for a systematic review that presents and discusses the research challenges and opportunities for designers in the IoHT. This paper presents a systematic review of reviews in IoHT. Following a presentation of the literature review and data analysis methodology, this paper summarises the key findings. It then provides an in-depth discussion of the key challenges that emerged from the thematic analysis of data and reveals the key opportunities for different areas of design research in the IoHT.

2 Methodology

The literature review was guided by the following research question: what are the key challenges and opportunities for design in home-based IoT for health and wellbeing?

Figure 1 provides an overview of the methodology employed. After the formation of the research question, a literature review was conducted based on the search strategy presented below. To augment our literature review findings we also incorporated technical review papers on the subject, especially ones which looked more generically on the use of IoT in healthcare. We employed thematic analysis (Braun & Clarke, 2008) to analyse the data from our own literature review and that of others and derive a number of themes. These themes were then employed to offer the discussion presented in this paper. The thematic analysis process and is discussed under the data analysis section below.

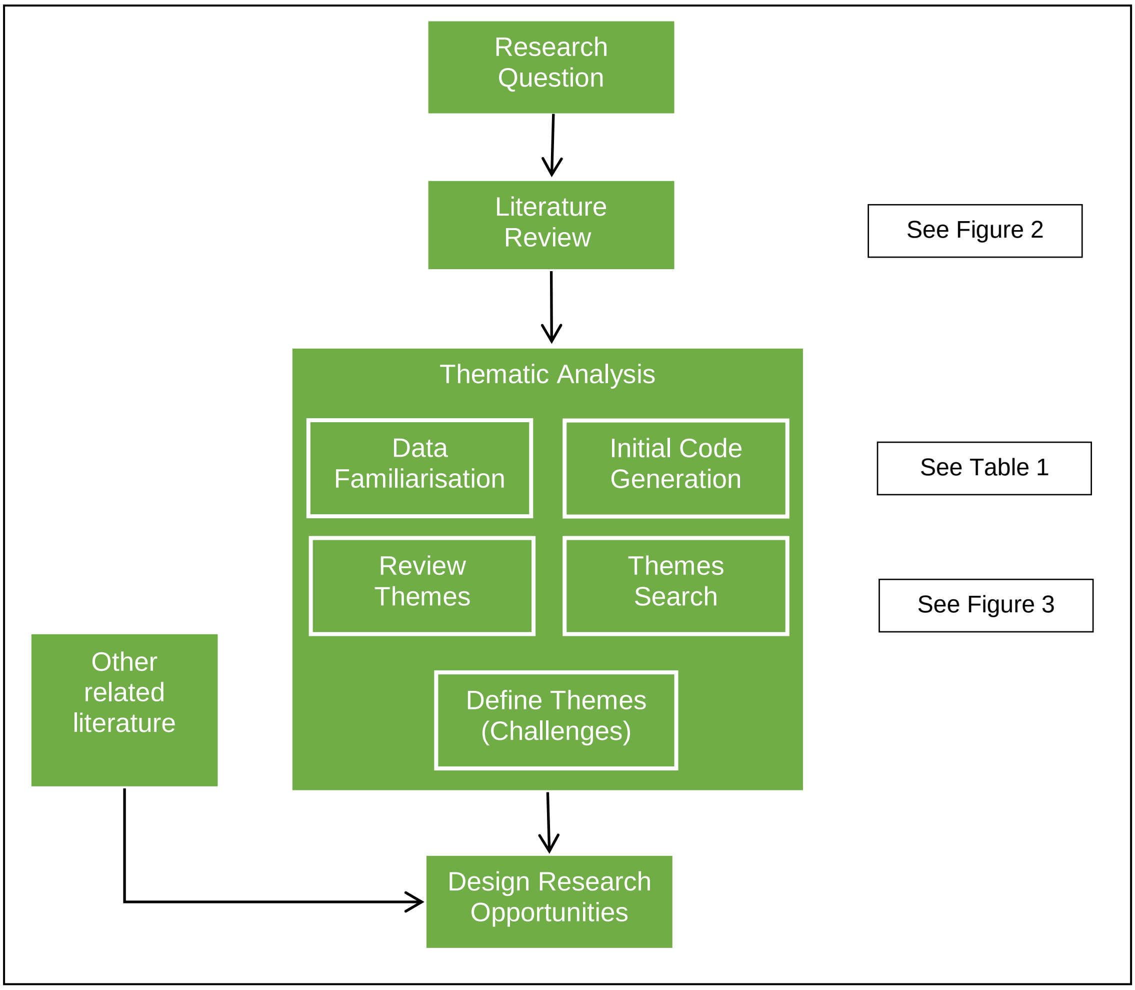

Figure 1: Literature review methodology diagram

2.1 *Literature Search Strategy*

The search strategy was developed in stages. An initial text search of SCOPUS and PuBMed was carried out using relevant terms in order to find exemplar articles from which to harvest indexing terms. Following this, the categories and keywords were fine-tuned to ensure that at least all exemplar articles were returned in the final database search. An extensive literature search was conducted using four electronic research databases. These databases were selected because they are amongst the most commonly used ones in the field of technology and health: SCOPUS, Web of Science, PubMed and MEDLINE. The search was performed using the following keywords: *"Internet of things" OR "IoT" OR "wearable" AND "health" OR "healthcare" OR "well-being" OR "wellbeing" AND "home" OR "house" AND "review" OR "literature" OR "survey" OR "systematic"*. All searches were conducted in July 2017 and each of the aforementioned search term was entered in each of the selected databases.

Firstly, the article titles and abstracts were read (by the authors) and the titles and abstracts that matched the research questions, inclusion/exclusion criteria and the keywords were retrieved. The results of the first screening provided the review team with a collection of papers, which were further screened by reading the full articles. It should be noted that in the case that the title and abstract did not contain enough information to decide on inclusion, the full article was read. Lastly, the papers included and reviewed were based on the initial research question as well as a second set of inclusion/exclusion criteria. All of the papers included were screened by at least two reviewers independently. Discrepancies were resolved by consensus or involvement of a third reviewer.

2.2 *Inclusion and Exclusion Criteria*

A number of inclusion and exclusion criteria were employed to refine the search results. Firstly, the search was limited to English text papers published in peer-reviewed journals, conferences, books, book chapters and review papers from January 2009 to July 2017. The reason behind the specific date selection lies in the fact that research interest in Internet of Things commenced in 2009, reaching its peak in 2011 (Suresh et al, 2014). Editorials, letters, technical reports and book reviews were excluded. In addition to this, articles which did not address the research question were excluded from the study.

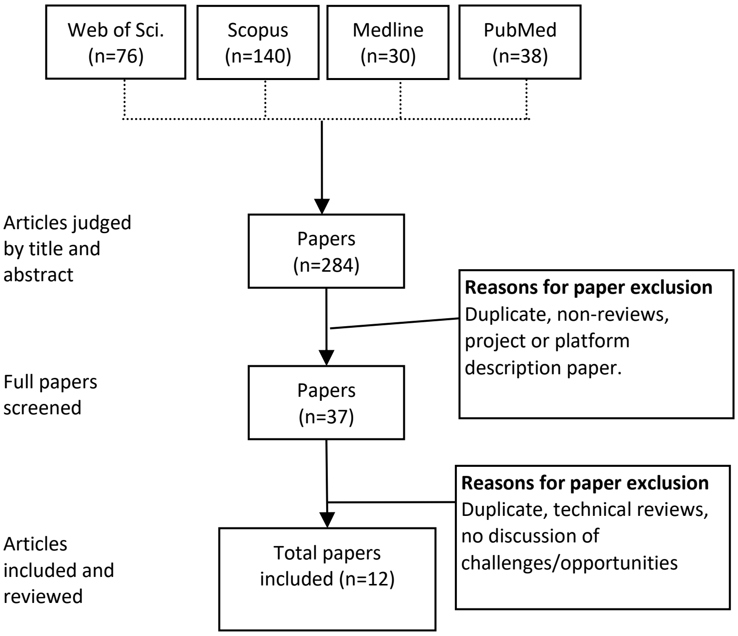

Figure 2. Literature Search Strategy.

2.3 *Data Analysis*

After the literary search was completed and the papers selected based on the aforementioned criteria, the data analysis commenced based on the thematic analysis methodology by Braun & Clarke (2008). Once the team was familiarised with the data, we began the code generation. This was done by looking at each paragraph and coding data by writing notes through the use of either sticky notes or electronic notes within the electronic version of the paper. After the data coding and collation we started to look for overarching themes based on the initial research questions. For inclusion, a theme should have been discussed in length by at least three or more articles. In our initial theme search several more sub-themes were identified, which in the review of the main themes were integrated into larger themes to allow for clarity and consistency. This process produced a number of themes, which were reviewed amongst the team and then consolidated and updated to provide the themes, shown in Table 1.

3 Findings

Our initial search of the four selected databases generated a total of 284 articles. After applying the inclusion criteria, presented above, 224 papers were excluded leaving 37 articles for further scrutiny. Of the 37 papers fully screened, 12 addressed directly the research questions and were selected to be included in the review.

Our thematic analysis of the selected review articles produced a number of themes, as illustrated in Table 1 and Figure 3. Starting from top to bottom, a total of 8 individual themes have been identified. These are: *acceptance, compliance & ease of use, data privacy and trust, design with* *stakeholders, wearability of IoT, culture and context, clinicians and healthcare structures, home care and chronic disease management, preventive & diagnostic*.

These have been clustered into two over-arching themes (namely design context and health context).

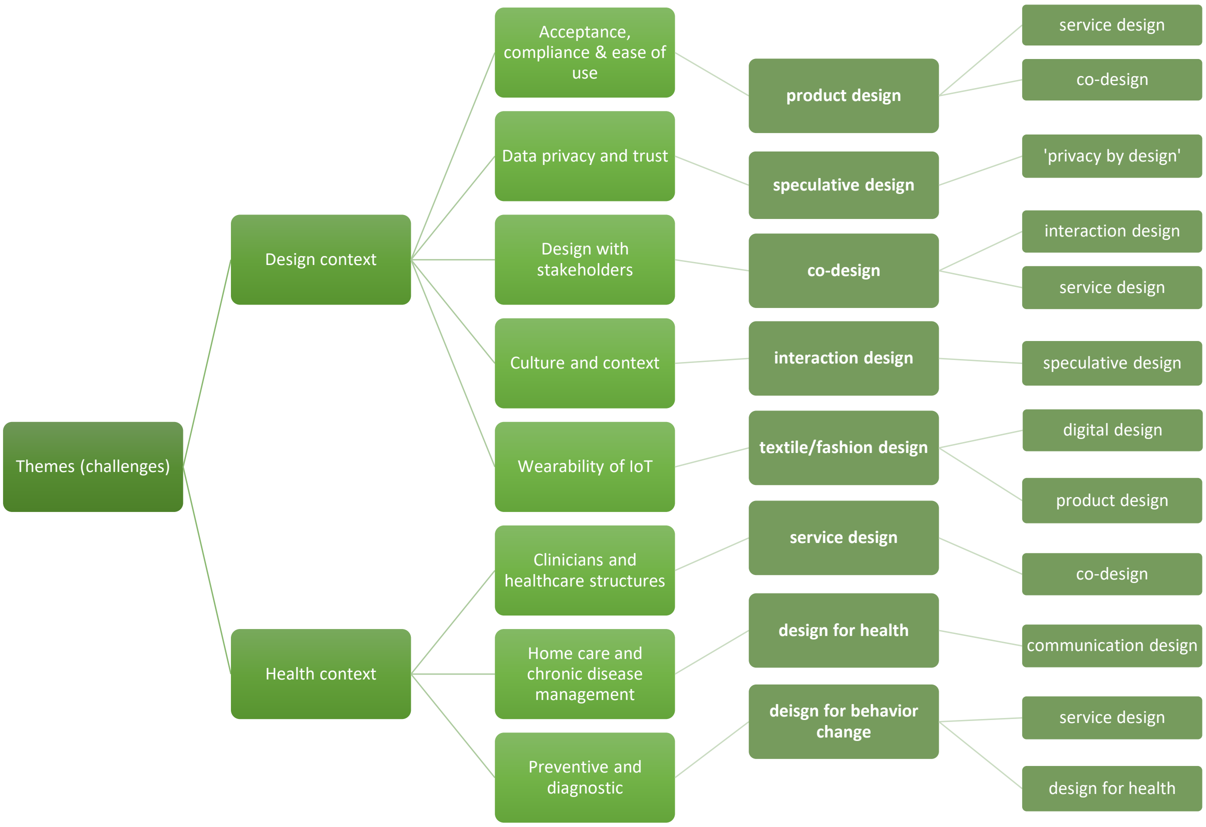

Figure 3: Literature review theme classification and link to identified design research opportunities

In the inclusion of the themes we also looked at the frequency, by which they were discussed in individual articles. As mentioned above, for a theme to be included it had to be discussed at length by at least three articles and be relevant to our research question. Table 1 lists all themes and indicates in which article they had been discussed.

This provided us with interesting data, as to which themes were discussed more in the literature and hence were seen as more critical. For example, one can see that the theme of 'acceptance, preferences & ease of use' and 'home care and chronic disease management', followed by 'wearability of IoT' are seen as the most significant challenges for design in the Internet of Health Things. Furthermore, the thematic analysis has revealed the diverse health areas and health diseases where the IoT has several applications. This ranges from physical activity monitoring to wellness and elderly care; and from *neurological and neurodegenerative disease* (e.g. stroke and Parkinson's) to other *non-communicable diseases* (i.e. diabetes and cardiovascular disease).

Table 1: Summary of emerging themes per author as revealed by the literature review analysis

		Themes							
		Design Context					*Health Context*		
Papers	*Paper health area focus*	Acceptance, preferences & ease of use	Data privacy and trust	Wearability of IoT	Culture and context	Design with stakeholders	Clinicians and healthcare structures	Home care and wellness	Preventive & diagnostic
Burns & Adeli, 2017	*Stroke, Parkinson's, spinal cord injury*	x		x			x		
Jeddi et al, 2017	*Elderly care*						x	x	
Wieringa et al, 2017	*Cardiovascular, diabetes, physical fitness/frailty*	x				x		x	x
Wang et al, 2017	*Stroke, spinal cord injury, cerebral palsy, Alzheimer, COPD, Musculoskeletal & other physical rehabilitation*	x		x			x	x	
Majumder et al, 2017	*Cardiovascular, neurological and pulmonary diseases, activity monitoring*	x	x	x					x
Ossig et al, 2016	*Parkinson's*			x				x	
Pasluosta et al, 2015	*Parkinson's*		x			x	x	x	
Patel et al, 2012	*Physical therapy & rehabilitation*				x			x	x
McAdams et al, 2011	*Not defined*	x				x	x		
Bergmann & McGregor, 2011	*Geriatrics, stroke, cardiac, spinal cord*	x		x	x	x			
Appelboom et al, 2014b	*Cardiopulmonary, vascular, glucose, neurological function monitoring, physical therapy & rehabilitation*		x		x			x	x
Mukhopadhyay, 2015	*Activity monitoring*	x	x	x					

4 Discussion

We shall discuss the design research opportunities in the Internet of Health Things (IoHT) through a close examination of the key challenges that have resulted from our thematic analysis of the review papers. These are depicted in Figure 3.

4.1 Acceptance, preferences and ease of use

The literature reveals that acceptance, preferences and ease of use of health-related wearable devices and IoT are amongst the top priorities and challenges in this field (Bergmann & McGregor, 2012; McAdams et al, 2012; Ossig et al, 2016; Burns & Adeli, 2017; Majumder, Mondal & Deen, 2017).

This highlights that the complexity of IoHT systems and wearables hinders wider adoption by service users. The reason behind this lies in the way such systems are designed and evaluated. Several papers highlight that prototypes of such products and systems are not adequately evaluated (Bergmann & McGregor, 2012; McAdams et al, 2012; Burns & Adeli, 2017). There is a lack of high-quality studies in this area (Bergmann & McGregor, 2012), resulting in numerous attractive systems presented in the literature, which are essentially clinically unproven prototypes (McAdams et al, 2012). This is due to prototypes either not being evaluated in the field (typically using simulations or healthy research participants) or being evaluated for brief periods of time (McAdams et al, 2012). The impact of such practices is that they tend to ignore the key problem areas to be addressed in wearable and IoT monitoring. Namely those associated with the end-user/sensor interface.

In terms of the design of such products, systems and services, it is clear that despite the importance of user preferences, they are rarely considered (Bergmann & McGregor, 2012; Ossig et al, 2016). In a systematic review Bergmann & McGregor (2012) found that only 11 out of a total of 843 papers had in fact explored user preferences. Evidently this is an area where design research can contribute considerably.

Several of the reviews offer basic design requirements and suggestions as to where attention should be placed to make IoT in health easier to use. Using as few wearable sensors as possible, without losing the most important clinical information (Ossig et al, 2016; Burns & Adeli, 2017; Majumder, Mondal & Deen, 2017) is being proposed as the way forward. As is **designing products**, which are small, discreet and are incorporated into everyday objects, so as not to interfere with the service user's daily activities (Ossig et al, 2016; Burns & Adeli, 2017).

As health IoT products and system will become redundant if service users and/or clinicians do not want to work with them, user preferences will have to be taken into account, in order to be able to design devices that will gain acceptance both in a clinical and home setting (Bergmann & McGregor, 2012). In light of this designers and design researchers will be called upon to address the challenge of **designing** robust **products and services**, which will be accepted and worn by a patient and that will work reliably for extended periods of time under real-life conditions in a home setting (McAdams et al, 2012). This is one of the key strengths of design research, for participatory design research approaches, such as co-design. This will not only inform but also critically lead the design of new products that end-users will see a clear benefit in using, as it will directly address their needs and preferences.

4.2 Data privacy and trust

In the context of the Internet of Health Things, an individual often can be identified by data resulting from such connected devices. Indeed, such personal information, especially in the field of health and healthcare, raise much higher concerns and challenges for privacy and trust (Appelboom et al, 2014b; Mukhopadhyay, 2015; Pasluosta et al, 2015; Majumder, Mondal & Deen, 2017).

Especially when one considers the acceptance of IoHT within the context of the home environment and continuous activity monitoring several more legal, ethical issues arise. This includes the balance between the patient as the owner of data, the documentation and use of the data (Appelboom et al, 2014b), patient identification and confidentiality (Mukhopadhyay, 2015), data sharing and management (Pasluosta et al, 2015; Majumder, Mondal & Deen, 2017).

Despite the demand for more research and technology development to ensure information privacy and data security (Mukhopadhyay, 2015; Majumder, Mondal & Deen, 2017), there is an unmet and urgent need for design research in this field too. Given the fact that data privacy within IoHT is a matter of ongoing vivid legal, social, and ethical debates (Appelboom et al, 2014b; Pasluosta et al, 2015) design research and especially **speculative design** can actively contribute in this area.

Speculative design is an approach that enable us to think about the future prospectively and critically (Sterling, 2009; Hales, 2013; Dunne and Raby, 2014). The prime objective of speculative design is to force an aspect of the future into the present so that it demands a response (Tonkinwise, 2014: 176). Speculative design creates narratives for these futures in a variety of formats – provocations, prototypes, products, images, films and so on – to express the urgency of change which is required and focus a debate around the action that could be taken (Kirby, 2010; Tanenbaum et al., 2012).

As the adoption of these technologies, within this context, depends on its acceptance in society (Pasluosta et al, 2015), speculative design could be employed as a tool to facilitate and encourage the drawing out of concerns. It can help raise questions regarding the societal, economical, legal and ethical issues of current and future IoHT. As the ethical discussion cannot not be addressed with a one-fit-all approach (Pasluosta et al, 2015), speculative design can in turn assist in fostering debate that leads to the design of IoHT products and services; that are not simply desirable by different stakeholder groups (service users, clinicians, etc.) but are also socio-ethically explored.

The challenges around data privacy and trust provide design researchers with a unique opportunity for research into '**privacy by design**'. With patient privacy and confidentiality always at the forefront (Appelboom et al, 2014b), designers can pioneer 'privacy by design' methods that enable the development of innovative solutions by making data protection by design and by default (Martín-Ruíz et al, 2017). In fact, work in this field has already commenced with principles and guidelines for the ethical design of Health-related IoT devices and data protocols being proposed (Mittelstadt, 2017).

4.3 Design with stakeholders

Users of IoHT can be very diverse. They could, on one hand, be skilled professionals, some even associated with healthcare provision – GPs, specialist consultants, ambulance workers, nurses. Alternatively, they can be members of the general public who may be applying/using the IoHT in their homes (McAdams et al, 2012).

Hence some of the key challenges for the development of IoHT are human factors design and creating a care model that is attractive to healthcare providers and patients alike (Wieringa et al, 2017). In terms of the latter challenge there are opportunities for service design research (Sangiorgi & Prendiville, 2017) on the development of new and modification of existing care and health services within this context. In terms of the former challenge, **interaction designers** (Fallman, 2008) can lead research on designing interactions between (smart health) things, contexts (home, community, clinic) and spaces (private, public) that increase user acceptance and experience.

This dictates the involvement of all stakeholders in the design of IoHT products and services. Despite most of the reviews being technical in scope what is made abundantly clear is that designing with stakeholders and especially service users is most critical (Pasluosta et al, 2015; Ossig et al, 2016; Wieringa et al, 2017). More active user involvement in the design process is presented as an opportunity for including patients into medical decision-making processes (Ossig et al, 2016) and for discovering and performing new diagnostic and treatment techniques (Pasluosta et al, 2015).

Given the existing success of **co-design** and participatory design research in health (Bate & Robert, 2006; Tsianakas et al, 2012; Bowen et al, 2013;), designers can play a leading role here ensuring the design of IoHT with stakeholders rather than on behalf of them. Democratising design in this manner will lead to more novel and personalised IoHT products, which are people-led rather than technology-led.

4.4 Culture and context

Culture and context forms another key challenge that will further affect the acceptance of any IoHT (Bergmann & McGregor, 2012; Patel et al, 2012; Appelboom et al, 2014b). According to the papers reviewed, culture and context are significant when one considers the home environment as well as the wider community.

In terms of the home, envisaged challenges relate to risks of social inclusion of users, especially if IoHT is perceived as limiting their independence and social interactions with other humans (Appelboom et al, 2014b). Furthermore, how the patient's or service user's family, partner or spouse experiences the technology in daily use, can also greatly influence acceptability of the equipment (Bergmann & McGregor, 2012).

Cultural barriers in the community, such as the association of a stigma with the use of health/medical devices for home-based applications (Patel et al, 2012; Bergmann & McGregor, 2012) need to be carefully considered. Form and aesthetics of IoHT (e.g. transparent design) will play a crucial role in not affecting normal daily behaviour, on one hand; and on the other hand not stigmatising service users. This is a field where **interaction designers** and researchers can make a strong impact. Here the focus will be in expanding interaction beyond digital products, environments and systems. But instead to critically explore new roles and contexts in relation to the social, cultural and ethical impact of emerging IoHT technologies and products.

Design ethnography could therefore contribute further research on the culture and context of IoHT, by exploring this space in more depth, whilst **speculative design** can help in opening it for public debate and priming of future health services (Tsekleves et al, 2017). By exploring future scenarios end-users and healthcare professionals will enhance their understanding of more complex social healthcare technologies and realize more clearly the potential role of healthcare technologies in their lives.

4.5 Wearability of IoT

A big challenge in IoHT is the availability of comfortable wearable sensors, which can be worn by the patient or the individual continuously and without any kind of discomfort (Bergmann & McGregor, 2012; Mukhopadhyay, 2015; Pasluosta et al, 2015; Burns & Adeli, 2017; Wang et al, 2017). Wearable IoT placement, movement freedom and accuracy are all closely interconnected.

Discomfort will discourage use and thus acceptance, whilst movement limitation, due to sensor uncomfortable placement will defeat the purpose of detecting and tracking movement accurately (Burns & Adeli, 2017). Thus, exploring methods to ensure accurate placement of wearable sensors and IoT products emerges us an unmet need.

Indeed, the literature shows limited systematic wearability assessment. The systematic review by Wang et al (2017) indicates that most included studies describe only superficially how to attach sensors on the human body, despite the way this placement being done, is very influential on both the accuracy and comfort of the IoT system.

The same review paper has also revealed that although sensors embedded in wearable appliances or clothing are only beginning to emerge (Wang et al, 2017), there is a clear user preference for this, due to being perceived as more comfortable and discreet (Bergmann & McGregor, 2012). However, there are still design research challenges to be explored, such as the proper selection of sensing materials, embedding techniques as well as stable sensor-skin interfaces (Majumder, Mondal & Deen, 2017).

Fashion and textile designers along with **product designers** can play a pivotal role in this field on the way IoT sensors are embedded into clothing. Furthermore, additive manufacturing processes, which have already proven to be useful for creating force sensors (Pasluosta et al, 2015), could be employed to experiment with new types of 'printed' sensor garments. Combining IoT with the rapid prototyping advantages of additive manufacturing, one could envision the possibility of patients uploading their disease-specific profiles and downloading their individualized treatment tools to print them at home inexpensively (Pasluosta et al, 2015). An area where **digital designers** could conduct research too, by developing the digital platforms that will enable the 3D printing of IoT.

4.6 Clinicians and healthcare structures

To make IoHT succeed, the challenge of fitting them into health care and home care structures will be as critical as the challenge to realize the core technologies that underlie them (Jeddi et al, 2017; Wieringa et al, 2017).

To achieve this one would need to convince clinicians of the relevance of IoHT use. This can be done by making easy-to-use, embed and accurate products that report patient conditions using the health assessment scales employed currently in practice (Pasluosta et al, 2015; Burns & Adeli, 2017).

Clinical evaluations form a tool that can assist in realising this. However, the literature shows that clinical evaluations of IoHT are scarce and are further needed to provide evidence on their effectiveness, in order to pave the path towards implementation in clinical settings (Pasluosta et al, 2015; Wang et al, 2017; Wieringa et al, 2017). In addition to clinical quantitative data, such as reporting on outcome measures, qualitative research data (arising from interviews, focus-groups, etc) are also required. These can capture the impact IoHT have beyond their clinical benefits, such as in the context of use in the home, perceived usefulness and control, personal lifestyle and overall subjective wellbeing.

Thus, as several of the previously discussed critical factors required (ease-of-use, accuracy, IoT wearability, culture and context) are far from being fully realised; and the evidence from clinical studies is scarce, the involvement of clinicians in the design of IoHT products and service becomes even more so critical. **Service designers** can make an impactful contribution in this area, by leading research which places IoHT within existing and newly designed health and care service structures. By employing **co-design** research methods they can design such services with clinicians, other healthcare professionals, the industry and service users.

4.7 Home care and chronic disease management

The Internet of Health Things creates opportunities that provide both patients and people at home a protagonistic role in the caring and management of their health (Pasluosta et al, 2015; Jeddi et al, 2017; Wang et al, 2017).

IoHT paves the way for enhanced home care, remote consultations (Wieringa et al, 2017) but also in monitoring health and wellness (Patel et al, 2012). One of the key advantages of IoHT commercially available technology will be the ability to achieve long-term monitoring of health. The benefits from this would be for both individuals and clinicians. For individuals, being able to monitor one's health and wellness, will provide empowerment and more personalised health and care provision. For clinicians, a quantitative way of assessing treatment efficacy, would be a valuable tool in disease management. Particularly, as by knowing what happens between outpatient visits, treatment interventions can be fine-tuned to the needs of individual patients (Patel et al, 2012)

There are however challenges too, as patient/person education and peer/community networks would be required to facilitate effective person-centred home care and personalised disease management. Opportunities for **design for health** research include exploring how to best integrate IoHT in the home environment, how to develop peer networks and empower individuals to manage their health more effectively and how to design products and services aimed at person-centred home care and wellness. Furthermore, there is a need to educate and enable individuals in taking a leading role in the monitoring and management of their own health. This is clearly a challenge that requires creative ways of communicating the benefits of health self-management and knowledge sharing of how one might achieve this. This is an opportunity for **communication design** research to embrace and explore.

4.8 Preventive and diagnostic

Apart from disease management IoHT offers additional applications in the field of diagnosis and prevention (Patel et al, 2012; Appelboom et al, 2014b; Pasluosta et al, 2015; Ossig et al, 2016; Majumder, Mondal & Deen, 2017; Wieringa et al, 2017).

Continuous monitoring of physiological signals could help to detect and diagnose several cardiovascular, neurological, neurodegenerative and pulmonary diseases at their early onset (Patel et al, 2012; Ossig et al, 2016; Majumder, Mondal & Deen, 2017). For instance, this can provide complementary information about the symptoms of people living with Parkinson’s disease or cardiovascular diseases. In these cases early detection of changes in a person health status (e.g. progression of symptoms) can inform when clinical intervention is required (Patel et al, 2012), potentially reducing hospital visits/waits and improving quality of life.

However, one of the most promising applications of IoHT lies in disease prevention. More precisely, activity and physiological monitoring within the home environment form potentially promising preventative methods in many different facets of medicine such as, cardiopulmonary, vascular, endocrine, neurological function and rehabilitation medicine (Appelboom et al, 2014b).

IoHT devices can be regarded as enablers for influencing human behaviour (e.g. exercise, dietary) (Wieringa et al, 2017). Home monitoring along with the quantified self-movement (Swan, 2013; Appelboom et al, 2014) could revolutionize patient behaviour as they adopt healthy behavioural changes into preventative measures (Appelboom et al, 2014b; Wieringa et al, 2017). As such, provided IoHT **services** are well designed, they could alter the way that governments fund healthcare services, set guidelines for protocols regarding preventative and post-operative monitoring and augment the physician-patient relationship. (Appelboom et al, 2014b).

There are therefore several opportunities for researchers active in **health** and **behaviour change** in exploring and establishing effective and reliable preventive methods. In terms of **behaviour design**, designers can research and design systems and services that place focus on a person’s internal and external health-promoting behaviours. Furthermore, a worthy area of investigation lies in identifying the barriers to the adoption of healthier behaviours and then exploring ways of ‘designing these out’ through new IoHT products and services.

5 Conclusion

In this paper we have conducted a systematic review of review papers and have employed thematic analysis to help us identify eight key challenges in the Internet of Things for health and care. Discussion and analysis of these themes has led to the identification of several design research opportunities across different design areas. Namely in *product design, service design, speculative design, interaction design, textile/fashion design, co-design, design for behaviour change and design for health*.

It is clear that IoT in health and care is not going away. There is already, as described above, a body of knowledge and various emerging dimensions. However, it is a complex and complicated ecosystem of products and services, users, suppliers and responders, individuals and communities. Much of the research currently is undertaken in the technology domain and where design research is applied it tends to be specific and fragmented.

The technology-push based development of IoHT along with their testing in lab-based and controlled experiment environments has limited the influence of design as well as other disciplines in this area. Furthermore, design researchers are yet to become key part of teams identifying the problems and designing the solutions. As this paper demonstrated, several of the challenges are now emerging from the technology-led research and development of IoHT, such as issues with acceptance, lack of end-user compliance and ease of use of IoHT, data privacy and trust issues, lack of engagement with stakeholders, issues with the wearability of IoT, disregard of the culture and context of use and complex healthcare structures. All these necessitate and pave the way for the design research community to play a leading role in the development and adoption of the next wave of IoHT.

However, if designers are to play such leading role, there are some crucial and pertinent points to address. First, we need to train designers for a role where they not only apply design to the Internet of Health Things challenges, but are able to lead multidisciplinary groups and make major decisions that will influence healthier lifestyles and ill-health prevention through IoT. To achieve this designers have to work and engage more with diverse sectors with a key focus on a) providing evidence of the impact of design and b) presenting these in a manner that the specialists in other areas can understand.

Because IoT and health is a system or constellation (Lindley et al, 2017), designers and design research are ideally placed to develop an understanding of that system and the elements in it. As already demonstrated design has the propensity to contribute significantly in the area of health (Tsekleves and Cooper, 2017). Furthermore, design research can enable people to understand where they are in it and indeed how they can contribute and develop it for the benefit of all; whilst protecting the vulnerable and ensuring the system is safe, secure and resilient. The time has come for the design discipline to come to the fore in delivering research for the future implementation of IoT in Health and Care.

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Design in Healthcare: challenges and opportunities

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Healthcare systems are becoming increasingly conscious of the quality of care delivered, along with the provision of value-driven services. Nevertheless, the majority of innovation in the realm of healthcare has been focused on products and services. Beyond being the major contributor to healthcare expenditure, these technology-driven innovations treat medical staff as the primary stakeholder and do little in the way of improving the quality of care for patients. This presents an opportunity to explore other forms of innovation in the context of healthcare. As a human-centred approach, design offers a method for holistically exploring problems, meeting stakeholder needs, and has been established as a means of driving innovation. This paper suggests that a design-led approach to innovation could increase quality of care and assist in creating value-driven services. To conclude, the paper contributes a framework, along with a set of examples, detailing four design objectives in the context of health and medicine.

innovation; design-driven; medical design; health and medicine

1 Introduction

Recent years have seen an increase in focus on value and quality of care in global healthcare systems (Kaplan, Porter, & Herzlinger, 2011; Olson, Dias, & Stowell, 2017). Despite numerous positive developments following this initiative, healthcare systems are complex, and often difficult to change. A major contributing factor is the need for healthcare systems to address the needs of numerous stakeholders (e.g., patient preferences and values, cost, efficiency, etc.) (Hunink et al., 2001; Porter & Lee, 2013). Even small changes in these systems, which could be easily implemented in other disciplines, are comparatively difficult to diffuse in healthcare. These difficulties manifest due to a range of issues; healthcare innovations require the navigation of multiple stage-gates for approval, face regulatory issues, require the support of leadership and management, and rely on the expertise and collaboration of numerous disciplines (Hanna, Manning, Bouxsein, & Pope, 2001).

Innovation in the context of healthcare has continued to focus on the design of medical products and devices (Norman & Verganti, 2014; Ogrodnik, 2012), which, as technology-driven solutions, have been cited as the primary driver for rising healthcare costs (Burns, 2012). While there is pressure to maintain and improve clinical standards in line with new technological developments, such innovations do not always support recent initiatives which aim to bring greater focus to the value and cost of innovation in healthcare. Furthermore, several studies show that non-technological solutions to health care challenges can have significant outcomes for both patients and medical staff (Brown, 2008; Norman & Verganti, 2014). Indeed, these design-led solutions require considerably smaller investments of time and resources, and offer an established method for understanding and addressing the needs of multiple stakeholders (Fraser, 2007).

While technology-driven solutions have their place in the context of healthcare, this paper proposes that design offers a method for better understanding healthcare challenges and conceptualising solutions which address growing demands for value and quality of care. This paper therefore explores the role of design in healthcare, presents a method for interpreting design opportunities in healthcare, and contributes a brief overview of prominent challenges and opportunities present in healthcare.

2 The role of design

The landscape of design is shifting (Buchanan, 2016; Heskett, 2001). Design, despite origins of making and styling, is progressively being adopted as a method of problem solving (Muratovski, 2015). Indeed, design is increasingly being recognised as a means of holistically unpacking complex problems and conceptualising solutions to address the needs of all stakeholders (Carlopio, 2009); even in areas not traditionally seen as the domain of design (Brown & Wyatt, 2010; Dorst, 2015).

In his earlier works Heskett defined the word ‘design’ as a noun (i.e., the general field of design, a plan or intention, or as a finished product) and as a verb (Heskett, 2001). As the discipline of design has evolved the role of design as a verb, i.e., as a thought-process, has become increasingly prominent (Brown, 2008; Manzini, 2014). While a plethora of methodologies embody this notion (Brown & Martin, 2015; Verganti, 2009; Wrigley, 2016), proponents of these methodologies agree that innovation, human centred design and understanding through observations are core elements of design (Brown, 2008). The design process typically begins with a holistic understanding of a problem, unpacking the customer’s needs, the end-user’s environment, social factors, market adjacencies, and emerging trends. Design looks beyond the immediate concerns of a problem, ensuring that the right dimensions are addressed (Carlopio, 2009; Holloway, 2009).

Design is often comprised of both theoretical and practical elements. Toggling between theoretical (abstract) and practical (concrete) realms allows design proponents to adapt observations and experiences from the concrete world into frameworks (insights) through a reflective process (Beckman & Barry, 2009; Buchanan, 2001). These insights are an articulation of the stakeholders’ latent needs, and are fundamental in realising innovative design outcomes.

3 Design in healthcare

This study is set against a growing body of work which calls for a rethink of the traditional approach to designing for social outcomes. Notably, *Design for Public Good* (UK Design Council, Danish Design Centre, Wales Design, & Aalto University, 2013) presents the value of responding to social challenges through a design-led approach. The need for innovation in the social sector is, for the most part, extensively outlined in prevailing literature (Liedtka, Azer, & Salzman, 2017; Shin & Mcclomb, 2013). Traditionally, design in healthcare has come in many shapes and forms, with design methodologies being used to explore a range of products (e.g., Bode, 2009; Malkin, 2007; Ogrodnik, 2012), services (e.g., Carr, Sangiorgi, Büscher, Junginger, & Cooper, 2011), processes (e.g., Plsek, 1997), and systems (e.g., Porter & Lee, 2013). While design has been established in healthcare, the applications of design in this area are mostly traditional (e.g. architecture and industrial design), with a plethora of unrealised opportunities. In their publication Nusem et al. (2017) outline four types of design utilisation, these include:

1. Solution-Centred Design - design primarily viewed as a means to solve an emerging and well-defined problem in practice;
2. Social-Centred Design - design used to achieve social outcomes, with design usually limited to a product or service and the desired outcome of the engagement often being predetermined;
3. Design for Competitiveness - design focused on driving innovation at the level of strategy or business model. Design is used holistically to define opportunities in practice, yet characteristically there are external forces or an internal vision driving change; and
4. Design for the Greater Good - design is used to drive strategy at a business model or policy-making level for the purpose of realising social outcomes.

Of the healthcare design examples previously noted, most fall into the first two orders of solution and social-centred design. In public healthcare, this could be attributed to change which is mandated, driven externally, or poorly funded and staffed. Indeed, even innovations which are well funded and supported can often fail. Admittedly, the journey to successful change in healthcare is rife with a multitude of barriers, including: (i) inefficient handovers between analysis, solution and implementation; (ii) a disjointed mix of various incremental solutions to challenges as they arise; and (iii) ill-considered and rushed pilot studies which are often expensive or risky (UK Design Council et al., 2013). Design addresses these issues by offering (i) a collaborative approach, which (ii) looks at systems and problems holistically, begins by understanding each of the stakeholders needs in order to ensure that any solution generated is appropriate, and (iii) iteratively tests through low-fidelity prototypes which design out risk (Nusem, Wrigley, & Matthews, 2016). As such, design is an appropriate methodology for overcoming the aforementioned challenges.

As a method of meeting stakeholder needs and solving problems, design has been established as a means of driving innovation (Plattner, Meinel, & Leifer, 2014; Wrigley, 2016). Organisations depend on successful innovation to thrive and meet the needs of their stakeholders, but even in fields such as healthcare, innovation is often seen as a luxury or burden when it should be seen as a core activity (Burns, 2012; Mulgan & Albury, 2003).

4 Interpreting design opportunities

Design problems are often highly complex (Dorst & Cross, 2001). Indeed, even once a need or opportunity has been identified in practice, there is a need to understand the type of design required to address it. This concept has been explored in literature, with several authors outlining and mapping a design proponent’s capabilities to their capacity to address a problem (Dorst, 2015; Dreyfus, 2004; Lawson & Dorst, 2009). Mosely, Wright and Wrigley’s (2018) framework, presents a synthesis of a series of models that investigate design expertise, and describes seven types of design across four levels of complexity. The framework outlined by Mosely et al. describes the types of design associated with, and required for addressing, a given problem in practice (see Table 1).

Beyond a classification of the types of design and their complexity, this paper seeks to categorise healthcare challenges and opportunities and to identify the corresponding level of design required to holistically address them. The author therefore offers a synthesis of two frameworks with the aim of exploring healthcare challenges from a design perspective. The framework identifies four basic objectives for using design in healthcare. These objectives differ fundamentally across two dimensions. First, by the degree to which the design context is constrained, i.e., whether the design must explore something specific (e.g. a single element of a challenge or opportunity) or where the scope is open ended. Second, where design is utilised to realise a prescribed (from a set of established options or in mimicry of prevalent trends) or an unprescribed outcome. The four quadrants identified in the framework also correspond to the degree of complexity which must be addressed by the designer, with problems becoming increasingly complex as the framework moves from the first to the fourth quadrant. The framework depicts four objectives for design utilisation in healthcare, as shown in the quadrants of Figure 1, with the matrix segmenting the objectives across the two aforementioned dimensions.

Table 1 Design Types and Complexity, adapted from Mosely, Wright and Wrigley (2018)

Design Type	**Complexity**	**Description**
Result-Focused	Simple	Design follows 'the rules of the game', concentrating on design conventions, customs and habits, and the set ways of working within a field (e.g. concentrating on the user and designing from their perspective)
Convention-Based		
Situation-Based	Complicated	Design is used to understand the situation or context and to create a response specific to that particular setting (e.g. identifying the 'core problem' of the problem situation)
Strategy-Based		
Experience-Based	Complex	Design is concerned with the process and development of new ways of working which are imposed upon a problem (e.g. reframing the design problem to develop something new)
Developing New Schema		
Redefining the Field	Chaotic	Design is revolutionary and disruptive, where the designer explicitly aims to redefine the field (e.g. the entire problem and solution are reconceptualised)

4.1 Result-centred design

In the first quadrant design is predominantly used to address a preselected context, where the criteria of design are not challenged and there is a prescribed type of outcome (e.g., to reduce the size of a product). As it is not within the scope of design to holistically unpack the context there is often a tendency to jump straight from the identification of a problem to the design of a solution. Only a basic understanding of design is required, and the design proponent can be novice or naïve yet still address all requisite criteria. Problems which are oriented towards issues experienced by staff (e.g., efficiency, workload, technical challenges, etc.) are often descriptive of this quadrant, as these are easy to identify and articulate. Such challenges don't require a deep sense of empathy to identify as most individuals have an intimate understanding of their own immediate frustrations and needs. One example which illustrates this quadrant is an ultrasound scanner designed and developed by Philips.

> *"The design contribution for this project involved access to user's community knowledge by observing and analysing actual conditions of use of the existing equipment in a number of hospitals, which identified mobility as a crucial dimension"* (Bertola & Teixeira, 2003, p. 188).

Previous iterations of the ultrasound scanner were large and immobile, which resulted in numerous challenges for medical staff. The design outcome from this project was a mobile console which could be manoeuvred around the patient (Bertola & Teixeira, 2003). This design presents a response to a challenge articulated by staff surrounding the mobility of the previous iteration of the device, with new technologies from existing products being adapted to improve the usability of the new device – a problem was identified and a solution was designed and developed.

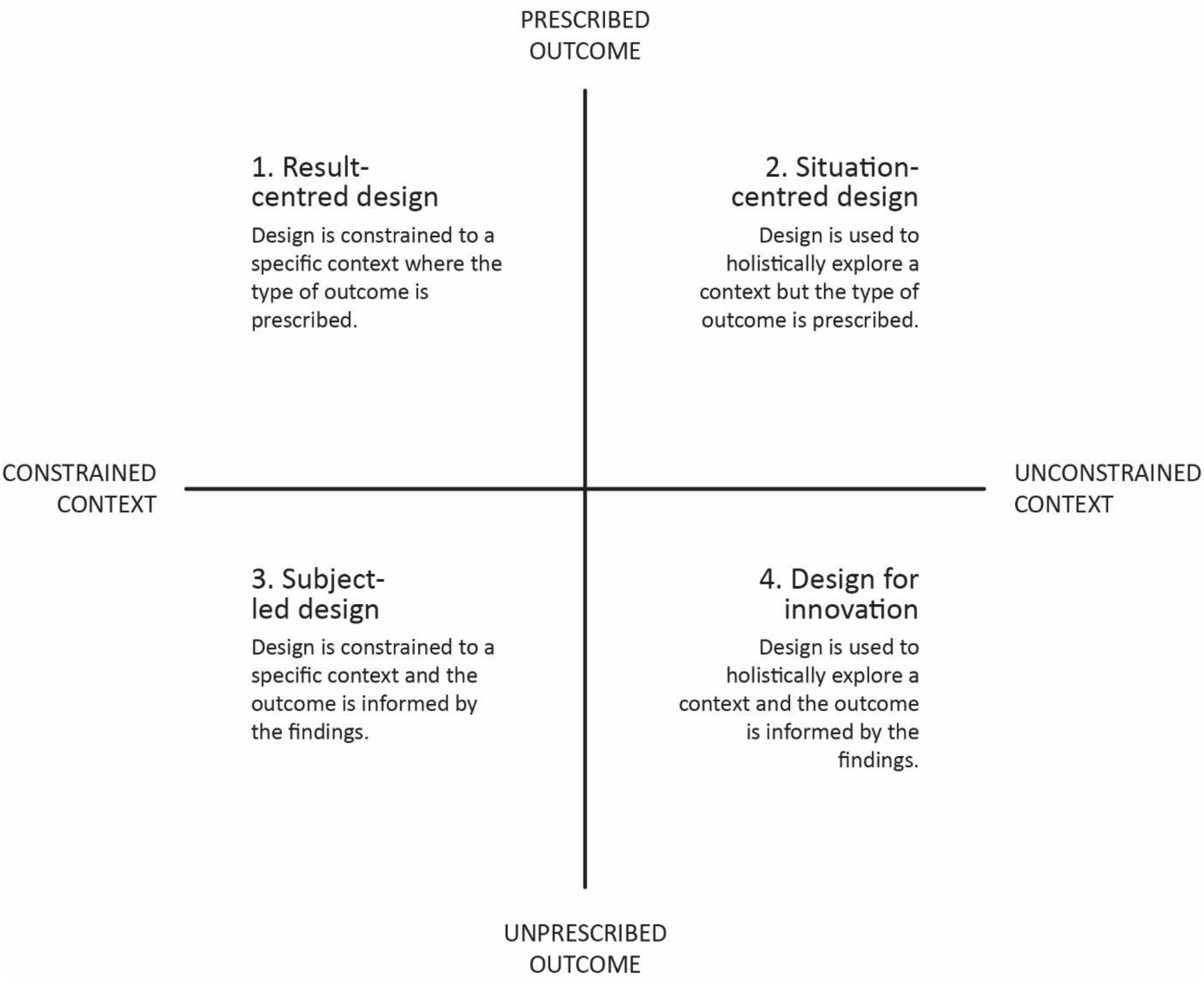

Figure 1 Interpreting design opportunities in healthcare (synthesis from Nusem, Wrigley & Matthews, 2017; Mosely, Wright & Wrigley, 2018)

4.2 Situation-centred design

While the use of design in the second quadrant allows the designer to holistically explore the problem, the design outcome is prescribed. The design criteria for such outcomes can be more difficult to articulate, and hence require the designer to have a large degree of competency.

Brown (2008, pp. 86-87) outlines one such example of design utilisation, where a group of designers explored the handover of care between nurses. Lacking a standardised method for exchanging information, nurses often worked overtime and failed to exchange critical pieces of information in-between shifts, resulting in patients feeling as though their care was not part of a continuum.

> *“The design that emerged for shift changes had nurses passing on information in front of the patient rather than at the nurses’ station … The result was both higher-quality knowledge transfer and reduced prep time, permitting much earlier and better-informed contact with patients”* (Brown, 2008, pp. 86–87).

This relatively simple change halved the time between the arrival of nurses and their first interaction with patients. The outcome outlined in this case was prescribed to improving the process utilised by nurses during handover, yet the context in which this happened and the stakeholders involved were not constrained.

4.3 Subject-led design

In the third quadrant design is used to explore a preselected context, yet the outcome is not prescribed. The designer is required to have a degree of expertise in order to navigate the needs of various stakeholders, and may be required to reframe the challenge at hand. This quadrant is often descriptive of challenges faced by patients (e.g., patient experience, value for patient, transparency of care, etc.) due to designs which have previously treated medical staff as the primary stakeholder(s).

One such example can be found in the context of a CT scanner (medical imaging system). Scanners required a relatively lengthy exposure, during which patients had to remain still. As radiographers were perceived as the core stakeholder for these devices, the response was to increase the imaging source's power and the detector's sensitivity in an effort reduce exposure time, despite this resulting in a higher dose of radiation. Instead, designers shifted the focus from technological innovation to the patient's emotional state during the scanning procedure (Norman & Verganti, 2014).

> *"Philips decided to change the meaning of the experience from that of a threatening, noisy, and uncomfortable medical procedure to a pleasant, relaxing experience. Instead of modifying the technical equipment, Philips modified the hospital environment before, during, and after the scanning procedure. Its redefinition allowed them to focus on the patient's emotional state, rather than on the technology"* (Norman & Verganti, 2014, pp. 94–95).

The redesign of the experience was still limited to the context of the scanner, yet the design outcome was not prescribed. Philips were subsequently able to capture value for a stakeholder which had previously not been considered. Indeed, as the patient experience was not ideal, the focus of this design was improving outcomes for all relevant stakeholders, not just for practitioners or those who commissioned the design.

4.4 Design for innovation

In the fourth quadrant design is used to explore a specific context with the aim of creating novel value for all stakeholders. Challenges in this context are often ill-defined and complex, or lacking an obvious resolution. The design process is required to be holistic in order to meaningfully address and meet all stakeholder needs. Proponents are required to be masterful of design, and must face ambiguity in contexts where no parallel solutions exist. Outcomes are expected to push the boundaries of the field and may redefine the field itself. One example of design in the fourth quadrant is the initiative outlined by West, Davey & Norris's (2014) to design out medical error.

> *"Medical error is a widespread problem internationally. Whilst education and training have a large part to play, it is recognised that the design of equipment, graphics, communication, processes, systems and environment can also contribute to error in healthcare. A lack of understanding of the end-user and/or the scenario of use of a design can lead to a confusing and complicated user experience, and can contribute to error. Furthermore, many designs are concerned only with their specific function, and make no allowance for the complex system into which they are placed"* (West et al., 2014, p. 241).

While effectively a number of cases which address smaller challenges, the initiative outlined by West et al. presents a holistic attempt to redesign an entire context with the aim of improving outcomes for both patients and practitioners, and is not focused on the individual challenges which are addressed through the initiative.

Collectively, these four quadrants outline the role of design in the context of healthcare. The framework outlined in Figure 2 demonstrates the role of design as a method for responding to challenges and opportunities in healthcare, and provides an overview of the subsequent complexity addressed by design proponents in these contexts. Additionally, the framework describes two major dimensions of design. First, the framework outlines design which is predominantly focused on outcome, where the type of solution is prescribed. Second, the framework outlines design in which the context is constrained. Designers should be conscious of both of these dimensions, as a prescribed outcome or constrained context inhibits a holistic design process and limits innovation.

5 Discussion

This research resulted in the identification of a number of challenges and opportunities in the context of healthcare, with examples of a number of these issues and opportunities outlined in Table 2. These issues and challenges have been categorised according to which of the four quadrants in Figure 1 are most suitable for addressing them. The following section of the paper elaborates further on the four objectives identified in Figure 2, and is supported by a set of example design scenarios.

Table 2 Design scenarios in healthcare

Result-centred design	**Situation-centred design**	**Subject-led design**	**Design for innovation**
No consideration of workflow and processes in newly designed environments.	*Patients with undiagnosed conditions which are discovered through unrelated treatment.*	*Staffing issues (e.g., understaffed due to low retention), meaning patients often need a return visit following diagnosis.*	*Lack of channels for patients both pre and post-care (e.g., initiating care and discharge) to be engaged in their care.*
Lack of standardised procedure for training and use of equipment.	*Outdated workflows that have evolved over time, with no deliberate design.*	*Patients with visible medical products are self-conscious.*	*Desensitised staff which see patients cases rather than individuals.*
Lack of standardised platform in hospital for collecting and storing patient data.	*Suboptimal experience in waiting rooms with issues around long wait times for patients.*	*Prolonged stay in sterile environments, with minimal interaction with other humans.*	*Services are not value-driven and do little in the way of ensuring optimal patient outcomes.*

Result-centered design is constrained in most senses. In this context there is often a predetermined notion of what needs to be designed or addressed, such as a specific product (e.g., a stethoscope) or an element of a specific artefact (e.g. clunky interface). Table 2 depicts two scenarios where there is no standardised procedure or platform within a specific context. From a design perspective the objective for these two scenarios is clear – to develop a standardised platform or procedure for the specific context. The process is not holistic in most senses, as the designer is often engaged on the premise of completing a task; there is little opportunity or need for the designer to unpack the context and gather insights to inform the design. Given that the process and outcome are so heavily directed the designer only needs a modicum of expertise.

Situation-centred design portrays scenarios where the context is unconstrained yet the outcome is prescribed. Regardless of an unconstrained context, it can be difficult to utilise findings and insights from the design process in the final design outcome, as they may not all be applicable. One such scenario is listed in Table 2, where patients live with undiagnosed conditions which are discovered as they are treated for a separate condition. The outcome here might be prescribed to a method or process for diagnosing these conditions earlier, whereas the context is open as there are many conditions which may go undiagnosed within the various disciplines in health and medicine. Key activities for this design objective may include empathising with stakeholders and defining a problem.

Under subject-led design the context is constrained but any outcome is welcome. The first example in Table 2 depicts one such scenario, where a patient with an external medical product (e.g., a prosthetic) is self-conscious. The context is constrained to a specific issue, yet the outcome can be any manner of design (e.g., a marketing initiative or a product with improved aesthetics). As the outcome is not prescribed the designer is required to gauge the appropriateness of a number of concepts. Key activities include prototyping and testing, necessitating a competent design proponent.

Design for innovation entails an unconstrained context and no prescribed outcome. This is often a complex undertaking, as it can be difficult to best determine the direction for design and the potential outcomes. One such scenario is outlined in Table 2, where services are not value-driven, meaning that patients and medical practitioners don’t do their utmost to ensure optimal patient outcomes. A design proponent navigating such a challenge must be masterful as the scope is broad and warrants the use of all aspects of design.

Beyond increased complexity as a designer moves through the four orders, this framework can assist design proponents to be conscious of the scope of their design project. The purpose of the framework contributed in this paper is therefore not to categorise challenges and opportunities within the framework, but to develop a tool to assist designers to better understand the complexity of a design project. The framework depicted in Figure 2 aims to assist proponents to challenge the scope of their work and to provide a means of progressing it through the four design objectives, allowing for a more holistic design process which doesn’t limit potential outcomes. Of course, many scenarios exist where the context is sufficiently developed and a specific design outcome is warranted. The risk is that while some challenges and opportunities may lend themselves to one of the four design objectives in health and medicine, for many it is not a clear fit. Indeed, by reframing a design scenario a proponent may find that it fits into several of the quadrants in Figure 2.

As established in literature, design methodologies are particularly suited where problems are complex, and solutions are required to address the needs of several stakeholders (Brown & Martin, 2015; Carlopio, 2009). With a number of the problems identified in Table 2 meeting these criteria, this paper proposes that design offers an established methodology for conceptualising, prototyping and testing potential solutions for prominent challenges in the context of health and medicine.

6 Conclusion

This paper has explored the emerging role of design in society, and more specifically in the context of healthcare. A synthesis of two design frameworks was illustrated, with the aim of developing an understanding of the types of design objectives in the context of healthcare, along with the degree of complexity associated with the challenges and opportunities which correspond to each quadrant in the framework. Finally, the paper elaborated on the framework and outlined a number of design scenarios, highlighting the design challenges associated with a prescribed outcome or constrained context.

As this research is only in its preliminary stages, the role of design has been limited to the identification and definition of potential objectives. Future research could provide additional case studies to further validate the four quadrants, explore the applicability of specific design methodologies in the context of health and medicine, and evidence design outcomes in public, private, national and international healthcare contexts.

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Healthy Self-Management Communities by Design

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Singapore is a densely populated urban island city state facing a rapidly ageing population and a rising prevalence of chronic disease. These challenges coupled with a complex healthcare landscape often results in poor healthcare encounters. Lifestyle interventions involving sustainable behavioural change is crucial in the holistic management of health, but these social determinants of health are often not adequately addressed during care encounters. This serve as an impetus to start shifting care beyond the hospital and into the community. However, shifting care into the community is a big step, requiring first an empathetic understanding of the community values. We used a mixed method research to inform the design of a self-management care ecosystem where residents of the community can be supported to exhibit health-promoting behaviours confidently through their daily social activities. The insights were shared through an exhibition to reach out to the healthcare professionals to reframe the way they think about delivering care to the ageing population of 200,000 residents in the northern segment of Singapore.

social capital; successful ageing; community-based perspective

1 Introduction

The ageing population and rising chronic disease prevalence impose great pressures on Singapore’s healthcare system. A recent local study done by the Centre for Research on the Economics of Ageing showed that one in four Singaporeans aged 65 and above have chronic disease (Boh, 2016).

> *As our population ages, we expect to see more of the elderly having not just one or two, but several chronic diseases at the same time. They might be managed concurrently by having a few specialists in the hospitals. The key to reducing the number of years spent in disability is prevention, early detection and treatment, as well as sustained lifestyle changes. (Ministry of Health, Singapore, 2017, p.27)*

Without good management, late complications from chronic diseases increase care cost to patients and decrease their quality of life. Good chronic disease care starts with patients and their caregivers understanding their own health. The prescriptive relationship between patients and healthcare professionals, sporadic unplanned patient education, lack of coordination and integration of services often result in health illiteracy and reduce patients' autonomy and ownership of their own health issues within broken systems in our healthcare.

The disconnect between clinical care and social determinants of health, especially during acute care episodes, is illustrated by in-depth analysis of our own patient profiles and volumes. Prior research have shown that an individual's behaviour within their physical and social environment account for at least 60 percent of their health, with healthcare contributing only 10 percent to their health (McGinnis, Williams-Russo & Knickman, 2002). In addition, the Southern Central Foundation's Nuka healthcare system found that the key to sustaining chronic care and achieving better outcomes was through building trusting relationships between healthcare workers and patients in their homes and community where they make their health choices. To be successful, long-term care plans that activate individuals through multiple regular touch points within their communities are needed.

Shifting care provision to the community is not a simple replication of the suite of services by hospital-trained staff with institutional mind-sets and experience. Rather, it requires a reframed and holistic understanding of the users in the community and their perspectives on health. Despite attempts to scale up clinical-community partnerships to address social determinants of health through the identification and formulation of toolkits for healthy places (Healthy Community Design Checklist, 2013), there is currently insufficient local research on such partnerships in the context of urban high-density environments.

This research aims to understand how the design of service offerings and public spaces can affect the level of social capital in the community, and ultimately health and wellbeing outcomes for an urban ageing population. The inquiry includes a series of literature review, quantitative and ethnographic observations to understand the local ageing community in the northern part of Singapore.

Finally, we describe how the understanding of the determinants of social capital in our local community was translated into the production of an exhibition to reach out to healthcare professionals, and the co-development of three wellness centres to build confident, resilient self-management communities, supported by a responsive healthcare system.

1.1 Background

Social capital refers to the networks, norms and social trust that facilitate coordination and cooperation for mutual benefit (Putnam, 1995), and can be measured in terms of 'bonding' and 'bridging'. Bonding refers to relationships between similar individuals, who may be family or kin, who share common language and educational norms. Bridging deals with connections between people who differ in age, socio-economic level, ethnicity or education (Szreter & Woolcock, 2004).

A study which examined the relationship between health and social capital for 40,000 older adults found that individual social capital has a causal beneficial impact on health and vice-versa (Sirven & Debrand, 2012). Research that looks into the relationship between social capital and the built environment has largely been based in areas with low population density, like the US or Australia (Brisson & Usher, 2005; French et al., 2013), hence limiting the applicability of these findings to Singapore which has one of the world's highest population density. Such studies have also revealed that the relationship is dependent on cultural influences (Kobayashi, Kawachi, Iwase, Suzuki & Takao, 2013).

In the late 1950s, a long-term framework was formulated (Chin, 1998) to address the two priorities of a newly independent Singapore: the provision of adequate housing and the generation of employment opportunities for the people (Dale, 1999). The concept plan envisaged the development of high- and low-density residential estates, industrial areas and commercial centres supplemented by transport infrastructure providing island-wide interconnectivity (Chin, 1998). This was followed by a home ownership scheme which aimed to give citizens a tangible asset in the country and a stake in nation-building (HDB InfoWEB, 2017).

As a consequence, citizens moved out from their communal living in villages known as *kampungs*, to public Housing Development Board (HDB) flats. Paired with a burgeoning birth rate, population density rose from 2540 in 1961 to 7910 people per square km of land area in 2016 with 82% of today's resident population living in these HDB flats (Housing & Development Board, 2017). These housing units were clustered into self-sustaining townships which were designed to meet the most common needs of residents through developments ranging from market places to shopping malls. Educational, healthcare and recreational needs were also met with various public amenities, reducing the need to venture out of town.

Chua's analysis on the transition from living in *kampungs* to the high-rise flats concluded that it resulted in the splitting up of the multifamily households in villages and the loss of a village sense of security. He also found that the segregated communities of users in the high-rise blocks are qualitatively different from the inclusive sense of a community comprising residents of vernacular villages (Chua, 1997). Twenty years on from Chua's research, these residents who once grew up in the *kampungs* have now grown old and have mostly retired. They now form the major utilizers of the existing public space and amenities, including healthcare services.

Research have already shown how older people with social support show greater health and wellbeing, lower premature mortality, greater recovery from illness and injury, and better adherence to good health habits (Rowe & Kahn, 1987, 1997). With the potential of social capital effecting these positive population health outcomes, our hospital started to increase their focus on engaging the community as a means of preventive healthcare, asking questions such as:

- Had the change in living space affected the social capital within the community?
- If so, how would it impact the ageing community?
- How might we then intervene to bring better health to the community?

2 Study Methods

2.1 Research Approach

To answer those questions, we undertook a mixed-method research project named "Project Orange" over a period of eight months. The research area covered a total land area of 1.3km^2 and we collected 259 hours of interview records conducted with 79 residents, together with 1796 photographs and videos. To gain a holistic view of the community, the field research spanned over different times and days throughout the eight month period, involving different community stakeholders, from the residents, to the store owners and even members from the merchant association (Table 1).

Table 1 Breakdown of research phases

Phase	Method	Period	Study site	No. of people
1	Data analysis + Secondary Research	Mar - Apr	Northern population of Singapore	-
2	Survey for heat map	Jun - Jul	100m around Chong Pang	49
3	Observation	Apr - Nov	300m around Chong Pang	
4	Interviews	Aug - Sep	300m around Chong Pang	25 residents 3 Store Owners 2 members from merchant association

2.2 Multi-Disciplinary Team

A multi-disciplinary team consisting of three designers, one data analyst, an operations staff and a geriatrician formed the core team for this project. Five members were embedded into the community to observe the older adults, their characteristics and motivations, and the community spaces that they frequent. At every phase of the research, the team also gathered to compare notes and synthesised their information gathered in order to arrive at concurrence.

2.3 Four phases of research

2.3.1 Phase 1: Determining the context

We reviewed the quantitative data of the demographic density of the northern population (Fig1), where we were to focus our population health management strategy. We selected Chong Pang at Yishun West as the main study site, as 26.4% of the residents who live there are already aged 55 and above. This would give us a glimpse of how the aged future could be like in 2020 (Choo, 1990), compared to other parts of the northern region. Unlike other areas, the community is fairly homogenous with 93% living in HDB flats as “heartlanders”, a term coined by then Prime Minister Goh Chok Tong as the relatively uneducated parochial dialect speakers (“Prime Minister’s National Day Rally Speech, 1999: First-World Economy, World-Class Home”,1999).

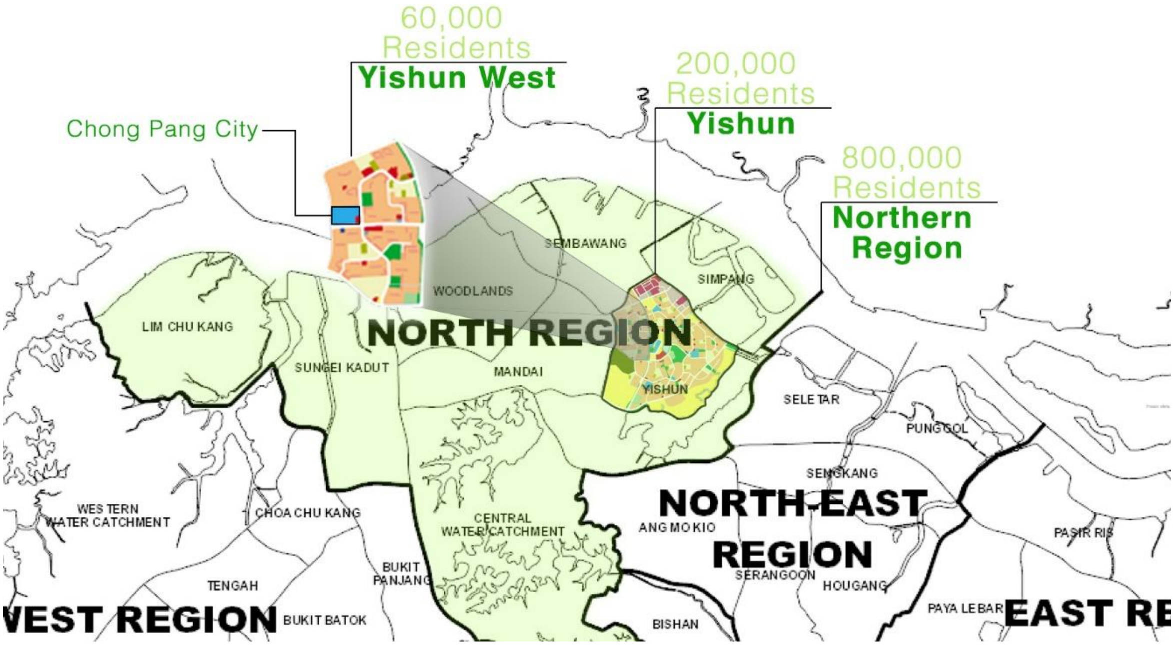


Figure 1. Northern Singapore, Yishun and Yishun West

Subsequently, a secondary research was conducted to better understand the history of the space, the people living there, and what they valued. This included online blogs documented by older adults residing in that area, and literature from the national archives. Members of the merchant association who served as the middlemen between the store owners and the different government agencies were also interviewed to help us understand the evolution of the services offered and the activities that happens in the main Chong Pang market.

2.3.2 Phase 2: Survey of hotspots within Chong Pang

We covered different sites within a 300m radius of Chong Pang market during the peak period of activity from older adults, and did a survey with a total of 49 residents. The intent was to understand where they came from, the frequency of their visits, and the hotspots where they congregated at. These information was first overlaid onto a map (Fig 2) to get a sense of the distance people were willing to travel, and subsequently mapped against different amenities, to know what people were willing to travel for. (e.g. food and amenities, clinics)

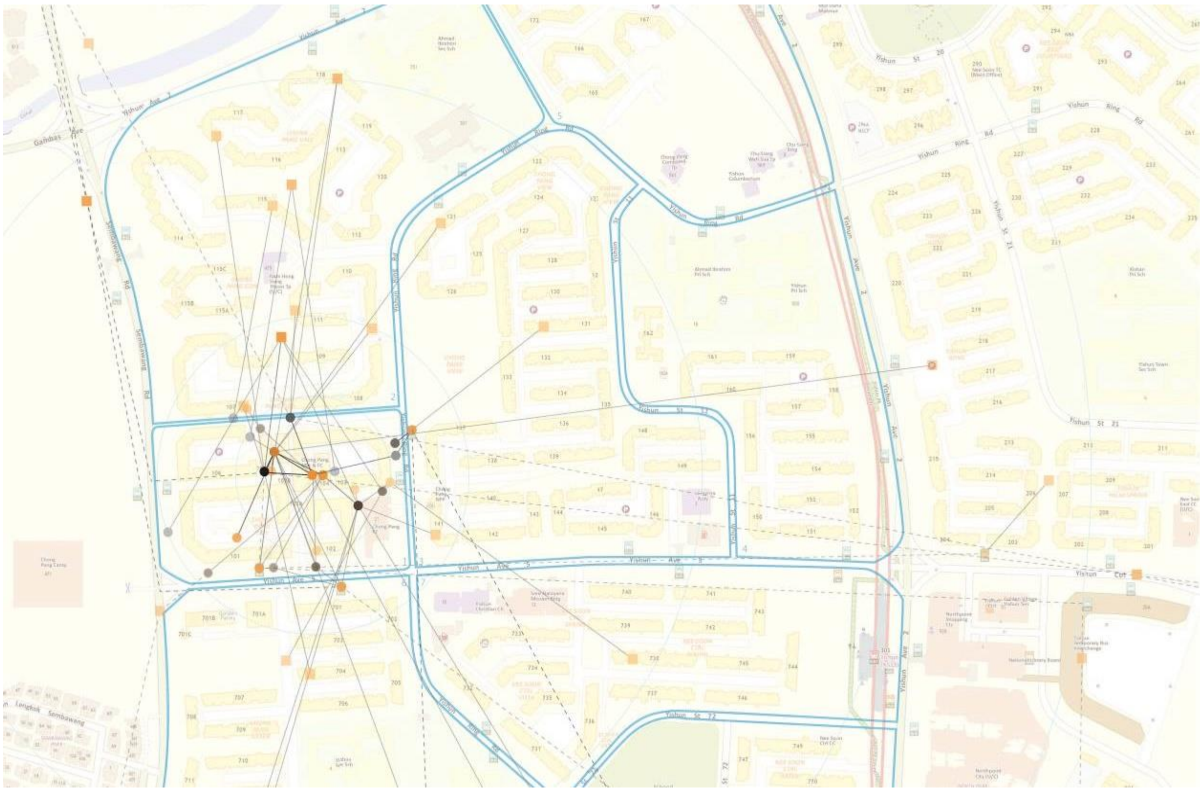


Figure 2: Heat Map showing the footprints of visitors in the space

2.3.3 Phase 3: Observations of activities that brought people together

Observations were done with photos taken over a period of 8 months to uncover how people use public spaces. Brief conversations with residents helped us to understand the things that we saw. The photos taken were then clustered and discussed in a sense making session (Fig 3), to reveal broad themes and insights about how the design of the environment and activities brought people together. This was a continually updated piece of work that was used to inform and triangulate our findings against literatures that we read and the interviews done at Phase 2 and Phase 4 of the research respectively.

Figure 3: Clustering Session

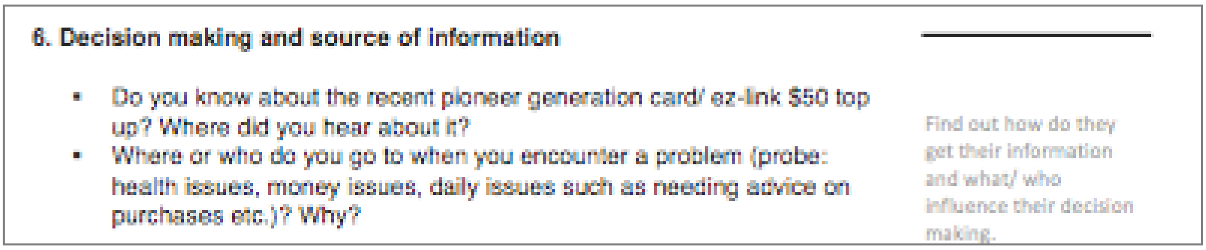
2.3.4 Phase 4: Interviews

To better understand the community dynamics and the individual roles the various residents fit into, archetypes were developed based on the common roles that the various residents performed in the community, supplemented by observations and conversations to identify who, what, why and when the older adults were using the public spaces (Fig 4).

Figure 4: Archetype wall

In-depth interviews were done with a group of older adults from each archetype to uncover their latent needs and their underlying attitudes and mind-set. 25 older adults were selected to represent a good mix of older adults of different age groups, gender and race from both the Chong Pang market and the neighbourhood. They were recruited based on their willingness to be part of the 1 hour interview.

The interview questions were kept broad and relevant to their experiences (Fig 5) to elicit stories from the older adults. This included questions about their perspectives about health and ageing, how they sourced for information, their intrinsic motivations and their hopes and fears about the future.



6. Decision making and source of information

- Do you know about the recent pioneer generation card/ ez-link $50 top up? Where did you hear about it?
- Where or who do you go to when you encounter a problem (probe: health issues, money issues, daily issues such as needing advice on purchases etc.)? Why?

Find out how do they get their information and what/ who influence their decision making.

Figure 5: Interview guide stating the question tagged to a recent nation-wide event

The recurring patterns that we identified in various interviews allowed us to distil common themes that mattered to the older adults.

3 Findings

3.1 The History of Chong Pang

In the 1950-1960s, people stayed in *kampungs* with their livelihood largely revolving around fruit and vegetable plantations. Religious leaders formed an authoritarian influence that managed disputes, taught values, and took care of the aged and destitute. Before the proliferation of televisions, villagers enjoyed the occasional outdoor film screening and opera performance, usually held during festivities. Basic healthcare came in the form of travelling dispensaries that made their way into the remote villages.

Figure 6. Transition of Yishun West from 1950 to 2017

Removal of infrastructure/practises that promoted the development of social capital. In 1976, these *kampungs* were cleared to make way for the first HDB flats in Chong Pang. Many residents from nearby villages moved into Chong Pang and became shopkeepers. With an emphasis on centralisation in governmental policies, religious bodies retired from the role as village authority but continued to support the social and welfare needs of the community through the provision of free clinics and meals for the poor and needy. Travelling dispensaries made way for Yishun Polyclinic (Primary Care Institution) which was built to meet people with healthcare needs efficiently within one location. By 2000, Chong Pang estate had grown to its present form - a sea of high-rise HDB flats surrounding the neighbourhood centre called Chong Pang City, the go-to place for many Yishun residents. (Fig 6)

Despite this seemingly successful transition however, the aforementioned analysis by Chua has shown that it had negative implications too. Taking a deeper look into his prior research showed that by centralising services, the average resident would also be consequentially less attached to it, thus reducing his or her desire to build a community together with its resultant social capital. (Chua, 1997)

Gradual erosion of existing social capital. Today, the original residents have grown old in the neighbourhood. Meanwhile, younger families and singles have shifted in from other parts of Singapore in response to housing and employment opportunities. The traditional businesses (hardware, household items, groceries, clothing, hairdressing) now compete for space with contemporary pop-up stores selling mass market personal devices and lifestyle accessories, maid employment services and tuition centres which cater to the newcomers. In a strange blend of the old and new, niche shops sell mp3 devices preloaded with Hokkien and Cantonese songs, giving the older persons something to hold on to in the realm of the unfamiliar. New users of common spaces are observed to place less emphasis on social interaction, focusing on their hand held personal devices instead.

By looking at the development of Chong Pang in a retrospective manner, it can be seen that Chong Pang' transition from a rural village to an urbanised residential town over the years have stunted the development of social capital among the population, exacerbated by the gradual displacement of the original *kampung* community.

3.2 The Place

The majority (90%) of those interviewed were fit and pre-frail individuals. Half (53%) of them lived within a 500m radius of Chong Pang City and frequented it at least five times weekly (Fig 7). The rest came from farther afield and visited less frequently – mostly to buy their groceries due to the wide variety of offerings. Interestingly, half of the people in the market used that space as a third place

(Oldenburg, 2005), to meet their social needs, instead of a mere transactional space to buy their daily groceries.

Residents who lived near to Chong Pang's market visited it more often and had stronger social capital within that community due to the high frequency of interactions, as they socialized amidst the hustle and bustle of the morning activities. This was reflected in the way residents seemed to know each other and exchanged greetings frequently. Residents trusted each other with personal items, including money, indicating a high level of trust.

In comparison, residents who lived further away had significantly less interaction. Neighbours passed each other by at the void deck (a common space on the ground floor of HDB flats), with minimal interactions exchanged). Personal items left in these void decks were chained up, with makeshift posters warning residents about thefts in the vicinity, reflecting a lower level of trust. This suggested that a successful third place for an urbanised area would be one within close proximity to people's homes (within a 500m radius) with amenities like a market to draw them in. This increases the frequency of visits to the space and the chance of interaction among residents, which then builds a higher level of trust within the community.

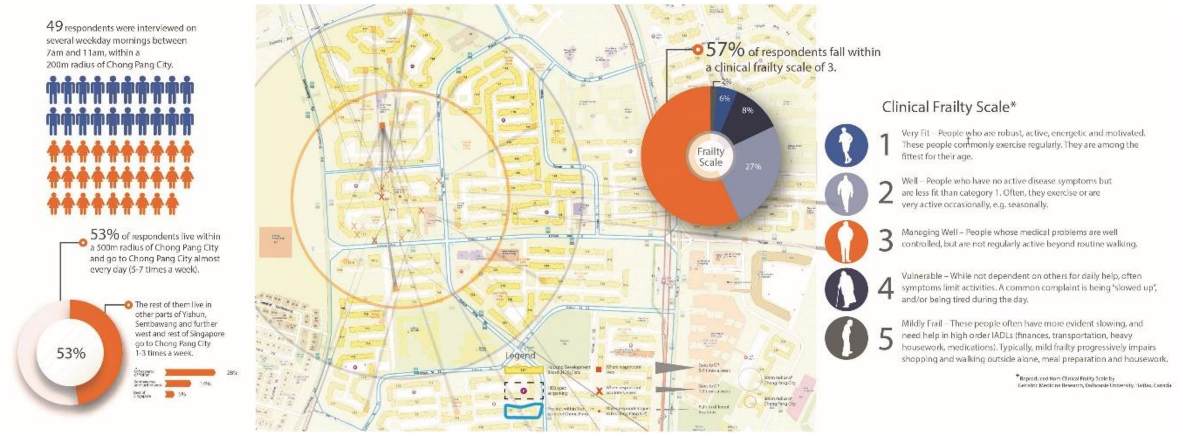


Figure 7. Infographic showing where people frequented at Chong Pang City

3.3 The Activities

It was observed that people came together in three manners. Firstly, communities were formed when people who shared similar interests gathered together, whether through formal or informal settings. Common spaces like clubs, schools, workplaces or even activity centres facilitated bridging, and they played an important role in connecting individuals with common needs. Good design of spaces that facilitated such activities encouraged access and utilization, being able to accommodate a variety of activities that met the needs of multiple groups. This created a gateway for residents in the neighbourhood to get to know each other. Such interactions played a pivotal role in relieving the anxiety and suspicion that arose from unfamiliarity.

Secondly, interactions were also effected through common roles. Activities that supported the fulfilment of a person's role were a natural way to bring people together, regardless of race, age or gender (e.g. grand-parenting). It was a common sight to see parents and grandparents gathering by the side of a playground exchanging parenting tips as the children played. Designing open and centralised spaces that supported such activities promoted high utilization and visibility for people to congregate and interact.

Lastly, spaces that allowed people to dwell around for social activities or chats were desirable. Commonplace items such as newspapers or a cup of *kopi* (coffee) were recognised as signals of 'availability' and served as effective conversation starters. We witnessed how creative the older adults could be in placemaking, as they ignored inappropriate built infrastructure and adapted their meeting places with their own furniture to suit their needs (Fig 8).


Figure 8. Adaptive vs Built Solutions

The building of such macro-communities plays a pivotal role in supporting residents when they are apart from their families and out in the community. Beyond a space where relationships are formed and strengthened, it also acts as a resource centre where the older adults can obtain information on the latest happenings from a trusted source and even to get contacts for job opportunities. The understanding of how the different activities brought people together in the community, allowed us to distil how spaces and programmes can be designed to build a natural community in our wellness centres.

3.4 The People

Among the residents, 5 clear archetypes were identified:

‘Connectors’ refer to residents who are always in the community space, rain or shine. They provide an overview of the relationships in the community, and connect you to the right people due to their wide networks.

‘Migrants’ are people new to this community space. They could either be residents who have just moved into this area, or residents who although have lived in that area for a long time, have not mingled much in the community space. The latter could be in between jobs, and are thus opportunistically using the community space to get potential job referrals. Migrants usually hang out alone, are new to the community space, and usually experience considerable problems in navigating their way to get what they want.

In contrast, ‘Dwellers’ are the people who form the bulk of the core community, the major utilizers of the community space. They exist in groups and they seek comfort in familiarity. Having a deep sense of belonging to their respective groups, they offer strong emotional support and influence to each other in the group, due to the significant amount of time they spend with each other.

Next, ‘Patrons’ are task driven, and they form the main consumers of the services and products in the community space. Their relationship with the community space is generally transactional and they are important in sustaining the businesses in Chong Pang.

Lastly, ‘Leaders’ are usually highly skilled and are passionate in contributing to the community, making them highly regarded as important assets.

The five archetypes helped us understand the community dynamics and the individual roles our respondents contributed to (Fig 9).

Figure 9. Archetypes identified within the community

In-depth interviews revealed the need for security and freedom, the importance of having roles and responsibilities, and staying connected while being relevant to the community were the key themes that mattered to the older adults.

For these older adults, financial security and good health provides them with the confidence to age well and face the anxiety of an uncertain future. Health is simply being able to sleep, eat, and move well. It is regarded as a by-product of being happy and contented with life. This is a stark contrast from the perception that most healthcare professionals hold, where good health is the end goal for people, and the concept of good health is focused on being disease-free.

A common worry articulated by the older adults is that ageing brings about serious health issues, with the attendant rising healthcare costs being a major setback for themselves and their families. These perceptions were reinforced by friends who had similar encounters. Social assistance schemes which allayed their anxieties through substantial government subsidies for their healthcare bills were appreciated and valued.

Another insecurity showed us how they view their diminishing roles in the community. The association of retirement with success is a common mind-set among the older adults. If an older adult is seen to be working hard, even though they are past the age of retirement (65 years old), they are frequently described as "having a hard life", due to the perceived lack of support from their families. Yet, retirement changes their roles and the responsibilities that define who they are in the family and community. Relinquishing their key roles and responsibilities which they have grown into over their productive years at work (e.g. as breadwinners, supervisors, and mentors), leaves many older adults, especially males, feeling collectively lost in the community space, leading to pre-mature ageing. Without economic engagement, older adults face the potential of fading into insignificance.

Through our conversations with the older adults, we learnt how perceptive they were towards the design of the environment and how it affected the quality of their daily interactions with their neighbours and the community. Particularly salient was the loss of strong ties and trust, termed as the *kampung* spirit. The design of the flats led to isolation as expressed by a resident. "Staying in a HDB flat is like staying in a cage. The windows are high, it's hard to exchange greetings unless the person is proactive."

Communal spaces that encourage the development of relationships allow older adults to be seen, heard and connected with their heartland community. People who regularly involve themselves in community activities derive more opportunities for deeper social networks built on trust and cooperation. This was seen in an example that we saw with an older resident, Mr. Tan, who is also a community leader. He made use of the plot of community garden that he was tasked to take charge of, and proactively gave some of the vegetables that he grew, to other older residents who needed an income. These older residents would then sell the vegetables in an ad-hoc, modest set up at the market space. A nominal fee was subsequently collected from the sales for the purchase of fertiliser, thereby keeping the effort sustainable. This ground up initiative shed light that when given the necessary platform, the community themselves can be useful assets, as they can step up and support each other with the resources that they have in a sustainable manner.

The uncertainty brought about by ageing coupled with dwindling financial and social resources creates anxiety for the average older adult in the community. This results in the gravitation of older adults into public spaces where they seek to connect with others and expand their social network, now that they have retired. The desire to re-create a community with high social capital just like the old *kampung* days in the neighbourhood was a common request that came out during many conversations with the older adults. A sense of belonging to a community that is tightly knitted, allows the older adults to participate and be valued, so that they can support each other in the community to age well.

4 Translation of Insights

4.1 Project Orange Exhibition

The insights collected from the research were curated and presented in the form of an exhibition (Fig 10) within a community hospital in Singapore. The exhibition of photos and videos shared the sounds and sights of the community and the compelling stories that have reframed the way we saw the older adults.

Figure 10. Project Orange Exhibition

To date, approximately 300 visitors have visited the exhibition, including overseas visitors from as far as the Netherlands. More recently, the exhibition was also a key highlight in a training and engagement programme for young doctors. The intent was to expose them to how the older adults are like in the community, beyond the patient that they are familiar with in a hospital setting, so that they can empathise and deliver better care in the future.

4.2 Design of a modernised kampung – Wellness Kampung

The Wellness Kampung initiative is a re-design of co-located community-based wellness and senior care centres, developed based on Project Orange's research, concepts of Ibasho Café (World Bank Group, 2015), Ray Oldenburg's concept of a "third place" (Oldenburg, 2005)), and "principles of the commons" (Stibb, 2011). This initiative is part of the healthcare institution's overall population health management strategy and care model in the northern part of Singapore – to build **confident, resilient self-management communities, supported by a responsive healthcare system.**

To appeal to the older adults' desire of having a tight knitted community, the Wellness Kampung was envisaged to be the neighbourhood gathering space, to meet the needs of local residents, in consultation with them. The strategy focuses on delivering health interventions through daily social programmes at the Wellness Kampung so that the residents can learn and practise health promoting behaviours with the support of the community. Through empowerment, activation, motivation, and support in their health journeys, the responsibility for health is returned to every individual.

4.2.1 Evoking nostalgia through branding

The design began with a name with which the residents could identify with, and hence get involved with on a regular basis. *Wellness* gives an aspirational goal of achieving healthy, active and engaged residents, and Wellness Kampung (养生村, hanyu pinyin *yang sheng cun*) was selected to deliberately leave out the connotation of senior care or eldercare. The word *kampung* connotes inclusiveness and the *gotong royong* (mutual aid) spirit, themes that the older adults frequently mention. Furthermore, the verb "berkampung" (to form a *kampung*) means to gather. It has been said that it takes a village to raise a child and increasingly, this phrase is applied to care for older adults as well. The knowledge about the history of the space also informed the design of the logo, to appeal to the residents. (Fig 11)

Figure 11. Logo Design for Wellness Kampung@115- Pineapple leaves served as a representation of the plantation that used to be in the area.

4.2.2 Spatial Design that facilitates community building activities

The Wellness Kampung is a space repurposed from the void deck of an HDB block, usually used as a thoroughfare for residents in the neighbourhood to get from one block to another (Fig 12). Inspired from Chong Pang Market where older residents in the nearby area congregated to use it as a third place, the Wellness Kampung was designed to be inclusive and flexible to accommodate various types of activities.

Figure 12. Repurposing of void deck spaces to become Wellness Kampungs

Compared to traditional walled activity centres, folding glass walls were used to minimise the differentiation between the interior and exterior space, serving as an invitation for residents to join in the programmes. Casual passers-by who would have just walked on by in the past can now walk in, linger for a while to observe, enquire, and ultimately stay on to use the space. Conversation starters that were commonly used in Chong Pang market, such as *kopi* and newspapers are also provided alongside with familiar chairs and tables in the multi-purpose space, to allow residents to move the furniture around and mingle with each other. An activity room also provides a conducive space where a wide range of programmes and activities are conducted to bring people of common roles and interests together. The open layout of the communal kitchen encourages collective use, facilitating the exchange of knowledge and recipes.

The range of available activities that were supported by the design of the space resulted in longer dwell times, providing opportunities for new friendships and the building of social capital. The natural formation of these social groups with strong bonds become the driving force at Wellness Kampung to help inculcate and sustain health promoting habits in the community.

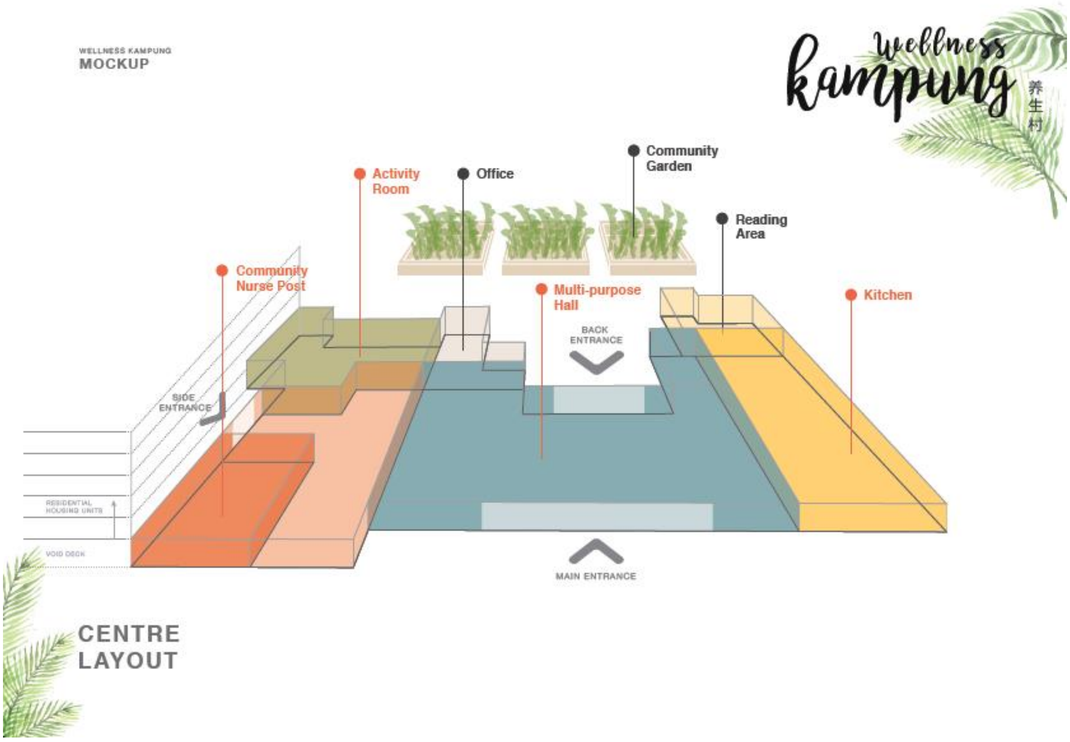


Figure 13. Design of space facilitates various types of activities

4.2.3 Programmes designed by leveraging on community assets

A retired community leader was identified and employed to run each of the three centres, as residents can relate and connect better to them. The programming of the activities was designed to be organic and flexible with little formal organisation to encourage co-design of activities that remain relevant and sustainable to the community. Ground-up activities were encouraged if any resident wanted to share a certain skillset, with the staff merely facilitating the process. The "invisible" organisation lowered the entry barrier to residents coming forward. One such example was a DIY exercise support group, initiated by a resident, for people with disease like stroke and Parkinson's disease to do rehabilitation activities and support each other 3 times a week. Residents got opportunities to volunteer and to give back to the community by supporting other residents with special care needs (e.g. non-ambulatory persons, stay-alone older adults etc.). These contributions affirm the dignity of both the giver and the recipient, adding meaning to relationships.

To support residents with questions related to health, a community nurse regularly runs consultation and education sessions. Residents could consult him/her on their health issues such as medications, physical monitoring and laboratory results. With the right knowledge, residents are encouraged to support their peers in the monitoring of their chronic diseases. The visibility and accessibility of the community nurse assured residents of timely and appropriate assistance as required.

4.2.4 Outcome

The three centres now cater to approximately 1500 registered residents, with each centre seeing an average of 60 residents daily. 74 new programmes have been started, including Daily Exercises, Social Engagement, Food and Nutrition, and Health Intervention. 19 (26%) programmes are led by healthcare staff, e.g. a fall prevention programme, Advance Care Planning advocacy sessions. 28 (38%) programmes are led by partners, e.g. intergenerational activities by five neighbourhood schools, Life After Stroke, and Autoimmune Illness support groups. 27 (36%) programmes are led by volunteers. One such volunteer is Mr Norman Wee who branded his aerobics sessions after himself (Weirobics). 18 out of 27 of these continue to be active over extended periods, proof that community resources can propel action and build self-supporting ecosystems.

Two stories are selected to demonstrate the components of such a supported self-management community. A 68-year old lady had sustained several falls, and was fearful of further falls whenever she wanted to leave her house. She became progressively homebound and continued to fall at home, requiring frequent hospital admissions. A community nurse encouraged her to go to the nearby Wellness Kampung where she was befriended by a 79-year old neighbour. Since then, the two neighbours have become good companions, and together they ventured out confidently into the community. At another Wellness Kampung, two neighbours voluntarily supported a 51-year old man with stroke and an 84-year old lady with Parkinson's disease, with "do-it-yourself style" rehabilitation. The two beneficiaries maintained improvements in their physical function. The community nurse maintains a reassuring and motivating presence for both the volunteers and the residents receiving support.

5 Discussion

Through Project Orange, we found that the transition from communal living in kampungs to the vertical living of high rise flats left a sense of nostalgia among older adults as they bemoaned the loss of ties and trust typically found in the old kampung spirit. The loss of a communal space where residents can gather and know each other results in low social capital within the neighbourhood. Retired residents are often seen gravitating towards community spaces where the human traffic is higher, so that they can be seen and heard. The understanding of the activities that attracted the community to come together, the older adults' perception of health and the nuanced signals of personal availability for conversations assisted us in the design of three wellness centres that have now been operating for almost two years.

5.1 Limitations

While the early success of these wellness centres have sparked interest to develop similar sites around Singapore, we are aware that a wholesale replication may not be successful in other areas of Singapore, based on the varied interests of the seniors in those areas, and the nuances of the local culture within those communities. Which of these insights can be extrapolated to the rest of Singapore and which are specific to Yishun? Will such initiative really build resilient communities that are ready to take charge of their health, therein reducing the strain on the healthcare system? There are many challenges ahead and these are questions that remain unanswered, as the Wellness Kampung is still in its early chapters. What we need is a longitudinal evaluation to illuminate the value of such an initiative in the areas of population health and community resilience.

5.2 Recommendations

Recommendations for design researchers working in this area, especially in the context of a multi-racial community include:

A multi-disciplinary core team of members with diverse backgrounds (e.g. socio-economic status, age etc) who were willing to listen, explore and contribute their domain expertise brought about synergy of collective strengths, with a balanced perspective, therein raising the quality of the research. The extended team comprised of natives who helped to increase the people networks and facilitate inroads into the community by "foreigners" (researchers).

The context of the field research study is important. Immersing in the sounds and sights of the daily activities of the people helped us to understand the local nuances within a community. This was useful in designing interventions with low barriers of entry.

A mixed method research that combined qualitative and quantitative data reinforced each other's utility, and enriched the data set by giving the research depth and magnitude. The application of various tools (secondary research, interviews, observations) on factors (History, Place, Activities, People) that influenced the local narrative, allowed us to gather data from multiple sources to reveal the community's unarticulated needs.

6 Conclusion

Design research provided the users' perspective on what mattered to them as health services. In contrast to services that were traditionally planned in isolation for the users, the Wellness Kampung took into account the existing behaviours of the users that eventually led to a high participation rate and an activated community.

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Mentian: Developing Design Fiction for Dementia Policy

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Acknowledging the challenges placed on healthcare by an ageing population, governments around the world are introducing policies on ageing and age-related illnesses. As emergent technologies and the UK government's policies mix and shape our futures there are numerous potential consequences and implications for people living with dementia, their carers, families and society at large. The 'What If?' project investigated the use of participatory design fictions to explore the future implications of UK dementia policy. A series of codesign workshops were conducted in the UK. The authors facilitated the workshops; participants included staff from a Voluntary Sector Organisation (VSO), a group of older people assembled by the Voluntary Sector Organisation in the Northwest, and another group assembled by a community organisation. In this paper, we present the design fiction, Mentian, conceived by a participant group, the process employed in its making and offer a discussion of participant ownership of the process and the application of design fiction as a method for policy debate. Finally, we identify areas for future research.

esign fiction; policy; ageing and dementia; codesign;

1 Introduction

Acknowledging the challenges placed on healthcare by an ageing population, governments around the world have been introducing policies on ageing and age-related illnesses, such as dementia ("Dementia | Care, Ageing and Aged," 2018; Department of Health and Social Care, 2015; Federal Office of Public Health and the Swiss Conference of the Cantonal Ministers of Public Health, 2018; Nakanishi & Nakashima, 2014; National Strategy for Alzheimer's Disease and Other Dementias Act, 2017). Simultaneously, over recent years, there has been a move to include more collaborative methods of engaging with publics, alongside traditional consultative practices, to encourage comment and debate on government policy (Bradwell & Marr, 2008). This has included experimentation with various forms of speculative design being used to address policy (Kimbell, 2015).

Engaging with the voluntary sector and the people they support through speculative methods to critique government policy and generate debate is a relatively new undeveloped area. The 'What If?'

project sought to investigate the use of a participatory approach to design fictions in order to explore the future implications of UK dementia policy from the perspective of VSOs and the older people with whom they work and in doing so a number of insights and challenges were revealed. After the presentation of related work, we examine the methods employed in the codesign workshops. Then, we elaborate on the codesign process and present the diegetic prototypes and design fiction. Lastly, we present the findings and discuss their implications before making our concluding remarks.

2 Related Work

In this section, we present the background around ageing and dementia policy and consider some of the challenges of using design fictions as a tool for facilitating citizen participation in the social, ethical and legal debates relevant to dementia policy.

2.1 Ageing populations and time bombs

Several governments across the globe have developed comprehensive plans to address the needs of people with dementia, including promoting public awareness of dementia and improving the quality of health care, social care and long-term care support and services for people living with dementia and their families. The Alzheimer Disease International's study in 2016 on dementia plans, found that there are currently 30 countries with national dementia plans and 22 countries with national dementia plan in development ("Dementia plans | Alzheimer's Disease International," 2016).

In the UK, the House of Lords Select Committee on Public Service and Demographic Change stated in the 'Ready for Ageing?' report (2013) that the Government and British society are "woefully underprepared" for a rapidly ageing society. The report outlined key projections about ageing, including the fact that there would be "80% more people aged 65 and over with dementia (moderate or severe cognitive impairment) in England and Wales by 2030 compared to 2010". The committee called for the Government and all political parties to open a debate on ageing society as there was no vision or coherent strategy on how to address the challenges that would emerge in coming years in health and social care, pension schemes and the labour market.

Shortly afterwards in September 2014, the Alzheimer's Society published an updated edition of its key publication 'Dementia UK' (Prince et al., 2014) detailing the anticipated impacts on the UK economy. According to this report, there are about 850,000 people living with dementia in 2015 and this number is forecasted to increase to over 1 million by 2025 and 2 million by 2051. The Alzheimer's Society estimated the annual cost of dementia to the British economy is £26.3 billion, with £4.3 billion spent on healthcare, £10.3 billion on social care (both publicly and privately funded) and £11.6 billion of opportunity cost of the work of unpaid carers of people with dementia.

2.2 Dementia policy and futures

As a result, in 2009, the Department of Health's Dementia Policy was launched, it aimed to raise awareness and understanding of dementia, increase diagnosis rates, make every hospital dementia-friendly, set new standards for dementia care and improve research in dementia (Department of Health, 2009). These goals are pursued in part through the Dementia Challenge programme first launched in March 2012, and then updated in 2015, by the then serving Prime Minister (Department of Health, 2012).

Alongside innovations from within the NHS and social care, the academy, pharmaceutical, health and technology companies are actively exploring potential methods for the diagnosis, prevention and cure of health conditions, such as dementia, as well as developing assistive technologies and strategies to better accommodate the needs of people living with dementia. As these emergent technologies and the UK government's policies mix and shape our futures there are numerous potential consequences and implications for people living with dementia, their carers, families and for society at large. With the number of older people living with dementia set to expand in the coming decades those futures will impact more than ever.

2.3 Co-creation approaches to policy
According to the European Commission, “renewing the legitimacy of public policy-making, especially through greater citizen involvement” (European Commission, 2015) is a significant challenge ahead of 2020. The health-related benefits offered by technological approaches are counterweighted by the societal, legal and ethical challenges concomitant with some techniques, such as the pervasive monitoring of people, that are necessitated by specific technologies (Brown & Adams, 2007). With the stakes so high, there is a need, therefore, for increasing public engagement and discussion on the social, legal and ethical issues arising from current and, more crucially, emergent technologies and for facilitating a range of interactions and debate between policy makers and citizens.

2.4 Design fiction
Speculative design is an approach, encompassing design fictions, that enables us to think about the future prospectively and critically (Auger, 2013). Concerned with progress and ideas for the better, speculative design also takes into account that better means different things to different people (Dunne & Raby, 2013). It does not focus on implementation, but on generating and discussing ‘what-if’ scenarios. It uses design thinking tools and methodologies such as brainstorming and rapid prototyping along with techniques borrowed from art, literature, film, psychology, philosophy, anthropology and ecology to create design fictions that “envision and ex-plain possible futures for design” (Ljungblad, Surholt, Barendregt, Lindgren, & Obaid, 2016).

While design fiction is about the direction of future technology and possible worlds (Bosch, 2012), perhaps more importantly it is about “creative provocation, raising questions, innovation, and exploration” (Bleecker, 2009). Indeed, one of its principal assumptions is the negation of the status quo and initiation of a discussion on possible worlds through confrontation with tangible objects or processes. At the heart of design fictions are diegetic prototypes, the realisations of future technologies that “demonstrate a technology’s need, viability and benevolence” (Kirby, 2010) through their encounters with technologies or people in the fictional world.

Design fictions are explorations of particular design spaces made possible by combining current and emergent technological advances with society’s slow-changing social, legal and ethical practices. However, they do not claim to predict the future, instead they place potential futures within our imaginative reach for consideration as to their preferability, and in so doing they take advantage of the fictional paradigm to catalyse debate about potential futures (Linehan et al., 2014). To that end, various forms of speculative design, including codesigned design fiction (Darby et al., 2016; Tsekleves et al., 2017), have been tested by the UK government to assess their potential to contribute to real-world policy development (Kimbell, 2015).

As a research method design fiction is still in formation, however it has been used by designers and design researchers to “explore the potential value of new design work” (Blythe, 2014) by generating domain insights, particularly with regard to the limitations and directions of possible investigations. It has also been used to develop knowledge about the practice of design fiction itself (Lindley, 2015). In the last decade, increasing attention has been paid to the use of fictive practices in design research, however participation’s engagement with fiction remains, as yet, underexplored (Knutz, Lenskjold, & Markussen, 2016).

3 Methods
The following section gives an overview of the ‘What If?’ project. It outlines the details of the planned workshops and the workshop process, it then describes the design concepts and diegetic prototypes generated and the design fiction produced. The same research team ran all the workshops.

3.1 Project Overview
The ‘What If?’ project followed on from the ProtoPolicy project that ran in 2015, as a part of the AHRC ProtoPublics programme. ‘What if?’ investigated the use of participatory design fictions to

imagine the future implications of ageing and, in particular, dementia policy initiatives in creative ways. A series of three workshops were originally planned – two workshops did not run following recruitment difficulties, so two more were organised in their place. From these workshops two design concepts were generated with one concept being developed into diegetic prototypes that then formed the basis of a design fiction video. The film was then shared with participants to elicit a critical response; initial feedback has been received, though more is required before a final version is produced.

3.2 What If? Workshops

The workshops WI1 n=1, WI2 n=5, WI3 n=9, WI4 n=3 and WI5 n=4 were held between July and December 2016. Participant ages ranged from 25 to 90 years old, with WI2 ranging from 25 to 65 and WI1, WI3, WI4 & WI5 ranging from 60 to 90. The venues were a university design studio in Lancaster WI1, Age UK head office in London WI2, community centres in Blackburn WI3, WI4 and WI5. The duration of workshops varied with WI2, WI3, WI4 and WI5 being three hours long, while WI1 was planned to last four hours.

Recruitment for WI1 was open, with posters in the city centre and email mailshots to the University of the 3rd Age advertising the workshop. WI2 recruitment was conducted by AGE UK and targeted staff with an interest in policy, they were invited to review dementia policy in advance of the workshop. WI3 recruitment was led by Age UK Blackburn through direct contact and calls to potential participants. Finally, for WI4 and WI5 the community organisation undertook the recruitment via email and word-of-mouth.

As dementia is primarily an age-related illness the project sought to work with participants who were over 60 years of age or who had an identified interest in the issues of older people. There was no professional experience of dementia in WI3 or WI5, however in WI2 all participants had either professional experience of working directly with people living with dementia or an in-depth knowledge of the condition and the attendant societal issues surrounding dementia at policy level. We did not target people living with dementia or informal carers for the workshops. However, over half of the workshop participants had direct experience of dementia.

Figure 1. WI3 participants discussing policy.

WI1 and WI4 failed to recruit, WI5 was abandoned partway through in favour of a discussion about the issues, and WI2 and WI3 were completed.

3.3 Workshop Process

The workshop began with participants sharing artefacts connected to their personal histories in order to discuss the idea that technology shapes our world. They then mapped their drawings of impactful technologies onto *A Technological Chart of our Recent Past*. Participants were then invited to share their understanding and experience of dementia through a series of question cards. Following on from these activities the workshop introduced the *Prime Minister's challenge on dementia 2020* (Department of Health, 2012) to participants for discussion and critique. Participants were invited to consider what they found reassuring, what was worrying, what was missing from the document, what assumptions underpinned the document and who the beneficiaries of the policy were, noting their insights down on flipchart paper. The insights were then prioritised and assessed by the groups as to their positive or negative impacts as they located them on *A Critical Chart of our Present Circumstance*.

Participants were asked to consider current technological interventions into dementia related areas before they were introduced to 10 technology trends drawn from Gartner's[1] annual assessment (Cearley, Burke, & Walker, 2015). The 10 trends identified were; the device mesh, ambient user experience, 3D-printing materials, information of everything, advanced machine learning, autonomous agents and things, adaptive security architecture, advanced system architecture, mesh app and service architecture and internet of things architecture and platforms.

In groups participants were invited to extend self-selected issues arising in *A Critical Chart of our Present Circumstance* as speculations in the present time and then begin to develop design concepts. The SCAMPER[2] cognitive heuristic was used to introduce an element of chance with the spin of a wheel determining what abstract concept would be used to challenge the design concept. To develop their technological design concepts further, as diegetic prototypes in a potential near-future, participants were given a *Blueprint Template*, this encouraged them to explore the elements of a product story and gave them space to form and reform their understanding of their original speculation. The final activity aimed to take the design concepts generated in the workshop and on *A Mapping of Projections for our Possible Futures*, locate them as to their positive or negative impact and their various probabilities, plausibilities, or possibilities as they extended out into the future.

3.4 Design Concepts

Of the three workshops that ran, only WI2 reached the point of generating design concepts, while WI3 and WI5 did not. WI2 participants developed two design concepts, entitled *Easing the burden on informal carers* and *The Multi-monitor.* In WI3 we reached the point of developing a number of broad speculations rooted in affirmative responses to need rather than policy critique. In WI5 we encountered a more fundamental difficulty as group members were unable to critique policy, they also lacked an understanding of dementia as a condition to such a degree that the workshop plan was abandoned.

3.4.1 Easing the burden on informal carers.

This concept was developed in response to the issue of overburdened informal 'family' carers, which the group felt was given too little support through policy. Their concept was twofold, an interactive virtual assistant giving round the clock support 'working for you' (i.e. person with dementia) and an application 'to allow informal carers to leave for a while' created by combining an 'army of formal carers' with 'wearable tracking' technology.

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[1] Gartner, Inc. is a leading research and advisory company, based in Stamford, Connecticut, USA, that provides technology-related insights and an annual trend analysis to business.

[2] SCAMPER (Eberle, 1995) provides a broad heuristic at an abstract level that designers may respond to in any way they see fit, at any point in the design process, to develop a design candidate (Yilmaz & Seifert, 2010).

3.4.2 *The Multi-monitor*

The group identified attention to multi-morbidities for people with dementia as being absent from policy. They stated the problem, as follows, ‘People with dementia typically have multiple conditions, which prevent effective management of their overall health.’ They envisaged a device that tracked vital health metrics to assist clinicians when a person with dementia was admitted to hospital and to assist day-to-day health management.

Figure 2. A WI2 participant works on the Blueprint Template.

3.4.3 *Further development*

The Multi-monitor concept was selected for further development because of the specificity of the critique that attention to multi-morbidities was absent from the *Prime Minister’s challenge on dementia 2020* (Department of Health, 2012). The speculation underpinning the multi-monitor concept was that “Data talks for me (to professionals) (to carers)”, *me* being the person with dementia. The underlying assumptions, built on current technological trends, were that health metrics would become increasingly reliable and that an Artificial Intelligence (AI) could translate and communicate them through natural language enquiries to health professionals and informal carers resulting in more responsive care for people with dementia and multi-morbidities. Desk research gave confirmation of the issues articulated by the participant group and presented a comprehensive outline of related issues (Scrutton & Brancati, 2016). Web searches highlighted the currency of public debate on health and biosensors (Caparas, 2016; Tozer, 2014), and on AI in the home, for example, Amazon Echo and Google Home, as technological trends entering public consciousness.

The Design Research Team went on to review the documentation, develop *The Multi-monitor* concept, and generate a number of diegetic prototypes to explore the design concept further.

3.5 *Diegetic Prototyping*

Jumping off from a design concept envisioning a possible future world, diegetic prototyping describes the process through which the features and physical dimensions of a product or service are iteratively tested and refined in order to establish the visual and narrative rhetoric of the design fiction. Simultaneously the designer seeks to realise the concept design, at least some degree, through a number of design artefacts or 'props' that articulate various dimensions of the design concept's argument. Finally, the 'props' are socialised within the possible future world through their interactions with others in the design fiction through storyboarding, improvising and scripting.

The diegetic prototyping process focused on breaking the concept down into its constituent elements and visualising the resultant artefacts for a design fiction film. The system described in *The Multi-monitor* concept was bound up in one object, to help better explicate the concept several artefacts were used to illustrate the system and to open space for human interaction. The artefacts included; a computer in the centre of the home, sensors to collect health metrics, an authorisation mechanism to allow the health data to be interrogated, a product information sheet, and a PAT (Portable Appliance Testing) label.

With simplicity, of both production and communication, in mind white stickers analogous to a medicinal pill were selected to represent the sensors. As medical data, often presented in charts or tables, was to be available to a verbal enquiry the medical table became a coffee table where consultation could take place. The table became the housing of the computing power needed for natural language processing and a useful way of keeping the data close to the person with dementia, as it would be sited in their own home. Linking the white circles of the sensors to those of the table made a visual connection in order to represent a potential system. On the tabletop, we pointed toward the idea of multi-morbidities by using a circular pattern featuring numerous white circles. A green cross, commonly associated in the UK with healthcare, was designed to light beneath a large central circle when the system was in use. A digital authorisation card that doubled as a business card, which pointed to role and corporate structure and provided a mechanism for the removal of patient consent for consultation was also envisaged. Two other artefacts, the PAT label and the Information Sheet, dated and described the product system, respectively.

As part of the process, consideration was given to the imagined audience for the design fiction; a closed group of professionals convened by Age UK to address the future of dementia care.
The artefacts described and pictured below; the information sheet, table and PAT label, the health professional's authorisation card and the sensor array, are the diegetic prototypes that collectively built the world of the design fiction.

3.5.1 Artefacts - Information Sheet

The Mentian™ consultation system is described through a talkative artefact[3], an information sheet, not presented within the design fiction, as follows:

> *The Mentian™ Consultation System gives accurate and lucid natural language responses to medical history queries, even for complex and atypical symptoms. Developed in partnership with the National Service for Health by Reid Lauder Technologies and supporting the NICE dementia pathway, the Mentian™ Consultation System is being introduced in the community to support people living with dementia.*
>
> *Working with the in-home Mentian™ Consultation System is simple and efficient, even when engaging with non-communicating people with dementia. Once the sensor array is fitted and operationally confirmed health and care professionals can track, share and manage complex multi-morbidities securely during the privacy of a home visit.*
>
> *The patient is fitted with an array of sensors to provide health metrics across a number of morbidities, including those most common for people living with dementia, chest infections and Urinary Tract Infections. The Mentian™ Consultation System encrypts all data transfers between the private server (Triple Modular Redundancy) and sensor*

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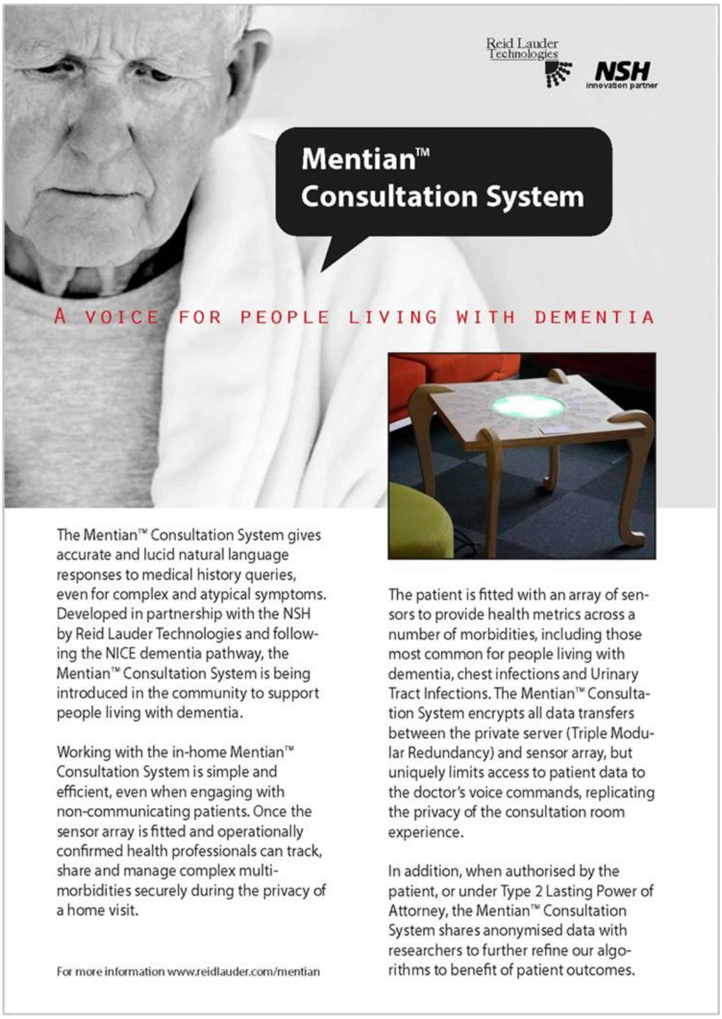
[3] Bastien Kerpsern, of the French design studio, Design Friction, introduced us to the term 'talkative artefacts' during the ProtoPolicy project (personal communication, December 3, 2015) to define an order of diegetic prototype that describe, primarily through text, an artefact in the diegesis, for example user manuals and collateral materials.

> *array, but uniquely limits access to patient data to the health professional's voice commands, replicating the privacy of the consultation room experience.*
>
> *In addition, when authorised by the patient, or under Type 2 Lasting Power of Attorney, the Mentian™ Consultation System shares anonymised data with researchers to further refine our algorithms to the benefit of patient outcomes.*

The information sheet sets out the context that the consultation system was created, and operates, in, including; a national service for health, the NSH – akin to the NHS – operating in an innovation partnership with a technology company, the system's integration within the NICE dementia pathway (National Institute for Health and Care Excellence, 2016) and introduction into community settings, and also highlights issues regarding data security, hardware redundancy and types of authorised access. In addition, the information sheet explains the user interaction and the expected benefits of the system.



Reid Lauder Technologies

NSH innovation partner

Mentian™ Consultation System

A VOICE FOR PEOPLE LIVING WITH DEMENTIA

The Mentian™ Consultation System gives accurate and lucid natural language responses to medical history queries, even for complex and atypical symptoms. Developed in partnership with the NSH by Reid Lauder Technologies and following the NICE dementia pathway, the Mentian™ Consultation System is being introduced in the community to support people living with dementia.

Working with the in-home Mentian™ Consultation System is simple and efficient, even when engaging with non-communicating patients. Once the sensor array is fitted and operationally confirmed health professionals can track, share and manage complex multi-morbidities securely during the privacy of a home visit.

For more information www.reidlauder.com/mentian

The patient is fitted with an array of sensors to provide health metrics across a number of morbidities, including those most common for people living with dementia, chest infections and Urinary Tract Infections. The Mentian™ Consultation System encrypts all data transfers between the private server (Triple Modular Redundancy) and sensor array, but uniquely limits access to patient data to the doctor's voice commands, replicating the privacy of the consultation room experience.

In addition, when authorised by the patient, or under Type 2 Lasting Power of Attorney, the Mentian™ Consultation System shares anonymised data with researchers to further refine our algorithms to benefit of patient outcomes.

Figure 3. The Mentian Information Sheet.

3.5.2 *Artefacts - Table*

The table was laser cut in plywood with the legs sliding into place with a pressure fit, for easy removal. The lightweight portable design provided a housing for an Arduino Uno, an NFC reader, colour LED lights and battery packs, which was accessed by a panel on the underside.

The table has a computer power cable inserted into one of its legs and one of the circles on the table top carries the 'NSH' logo on a contrasting black substrate.

Figure 4. The table.

3.5.3 Artefacts - Mentian Sensor Array

The Mentian™ Consultation System Sensor Array features 173 individually numbered sensors per panel and a single panel provides sensors tracking a particular morbidity. The case holds three panels, HD indicating Heart Disease, UTI indicating Urinary Tract Infection and CI indicating Chest Infection. On each panel circular white stickers represent the sensors.

Figure 5. Sensor Array

3.5.4 Artefacts - Health professional’s authorisation card

On the front side, alongside a picture of the nurse and a health service logo, the text reads:

> *My name is Paul I am your Nurse today. If you want to stop the consultation, at any time, simply give this card back to me.*

Consent for the consultation hinges on the authorisation card being laid in place, on the black NSH logo, on the table. When the authorisation card is placed on the logo the central circle of the table lights up with a green light and the system is ready for use.

On the rear side, alongside a Near Field Communication tag, the text gives the Nurses name and registration number above the health service logo. Below, the text indicates the corporate structure of the health care service within which the consultation takes place. The health professional is a specialist nurse prescriber ‘*Dementia Nurse Practitioner – Prescribing*’, within a division focused on a single home-based technological solution ‘*Mentian Home Care Division*’ and within a regional hub dedicated to issues around ageing ‘*NW Ageing Super Hub*’. The authorisation card is seen at a distance in the film.

Figure 6. The health professional’s authorisation card.

3.5.5 Artefacts – PAT test label

The PAT test label provided a simple way to visually stamp the date of the consultation system within the fictional world. By providing a test date of mid-July 2021 and a re-test date of mid-July 2022 we were able to indicate a near future four to five years ahead. Though the date on the PAT test label was not featured in the film.

3.6 Mentian – Design Fiction

With the diegetic elements of The Mentian Consultation System complete, a structure for the design fiction film was outlined to highlight the system and its use in an affirmative frame. The roles required for the design fiction film were also established. The researcher took the role of Nurse Practitioner, Paul, and professional actors took the role of Ron Murdoch, a person with mid-stage dementia, and Mentian, an AI natural language processor. The professional actor playing Ron had extensive direct experience of caring for a family member living with dementia, which was useful in devising the improvisation.

The design fiction was improvised over the course of a morning. The actors were given an explanation of the system and shown the various diegetic prototypes. Then, over a number of improvisations, the group devised and shaped the consultation and the various roles within it and focussed their interactions with the ‘props’. The researcher carried out the filming and edited the material for presentation of a work-in-progress version. The film featured a person living with dementia in his own home in consultation with a health professional who made use of the Mentian consultation system.

Figure 7. Still from the 'Mentian' design fiction featuring Ron with Nurse Practitioner, Paul.

A work-in-progress design fiction film was subsequently shared with our Age UK liaison. The design fiction is currently being shared with the participant group to gather further feedback before a final version is produced.

4 Findings and Discussion

Demonstrating the entire project process, the previous section offered an overview of the project, and outlined the planned workshops and processes. It also gave a description of the design concepts and diegetic prototypes generated and the work-in-progress design fiction produced. In the next section we discuss the response to the design fiction from WI2 participants.

4.1 Feedback on the design fiction

Following the presentation of the work-in-progress design fiction film, Mentian, initial feedback from our Age UK liaison and another WI2 participant was positive. Their insights centred on the degree of participant contribution, the appropriateness of focusing on a consultation, some snagging of the 'product' system featured within the diegesis, the structure of the film, and the potential of the design fiction to generate debate.

4.1.1 Contribution

The design concept was transformed by the research process and researcher contribution following the workshop and as a result there was a need to clarify the depth of the participant contribution, with Participant 2-WI2 asking: "…approximately how much of what we at Age UK did went into your team's thinking around this?" In fact, the Age UK National Office developed the idea of 'The multi-monitor' in the codesign workshop and 'Mentian' was a direct extension of the original speculations, "Can technology provide the means to 'talk' for someone about their health (where they cannot)?" and "A device is available to monitor multiple health metrics and translate for professional and carers". The research team concentrated primarily on visualising the 'The multi-monitor' concept for a film output as a design fiction. However, it is important to note that the exercise of translation from design concept to filmed fiction left participants unsure as to the depth of their own contribution. This issue may have been exacerbated by the significant period of time elapsing between the workshop and the presentation back of the film, as well as the fact that participants were not themselves engaged in the prototyping process or the creation of the design fiction.

4.1.2 Focus

The research team decided to focus the design fiction on a professional consultation with a person living with mid-stage dementia. The decision was made to maximise the visibility of multi-morbidities and to highlight potential issues with the consultation system, in order to catalyse debate about possible practices for the care of people living with dementia and multi-morbidities.

As can be seen in the quote below, where a participant had direct experience of working with people with dementia, and consultations, the appropriateness of the context of use and patient consent were raised and found wanting. In addition, alternative approaches to the context of use were posited.

> *"This approach is likely to cause distress and confusion to the person. The data would be better collected prior to a consultation to inform the medical professional. This would be different if the person had capacity and had consented and understood why the product was being used. But for the intended user, I don't think this approach is appropriate."*
> *Participant 3-WI2*

However, where the participant did not have direct experience of consultations their lack of knowledge meant that they suggested potentially problematic structural changes to the design fiction.

> *"Not being familiar at all with how dementia consultations ordinarily go, I'm wondering if it would be reasonable to see that contrasted with how Mentian would work?"*
> *Participant 2-WI2*

The participant considered having the design fiction describe current practice in dementia consultation and then counterposing that description with the technological future version. Though a design fiction is not a neutral presentation of a future, to add a depiction of current practice risks shifting the focus of debate away from futures and toward potentially contested versions of the present.

Varying degrees of knowledge about consultation practices left the participants with an unequal access to the world of the design fiction. By using the consultation as our focus, we unwittingly undermined the design fiction, making it harder for it to render its audience equal by virtue of no-one knowing either the terms of the conversation or what the future looks like. Perhaps, had we focused on a caring situation, rather than a professional consultation in the speculation, these issues may not have presented themselves.

Currently our research has focused on gathering critical insights on policy and co-creating design concepts to underpin the development of design fictions. However, as we move toward greater degrees of participation in the prototyping and production of design fictions we will need to consider how they remain orientated to the future and accessible to their intended audiences. We will also need to further consider the role of narrative focus in assuring that accessibility.

4.1.3 Snagging

The research team knew that stick-on sensors would be inappropriate for tracking metrics in particular conditions, e.g. UTIs. We also recognised that they would be uncomfortable in daily use for older people living with dementia and impractical in that the sheer number of sensors required to collect metrics across multiple conditions would make such a system unfeasible. Nevertheless, stick-on sensors had the advantage of visually communicating the story of the product system effectively and we hoped their relatively obvious failings would prompt debate about better ways to meet the issues that multi-morbidities present.

However, participant focus was drawn to quotidian practical issues,

> *"…how you'd keep patients from picking off the sensors? And what happens with them when bathing, etc?" Participant 2-WI2*

After noting that ageing skin may be irritated by stick-on sensors Participant 3-WI2 speculated further, and opened a space for ethical debate, even though they themselves didn't proffer any position:

> *"Sensors inserted under the skin? Would these alternatives provide the same level of data/monitoring? What are the ethics, consent issues regarding this?" Participant 3-WI2*

Attempts to resolve the pragmatic issues of use, such as tamper proofing and waterproofing the health sensors, speak to an 'affirmative' perspective and, potentially, a readiness to accept the technological solution presented. While participants' reticence to making any ethical commentary suggests that it may prove difficult to stimulate deeper debate, it is interesting to consider if this is a result of the degree of grounding knowledge about the fictional world, the fictional method, or implicit power relations.

As the quote below indicates, ownership of the process has remained with the researchers, however there is also a clear commitment from the participants to seeing the process through. Responding to the question of whether there might be merit in sharing the design fiction with older people and care professionals P2-WI2 responded unequivocally:

> *"I definitely think the design fiction would be good to go out there for debate etc after tweaking a bit. I also agree that sticky patches for intel might not work well… …but that could bring up points from others about what WOULD work if you want to leave that as is... ." Participant 2-WI2*

In addition to increasing participants' ownership of process a number of challenges for further consideration are raised by these responses. Affirmatively framed diegetic prototypes provide a solution to real world problems and may be presented in a fictional future world to stimulate policy debate about real world issues. They have to be sufficiently grounded and detailed to suspend disbelief in the face of close techno-social questioning, while simultaneously inspiring far-reaching future visions. It is this potential oscillation in thought and debate that the design fiction hopes to inspire. Some participants comments have a tendency to identify and proffer solutions to problems within the diegetic prototype which may divert attention from the policy issue at the centre of the fiction. However, the attention to such detail has the potential to initiate deeper discussion in support of policy debate that explores ethics-in-action, and the technical and social scaffolding that supports diverse alternative futures.

4.2 Limitations

The participatory design fiction process described requires a significant contribution of time, energy, attention and ability from participants and over the five workshops we attempted to run that combination was found in just one setting. Further research is needed to establish whether the participatory design fiction method will work with a wider range of group configurations, it would be particularly interesting to explore if a group of older people and VSO staffers working together could progress through the process. It would also be revealing to work with a wider range of groups to consider the impact of various motivations for participation. There was limited contact time with participants in the 'What If?' project, so it would also be useful to explore participation processes over extended periods.

In 2012 translations of policies in England ceased (The Department for Communities and Local Government) with implications for policy debate in diverse communities, additionally the lexicon of government policy is difficult to access for people with limited literacy skills. These access barriers to engagement need to be better attended to in the planning of future work. The findings of this paper are context dependent, however they point to a need for further research to identify more generalisable principles.

5 Conclusion

The 'What If?' project investigated the use of a participatory approach to design fictions to explore the implications of UK dementia policy from the perspective of VSOs and older people, in doing so a number of insights and challenges were revealed. Having been through the workshop process participants recognised the potential value of design fiction in their own exploration of policy implications and for stimulating policy debate with a wider audience. The process also uncovered significant obstacles that need to be addressed in terms of managing the oscillating focus on the detail of the diegetic prototype and the wider socio-technical aspects of the future world in which the diegetic prototype lives, and extending participant contribution across the design process.

As researchers, we are investigating a method to explore and critique possible futures at the intersection of technological advancement and government health policy. The findings of this research suggest that we need to create slower, more expansive design fiction interventions around health policy to give space for people of diverse abilities and experience to explore and imagine futures afresh. Our research also suggests that affirmative and critical diegetic prototypes may shape the discursive space around policy differently, a possibility that requires further investigation.

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Socio-Cultural Factors in Diabetes Care in South Korea

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In this study, the author reports findings and design outcomes from a 16-week healthcare design course led by two instructors in collaboration with medical experts at a tertiary medical institution. The research team investigated South Korean socio-cultural factors that adversely affect people's health and trigger diabetes onset: excessive working hours and drinking culture, social stigma and patients' hiding behaviours, and reliance on unverified information from online communities. The same factors also pose serious difficulties in diabetes patients' diet and exercise management. To address the problems, students proposed four design concepts: (1) a portable, integrated blood glucose meter and insulin pen, (2) a mobile application for verified diabetes information from licensed medical personnel, (3) a smart lunch system for safe out-of-home meals, and (4) an improved design of health check-up report format for patients with low health literacy.

South Korean culture, diabetes care, socio-cultural factors

1 Introduction

In South Korea, currently 4.8 M people or 13.7% of the population is diagnosed with diabetes mellitus (DM, hereafter), and it is a growing trend (Korean Diabetes Association, 2017). Between 2012-2016, the number of patient visit for DM treatment totals up to 12.17 M; the cost amounts to approximately 8 billion USD (Lee, 2017).

While type 1 diabetes (T1DM) is "an autoimmune disorder in which the body attacks its own insulin-producing pancreatic cells", and "the disease is not something they brought on themselves" (Brody, 2015), type 2 diabetes (T2DM) is attributed to two major causes: the person's lifestyle choices and genetics. Lack of physical activities, excessive calorie intake, and resulting obesity significantly raise chances of getting T2DM.

To prevent T2DM and other endocrine disorders, doctors recommend weight control, sufficient physical activity, and healthy diet ("Simple Steps to Preventing Diabetes", n. d.). Following the guideline, however, has not been easy for South Koreans. Between 1998-2015, the daily energy intake for South Korean men has increased from 2,196 kcal to 2,489 kcal, while physical activity has decreased for both men and women (Yun, Kim & Oh, 2017). At this moment, nationwide efforts are called for to prevent DM epidemic, in educating individuals on the disease while removing socio-cultural barriers to a healthy lifestyle.

In this paper, the author reports outcomes from a 16-week undergraduate-level healthcare design course with 15 students, led by two instructors, in collaboration with S hospital (a tertiary medical institution located in W city). While design is relevant to diabetes care in many aspects, this class specifically aimed to investigate design problems coming from cultural characteristics and social environment, such as workplace culture, and the needs of patients who are either enrolled or employed, so most vulnerable to the problems.

2 Research activities

Through the research phase (Week 1 through 7) activities, students gained a broad understanding of the disease itself, patients' daily activities, concerns, struggles, and their indigenous interventions to deal with the disease. The activities do not include interviewing S hospital patients, however, because an expert interview (J. Huh, personal communication, March 17, 2017) revealed that the majority of incoming patients are elderly over 65 from rural areas, while the class aims to develop products/services for younger patients. Though prevalence rate (30.4%), awareness rates (85.2%) are higher among the elderly patients (Diabetes Fact Sheet in Korea 2016, 2017), due to their multimorbidity and inactive lifestyles, elderly patients' diabetes care is trickier, and their attitudes towards treatment options are rather passive-conservative compared to younger patients. Patients between 50-64, in contrast, shows the strongest odds ratio of treatment adherence (Park, 2014, p.85), and they have a broader range of needs in diverse social contexts.

Review of research literature in endocrinology (Appendix A) Instructors provided scientific research articles and documentary films as part of required reading for class discussion. Additionally, students collected 98 news articles written between 2014-2017 on diabetes for assignments. Before meeting with medical experts and patients, the references equipped students with a basic understanding of DM, in the areas of:

- Pathology of DM: how insulin and glucagon control BG levels, causes and symptoms of DM, diagnostic criteria, dangers of hyper- and hypoglycemic states, and possible complications
- Treatment options (e.g., gastric bypass surgery)
- Care activities: medication, insulin/glucagon injection, diet, and physical activities
- Social perception of the disease in South Korean culture and how patients act in response

Expert interviews Students attended activities with medical experts from S hospital in:

- Two introductory lectures on DM, with two endocrinologists and a general physician in the department of preventive medicine: types, causes, diagnosis, and treatment options of DM were explained, and students' collective interview followed where the doctors resolved students' questions and misconceptions.
- A dietetic education session: a nutritionist lectured on DM patients' dietary requirements, optimal calorie intake calculation, food groups and exchange list, glycemic index of food items, and cases of detrimental patient behaviour (e.g., trying unfounded folk medicine).
- A physical activity education session: Students visited W city public exercise and rehabilitation facility to partake in a first-hand experience of body composition analysis, BG monitoring, muscular strength, endurance and flexibility test, and a brief lesson of exercise guidelines for DM patients.
- A lecture on diabetes care product development: a researcher from a BG meter manufacturer gave a talk on current global and Korean market landscapes of diabetes medications and BG meters, available technological options, and his experiences with the DM patients as customers.

Observation of ambulatory care sessions Both instructors and students participated as observers in ambulatory care activities to learn about communication tactics between doctors and patients with lifestyle diseases. The class followed a physician and nurse team to four business sites in W city. Per each site, 10 to 20 workers attended meetings: they were either diagnosed with endocrine disorder or at high risk of developing it, from workplace preventive health screening. Following observation protocol (Appendix B), students made observations on:

- How the doctor explains scientific concepts (e.g., hyperlipidemia, low-density lipoprotein)
- What questions patients ask
- What unhealthy habits they developed at work and why they cannot change them
- How they respond to bad news of having health problems.

Online DM community posting collection Postings from three online communities are analysed to obtain a better understanding of DM patients' daily concerns and behaviours. While limited number of not unlike observations are possible at S hospital—the majority of patients are elderly T2DM from rural areas—the community postings are valuable data from all types of (T1DM, T2DM, and gestational DM) patients living in diverse circumstances.

- *Dangsamo* (http://cafe.naver.com/dangsamo/): *Dangsamo* is an acronym of "diabetes patients' association" in Korean. This community has 20,091 active members and 435,742 postings in total. Among their several discussion boards, approximately 450 recent postings from *All topics* and *Diaries* boards are collected for analysis.
- *Diaries of diabetes patients* (http://danapump.tistory.com): A blood glucose monitor brand *Danapump* hosts this discussion board where 23 postings are available.
- *Friends with diabetes* (http://www.iddm.kr/): An association of T1DM patients. Out of 9,703 postings, 100 recent ones are collected for analysis.

Data analysis methods Students in this class are (with a few exceptions) design majors in their junior and senior years experienced in qualitative data analysis. Part of the lecture was a review of analysis methods student teams can apply, considering types of their data and design solutions:

- Ishigawa (fishbone) diagram (https://goo.gl/XoBeqH) for problem framing: causes of DM, and patients' difficulties caused by DM are analysed with it.
- Flowchart (https://goo.gl/roYtV1) for understanding current diabetes diagnosis criteria and treatment guidelines. Students also utilized flowcharts to build interaction logics for their products (smartphone apps, e.g.).
- Positioning map (https://goo.gl/W258fT) for competition analysis: current products/services were reviewed in comparison, to spot new market opportunities.
- Spradley's universal semantic relationships (1980, as cited in Whitehead, 2005) for encoding themes from lecture, interview, and observation data.
- Fogg behaviour change model (Fogg, 2009) to evaluate patients' current motivation, ability and trigger for behaviour changes as part of design requirement analysis.
- Persona writing (https://goo.gl/8PuZam) for description of target audience and use context in students' product/service proposals.

Analysis revealed that, among research activities, endocrinology literature review and medical doctors' lectures are broadly relevant to all emergent themes, whereas ambulatory care observation, dietetic education session, BG meter manufacturer lecture, and DM community postings are specifically connected to some of the themes (Figure 1). Themes emerged at the end of data analysis were triangulated with another round of literature review.

3 Findings: Socio-Cultural Factors specific to South Korean Culture

In this section, the author will discuss themes that emerged from collected data in three sections. First, doctors' recommendations for diabetes prevention are rather clear, "stay lean and move a lot".

Some aspects of South Korean workplace culture, however, are strong barrier to a healthy lifestyle. Second, after DM onset, patients experience a double whammy of hardships: hiding the disease to maintain social relationships, while staying away from unhealthy diet and drinking at social gatherings. Thirdly, findings from patients' online community postings show they frequently rely on unverified, non-expert, peer opinions for making daily food and medical choices, because professional medical personnel are not always accessible to help.

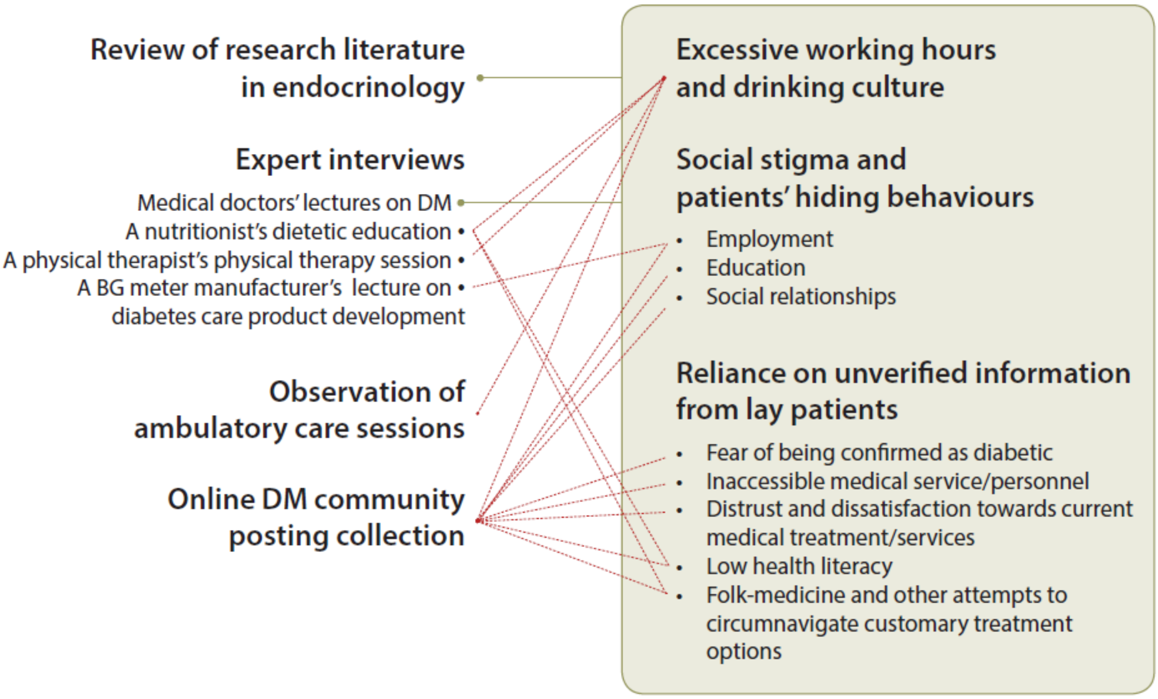

Figure 1 Research activities and findings.

3.1 *Excessive working hours and drinking culture*

Observations made during ambulatory care sessions exemplify how South Koreans can develop lifestyle diseases, such as DM and/or hyperlipidemia, at work. Emergent themes include:

- Stress from work is frequently mentioned and it causes detrimental habits of having excessive amount of sugary coffee, or drinking/smoking to relieve stress.
- Patients' insufficient health literacy prevents them seeing the gravity of their blood test results. The physician spent some time to interpret the readings for them using various metaphors ("blood vessels and blood are like highways and cars") and vascular age calculation, which surprised and motivated some patients. The physician also recommended keeping blood lab results on their smartphones as constant reminders.
- Drinking is part of work. A person (who has been working in Sales Department for 25 years) mentioned having different drinking occasions five days a week. As he did not know how much alcohol intake is allowed per day, the physician explained it for him with warning about cirrhosis.
- Some patients, however, were still in denial after the consultation, and were busy finding excuses for smoking and drinking ("Isn't it ok if I take cirrhosis meds while drinking?", "I hear nicotine patch is worse than smoking, as nicotine will stay in blood", "Well, I can always sober up in the morning… so…").

Themes repeatedly emerged here were corroborated with research literature. A recent news article ("After 15 years of hard work, what he got is obesity", 2017) reports how long working hours and irregular work schedules cause sleep deprivation, lack of exercise, and late night snacking/drinking among Korean workers. Jung (2011)'s study concludes that drinking, workload, and stress are correlated to the patients' excessive calorie intake, reduced physical activities, and lower sleep hours.

In fact, one important part of South Korean work culture is attending social gatherings: *hoesik* (회식, literally "eating together"). The problem is, firstly, popular *hoesik* menus (e.g., grilled pork belly BBQ with drinking) are high in calories and fat, thus it can derail patients from their dietary goals. Secondly, a typical *hoesik* entails heavy drinking (more than 50~60g of alcohol intake) that is also correlated to increased blood pressure, triglyceride, abdominal fat and weight gain (Sung, Kim & Reaven, 2007, as cited in Jung 2011) that develop into liver problem, high LDL cholesterol and high blood glucose levels. Thirdly, *hoesik* is typically scheduled after working hours, and it continues until very late hours. There is a positive correlation between sleep shortage and abdominal obesity. As a result, frequent attendance to *hoesik* is a threatening factor to the health of Korean workers (especially for men) in general, and detrimental to employed DM patients.

3.2 Social stigma and patients' hiding behaviours

Patients, however, cannot openly share their health conditions at work and excuse themselves from drinking, because they are too afraid of losing employment status. "The patients I met looked calm and dethatched" said a BG meter manufacturer (H. Park, 2017, personal communication, April 17, 2017), "… and they are afraid of being exposed to have DM. They know employers do not want to hire the diabetics. Whatever happens to patients at work can be attributed to workplace hazard." Regardless of intention, discriminatory acts against DM patients are reported in the following areas.

3.2.1 Employment

In South Korea, where the practice of recruitment health screening is still prevalent despite its unconstitutionality, DM patients are concerned about losing job opportunities. "Korean diabetes patients show a strong tendency to hide their conditions due to fear of being stigmatized at work and in other social relationships", commented a doctor (Park, 2008, translated from Korean text).

The recruitment health screening process is officially abolished in 2005 for private sector with a few exceptions. In reality, however, most employers require it as the last stage of hiring process (Kim, 2016; Son, 2017). A typical physical examination includes blood test for basic metabolic panel, urine test, head, eye, ear, nose and throat exam (HEENT), motor system examination, spirometry, and electrocardiogram test. While the government recommends the screening as a means of matching employees' skillsets with suitable positions AFTER hiring them (G. Park, 2015), some applicants are filtered out due to their health conditions:

> *A former HR department employee at a pharmaceutical company revealed that "Applicants with hepatitis, diabetes, and hypertension are filtered out in the hiring process on hiring managers' decisions […] and we inform them they are rejected because their skillsets are not matching up to what we are looking for." (K. Kim, 2016, translated from Korean text)*
>
> *I applied to a position at a private university [. …] During the last job interview, the university board chair who happened to be an MD asked "How much do you weigh?", and I was perplexed but answered, "87kg" which is in fact 10kg lighter than what I really weigh. The chair told me to my face, "With that weight in 20s', you will certainly have hypertension and diabetes in 40s, you cannot work here…". I was very upset, but I just replied, "I will try to lose weight…" I felt very humiliated. (Moon, 2014, translated from Korean text)*

3.2.2 Education

For the same reason, school-aged patients can be denied of educational opportunities.

> *Jung-sang, a 6-year old with T1DM, needs insulin shots while attending kindergarten. His parents waited for one year to send him to a private kindergarten where nurses are available, but the kindergarten refused to accept him. "They did not want to be bothered with insulin shots. They said my son can still come, but only at his own risk", his mother said. (Chun, 2016, translated from Korean text)*

The schools, however, believe that they are acting in the patient's best interest. Only 49.2% of school nurses are willing to help patients with injection, because they do not feel confident about glucagon injection, hypoglycemia care, and types/onset/peak hours of insulin. They feel confused about where their responsibilities end in students' diabetes care (Kang, 2015).

Growing up with DM and associated stigma, school-aged patients show hiding behaviours. Choi (2000)'s qualitative study reports how juvenile patients struggle to avoid being marginalized as the sick and weak: "When my classmates try to marginalize me during competitive sports, saying 'you need to rest because you are not well', it hurts my feeling much." (Choi, 2000, p.43, translated from Korean text). Ironically, patients' hiding behaviours diminish their socializing opportunities; they give up participating activities midway, when they cannot secure time and places for medication in private, or when their friends offer alcoholic drinks and cigarettes (Choi, 2000, p.46). Hiding behaviours can also put patients at bigger risks of having hypoglycemia or diabetic ketoacidosis when no one around them knows how to help.

3.2.3 Social relationships

Patients and their family members also struggle to maintain social relationships at schools, work, and home. Marrying DM patients is considered reckless, even to people who currently live with DM patients. On an online community, a woman shared an issue with a diabetic boyfriend. Out of 37 replies, 32 show strong objection to this marriage.

> ***Posting:** I recently found my boyfriend is diabetic, and I know it may lower his sex drive … but recently I suspect he avoids having sex with me with many excuses. […] Now I am worried that I might have a sexless marriage. Should I reconsider it? I want to hear what you guys think.*
>
> ***Reply:** Sexless relationship is less of a concern. You should google 'diabetes complications' right away. […] Your life will be hell once it begins on your boyfriend. My mother-in-law has been suffering from DM for 30 years, now she has hypertension, diabetic retinopathy operation (and she got weak vision), and needs to be hospitalized with hypoglycemia shock a few times a year. […] now I am fearing my husband will get it too. ("My boyfriend is diabetic...", 2016)*

T1DM patients' insulin/glucagon injection at public places can be absurdly mistaken as drug injection:

> *In an interview, Seungbae, a T1DM patient said, "I need to inject insulin four times a day, and when people see me doing so, they ask if I am doing drugs, or refuse to hire me. […] So I began to hide in restroom stalls for insulin shots. The hectic schedule at work sometimes did not leave me time to go to restroom, however. I missed few shots and health condition got worse." ("Seungbae, type 1 diabetes patient", 2014, translated from Korean text)*

Parents of T1DM patients also have to endure outrageous misunderstanding:

> *Ms. Kim, a mother of a diabetic child said, "People around me wonder why my child needs injection at such a young age. They think I have not been feeding her properly." (Chun, 2016)*

Such misunderstandings lead to hiding behaviours and insulin treatment refusal prevalent among Korean patients. Currently only 11% of the T2DM patients are on insulin treatment, while 77% of them are on medication (Min, 2017). A recent survey shows that 70% of the respondents are postponing insulin treatment even though they were recommended to start it immediately (C. Kim, 2016). The low adoption rate is rooted in a long-lasting misunderstanding that insulin has an addictive effect, plus fear of needles. Mr. Kwon, a medical doctor, said "I have seen a patient who left for different hospitals when I prescribed him insulin injection. Medication, however, has its own limits." (Min, 2017)

3.3 Reliance on unverified information from lay patients

The dietetic education session with a nutritionist, and an analysis of DM patients' online community postings indicate some patients' reliance on unverified information. Weitzman, Cole, Kaci & Mandl (2011)'s study concludes that the quality/safety of English-spoken DM community sites is variable: among 10 sites, only 50% shows content aligned with scientific recommendations/clinical practice, 20% has audits and association links, and three show advertisement for unfounded *cure* (p. 292). In fact, on Korean-spoken DM communities as well, patients and their families consult other lay patients on treatment, care, and glucose reading, out of following motivations.

3.3.1 Fear of being confirmed as diabetic

45.7% of DM patients wait longer than a month before visiting hospitals because they are too afraid of being confirmed as diabetic (Oh, Park, Shim, and Lee, 2006); perceived seriousness of the symptom, and barriers to doctor visit (e.g., difficulty of making appointment) are deciding factors in prompting treatment-seeking behaviours. The patients are cognizant of their problems, however, and monitor BG levels regularly. They also post BG readings on community sites for opinions. In reply, other community members encourage immediate hospital visits for accurate diagnosis.

> ***Posting:** […] my recent morning fasting BG reading is between 129~131, after meal reading is 149. […] I want to see doctors for accurate diagnosis, but, in addition to my busy schedule, I am too afraid to know I am diabetic, […]. Should I really go to the hospital? Or can I wait for months to see if it gets worse? Please recommend good hospitals for me. […]*
>
> ***Reply:** Surely your fasting BG level is high. Stop night snacking and wait for 2 weeks. If you don't see any improvement, I suggest you go and see a doctor. I would say you should go immediately, but I feel for you, you don't like to hear the bad news.*
>
> ***Reply:** I suggest you go immediately, I also hesitated and ruined my liver as well. Your fasting BG level is certainly high.*
>
> *("Should I see a doctor?", 2017, translated from Korean text)*

3.3.2 Inaccessible medical service/personnel

DM patients have myriads of questions on daily choices of food and other care activities. Instead of consulting a doctor, they post the questions online to learn from other patients' knowledge. Majority of questions are on food choices—what is safe to eat—which implies limitations of current nutrition education with standardized materials. Lim et al. (2009)'s study concludes that "individualized nutrition education was effective in adherence to diet recommendation and in improving glycemic control and lipid concentrations."

Distrust and dissatisfaction towards current medical treatment/service

Yoo (2015)'s study reports the discrepancy between DM patients and medical personnel on the perceived quality of current medical service. On a 5-point scale, patients' average rating of medical service was much lower (2.95) than self-rated (3.91). On one of the DM communities, patients wrote:

> ***Posting:** […] Normally my after-meal BG level is around 130. Whenever I visit this hospital, BG reading there soars up to 190~230. I asked if their BG meter functioned, and they insisted that the reading was accurate and it was simply high. I am now using*

> *Perfoma BG meter and its margin of error is just ±5. They could not explain the incongruency between the high BG level and my glycated hemoglobin reading being 5.5. […] Now I stopped trusting this hospital. I went another one and they recommended stopping medication as HbA1c value is just 5.5, while this hospital insists on medication. Should I transfer to another hospital?*
>
> ***Reply:*** *Why don't you bring your own BG meter and show them the difference? And there is a chance that the doctor is not an endocrinologist. If medication is too strong for your condition, you might suffer from hypoglycemia.*
>
> ***Reply:*** *I have been to many hospitals, and trust matters. Experienced doctors at large hospitals are trustworthy. I have experienced misdiagnosis and risked my life several times. […] Try one or two other hospitals specialized in DM treatment.*
>
> ***Reply:*** *At primary healthcare institutions, BG reading can be inaccurate, their BG meters and test strips are not maintained as carefully as secondary care facilities. The secondary healthcare facility I went before tests all BG meters for accuracy every morning at 4 a.m. Tertiary care facilities do so. […]*
>
> *("I cannot trust this hospital", 2017, translated from Korean text)*

3.3.3 Low health literacy

Observations made during ambulatory care visits reveal that some patients did not recognize pathogenesis or severity of endocrine disorders they have, so the physician explained them using various metaphors, while warning them with vascular age calculation. On DM communities, patients share their health check-up reports when they are not sure about medical terms or why the readings are not as optimistic as they expected:

> ***Posting:*** *My recent workplace health screening report came, and it reads:*
>
> > *Fasting insulin 1.29 […]*
> >
> > *Blood urea nitrogen 19.6 (normal up to 20)*
> > *Serum creatinine 0.6 (normal up to 0.9)*
> > *Blood urea nitrogen / creatinine ratio 32.67 (normal up to 26)*
>
> *I do not know what they mean… I was just told that I did not have any problems. Because it was a free health check-up, I have no one to consult.*
>
> ***Reply:*** *[…] I hear BUN reading varies a lot, after having protein-rich meals or cardio exercise. You should visit the hospital that conducted the check-up and ask. I have also consult my doc last time my BUN/creatinine ratio was too high.*
>
> ***Reply:*** *Usually they write something in the MD note section, if you really have problems. If you're still not sure, visit clinics nearby with the report.*
>
> *("Let me hear what you think of my check-up results...", 2017, translated from Korean text)*

Patients' knowledge in nutrition is not solid either. A nutritionist organizing and conducting dietetic education session mentioned that most patients are elderly, and a few of them are illiterate. Concepts necessary in diet management, such as food exchange list or glycemic index, can be incomprehensible for them. Repeated lessons are recommended, but most patients attend her session just once (E. Shim, personal communication, April 7, 2017).

3.3.4 Folk-medicine and other attempts to circumnavigate customary treatment options

The nutritionist also met patients who tried folk-medicine—e.g., silkworm powder, white mulberry—that are rumoured to lower BG level, but some varieties of it can do more harm than good, such as causing kidney failure. (E. Shim, personal communication, April 7, 2017)

Patients try folk medicine as a quick and easy cure, with or without standard DM treatment. It is problematic in that (1) there is not much systematic pharmacological research available on the usage, dosage, or side effects of the substances, (2) it is sold with unfounded claims—“works better than medications” or “with this, there is no need to restrict your diet”—that patients and their acquaintances believe without vetting the claims, and (3) it interferes with standard DM treatment and sometimes endangers patients’ lives—a patient had wild toad and poisoned herself (K. Kim, 1996, pp. 113-117). Another patient tried Nepalese wild honey because it was sold with exaggerated advertising of “impressive therapeutic effect for diabetes”; she suffered from gastritis and colitis for 15 weeks (Shin and Kim, 2016).

On communities, patients exchange their opinions on folk medicine, without expert intervention or guidance. Safety measures of filtering out postings with ungrounded claims are urgently called for.

> ***Posting:*** *I googled ‘diabetes’ and one site recommends bitter melon. I ordered a box of it. Will it be ok to drink the juice? Here, I haven’t met anyone doing so.*
>
> ***Reply:*** *Jerusalem artichokes, bitter melon juice, … they are just teas. Do not rely on them to lower BG levels, they might be better than drinking coffee, though. I have seen a few people who said they have witnessed its effectiveness… diet and physical activities are the best medicine.*
>
> ***Reply:*** *I drink bitter melon tea, too. I like it.*
>
> ***Reply:*** *I just have it as tea whenever I want some teas. It was ok.*
>
> ***Reply:*** *I do not recommend it. Drinking juice can harm your kidney.*
>
> *(“Want to know about bitter melon”, 2017, translated from Korean text)*

4 Design solution development

With insights gained from the research activities, students developed design concepts during Week 8 through 15 in four teams, to address key design problems they have identified: (1) patients’ hiding behaviours to avoid social stigma, (2) relying on unverified information on DM community sites, (3) difficulties of finding safe and balanced out-of-home meal choices, and (4) low health literacy. The researcher from a BG meter manufacturer was invited to the final critique for expert opinions. He commented on feasibility, marketability, and technological aspects to consider for each project. For instance, a team tried to reduce the physical dimension of a BG meter for enhanced portability, but their design was not realistic to hold batteries that meet voltage requirement. Non-invasive glucose monitoring methods—that students preferred, as it resolves patients’ discomfort towards blood and needle—are reputed to be not mature enough for mass market, as their margins of error are still higher than that of lancet-and strip methods. From the critique session, students found hints for further developments.

Figure 2 Top-left: A bulky pouch for DM care that many patients carry around. Right: This concept of portable, integrated BG meter and insulin injector intends to assist patients for more discreet DM care in public places and on the move.

4.1 Pocket-sized integrated BG meter and insulin injector device

Design problems:

- Patients show strong dissatisfaction with current lancet-and-strip BG monitoring and insulin injection, due to the discomfort caused by needles or blood (Yoo, 2015).
- BG monitoring and injection are required during outdoor activities (e.g., hiking with others, attending physical education classes), and after every food intake, at various locations and time. Current BG monitoring and injection paraphernalia package (Figure 2, top-left), however, is cumbersome and inconvenient. It does not allow for portability.
- Patients want more discreet DM care experience in public places, as injection at public places can feel embarrassing, and it can be misunderstood as drug use (Seungbae, Type 1 Diabetes patient, 2014).
- CGM (Continuous Glucose Monitoring) and insulin pump devices are available in the market, but the devices are rather costly due to required device change in 3-day interval, and sensors are watertight for up to 30 minutes only; In South Korea, currently health insurance does not cover the cost (S. Shin, 2017).

For DM patients' daytime BG monitoring at work and at schools, one of the student teams developed a design concept of pocket-sized integrated BG meter and insulin injector device (Figure 2, right): the device holds an earlobe clip for non-invasive BG monitoring, a storage space that holds three short insulin pens, and three toggle buttons that push/pull those pens out. Parents can fill the pens with fixed doses of insulin at home, to prevent over- or underdosing accidents. For BG monitoring, patients just pull out the clip and use while hiding the device in the bag. For insulin injection, patients push the needle side of the device against their skin and hit one of the toggle buttons. As most part of the pen is hidden, injection experience is more discreet. While many would argue that hiding behaviours might endanger the patient's life, patients' mental pain of being discriminated and isolated due to the disease also expose them to the risk of economic hardship, psychological morbidity and suicidal attempts (Sarkar & Balhara, 2014). Integrated BG meter and insulin pen is expected to increase frequency of out-of-home BG monitoring and injection, while giving patients more control over their medical safety, privacy, and the range of activities they can participate. The pocket-sized device that is always available can deliver mental relief for patients.

Figure 3 Modang app: (a) Users login as either an medical expert or a lay person. (b) Doctors start by registering their expertise areas. (c) Patients' postings are categorized by topics and assigned to experts. (d) A doctor-patient exchange of comments on hand numbness. (e) For each expert, his/her profile is available on slide-out panel.

4.2 MODANG: a mobile application for verified, reliable diabetes information exchange

Design problems:

- Patients rely on non-expert knowledge and opinions from anonymous online postings for daily decisions (e.g., "What vitamin supplement is good for DM patients?")
- Patients with low health literacy rely on other patients to read their health check-up reports, because hospitals do not provide easy and sufficient explanations for them.
- Patients observe symptoms and phenomena they cannot comprehend (e.g., morning BG level patterns that do not make sense to them); they need someone to provide more plausible explanations on why. Currently, experienced community members—also DM patients—are filling up the role.
- Patients seek for folk medicine as a quick and easy solution to manage BG levels; DM patient communities are a popular place to exchange information on it. Folk-medicine, however, is not safe, because pharmacological research on the usage, dosage, or side effects of the substances are not available.

Second team proposed a concept of mobile application, MODANG, "Diabetes Care for Everyone" in Korean (Figure 3): the app is a collaboration platform for medical experts and patients to access and monitor DM patient community postings, to prevent inaccurate information spreading among them. Medical experts are expected to volunteer on this platform replying questions and encouraging patients to maintain healthy, safe behaviours. Regarding what motivates them to participate, the team argues that (1) physicians from primary care institutions—mostly local, undersized clinics with a capacity of less than 30 beds—would want to contribute, to build solid reputation as an individual doctor and as a medical institution with expertise, and (2) to understand their patients better, because many postings show discrepancies between what patients say during a hospital visit, and what they actually do. Such insights can be developed into new medical solution ideas.

Figure 4 Dang-rak scale, lunchbox and app system. (a) The lunch box is stackable and each container can be measured on the scale. (b) A companion app. (c) Each category of food is weighed for rough calculation of calories. (d) The app shows how much you ate per meal, considering your daily calorie recommendation.

4.3 DANG-RAK: a lunch box for the diabetic

Design problems:

- In Yoo (2015)'s study with 45 participants, patients showed strong dissatisfaction with current diabetes food chart issued from Korean Diabetes Association: the list of food on the chart is limited, and keeping diet diary in reference to the chart is burdensome and difficult.
- Employed patients often struggle with lunch options when they eat at restaurants, because they do not know exactly how many calories are there, or how balanced the meal is nutrition-wise. Preparing lunch themselves is a safe and economic option, if circumstances permit.

Third team developed a concept of stackable lunch box, DANG-RAK ("Enjoy Meals with Diabetes") to assist with patients' out-of-home meals (Figure 4). The product comes with four separate containers for different food groups (grain and other carbohydrate sources, meat, fish, vegetables and fruits) and a scale, to allow for rough but easier estimation of calorie intake and nutritional balance. The lunch box is used with a DM care app where patients regularly record their meals; DANG-RAK scale sends calculated calories from different containers to the app.

4.4 Design renewal of current health check-up report

Design Problems:

- On online communities, patients with low health literacy rely on other patients to read their health check-up results. They do not understand where the problem is or how serious it is. The report is written in medical terms that lay persons cannot understand.
- Current health check-up reports just show readings, without clear directions on what to do about them, or who to contact for further actions.
- Printed health check-up reports are often stored in drawers and the readings are forgotten within a few weeks.
- The report format is text-heavy, while its readability is low with poor typographic treatment.

Another team proposed an improved design and contents of health check-up report (Figure 5). The new format intends to:

- Visualize measurements (e.g., blood pressure chart) and improves readability with better typographic treatment.
- Highlight problem areas in red, where patients need to pay immediate attention.
- Be written in plain language when possible, for patients with low health-literacy.
- Provide clear action items and recommendations for problem areas.

- Allow for detaching the first page summary and recommendations to put it up on the wall, as a constant reminder for his/her health problems.

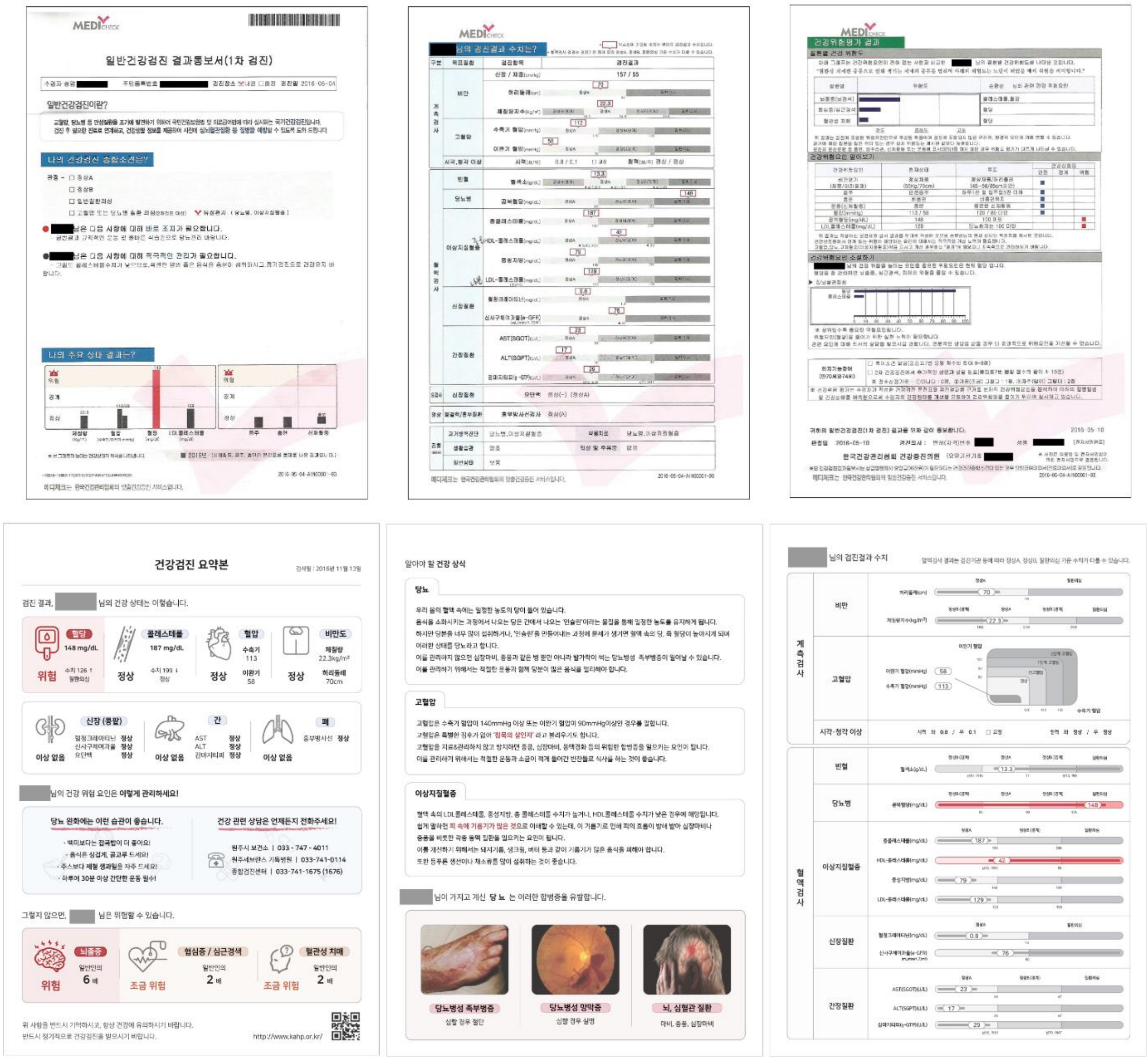

Figure 5 Top-row: Current standard health check-up report format. Bottom-row: Students' proposal of new format, for improved comprehension for lay patients.

5 Discussion

So far, the author reported insights gathered from research activities and how students developed product concepts from them in this 16-week studio class. The most intriguing finding for the author is that the data from different sources tell stories from two perspectives. On one hand, endocrinology literature and expert lectures constitute a discourse around *cure* from medical personnel's point of view. For them, DM patients are people who simply need to comply to treatment to achieve health goals. On the other hand, ambulatory care observation and DM community postings reveal patients' side stories of *living with DM* while maintaining various qualities of social life: patients' pursuit of dignity and security, distrust and dissatisfaction towards current medical services, anxiety and uncertainty they experience daily were vividly painted in their questions and answers. The author wonders if DM care products are being developed and evaluated in terms of how the products better the quality of patient's social life, in addition to their functionalities.

In this section, the author discusses implications of research findings and students' design proposals for the healthcare field, with patients' two psychological dimensions that influence their behaviours and purchase decisions in socio-cultural context: (1) choices between physical or psychological risks, and (2) patients' attitudes, strict or lax, towards treatment.

5.1 Taking physical or psychological risks

Living with diabetes is making daily choices that come with either physical or psychological risks. Patients who are either being educated or employed set implicit boundaries of personal trust: how much and to whom to share their health circumstances. The wider the boundary is, patients have more people to ask for help in case of emergencies, but as the boundary grows the psychological risk of being discriminated or marginalized increases as well. For instance, carrying "I am diabetic" badge can save a patient's life in hypoglycemic emergency situation, it also makes sensitive, private information visible to everyone. Furthermore, for patients who want to be involved in active social interactions, *Saving Face* matters: they are afraid of looking different, or even worse, weak. That fear can prevent them from strictly adhering to treatment/management activities, such as taking a lunch-box to the office every day to avoid having calorie-rich lunch with colleagues. Dang-rak lunchbox (Figure 4) might be a useful solution for balanced diet, but it does not help patients smoothly blend in, unless they are already surrounded by diet-conscious people.

DM care products highly effective in cure but draw unwanted attention can expose patients to other types of risks. Patients' social circumstances, and where patients' priorities are between physical or psychological safety should be considered more in the process of DM care product development, as they can influence patients' purchase decision and product usage. Integrated BG meter and insulin injector device (Figure 2) directly addresses this issue as a more discreet DM care option.

5.2 Patient attitude towards treatment compliance

While most DM care products in the market are designed for ideal patients who faithfully comply to prescribed treatment regimen, real-life patients can be strict or lax. Some patients, for example, use two or more BG meters because reading difference between them can be as high as 44 ("BG readings too different between meters", 2018). Others show rather lax attitude while rationalizing their behaviours that "only God knows when and how a person dies", and they want to talk other patients into deviating behaviours ("Live the way you want", 2016). Patients' weak self-control—along with abovementioned socio-cultural barriers to a healthy lifestyle—can lead to low treatment compliance rate and easy cure (e.g., folk meds) seeking. In managing chronic disease, patients' self-control and emotional processing ability affects juvenile DM patients' health outcomes (Hughes, Berg, & Wiebe, 2012), and the author conjectures the same goes to adult patients.

Products/services for motivating patients, not for motivated patients, are conceivable. One positive function of online DM community is patients encouraging each other to stick to their health goals. Modang, a supervised DM patient community (Figure 3) also aims to provide emotional supports for patients. DM care products with net connectivity, in the same vein, can send notices when a patient stopped using them (meaning s/he stopped medication or injection) for a specified period of time, to ask medical personnel checking up on the patient.

6 Conclusions

In this study, the author reported findings and design outcomes from a 16-week healthcare design course led by two instructors in collaboration with medical experts. Students investigated South Korean socio-cultural factors that adversely affect people's health and trigger diabetes onset: excessive working hours and drinking culture, social stigma and patients' hiding behaviours, and reliance on unverified information from online communities. The same factors also pose serious difficulties in DM patients' diet and exercise management. To address the problems, students proposed four design concepts: (1) a portable, integrated BG meter and insulin pen, (2) a mobile application for verified diabetes information from licensed medical personnel, (3) a smart lunch system for safe out-of-home meals, and (4) an improved design of health check-up report format for patients with low health literacy. The proposed concepts are meaningful in that two of them directly address psychological dimensions in DM care that have not been considered enough during product development—patients' psychological risks of being exposed to have DM, and lacking strong motivation to comply to treatment. The findings from this study is relevant to other life-style diseases such as hypertension and hyperlipidemia that sometimes accompany T2DM, in that the diseases are also caused from sedentary lifestyle and excessive calorie intake. The proposed concepts need much development in future studies, with a series of user testing and concept refinement.

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Min, S. K. (2017, October 2). Diabetes patients inject avoiding public eyes. *MoneyToday*. Seoul, South Korea. Retrieved from http://news.mt.co.kr/mtview.php?no=2017092613321461673

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Shin, S. (2017, September 23). Ministry of Health and Welfare tries to provide more insurance benefits for T1DM. Seoul, South Korea. Retrieved from http://www.newsmp.com/news/articleView.html?idxno=175315

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Appendix A. References provided as part of course materials

A1. Scientific research articles

Students read the following articles to learn about pathogenesis, treatment, management of DM, complications, factors affecting patient behaviour (e.g., medication compliance) including health literacy, theories of persuasive design for behaviour change, and qualitative data analysis frameworks.

Choi, C. (2009). Pathogenesis of insulin resistance. *The Korean Journal of Medicine*, *77*(2), 171–172.

Fogg, B. J. (2009). A Behavior Model for Persuasive Design. In *Proceedings of the 4th International Conference on Persuasive Technology*.

Han, S. J. (2011). Exercise in the Elderly with Diabetes. *The Journal of Korean Diabetes*, 12, 37–40.

Hong, K. (2007). A case study of diabetic patients' medication consultation. *J. Kor. Soc. Health-Syst. Pharm.*, *24*(3), 188–195.

Jekal, Y., Lee, M. K., Kim, E. S., Park, J. H., Lee, H. J., Han, S. J., … Jeon, J. Y. (2008). Effects of Walking and Physical Activity on Glucose Regulation among Type 2 Diabetics. *KOREAN DIABETES J*, 32, 60–67.

Kim, C. (2011). Nutritional management for patients with diabetes. *Hanyang Medical Reviews*, *31*(4), 220–227.

Kim, J. (2011). Measuring the level of health literacy and influence factors: Targeting the visitors of a university hospitals outpatient clinic. *Journal of Korean Clinical Nursing Research*, *17*(1), 27–34.

Kim, S. (2011). Medication Adherence of Elderly with Hypertension and / or Diabetes-mellitus and its Influencing Factors. *Kor. J. Clin. Pharm.*, *21*(2), 81–89.

Korean Diabetes Association: Diabetes Diet. (n.d.). Retrieved March 1, 2017, from http://www.diabetes.or.kr/general/food/index.php

Lee, H. (2014). Pancreatic Function for the Digestion of Nutrients. *The Korean Journal of Pancreas and Biliary Tract*, *19*, 39–45.

Lee, I. (2004). Pathogenesis of T2DM: Insulin resistance and decreased insulin secretion. *Annals of Pediatric Endocrinology & Metabolism*, *9*(1), 1–4.

Noh, M. (2014). Quality of Carbohydrate and Diabetes Mellitus. *The Journal of Korean Diabetes*, *15*(2), 104–109. Retrieved from https://synapse.koreamed.org/DOIx.php?id=10.4093/jkd.2014.15.2.104

Seo, J. Y., Bae, S. H., Woo, Y. J., & Kim, C. J. (2010). The Precipitating Factor and Clinical Features of Diabetic Ketoacidosis. *Chonnam Medical Journal*, *46*(2), 94–98. https://doi.org/10.4068/cmj.2010.46.2.94

Song, S., Choi, H., Lee, S., Park, J., Kim, B. R., Paik, H.-Y., & Song, Y. (2012). Establishing a Table of Glycemic Index Values for Common Korean Foods and an Evaluation of the Dietary Glycemic Index among the Korean Adult Population. *Korean Journal of Nutrition*, *45*(1), 80. https://doi.org/10.4163/kjn.2012.45.1.80

Weiss, B. D., Mays, M. Z., Martz, W., Castro, K. M., DeWalt, D. E., Pignone, M. P., … Hale, F. (2005). Quick assessment of literacy in primary care: The Newest Vital Sign. Annals of Family Medicine, 3, 514–522. https://doi.org/10.1370/afm.405.College

Whitehead, T. L. (2005). *Basic classical ethnographic research methods. Ethnographically Informed Community and Cultural Assessment Research Systems (Eiccars) Working Paper Series.* https://doi.org/301-405-1419

Yang, S. J., & Choi, K. M. (2011). Effect of Exercise on Cardiovascular Disease in Patients with Diabetes Mellitus (Aerobic vs. Resistance). *The Journal of Korean Diabetes*, 12, 25–28.

A2. Documentary films:

Episodes from Korean TV documentary series Best Doctors (EBS) and Secret of Life (KBS) were chosen, as the films vividly illustrate how T2DM is developed, prognosis of DM, and dangers of DM complications in detail, along with patient and doctor interviews. Part of the films discuss periodontitis and arthritis: the diseases are common to old-aged DM patients, and they both aggravate, and are aggravated by, diabetic conditions.

Choi, T., Lee, N., Lee, S., Moon, H., Yun, C., Lee, C., … Kim, J. (2016). *Secret of Life (TV series) Ep. 604: Diabetes Complications.* Korea, Republic of: KBS (Korean Broadcasting System). Retrieved from http://www.kbs.co.kr/1tv/sisa/health/view/vod/index.html?kwd=604

Hwang, H. (2014). *Secret of Life (TV series) Ep. 518: You're going blind - three diseases that affecting your vision.* Korea, Republic of: KBS (Korean Broadcasting System). Retrieved from http://www.kbs.co.kr/1tv/sisa/health/view/vod/2334909_91757.html

Hwang, S., Park, J., Ryu, G., Chang, G., Lee, J., & Yun, S. (2015). *Best Doctors (TV series) Ep. 392: Periodontal (gum) disease, Life threatening disease.* Korea, Republic of: EBS (Educational Broadcasting System). Retrieved from http://www.ebs.co.kr/tv/show?prodId=454&lectId=10283993

Hwang, S., Park, J., Ryu, G., Chang, G., Lee, J., & Yun, S. (2015). *Best Doctors (TV series) Ep. 393: Diabetes, Life threatening disease.* Korea, Republic of: EBS (Educational Broadcasting System). Retrieved from http://www.ebs.co.kr/tv/show?prodId=454&lectId=10286093

Lee, Y., Hwang, S., Chang, K., Yoon, S., Choi, S., & Chung, J. (2016). *SBS Special Ep.430: Are you still having sugar?* Korea, Republic of: SBS (Seoul Broadcasting System). Retrieved from http://allvod.sbs.co.kr/allvod/vodEndPage.do?srs_id=22000065217

A3. 98 Newspaper articles student searched with keyword 'Diabetes'. Due to the limited space, the author listed a few of them here as examples:

Cho, D. (2015, May 5). Having to hide insulin injections, ... "Care is a cure" for school-aged diabetics. *SBS News8*. Seoul, South Korea. Retrieved from https://news.sbs.co.kr/news/endPage.do?news_id=N1002961648

Cho, D. (2015, July 7). Diabetic complications: Chronic renal failure. The Korea Times. Seoul, South Korea. Retrieved from http://www.koreatimes.com/article/20150707/928410

Choi, E. (2016, April 5). 2.52 million diabetes patients are treated per year ... medical expenses exceeded 1.8 trillion Korean won. *Dailypharm.com*. Seoul, South Korea. Retrieved from http://www.dailypharm.com/News/210327

Corbin, L. (2016, December 6). DietSensor laser, app help those with diabetes count carbs. *ABC.com*. GLENDALE, Calif. Retrieved from http://abc7.com/health/dietsensor-laser-app-help-those-with-diabetes-count-carbs/1668790/

"For sweet potatoes, calorie changes depending on cooking methods: grilling or steaming." (2015, April 28). *DongA.com*. Seoul, South Korea. Retrieved from http://news.donga.com/3/07/20150428/70960172/2#csidxf5291efcad3f5be935b8766356b60c1

"GlucoTrack", a blood-free blood glucose meter for diabetics. (2017, January 18). *Seoul Shinmun*. Seoul, South Korea. Retrieved from http://www.seoul.co.kr/news/newsView.php?id=20170118500051

"[Health Talk] Causes of Elderly Death." (2014, October 28). *Junsungki.com*. Retrieved from https://www.junsungki.com/goheyday/article/details.page?&name=article_255&magazineSeq=255

"Join Medical launches GlucoTrack, BG meter without finger prick, in Korea." (2017, January 18). *Hankyung.com*. Seoul, South Korea. Retrieved from http://news.hankyung.com/article/201701182546a

Joo, A. (2017, February 14). Up to 20% premium discount if you quit smoking. *DongA.com*. Seoul, South Korea. Retrieved from http://news.donga.com/BestClickIlbo/3/all/20170214/82851372/1#csidx3a6b46ebc81b4afbadf82a53ff6f784

Kim, H. (2009, July 7). "Lean diabetes" specific to Koreans surge. *DongA.com*. Retrieved from http://weekly.donga.com/List/3/all/11/87902/1

Kim, J. (2017, April 4). School-aged diabetes patients are left to themselves to give their own insulin injections in toilets. *Segye Ilbo*. Seoul, South Korea.

Kim, S. (2013, November 1). Types and cost of cataract surgery. *Kyunghyang Shinmun*. Seoul, South Korea. Retrieved from http://news.khan.co.kr/kh_news/khan_art_view.html?artid=201311011517132&code=900303

Koo, H. (2017, March 2). The last 10 years to live in pain ... Expense of older age medical expenses. Seoul, South Korea. Retrieved from http://news.jtbc.joins.com/article/article.aspx?news_id=NB11431675&pDate=20170302

Lee, B. (2016, March 29). Old diabetic patients take six medicines a day ... Drug Interactions should be considered when you prescribe for them. *Chosun.com*. Seoul, South Korea. Retrieved from http://health.chosun.com/site/data/html_dir/2016/03/28/2016032802624.html

Lee, G. (2012, May 30). GI is high in peaches, low in sweeter apples. *Chosun.com*. Seoul, South Korea. Retrieved from http://health.chosun.com/site/data/html_dir/2012/05/30/2012053000039.html

Lee, J. (2006, November 14). Diabetes symptoms in the mouth. *Kyunghyang Shinmun*. Seoul, South Korea. Retrieved from http://news.khan.co.kr/kh_health/khan_art_view.html?artid=200611140918181&code=all

Lee, J. (2017, April 13). Apple is rumored to be developing needle-free BG measurement technology. *ZDnet*. Seoul, South Korea. Retrieved from http://www.zdnet.co.kr/news/news_view.asp?artice_id=20170413113519&type=det&re=

Lee, K. (2016, November 28). Causes of arteriosclerosis in Korean diabetic patients: small, dense, low-density lipoprotein(sdLDL). *Chosun.com*. Seoul, South Korea. Retrieved from http://health.chosun.com/site/data/html_dir/2016/11/28/2016112800956.html

Park, H. (2010, December 9). [Health]Unfortunate combination of diabetes and obesity. *Kyunghyang Shinmun*. Seoul, South Korea. Retrieved from http://news.khan.co.kr/kh_news/khan_art_view.html?artid=201012092119065&code=900303

Park, J. (2016, July 25). Gastroenterology shows excellent therapeutic effect to "lean diabetes" specific to Koreans. *Chosun.com*. Seoul, South Korea. Retrieved from http://news.chosun.com/site/data/html_dir/2016/07/24/2016072400667.html

Ryu, J. (2017, April 10). Korean Diabetes Association Announces Award Winners for Insulin Therapy Testimonials Contest. *ACROFAN*. Seoul, South Korea. Retrieved from http://kr.acrofan.com/detail.php?number=40729&type=&lang=&UA=

Sohn, J. (2017, January 30). Excessive working hours in South Korea continue unabated. *Chosun.com*. Seoul, South Korea. Retrieved from http://news.chosun.com/site/data/html_dir/2017/01/31/2017013100209.html

Sohn, Y. (2016, August 1). Dr. Kitchen, a dietary service company for diabetic patients, attracts KRW 1.4 billion worth of investment. *Platum.kr*. Seoul, South Korea. Retrieved from http://platum.kr/archives/64047

Song, B. (2004, January 6). 2. Diabetes and cerebrovascular disease. *Medical Observer*. Seoul, South Korea. Retrieved from http://www.monews.co.kr/news/articlePrint.html?idxno=13171

Song, S. (2013, February 18). [Medicine] Increase in childhood diabetes. *Joongboo Ilbo*. Incheon, South Korea. Retrieved from http://www.joongboo.com/news/articleView.html?idxno=838356

"Three principles of diet for the diabetics." (2017, April 4). *Chosun.com*. Seoul, South Korea. Retrieved from http://news.chosun.com/site/data/html_dir/2016/05/04/2016050400749.htm

"Why do people with diabetes do not check blood glucose?!" (2011, September 6). *Chosun.com*. Seoul, South Korea. Retrieved from http://health.chosun.com/site/data/html_dir/2011/09/05/2011090501737.html

Wortham, J. (2016, March 23). We're More Honest with Our Phones Than with Our Doctors. *Nytimes.com*. Retrieved from https://www.nytimes.com/2016/03/27/magazine/were-more-honest-with-our-phones-than-withour-%0Adoctors.html

Yang, Y. (2016, May 9). Childhood diabetes incidents increased 31% in 10 years. *Medical Observer*. Seoul, South Korea. Retrieved from http://www.monews.co.kr/news/articleView.html?idxno=91272

Zolfagharifard, E. (2015, June 4). Count calories using PHOTOS: Google's Im2Calories app will reveal nutritional value of meals from your Instagram snaps. *Mail Online*. Retrieved from http://www.dailymail.co.uk/sciencetech/article-3109726/Count-calories-using-PHOTOS-Google-s-Im2Calories-app-reveal-nutritional-value-Instagram-snaps.html

Appendix B. Field Observation Protocol

- Arrive at designated location on time.
- Wear name tags.
- Students are allowed to take notes.
- Do not use smartphones at all for anything, turn off the phone during observation.
- Comply to medical personnel's direction in his/her office.
- Write down all your questions and ask them when the doctor's shift is over.

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Cascading Mentorship: Designing a Support Tool for Patients with Ventricular Assist Devices

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A ventricular assist device (VAD) is a surgically implanted mechanical pump attached to the heart to assist its function in patients with advanced heart failure. This paper investigates the current state of training being provided to VAD patients and caregivers, and whether it adequately prepares them for the VAD lifestyle. The study consisted of a literature review, a content analysis and interviews conducted with stakeholder representatives. A co-design process led to the development a holistic interactive prototype that was evaluated by one VAD caregiver, one VAD biomedical engineer, and one VAD surgeon. Four key themes emerged from the research examining the VAD patient and caregiver training experience: (i) uncertainty, (ii) misinformation, (iii) gratitude, and (iv) preparation. Five overarching themes emerged as design recommendations: (1) artificial onboarding, (2) contextual empathy, (3) ongoing support, (4) physician connectivity, and (5) emergency scenarios. Findings suggest the need to focus on not just the patient, but equally on the VAD caregiver. Design opportunities include the optimisation of both training tools and VAD communication relating to emergency scenario preparation.

medical design; patient relationships; patient-centric design; VAD caregiver.

1 Introduction

Chronic heart failure is a complex and widespread disease, affecting an estimated 300,000 Australians (National Heart Foundation of Australia, 2011), with another 30,000 new cases diagnosed each year (Australian Institute of Health and Welfare, 2011; Sahle, Owen, Mutowo, Krum, & Reid, 2016). There were over 167,000 hospitalisations where heart failure and cardiomyopathy was recorded as either the principal or secondary diagnosis which represented 1.6% of all hospital admissions during 2014–15 (Australian Institute of Health and Welfare, 2016). A ventricular assist device (VAD) is a surgically implanted mechanical pump attached to the heart to assist its function in patients with advanced heart failure, saving and extending the recipients life for 5-10 years (Boyle et al., 2009) or possibly more (Gustafsson & G.Rogers, 2017) while they wait for an available donor.

In addition to the implanted VAD pump, there are a number of additional external components that require constant monitoring and maintenance to ensure its proper function, including the controller (*Figure 1*) and external battery pack. These are connected to the pump via a driveline that extends from the internal VAD through an exit site on the patient's abdomen.

Figure 1 Ventricular Assist Device (VAD) and controller (image taken by author)

While this technology is revolutionary and lifesaving (Starling, 2010), it has a significant impact on the patient's and caregiver's quality of life as it places a number of limitations that can burden those who rely on the device (Jessie Casida, 2005; Muldoon, Barger, Flory, & Manuck, 1998). Daily activities such as showering, eating, exercise and sleeping can become complicated with the extra VAD management required (Starling, 2010).

Successful medical device development requires various input from many different disciplines, such as industrial design, engineering, clinical, regulatory, marketing, sales and business expertise (Privitera, Southee, & Evans, 2015) to design and deliver not only the artefact itself but also the ongoing user interaction surrounding a device and the system and environment it exists within. The role of the designer here is often that of user advocate, providing insight and opinion (Privitera et al., 2015), as well as aesthetic design, form giving, human factors application and testing, along with contextual inquiry/ethnography methods (Petrie, Aidan; Copeland, 2011).

The aim of the current study was to better understand and gain insight into the existing state of training and preparation for VAD stakeholders, primarily the patient and their caregivers, and then to design and evaluate a design-led solution with these stakeholders. User issues with the VAD journey were identified and explored using a design process. The research findings uncovered the need to focus on not just the patient, but equally on the VAD caregiver and the opportunities surrounding both these stakeholders, and others.

In addition, the authors have attempted to improve the VAD user experience using a design process to explore the potential re-design of patient and caregiver training from the insights revealed in the research findings. The research suggests that alarms and emergency scenarios are a critical concern for patients and caregivers, as they provide a major point-of-failure of use-errors. This was identified through primary and secondary data, as well as through creation and evaluation of a prototype which supported better training through a design innovation approach.

Through this design innovation process the authors investigated the daily lives of VAD patients and caregivers once they had left hospital care, to determine whether the training received adequately prepared them to physically and mentally maintain the device. This process uncovered a set of design considerations aiming to improve the patient experience, facilitate collective resilience in the relationship between patient and caregiver, promote responsible independence, and improve the communication to clinicians.

2 The VAD Experience

2.1 Treatment Paths

VADs are utilised in four primary treatment paths for patients suffering from acute heart failure (Boling, Hart, Okoli, & Halcomb, 2015; Jakovljevic et al., 2017; Kaan, Young, Cockell, & Mackay, 2010; Makdisi, Makdisi, & Bittner, 2017; McLarty, 2015; Prinzing et al., 2016; van Manen, 2017):

- *Bridge to transplant* in which it aims to keep the patient alive by taking over (or partially taking over) the pump function of the heart while waiting for a donor heart.
- *Destination therapy* where the patient is not eligible for a transplant, a VAD is implanted as a long-term solution. They can however be re-listed for transplant if they become eligible while on VAD treatment.
- *Bridge to recovery*, used to support the heart until it recovers enough function for the VAD to be removed without transplant.
- *Bridge to decision,* where the patient condition is unstable or uncertain, a VAD implant can ‘buy time’ until a more informed decision can be made regarding transplant or otherwise

Once all other treatment options are exhausted, patients who suffer from late-stage heart failure could be considered for VAD implantation by their physicians and frequently they have very little time before the implant window closes (Yang, Zimmerman, Steinfeld, Carey, & Antaki, 2016). At this time, they are hospitalised and bedridden; often with feelings of uncertainty and fear for their future (Hallas, Banner, & Wray, 2009) as they are informed of the challenging treatment pathway ahead of them, with the genuine possibility that this treatment will continue until their death.

After they recover from their invasive VAD implant surgery the patient remains under intensive care for a number of days, before they are recommended to go through an extensive 4-6 week rehabilitation and training process on how to care for and maintain this device (Jakovljevic et al., 2014; Wilson, Givertz, Stewart, & Mudge, 2009). Family and caregivers also experience the severe emotional burden (Casida, 2005) of the VAD implantation and lifestyle adaptations (Starling, 2010), as all VAD patients are required to have a caregiver to be there with them at every step of the journey. The caregiver’s role is full-time so the carer must adapt to the jarring lifestyle impacts the VAD treatment can have (Kaan et al., 2010).

2.2 Stakeholders

There are a variety of stakeholders to consider when designing for VAD treatment. Here we categorise these stakeholders as users, direct stakeholders, and indirect stakeholders in order to understand the greater context of those within this problem space.

- *Users - Patient*: the patient is someone who has received a VAD as treatment for heart failure, and is now having to adapt their lifestyle to accommodate the changes associated with VAD implantation (Marcuccilli, Casida, & Peters, 2013; Starling, 2010).
- *Users - Caregiver*: the caregiver is a family member, spouse, or friend that has elected to be the primary carer of the patient. They must receive training on how to use and maintain the patient's VAD, clean the driveline site, ensure medication is taken, ensure the patient adheres to dietary guidelines, as well as be there emotionally for the patient to provide support (Jessie Casida, 2005; Kaan et al., 2010).

- *Direct stakeholders*: Physicians are the primary point of medical contact for patients and/or caregivers, with regularly scheduled meetings and check-ups designed to ensure that the patient's VAD is operating as expected. Nurses play a role in VAD implantation and end-of-life decision making, which can lead to strong emotional relationships being projected onto the nurses by patients and caregivers (Gibson, Henderson, Jillings, & Kaan, 2013).
- *Indirect stakeholders*: suppliers/manufacturers etc.

2.3 The User Experience

The training process for the patient and caregiver is fundamental to ensure prolonged device function, which allows a smooth transition from the hospital to a home environment (Wilson et al., 2009). It is obvious leaving patients and caregivers potentially unprepared and at risk of making errors in situations that could mean life or death. Even something as simple as ongoing care of the driveline exit site to minimize the risk of infection can benefit from education tailored to patients and caregivers (Barber & Leslie, 2015). However, VAD training is currently limited, inconsistent between institutions nationally and internationally, and restricted to VAD-equipped hospitals and medical staff (J. M. Casida, Aikens, Craddock, Aldrich, & Pagani, 2017; Jesus Casida, 2017; Hawkins, Fynn-Thompson, et al., 2017; Hawkins, Ventresco, & VanderPluym, 2017).

Existing research (Gibson et al., 2013) has explored the experience of nurses who primarily deal with VAD patients and revealed the complexities that emerge from direct exposure to these patients, such as developing exclusive professional knowledge that is not always valued or best utilised, forming emotional connections with patients who will inevitably pass away at some stage, witnessing adverse events, and dealing with the uncertainty of "second chances" along with the nuances of human experience.

The study also highlights the anxiety, loss, pressure, and emotional stress that family caregivers go through, highlighting the VAD implant journey can be more stressful and difficult for family caregivers than for patients. In fact, there is evidence that VAD caregivers suffer higher rates of Post-Traumatic Stress Disorder than VAD patients themselves (B. Bunzel, Laederach-Hofmann, Wieselthaler, Roethy, & Drees, 2005; Brigitta Bunzel, Laederach-Hofmann, Wieselthaler, Roethy, & Wolner, 2007; Kaan et al., 2010). Moreover, a study by Chapman, Parameshwar, Jenkins, Large, & Tsui (2007) explored the impacts that VAD treatment can have on the patient's physical and psychological wellbeing, highlighting significant issues such as patients and their families needing additional psychological and emotional support during and after use of a VAD, and that assessment before implantation of a VAD can sometimes reveal the need for additional support.

A decision support tool is one solution to assist practitioners in making the right choice for VAD implantation. A study by Yang, Zimmerman, Steinfeld, Carey, & Antaki (2016) revealed a lack of perceived need and trust for machine intelligence by physicians for VAD decision support tools. However, the research suggested that the use of machine intelligence could help with clarifying and monitoring of a patient's condition as well as managing decisions to escalate treatment. The study was focused on the impact that design-led decision support tools could have on the clinical decision process around VAD implants, as well as attempting to identify key ways to seamlessly integrate these tools into the clinician's work so that they would be more willingly accepted (Yang et al., 2016).

2.4 Current VAD Training Resources

Patients and caregivers undergo an essential training process to prepare for post-hospital life. They must be able to understand the care of drivelines and demonstrate competency in performing daily self-care routines such as sterile dressing management using disinfectant, masks, and sterile gloves with competency testing by physicians (Englert, Davis, & Krim, 2016). Commonly, the resource that patients and caregivers are provided with takes the form of an information pack which can vary between medical institution and VAD manufacturer, with the curation of this pack being at their physician's discretion (*Figure 2*).

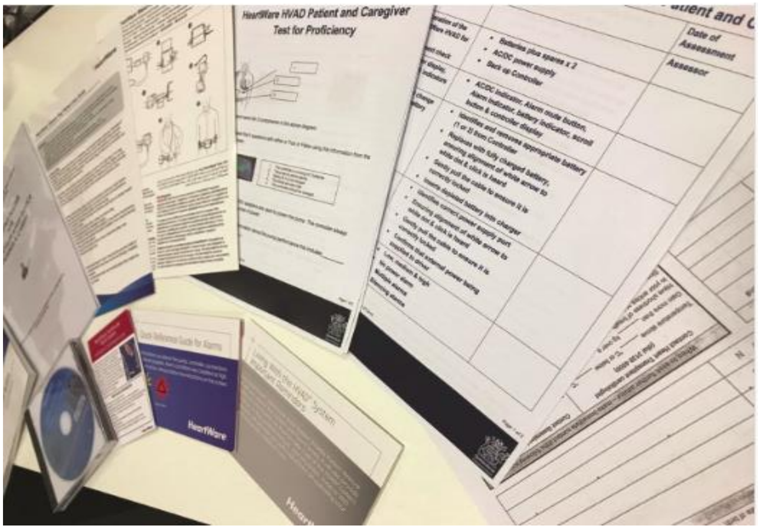

Figure 2 Example resources provided in information pack for training and VAD essentials for home use

In addition, there are both theoretical and practical proficiency tests that are prerequisite for both patient and carer to complete in order to meet their physicians' standard before discharge from hospital, as well as Flow Sheets (i.e., physical forms that patients and caregivers are required to fill out to track a number of critical daily maintenance tasks and VAD controller data). These are delivered at regular scheduled hospital visits for physicians to be able to track and monitor device function.

3 Methods

For the purposes of this research exploring the issues relating to VAD patient and caregiver training, an iterative user-centered design process was utilized to identify and overcome some of the issues raised. This research design process consisted of the following stages: (1) content analysis of current digital VAD training and resource platforms; (2) identification of user requirements; (3) prototyping and co-design of a training solution concept.

3.1 Stage 1: Content Analysis

A qualitative content analysis (Nusem, Wrigley, & Matthews, 2017; Straker, Wrigley, & Rosemann, 2015) of existing digital platforms was performed in order to gain a greater understanding of the existing VAD solution landscape. The purpose of this was to identify the standards with current VAD solutions, as well as to detect gaps within the market for potential opportunities. Thus, digital platforms were selected for inclusion based on providing benefit to VAD patients and/or their caregivers specifically. Platforms that were unreleased or did not have an interactive demo available to the authors were excluded.

Three digital platforms were selected – VADable App, CORA Patient Counsellor and MyLVAD – as exemplars due to their search ranking and/or recurrence in results within various search terms. For the selected digital platforms, key strengths and weaknesses were assessed and general observations about the usability of the platforms were included based on the perspective of a VAD patient (Tsiouris et al., 2015).

3.2 Stage 2: Identification of user requirements

A literature review was conducted to gain an insight into the current VAD user experience, with a focus on patient usability and patient experience. Insights gathered from the existing literature were processed through several user empathy methods during Stage 2 in order to visualise, translate and summarise the research findings as well as provide reference material to ensure any derived solution could be re-evaluated against the user research. These include personas, journey mapping, affinity diagramming, and extreme persona-based scenarios. Findings from Stage 2 informed the third stage: prototyping and co-design.

3.2.1 Personas

Personas are archetypal representations of the target stakeholders that are formed out of the insights and themes uncovered from user research. They provide an empathetic point of reference for assessing the value of concepts, as well as providing various unique perspectives that can be utilised when evaluating with role-playing and scenario walkthrough methods (Pruitt & Adlin, 2010). VAD patient and caregiver personas (*Appendix A*) were developed to visualise and characterise the insights gathered from user research empathetically.

3.2.2 Journey Mapping

Journey mapping is the process of visualising all aspects of the user experience to provide a holistic representation of the current interactions and pain points, for example points of friction within a solution or service that have an adverse effect on the experience of the user (Nenonen, Rasila, & Junnonen, 2008; Wrigley, 2013). Developing a user journey map provided a sense of empathy and understanding of the number of touchpoints (a digital or physical point of interaction with a solution or service) and detailed experiences of a patient undergoing the VAD surgery and recovery process; which allows for the discovery of gaps that could lead to potential opportunities for design-led solutions. Moreover, it can also be used as a point of reference for evaluating concepts and solutions to ensure that all aspects of the patient experience are considered.

To identify key pain points for different stakeholders, the VAD experience was mapped into six distinct phases including, Introduction, Surgery, Recovery, Adapting, Living and End of Treatment. Results revealed a deeper understanding of the contextual issues surrounding VAD patients and their caregivers, while also uncovering key issues and identifying possible opportunities for the design of a training tool (*Appendix B*).

3.2.3 Affinity Diagramming

Affinity diagramming was utilised as a process to facilitate refining and synthesising a broad range of user data from various research methods into clear patterns and groupings (Holtzblatt, Wendell J. B, & Wood, 2005). A number of trends were discovered during this process, which were written from the perspective of the user in order to maximise empathy.

3.2.4 Extreme Persona Based Scenarios

An extreme persona, who is not a direct user of the product, was developed around a caregiver whose own child had undergone VAD treatment. This persona was developed with the aim of eliciting a strong sense of empathy within research participants which include dialogue techniques, narratives and imagination (Krüger et al., 2017). This encouraged participants to shift their mindset significantly and engage with the prototype through an entirely different lens of user needs and stakeholder goals.

3.3 Stage 3: Prototyping and Co-design

Stage 3 involved a prototyping and co-design session with one VAD caregiver and one biomedical VAD engineer. Prior to the workshop, and in order to inform workshop questions, a range of design resources had been developed including Personas (*Appendix A*) and Journey Maps (*Appendix B*). Participants in the co-design and prototyping session were prompted by questions by the researchers, and the workshop concluded with a participant evaluation of an initial prototype. Data were captured by a research assistant taking observation notes, photographs, and audio recording with consent. These recordings and observation notes were evaluated using thematic analysis to inform prototype iteration as well as to validate a tangible concept with these stakeholders. In addition to these tools, an initial prototype was developed of an interactive training platform designed to empower and train caregivers to in turn teach their VAD patients.

4 Findings

The aim of this study was to gain insight into the current state of training and preparation for VAD stakeholders, primarily the patient and their caregivers, as well as improve the VAD training process for patients and caregivers. The focus of this study became on the adaptation stage, which was indicated to be a critical phase for the caregiver as they are coming to terms with being responsible for the patient's well-being, while having to follow a strict regime to protect the function of the device.

A content analysis (*Table 1*) was conducted on three existing VAD lifestyle solutions included VADable, MyCORA (2017) patient counsellor and MyLVAD (2017). All three solutions were digital in nature, ranging from a mobile application, to a website-based service to an online community and resource hub. However, a number of gaps were exposed:

- No real-time assistance in emergency scenarios.
- Only provided in certain stages of VAD journey e.g. decision-making stage.
- Unintuitive interfaces e.g. limited accessibility considerations, despite the mean age of a VAD recipient being 59 as determined by Tsiouris et al. (Tsiouris et al., 2015).
- Tone of communication e.g. confrontations about mortality, delivering of negative results.

Table 1 Content analysis of VAD solutions

	VADable App	**CORA Patient Counsellor**	**MyLVAD**
Description	VADable is a digital platform that the patient inputs daily information relating to the function of their VAD, much like the pen and paper flow sheet typically in use with VAD patients.	CORA is a service designed for both patients and physicians in order to assist the decision for VAD therapy in cases of advanced heart failure, as well as provide a few supplementary resources for post-surgery life.	MyLVAD is an online community and resource hub for LVAD patients and their loved ones. It provides a variety of information on VAD topics, with a primary focus on what to expect when living with this device.
Strengths	Daily collection of data for VAD team.	Variety informative videos explaining the LVAD, the surgery, & testimonials from patients.	Introductory articles on what to expect with the VAD journey
	Integrates with iPhone built-in health metrics by syncing with Health app	Interactive tools to determine whether an LVAD is right for you	Community forum for users to discuss living with a VAD, as well as sharing tips and asking for help from experienced patients/ caregivers
	Patients upload photos of the device and their exit site for remote infection assessment	Accessibility options for vision impaired users	
Weaknesses	Lengthy and unintuitive onboarding process	Unintuitive navigation	Lack of moderation and input professionals
	Elderly patients could easily forget to make updates	Very confronting to patients about their mortality	This kind of community needs a dedicated team to respond to medical emergencies, as patients/caregivers will ask for advice on life threatening issues without any response
	Accessibility leaves much to be desired for users with poor eyesight	Delivers negative results in an unfriendly and un-empathetic way	

Following the content analysis, a literature review (*Table 2*) highlighted existing research in the field of VAD user experience, showcasing a number of important themes that were prevalent for a variety of VAD stakeholders, with a focus on patients, caregivers, and physicians. There was a common thread in a number of these studies that evaluated the ability for patients and caregivers to respond in emergency scenarios with a focus on the communication from the VAD controller visual interfaces and auditory alarms. The research insights highlighted the emotional burden of being a caregiver for a VAD recipient as well as identifying the current training and monitoring approach for VAD implantation. Four key themes (further detailed in *Table 3*) emerged from the research examining the VAD patient and caregiver training experience: (i) uncertainty, (ii) misinformation, (iii) gratitude, and (iv) preparation.

Table 2 Findings from literature review

Literature	**Description**	**Literature Findings**	**Reference**
Nursing Patients with Ventricular Assist Devices: An Interpretive Description	This study explores the experience of the nurses who primarily deal with VAD patients, and the complexities that derive from direct exposure to these patients.	The experience of the VAD implant can be more stressful and difficult for family caregivers than for patients	Gibson, et al. (2013)
		Witnessing the implantation of the VAD has been discussed as a potential contributor to symptoms of post-traumatic stress disorder in family caregivers	
Investigating the Heart Pump Implant Decision Process: Opportunities for Decision Support Tools to Help	This study is focused on the impact that Decision Support Tools could have on the clinical decision process around VAD implants, as well as attempting to identify key ways to seamlessly integrate these tools into the clinician's workflow.	When clarifying and monitoring patient condition as well as managing care escalation, machine intelligence can and should help	Yang et al. (2016)
		Our findings reveal a lack of perceived need and trust for machine intelligence	
Psychological Issues for Patients With Ventricular Assist Devices	This study explores the impacts that VAD treatment can have on the patient's mind and body.	Some patients and their families need additional psychological support during and after use of a VAD.	Chapman, Parameshwar, Jenkins, Large, & Tsui (2007)
		Assessment before implantation of a VAD device can sometimes reveal the need for additional support.	
Beyond the VAD: Human Factors Engineering for Mechanically Assisted Circulation in the 21st Century	This study investigates the need for user-centered design approaches to medical device design as a response to prevalent use-errors that can critical failures with mechanical circulatory systems.	An important aspect of VAD development is the usability of the device from implantation to patient discharge from the hospital.	Throckmorton, Patel-Raman, Fox, & Bass, (2016)
		Human error in the usage of medical devices accounts for a major portion of preventable problems.	
Intuitive Use and Usability of Ventricular Assist Device Peripheral Components in Simulated Emergency Conditions	This study evaluated the usability of VADs and their component interfaces by creating simulated VAD scenarios in order to identify key design implications for manufacturers.	Reports of life-threatening situations due to misunderstanding of procedures are well-known within the field of VAD but have often been attributed to clumsiness of users or caregivers.	Geidl et al., (2011)
		Of all the participants, 18% complained about misleading communication with the device, affecting solution of the given problem.	
Usability of Ventricular Assist Devices in	This study analyzed the various usability concerns for VAD patients in their daily lives,	Confidence in safe use of the system decreased significantly with age, from 80% at age 20–30 years to 33% at 70–80 years.	Schima et al. (2014)

Literature	Description	Literature Findings	Reference
Daily Experience: A Multicenter Study	while comparing these results between a number of VAD manufacturers.	With VADs, usability is of particular importance: erroneous actions may lead to fatal errors, and, in particular situations, correct reactions must follow immediately.	

Building on the insights gained in Stage 1 and Stage 2 of the research, in Stage 3 the scope of the prototype design and development focused primarily on training a VAD caregiver in the proficiencies of VAD alarms, while progressively testing their competency as they advanced. This prototype included a digital interface as well as a physical wearable that provided dynamic auditory and visual representations of the alarms that the participants were learning about as part of a holistic and tangible training experience. Results highlighted that the current training process for VAD users is focused is on the patient, however, it is the caregiver who is responsible for the ongoing support and medical treatment of the patient. With the scope of the prototype being focused on the training and preparation for emergency scenario response competency, a number of insights specific to alarm scenarios were uncovered. Table 3 details the user requirements and themes associated with the results.

Table 3 The four key themes emerging from the VAD patient and caregiver training experience

User	Requirements	Themes
Indirect Stakeholders	Training availability for ambulance workers	**Misinformation (ii)**
	Automate flow sheets to minimise manual data entry by patients	**Misinformation (ii)**
	Patient confidentiality	**Preparation (iv)**
	Greater understanding of the patient's home life	**Preparation (iv)**
VAD Caregiver	Remote digital connectivity to physicians	**Gratitude (iii)**
	High fidelity visuals of procedures and components	**Uncertainty (i)**
	Streamlined, actionable information during emergency scenarios	**Preparation (iv)**
	Interfaces and information needs to meet accessibility guidelines	**Misinformation (ii)**
	Recurring proficiency tests to refresh knowledge and ensure competency	**Preparation (iv)**

5 Discussion

Further to the research findings above, a number of overarching themes emerged as design recommendations to consider when shaping the design development of a patient/caregiver training tool. These were: (1) artificial onboarding, (2) contextual empathy, (3) ongoing support, (4) physician connectivity, and (5) emergency scenarios.

5.1 Artificial Onboarding

While the VAD is revolutionary in its ability to prolong the life of end-stage heart failure patients while allowing them to maintain a somewhat active, albeit restricted, lifestyle, it requires both patient and caregiver to learn critical proficiencies and knowledge in a rapid timeframe.

This VAD ‘crash course’ occurs once the patient has been deemed fit to begin rehabilitation, which can be a very traumatic time as they come to terms with this foreign device. This can impact the abilities of both patient and caregiver to retain information (B. Bunzel et al., 2005; Brigitta Bunzel et al., 2007). Reports of life-threatening situations due to misunderstanding of procedures are well-known within the field of VADs but have often been attributed to clumsiness of users or caregivers (Geidl et al., 2011).

While some research (Geidl et al., 2011) indicated that simulating the VAD lifestyle for patients prior to surgery would help lessen the jarring impact of the device as part of an onboarding process, additional research highlighted that this would be impossible for the patient due to them being hospitalized and bedridden with end stage heart failure, as well as the fact that there is usually a very short time frame between physicians deciding on VAD treatment and the VAD being implanted (Friedman & McMahon, 2014; Yang et al., 2016).

Therefore, simulation training tools (Hawkins, Fynn-Thompson, et al., 2017; Hawkins, Ventresco, et al., 2017) would have the greatest benefit for caregiver, and would allow them to build their proficiencies while the patient is undergoing surgery or in ICU. This would allow the caregiver to become the patient's mentor when they are ready to begin their training and rehabilitation.

5.2 *Contextual Empathy*

In response to the user challenges described throughout this paper, the authors created and tested a holistic, interactive training tool designed to simulate the tangible experience of wearing and maintaining a VAD (*Figure 3* and *Figure 4*). This design solution was intended to prepare the caregiver from the VAD patient's perspective, providing a level of contextual empathy. That is, the experience of using and wearing the training tool was designed to help caregivers to empathetically understand the psychological impact of VAD treatment during everyday life, in addition to surgical, technical, and hygienic aspects (Schima et al., 2014). Everyday life with a VAD can be complicated by: unintentional dropping of the controller and battery pack bag, disconnection of cables leading to pump stop, discomfort from wearing the accessory bag, handling of alarms, and the need to have a confident fail-safe action in emergency situations (Schima et al., 2014).

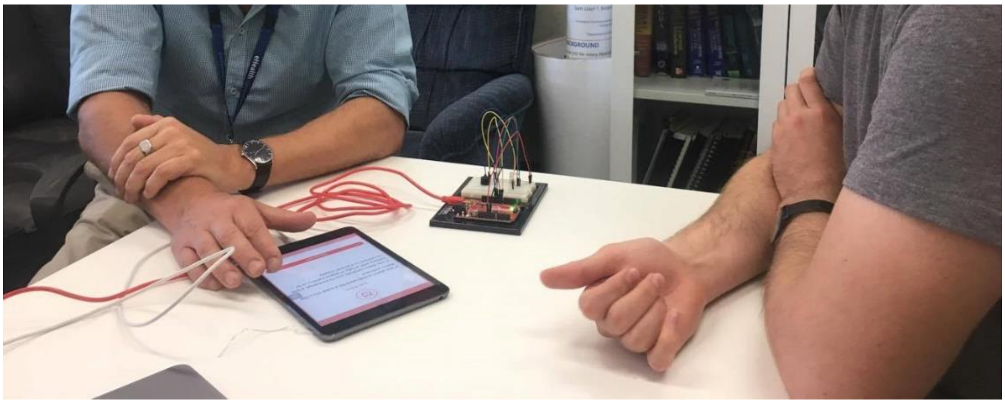

Figure 3   VAD stakeholder interview and prototype evaluation

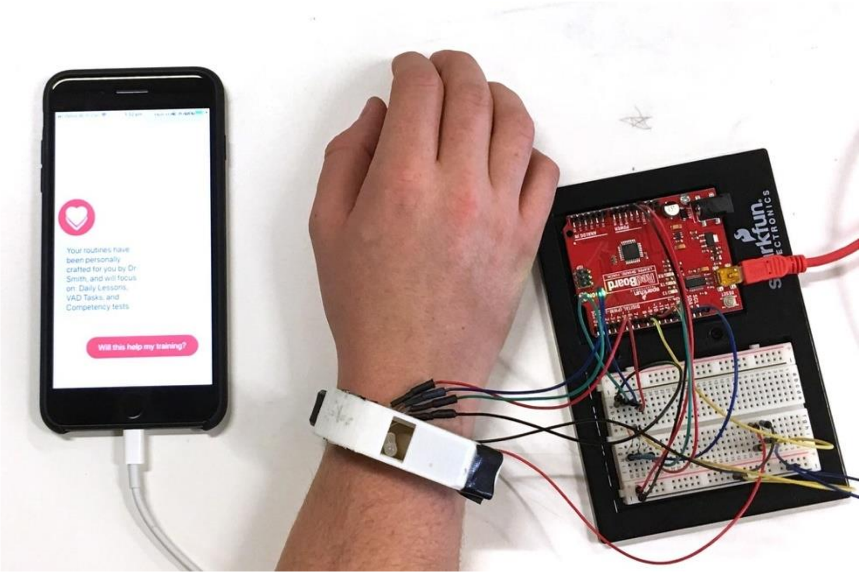
Your routines have been personally crafted for you by Dr Smith, and will focus on: Daily Lessons, VAD Tasks, and Competency tests.

Figure 4 Holistic prototype simulating a tangible interactive experience

5.3 Ongoing Support

In this study, an analysis of existing VAD support solutions highlighted many gaps in the market landscape. While the each of the solutions that were explored had their own purpose and specific issues that they were addressing, patients and caregivers would need to maintain and use a number of these solutions over the course of their VAD treatment.

Findings indicate a need for an end-to-end solution that can train the caregiver (and by proxy the patient) as well as provide ongoing support in maintaining the daily routines and tasks that are frequent along the VAD journey. A standardisation of alarms, labels, connectors, and international guidelines for VAD patient management could potentially optimise the clinical outcome and improve patient safety and satisfaction (Schima et al., 2014; Schlöglhofer & Schima, 2018).

5.4 Physician Connectivity

In addition, both the VAD caregiver and physician interviewed expressed a desire for a level of remote digital connectivity to minimise face-to-face visits when there was an uncertainty or a perceived complication - especially in relation to providing Flow Sheet data and potential infections discovered when cleaning the patient exit site (see *Figure 5*). The caregiver expressed that they would frequently email their physician photos of the exit site to get their professional opinion on whether treatment was required.

Similar remote connectivity functionality was present in one of the analysed existing digital support tools, VADable, a ResearchKit study app launched by the USC Keck School of Medicine’s Cardiology Department. VADable facilitates the sending of daily Flow Sheet information (pump speed, pump flow, pulsatility index, power) to a patient’s physician.

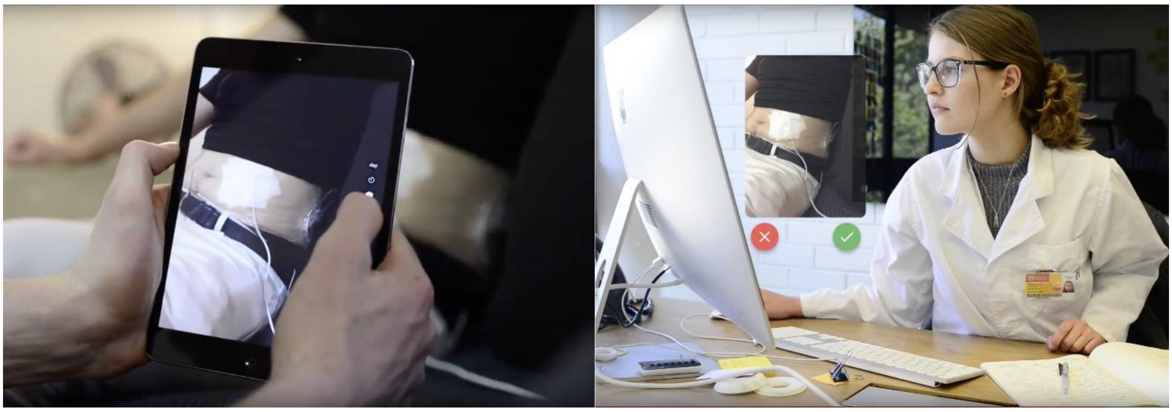

Figure 5 Simulating remote medical connectivity functionality of physician exit-site infection diagnosis

5.5 Emergency Scenarios

A prevalent concern for VAD patients and caregivers was that of alarms, and controller faults in the event of an emergency scenario, with Schima et al. (2014) finding in their study that only 13% of the elderly felt safe in connection with emergency situations (by contrast, 47% in the 20–30 years group). In these scenarios, it is crucial for VAD patients and caregivers to be adequately prepared to identify and address the issue. Misunderstanding of procedures (Geidl et al., 2011) to prevent a potentially fatal outcome can be attributed in part to a user misunderstanding the communication of an event or issue from the device itself. The experience of addressing an issue in practice can be much more traumatic and stressful than learning theoretically in a simulated non-critical scenario, especially if the user hasn't experienced or revised the potential emergency situation for a period of time.

This phenomena has been demonstrated in a study by Geidl et al. (2011) where 18% of participants complained about misleading communication from the device, which then affected the resolution of a given problem. For example, the annoyance of the acoustic alarm, too much information on the emergency card, and fear of committing an operating error that might aggravate the problem.

Additionally, research conducted by the authors of this paper highlighted that throughout the training process and within emergency situations it is important to provide high fidelity visuals and critical information delivered in a streamlined, actionable manner. This could potentially improve patient and caregiver cognition by incepting a one-to-one conceptual map, or mental model. As expressed by a VAD caregiver during their interview:

> *"No animations, no diagram, do it real. Keep it really real. [...] When people are seeing it visually done, it makes sense."*
>
> *"[The way the doctors speak] It's a different language that is spoken to me and that's it. Talk in black and white. Not in colour. You've been at university for years learning in colour. We don't need that. Just tell me black and white. Just tell me what I need to know."*

The importance of clear communication of information was also discussed by Geidl et al. (2011), uncovering that information structured as advice may be more easily understood than status information. For example, in the case of an unintended driveline disconnection, the advice of "reconnect the blue cable with the blue connector" may lead to a faster reaction than "error: driveline disconnect" or other purely diagnostic information (*Figure 6*).

Figure 6 Simulating emergency response proficiency checks during VAD home life

6 Design Implications

In addition to the five design recommendations discussed above, one key design implication uncovered through the authors' research was the insight that training should be focused on the caregiver during the rehabilitation stage, equipping them to feel confident and able. Additionally, important design considerations were uncovered for the design of a training tool for VAD patients and caregivers.

These included:

- Ensure patient confidentiality when dealing with data.
- Ensure the design of both digital and physical solutions meet accessibility guidelines.
- Ensure a frictionless experience in times of emergency.
- Ensure the language employed in the solution and documentation are respectful and understanding of the patient's condition.

7 Further Research

It was a common theme throughout the authors' research that the level of detail in the training provided by VAD physicians to patients and their caregivers was limited by the physician's own training and understanding of the VAD lifestyle within a hospital context. A number of coping strategies (Jessie Casida, 2005; Savage & Canody, 1999) for daily life were innovated by VAD patients and caregivers themselves in an attempt to improve on their quality of life and minimise the struggles of activities they took for granted prior to treatment, such as showering.

The findings of this paper suggest that it is imperative to scale research in this area. Additional research could be conducted with a much larger multi-centre sample of current and past VAD patients and caregivers to uncover user-generated innovations, coping strategies and 'life hacks'. These user-generated innovations could then be fed back into the training process in order to better prepare future VAD patients and caregivers with support tools, as well as inform practitioners and VAD manufacturers in order to potentially advance future clinical practice and VAD designs.

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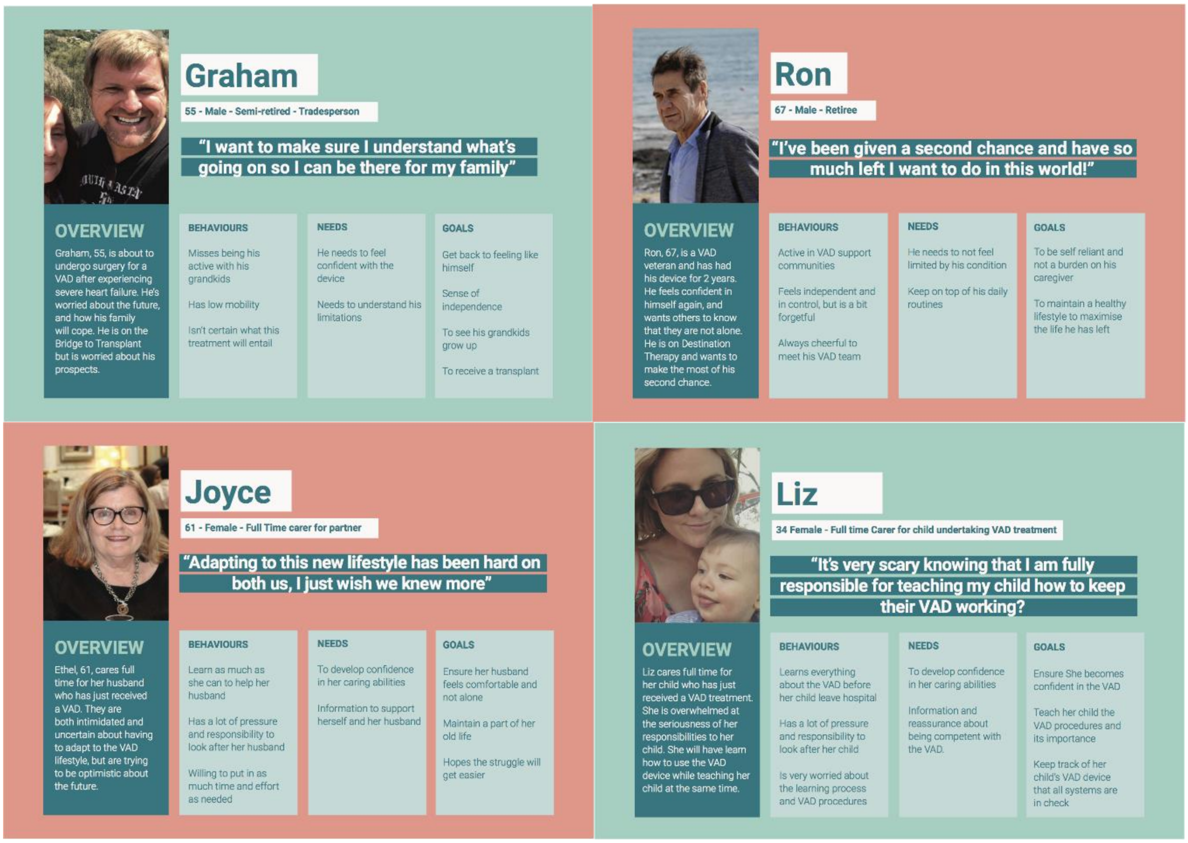
Appendix A: Personas



Graham

55 - Male - Semi-retired - Tradesperson

"I want to make sure I understand what's going on so I can be there for my family"

OVERVIEW

Graham, 55, is about to undergo surgery for a VAD after experiencing severe heart failure. He's worried about the future, and how his family will cope. He is on the Bridge to Transplant but is worried about his prospects.

BEHAVIOURS

Misses being his active with his grandkids

Has low mobility

Isn't certain what this treatment will entail

NEEDS

He needs to feel confident with the device

Needs to understand his limitations

GOALS

Get back to feeling like himself

Sense of independence

To see his grandkids grow up

To receive a transplant

Ron

67 - Male - Retiree

"I've been given a second chance and have so much left I want to do in this world!"

OVERVIEW

Ron, 67, is a VAD veteran and has had his device for 2 years. He feels confident in himself again, and wants others to know that they are not alone. He is on Destination Therapy and wants to make the most of his second chance.

BEHAVIOURS

Active in VAD support communities

Feels independent and in control, but is a bit forgetful

Always cheerful to meet his VAD team

NEEDS

He needs to not feel limited by his condition

Keep on top of his daily routines

GOALS

To be self reliant and not a burden on his caregiver

To maintain a healthy lifestyle to maximise the life he has left

Joyce

61 - Female - Full Time carer for partner

"Adapting to this new lifestyle has been hard on both us, I just wish we knew more"

OVERVIEW

Ethel, 61, cares full time for her husband who has just received a VAD. They are both intimidated and uncertain about having to adapt to the VAD lifestyle, but are trying to be optimistic about the future.

BEHAVIOURS

Learn as much as she can to help her husband

Has a lot of pressure and responsibility to look after her husband

Willing to put in as much time and effort as needed

NEEDS

To develop confidence in her caring abilities

Information to support herself and her husband

GOALS

Ensure her husband feels comfortable and not alone

Maintain a part of her old life

Hopes the struggle will get easier

Liz

34 Female - Full time Carer for child undertaking VAD treatment

"It's very scary knowing that I am fully responsible for teaching my child how to keep their VAD working?

OVERVIEW

Liz cares full time for her child who has just received a VAD treatment. She is overwhelmed at the seriousness of her responsibilities to her child. She will have learn how to use the VAD device while teaching her child at the same time.

BEHAVIOURS

Learns everything about the VAD before her child leave hospital

Has a lot of pressure and responsibility to look after her child

Is very worried about the learning process and VAD procedures

NEEDS

To develop confidence in her caring abilities

Information and reassurance about being competent with the VAD.

GOALS

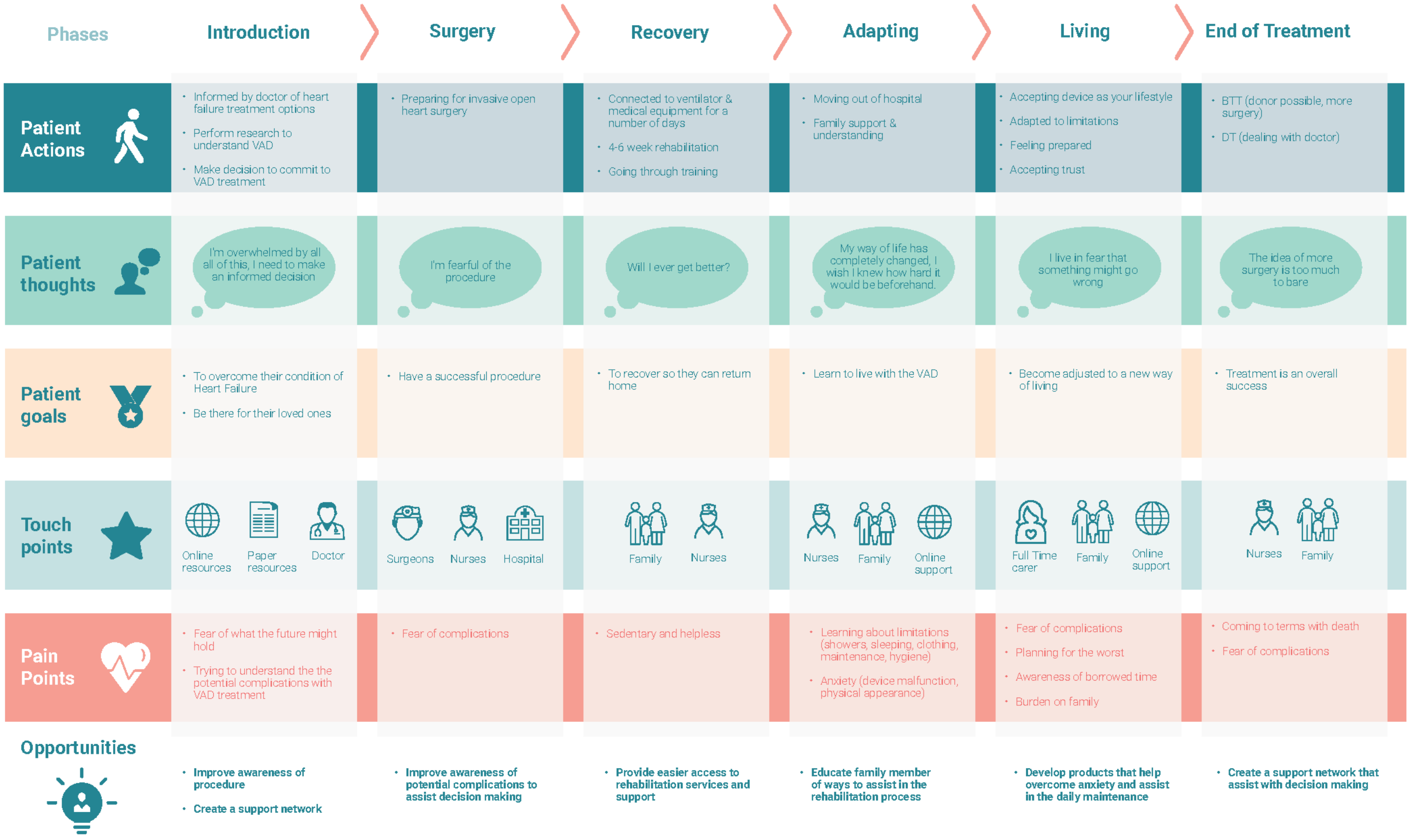
Ensure She becomes confident in the VAD

Teach her child the VAD procedures and its importance

Keep track of her child's VAD device that all systems are in check

Personas: VAD stakeholder personas included: a patient in the Introduction phase about to have a VAD implanted (top left); a patient in the Living phase who has lived with his device for two years (top right); a Caregiver in the Recovery phase beginning her VAD training (bottom left); and an extreme persona in the Adapting phase of a parent Caregiver having to care for their VAD child (bottom right).

9 Appendix B: Journey Maps



Phases	Introduction	Surgery	Recovery	Adapting	Living	End of Treatment
Patient Actions	• Informed by doctor of heart failure treatment options • Perform research to understand VAD • Make decision to commit to VAD treatment	• Preparing for invasive open heart surgery	• Connected to ventilator & medical equipment for a number of days • 4-6 week rehabilitation • Going through training	• Moving out of hospital • Family support & understanding	• Accepting device as your lifestyle • Adapted to limitations • Feeling prepared • Accepting trust	• BTT (donor possible, more surgery) • DT (dealing with doctor)
Patient thoughts	I'm overwhelmed by all all of this, I need to make an informed decision	I'm fearful of the procedure	Will I ever get better?	My way of life has completely changed, I wish I knew how hard it would be beforehand.	I live in fear that something might go wrong	The idea of more surgery is too much to bare
Patient goals	• To overcome their condition of Heart Failure • Be there for their loved ones	• Have a successful procedure	• To recover so they can return home	• Learn to live with the VAD	• Become adjusted to a new way of living	• Treatment is an overall success
Touch points	Online resources Paper resources Doctor	Surgeons Nurses Hospital	Family Nurses	Nurses Family Online support	Full Time carer Family Online support	Nurses Family
Pain Points	• Fear of what the future might hold • Trying to understand the the potential complications with VAD treatment	• Fear of complications	• Sedentary and helpless	• Learning about limitations (showers, sleeping, clothing, maintenance, hygiene) • Anxiety (device malfunction, physical appearance)	• Fear of complications • Planning for the worst • Awareness of borrowed time • Burden on family	• Coming to terms with death • Fear of complications
Opportunities	• **Improve awareness of procedure** • **Create a support network**	• **Improve awareness of potential complications to assist decision making**	• **Provide easier access to rehabilitation services and support**	• **Educate family member of ways to assist in the rehabilitation process**	• **Develop products that help overcome anxiety and assist in the daily maintenance**	• **Create a support network that assist with decision making**

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Design for Multi-Dimensional Stages of Lymphoedema Self-Management

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This study investigates the experience of people with the chronic medical condition lymphoedema, to inform the design of new products. Articles from literature that describe lived lymphoedema experiences are thematically synthesised from a behavioural lens. People with lymphoedema go through stages toward achieving levels of expertise, motivation and routine, to maintain effective self-management in the long-term. A preliminary framework is proposed that presents four themes (competence, autonomy, daily routine and socio-psychological) and their stages. The purpose of the framework is to assist designers in understanding how people with lymphoedema experience self-management. Focusing on facilitating a transition through these multi-dimensional stages is suggested as a means to aid the design of supportive health products. Related design implementations are discussed through product examples. This framework is developed as part of a wider research project, where the following stages will be concerned with refinement of the framework through primary research with people with lymphoedema and their healthcare providers.

design for self-management; lymphoedema; chronic conditions; health and wellbeing

1 Introduction

Lymphoedema is a chronic swelling caused by the failure of the lymphatic system. The swelling can occur in any part of the body, but usually affects arms or legs. Symptoms are heaviness, pain, stiffness, numbness, poor range of motion and acute infections. It can be encountered at any age due to congenital abnormality or after cancer therapy, cellulitis and trauma. The prevalence of lymphoedema is increasing; it has been reported that five out of every 1000 people in Wales have the condition (M. J. Thomas & Morgan, 2017).

This paper is an initial part of a doctoral study and aims to inform primary research in preparation to co-design self-management support systems, with the active involvement of people with lymphoedema and their healthcare providers. Findings of the literature review describing the transition to self-management that people with lymphoedema experience is presented with related design implementations.

Self-management implies a shift of care from clinic to home. This transition benefits healthcare systems by decreasing the number of clinical visits, and people with lymphoedema by diminishing the impact it has on their lifestyle. Unlike an acute illness, patients with chronic conditions make day-to-day decisions about how they manage their health for the rest of their life (Anderson & Funnell, 2000). They control levels of adherence with prescribed tasks necessary to managing their condition. According to the World Health Organisation, nearly fifty percent of people with chronic diseases have poor adherence to their treatment (Sabaté, 2003). From a patient's perspective, adherence to treatment requires additional daily tasks and a change in behaviour, which needs medical, social and emotional support (Corbin & Strauss, 1985; Dwarswaard, Bakker, Staa, & Boeije, 2016). Design has an important role in addressing those support needs and promoting healthy behaviour (Tsekleves & Cooper, 2017). Appropriate design can improve behavioural and clinical outcomes (Balaam et al., 2011; Moffatt & Murray, 2010; Nunes et al., 2015; Sawesi, Rashrash, Phalakornkule, Carpenter, & Jones, 2016), however, the everyday support needs of people with lymphoedema is rarely investigated in this context (Chamberlain, Wolstenholme, & Dexter, 2015; Galiano-Castillo et al., 2014).

Gaining insights about the lived experiences of people with lymphoedema is fundamental for designing support products and systems that aim to facilitate self-management. The benefits of User-Centred design approaches at eliciting the active participation of patients and clinicians for developing healthcare products are acknowledged (Bate & Robert, 2006; McCarthy et al., 2016; Pickles, Hide, & Maher, 2008). This paper aims to describe the experience of people with lymphoedema towards effective self-management, and discuss possible approaches to design for assisting people in this transition.

2 Background

2.1 Lymphoedema Self-Management

The mainstream care of lymphoedema follows a Complete Decongestive Therapy (CDT), which consists of two phases: reduction and self-management. The reduction phase is an intensive daily procedure of lymphatic massage, compression bandaging and skin care carried out by a lymphoedema therapist three times a week for around 3-8 weeks. After the success of the reduction phase, people with lymphoedema are responsible for carrying out these laborious activities by themselves for the rest of their life; by wearing compression garments, doing massage and skin care as well as being cautious about injuries and signs of infections. People who wear prescribed compression garments and exercise experience less pain; however, nearly half of the people continue bearing some symptoms and face at least one infection episode after their diagnosis (Deng et al., 2015). Many people with lymphoedema do not consider selectively applying the prescribed tasks as non-adherence "but as a strategy of making the changes in their lives feasible'' (Fu, 2005, p. 455). Hence, it is critical to understand everyday self-management strategies of individuals and how they have developed those in order to design for them.

2.2 Design for Supporting Self-Management

User-Centred Design approaches prioritise the voices of the end users during the whole design process to design products that people actually need, want to buy, can use and want to use in the long term. Participatory design and co-design methodologies present opportunities for designers to engage with people/users during the design process. In healthcare, patient involvement in design is highly valuable, since specific symptoms of medical conditions and the variety of health journeys make it even more challenging to empathize. Various User-Centred approaches have been implemented in healthcare to address those challenges (Balaam et al., 2011; Bate & Robert, 2006; McCarthy et al., 2016; Pickles et al., 2008). Still, it is discussed that failing to utilise well-established behavioural theories of psychology limit the effectiveness of healthcare products and services (Nunes et al., 2015; Riley et al., 2011; Sawesi et al., 2016). There is a call for systematically eliciting dynamic and diverse needs of patients while effectively employing health behaviour theories (Chiauzzi, Rodarte, & DasMahapatra, 2015; Kanstrup, 2014; Nunes et al., 2015). Moreover, new approaches are needed to make that information feasible to design applications. Even though multidisciplinary literature provides in-depth qualitative studies describing the experience of people with chronic conditions, it is not presented in a way that provides insights for design purposes. This paper synthesises the literature of the experience of people with lymphoedema and related behaviour change models, to present guidance for designers.

3 Development of the Framework

In preparation for qualitative studies with lymphoedema patients, a broad literature review was undertaken exploring studies related to chronic conditions and self-management, related products and technologies, design approaches, and behavioural theories. From this, two focussed bodies of literature were further investigated: literature that describes experiences of people with lymphoedema; and, behaviour change theories. The purpose of this more focussed review was to extract a better understanding of the needs of patients.

A wide range of qualitative studies were reviewed; arising from this review, 10 articles were purposefully selected that presented in-depth descriptions of the lived experience of adults with lymphoedema (see table 1). These articles are thematically synthesised following three stages as discussed by J. Thomas and Harden (2008). First, the findings of reviewed articles were analysed and clusters were named, and then those were organised to create descriptive themes. During the final phase of the thematic synthesis, the themes were interpreted through our research question: How do people with lymphoedema experience the transition towards effective self-management?

Table 1 List of the thematically synthesised articles about the lymphoedema experience.

	Reference	Number	Lymphoedema Type	Data Collection Method / Data Analysis Approach	Country
1	Ridner et al., 2016	21 women	Breast Cancer Related Lymphoedema (BCRL)	Focus group interviews / Qualitative Descriptive	USA
2	Jeffs et al., 2016	21 women	BCRL	In-depth interviews / Grounded Theory	UK
3	Barlow et al., 2014	14 women	BCRL	Semi-structured and focus groups interviews / Qualitative Descriptive	UK
4	Meiklejohn, Heesch, Janda, & Hayes, 2013	3 men, 26 women	Lymphoedema after cancer therapy	Focus group and telephone interviews / Contents Analysis	Australia
5	Ridner, Bonner, Deng, & Sinclair, 2012	39 women	BCRL	Writings at home for two weeks / Qualitative Descriptive	USA
6	Fu, 2010	34 women	BCRL	In-depth interviews / Descriptive Phenomenological	USA
7	Bogan et al. 2007	3 men, 4 women	Non-cancer-related lymphoedema	Semi-structured interviews / Qualitative Descriptive	USA
8	Greenslade & House, 2006	13 women	BCRL	Semi-structured interviews / Phenomenological	Canada
9	Thomas-MacLean, et al. 2005	22 women	BCRL	Semi-structured and focus group interviews / Not mentioned	Canada
10	(Williams, Moffatt, & Franks, 2004)	15 men & women	Lymphoedema both after cancer and non-cancer related	Phenomenological Interviews / Phenomenological	UK

Themes about gaining control, expertise and habits emerged, showing various levels towards self-management goals. To understand the constructs of these descriptive themes, behavioural theories were investigated. The correlation between the findings of this review and behavioural theories enabled the synthesis of four main themes and their related stages: competence, autonomy, daily routine and socio-psychological.

A dominant aspect identified is the dynamism of those themes; people with lymphoedema are explicitly aware of the various phases they are going through. This is illustrated in the case of one person interviewed as part of the thematic synthesis, who stated that "I suppose it's like a grieving process, you've got to go through different stages" (Meiklejohn et al., 2013, p. 6). The subthemes of competence, autonomy and daily routine revealed several stages people experience while they are adjusting to life with lymphoedema. The last theme encompasses the socio-psychological aspects which is structured around main influential actors.

Four themes are discussed in the following sections: 3.1) Competence: Novice to Expert, 3.2) Autonomy: External to Intrinsic Motivation, 3.3) Everyday Routine: Intention to Action, 3.4) Socio-psychological. Each theme is elaborated around lived experiences of people with lymphoedema in relation to aspects of behavioural theories, and related design implementations are discussed.

3.1 Competence: Novice to Expert

People need to think that they can successfully perform the recommended self-management task, in order to consider doing it. Perceived confidence as a prerequisite for behaviour, is mentioned as "competence" by Ryan and Deci (2000) and "self-efficacy" by Bandura (1977).

Even though diagnosis of the condition is primary, some people had to cope with lymphoedema without knowing for extended periods (Bogan et al., 2007; Williams et al., 2004) and some diagnosed themselves from online sources (Barlow et al., 2014; Ridner et al., 2016). After diagnoses, the lack of information and support is still the main source of frustration for many people with the condition (Barlow et al., 2014; Fu, 2010; Greenslade & House, 2006; Ridner et al., 2016; Thomas-MacLean et al., 2005; Williams et al., 2004).

Dreyfus and Dreyfus (1980)'s "Skill Acquisition Theory" describes skill levels and emphasises the importance of established cases and experience for learning new skills. Their four skill levels are adapted to describe how people with lymphoedema gain competence and build expertise (Figure 1). Their fifth level is called "mastery" and described as being absorbed in the activity. That was excluded, since no such evidence was found in the literature review for lymphoedema self-management.

Figure 1 Competence and related design implementations. Skill Acquisition levels adapted from Dreyfus and Dreyfus (1980)

Novices know rules but cannot correlate those with specific situations (Dreyfus & Dreyfus, 1980). This is reflected in lymphoedema when an individual first learns about self-management tasks, but does not know how to integrate them to daily life and their practical effects to their symptoms (Fu, 2010; Greenslade & House, 2006; Jeffs et al., 2016; Meiklejohn et al., 2013; Ridner et al., 2012; Williams et al., 2004). A study exploring lymphoedema self-management education in the USA presented that, even though people receive education about lymphoedema, around 30% do not find it adequate for themselves (Ridner, Dietrich, & Kidd, 2011).

> *I'm more practical. I prefer someone to show me, and she [lymphoedema therapist] has shown me but only once and I can't, I didn't take it in. (Jeffs et al., 2016, p. 5)*

Competence is acquired with experience or when the context of the rules are provided with real world examples (Dreyfus & Dreyfus, 1980). After the initiation of the behaviour, people's competence is highly affected by their experience of success and failure. Bandura (1977) names this "performance accomplishments". Being aware of the possible consequences of not doing self-management is a major motivator for many people (Bogan et al., 2007; Jeffs et al., 2016; Williams et al., 2004), still some choose not manage their lymphoedema despite knowing its impact to their swelling (Fu, 2010; Jeffs et al., 2016; Ridner et al., 2012). People with lymphoedema mention how they start to feel the benefits of self-management (Bogan et al., 2007; Jeffs et al., 2016), however, it is a long-term investment and not feeling the benefits right-away can be a barrier for some (Jeffs et al., 2016; Ridner et al., 2012).

Proficiency comes with experience in a variety of situations (Dreyfus & Dreyfus, 1980). People with lymphoedema express how they develop ways to plan their self-management for changing situations such as flights, holidays and days that require overusing the affected limb (Ridner et al., 2016; Williams et al., 2004). Acknowledging the effects of various self-management aspects to individual symptoms by experience, provides people the competence to adapt and alter those occasionally (Fu, 2010; Jeffs et al., 2016).

People with lymphoedema assess their swelling by "size, appearance, internal sensations, and the feel or consistency of their swollen limb" (Jeffs et al., 2016, p. 8). Healthcare providers measure the limbs to compare with their previous notes as well as carrying out a subjective assessment. Measurable characteristics of chronic conditions are mostly preferred in clinic because of their ability to provide objective comparisons. Some people with lymphoedema want to be measured by nurses (Williams et al., 2004), "I may not notice it, but a tape measure would." (Jeffs et al., 2016, p. 6). Still, the subjective measures and sensations can be different compared to the objective measurements:

> *When I've come and told the nurse here I think my arm is quite swollen she measures it up … and will say, 'Oh, it's only about 30 or 50 mls difference in volume.'…if you measure it in a glass of water, [that] is pretty small … but the impact I think is way more than what the volume states. (Jeffs et al., 2016, p. 8)*

Expertise is gained when people can intuitively make decisions without conscious thinking (Dreyfus & Dreyfus, 1980). In lymphoedema, being an expert is expressed in relation to having a daily routine, taking control and feeling competent about controlling the fluctuations of their swelling (Barlow et al., 2014; Jeffs et al., 2016; Meiklejohn et al., 2013; Ridner et al., 2016).

Design implementations for assisting the transition towards "expertise" are discussed in the next sections.

3.1.1 Skill Development

It is shown that education programmes focusing on self-management skills are better at improving clinical outcomes compared to programmes providing only information (Bodenheimer, Lorig, Holman, & Grumbach, 2002). Utilising online platforms for the dissemination of information is common and opportunities arise for facilitating skill development. For instance, Lymphoedema Network Wales e-mails evidence-based videos made by patients as a part of their patient education (Thomas & Morgan, 2017). Fu et al. (2016) developed a web-based system for women after breast cancer therapy. Their system starts with providing tools to let people evaluate their lymphoedema symptoms and delivers daily strategies for having optimal lymphatic flow (Fu et al., 2016).

3.1.2 Self-Monitoring

Experiencing the consequences and benefits of self-management increases the motivation as mentioned frequently by people with lymphoedema (Barlow et al., 2014; Bogan et al., 2007; Jeffs et al., 2016; Williams et al., 2004). Kikuhime Telecare System (McLaren, Helmer, Horne, & Blanchonette, 2010) uses sensors placed under bandages for measuring compression continuously. Li et al. (2016) developed an ultra-thin and flexible sensing system that can be worn with compression garments without adding extra thickness. These two devices provide information about the compression to the wearer and the therapist. Measuring the limb circumference from defined sections is the common method used by lymphoedema specialists to follow swelling progress. For some people those measurements are very critical and their main reason to see their specialists (Jeffs et al., 2016). E-Cuidate is a software that enables people to log measurements manually and share these with their therapists (Galiano-Castillo et al., 2014). Another approach is measuring the circumference continuously by a sensor embedded cuff (Fallahzadeh et al., 2015).

3.2 Autonomy: External to Intrinsic Motivation

Autonomy is defined as an individual's perception about their volition in giving decisions and being in control. Anderson and Funnell (2000) emphasise the importance of autonomy in self-management of chronic conditions by "It's not that people are unwilling to change, it's that people are unwilling to be changed" (p. 603). According to Ryan and Deci (2000), autonomy together with competence and relatedness are the prerequisites of motivation. Ryan and Deci (2000)'s Self-Determination continuum is adapted to explain how people with lymphoedema ultimately identify self-management as critical for themselves and integrate it into their everyday life (Figure 2). Their final stage called "intrinsic motivation" (Ryan & Deci, 2000) was not included, since lymphoedema self-management tasks are not naturally interesting or delighting.

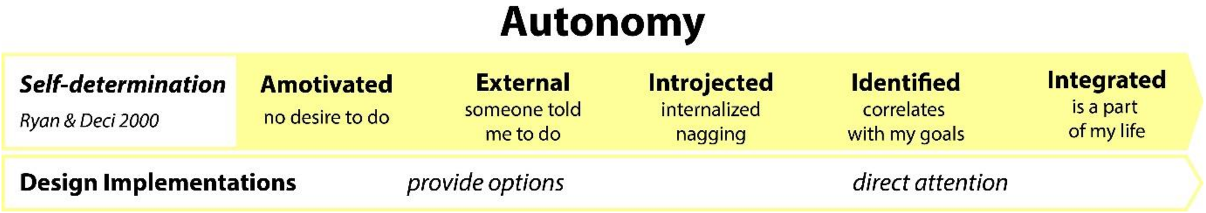

Figure 2 Autonomy and related design implementations. Types of motivations are adapted from Ryan and Deci (2000)

Amotivation can be a result of not expecting or giving value to the outcome, or not feeling competent for achievement (Ryan & Deci, 2000). One study shows that 20% of the participants do not believe they can make a difference in their lymphoedema by what they do (Ridner et al., 2011).

> *Lymphoedema seemed to be something like an incoming tide; … there didn't seem to be anything you could do about it. (Meiklejohn et al., 2013, p. 7)*

Corresponding to **external** motivation concept of Ryan and Deci (2000), some people mention aspects of self-management as something that was told to them, and explain how they tried doing it, but cannot continue in the long term (Fu, 2010; Jeffs et al., 2016).

> *I did wrapping for a while. It was not particularly effective for me but I did it because I was told to. Wrapping is time-consuming and awkward, so it's not just down to whether I can do it or not — I was actually depleted by wrapping. (Fu, 2010, p. 8)*

Introjected motivation is defined as feeling guilty about not doing something (Ryan & Deci, 2000), which is expressed by women as feeling bad (Fu, 2010) and faulty (Greenslade & House, 2006) about not self-managing properly.

People who perform activities because they value its goal and outcome are holding **identified** motivation (Ryan & Deci, 2000). People with lymphoedema frequently identify the consequences of not doing self-management as their main motivation (Bogan et al., 2007; Jeffs et al., 2016). The fear of results of not self-managing is even more dominant for the ones who experienced severe symptoms because of late diagnosis (Bogan et al., 2007).

> *I've made myself realise that I've got a choice: I either wear it [the sleeve] and my arm will hopefully gradually go down even more, or I don't wear it and I end up not being able to do anything or I've damaged my arm because I get cellulitis [infection]. (Jeffs et al., 2016, p. 5)*

By building habits and routines around their self-management activities, people with lymphoedema build **integrated** motivation (Barlow et al., 2014; Bogan et al., 2007; Fu, 2010; Jeffs et al., 2016; Meiklejohn et al., 2013; Williams et al., 2004).

Design implementations for assisting the transition towards integrated motivation are discussed in the following sections.

3.2.1 Provide Options

Ammerlaan et al. (2016) designed a web-based self-management intervention, and discuss the need to address autonomy by letting people choose from various educational modules according to their personal goals. Similarly, drawing a “possibility tree” to provide options and explain different routes to accomplish different goals is suggested as a design strategy (Lockton, Harrison, & Stanton, 2010).

3.2.2 Direct Attention

Designing to increase autonomy implies transforming the role of design from designing to motivate people, to designing for enabling people to be motivated by themselves (Bisset & Lockton, 2010). Interventions that are “nudging” people by sending notifications for changing their health behaviour, are criticised to be leading the decisions and keeping their users passive (Schüll, 2016), hence hindering autonomy. Niedderer (2013) discusses that design can be utilised to stimulate one’s mindful awareness by “shifting the focus from an external to an internal locus of control” (p. 4567). Similarly, “nakedness” is a tool described by Lockton et al. (2010) as removing the elements that people are taking for granted to make them more aware of their surroundings.

People with lymphoedema express their constant consciousness of pain and swelling (Barlow et al., 2014; Greenslade & House, 2006; Meiklejohn et al., 2013; Thomas-MacLean et al., 2005), designing to refocus attention from negative situations is suggested as a design strategy (Casais, Mugge, & Desmet, 2016).

3.3 Everyday Routine: “Intention to Action”

During the clinical therapy of lymphoedema (reduction phase of the CDT), people cannot drive or take a shower when the bandages are on and usually cannot continue their regular work routines. The constraints of having bulky bandages is frustrating, still some people are more anxious about coming to the end of the therapy and coping with it at home without therapist assistance (Ridner et al., 2016; Williams et al., 2004). Unlike clinical therapy, people at home cannot access the encouragement and aid clinicians provide. People should make a volitional choice for self-management and create time while keeping up with their other responsibilities, which is quite different from attending an appointment in a clinic.

Intention is a prerequisite of behaviour (Ajzen, 1985); still even people with positive intentions in self-management are observed to be unsuccessful in reflecting that to their behaviour (Berg, Evangelista, Carruthers, & Dunbar-Jacob, 2011). Webb and Sheeran (2006) investigate the links between intention and the actual behaviour, and they show the importance of volitional and habitual controls for describing the gap found between those. Triandis (1977) defines behaviour partly deliberate influenced from intentions and partly autonomic influenced from habits.

The stages of change model of DiClemente and Prochaska (1983) suggests five stages that people go through for sustaining a health behaviour change. During the first three stages, people build intention and prepare for change, while the last two is when they actually perform the new behaviour. Tang and Bhamra (2008), in their study about changing energy consumption behaviour, draw a sequence for building new habits. The stages of change (DiClemente & Prochaska, 1983) and the habit building process (Tang & Bhamra, 2008) are adapted to express the stages people with lymphoedema go through for building and maintaining self-management habits (Figure 3).

Some people with lymphoedema are attached to their old habits and express reluctance to change (Fu, 2010; Ridner et al., 2012)

> *The fact that I now have to live with so many restrictions on how I do my daily routine is something I have not come to terms with. (Ridner et al., 2012, p. 8)*

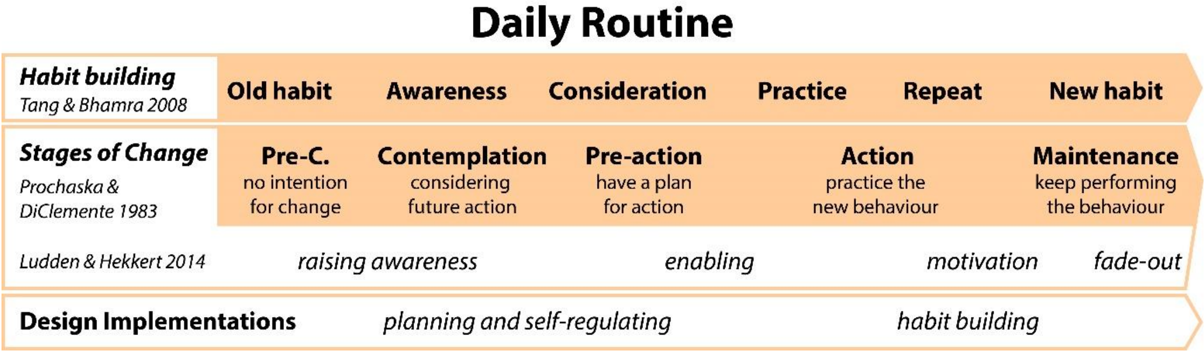

Figure 3 Daily Routine and design implementations. Habit building stages adapted from Tang and Bhamra (2008), Stages of Change adapted from DiClemente and Prochaska (1983), and Stage-matched design strategies adapted from Ludden and Hekkert (2014)

Some people with lymphoedema have difficulty in taking action, even though they have awareness (Jeffs et al., 2016; Ridner et al., 2012), while some others take action, but fail to repeat those (Fu, 2010; Ridner et al., 2012)

> *I've been having a hard time keeping to a schedule for my arm. I would try a week or so then I would mess up with the schedule. (Fu, 2010, p. 9)*

For many other people, building a daily routine around self-management helps to lessen the effects of lymphoedema on their life, feel in control and gain normalcy; since they think less about it, but do more (Bogan et al., 2007; Jeffs et al., 2016; Meiklejohn et al., 2013; Williams et al., 2004).

> *Before I get dressed or anything else, I do the exercise and it's just part of my morning routine. And I think it's that routine-ness of it, you stop thinking about it, you just do it. And I think that makes life a lot easier. (Jeffs et al., 2016, p. 3)*

Design implementations for assisting people to build and maintain a daily routine are discussed in the following sections.

3.3.1 Design for Stages of Change

As discussed earlier, the stages of change theory distinguishes different stages of readiness for change (DiClemente & Prochaska, 1983). Ludden and Hekkert (2014) draw into that theory and define stage-matched design strategies: “raising awareness, enabling, motivation and fading out”. Raising awareness is suggested for people without intention to change and while they start to consider action. “Enabling” strategies are advised to make individuals, who consider change, to start performing the new behaviour. “Motivational” strategies are suggested to help people in maintaining the new behaviour (Ludden & Hekkert, 2014). It is discussed that designing for people at different stages of change, but not only the ones who are already motivated to change, enables designers to address a wider population (Karapanos, 2016).

The thematic synthesis presented in this paper suggests that people with lymphoedema go through stages not only in terms of their readiness for change, but also for building competence, autonomy and habits. The stages of change theory and stage-matched design strategies (DiClemente & Prochaska, 1983; Ludden & Hekkert, 2014) are adapted and incorporated within “daily routine” theme in parallel to habit building (Figure 3).

3.3.2 Planning and Self-regulating

When people make plans about accomplishing their goals, they are more inclined to perform those activities by volitional control. Interventions that help people to draw a personal programme (such as dairies, action planning and coping planning) suggested to be useful in increasing volition of people who are already motivated for change (Sniehotta et al., 2005). Setting challenges and targets are ways to support people in consciously identifying their goals (Lockton et al., 2010; Michie et al., 2013).

3.3.3 Habit Building

Habits are automatic actions as a response to cues, developed by consistent repetitions (Lally & Gardner, 2013). Fogg (2009) underline the importance of "triggers" to tell people, who are already motivated and capable of, to perform an action at a specific time. After performing an already existing routine, adding a new small behaviour and gradually increasing that action is suggested for creating new habits (Fogg, 2009).

Lally and Gardner (2013) discuss satisfaction with the new behaviour as being critical for the consistent repetition required to build habits. People with lymphoedema have different opinions about the definition of success in self-management; some people believe that they are successful if their swelling does not increase, while for others that means poor progress (Jeffs et al., 2016). Setting realistic expectations and emphasising the importance of undervalued outcomes are suggested for promoting habits as well as providing cues and feedback (Lally & Gardner, 2013).

3.4 Socio-psychological

The social and psychological aspects of chronic conditions discussed to be usually neglected (Corbin & Strauss, 1985; Dwarswaard, Bakker, Staa, & Boeije, 2016; Lorig & Holman, 2003). The literature demonstrates the importance of four main actors for people with lymphoedema: family & friends, healthcare providers, peer patients and other people around. Socio-psychological aspects are organised in relation to those actors (Figure 4).

Some people with lymphoedema say that they cannot access any help because of being alone, or they feel their needs are not understood within their family (Fu, 2010; Ridner et al., 2012; Ridner et al., 2016). Having supportive **family and friends** around**,** provides physical support, such as help in wrapping the effected limb as well as emotional support. People with lymphoedema express how they change the way they do chores at home according to their changing capabilities or had to ask for help (Bogan et al., 2007; Fu, 2010; Greenslade & House, 2006; Ridner et al., 2016; Thomas-MacLean et al., 2005). Some people express their reluctance to ask for help because of their concerns about being a burden to them or losing their independence (Ridner et al., 2012; Ridner et al., 2016).

> *…it just makes you feel as though you can do things…..instead of having somebody else to do them for you...and it just makes you feel more useful to yourself... (Barlow et al., 2014, p. 11)*

Collaboration between **healthcare providers** and patients is critical for effective self-management support (Anderson & Funnell, 2000; van Hooft, Dwarswaard, Jedeloo, Bal, & van Staa, 2015). Some people with lymphoedema express how building a strong relationship with their lymphoedema therapists helped them (Barlow et al., 2014; Bogan et al., 2007; Williams et al., 2004).

> *…they [lymphoedema therapists] said they can't cure me but they will keep it under control and that is precisely what they did…I think I began to have some confidence when I could see that what they were doing was working and I became more confident again. (Barlow et al., 2014, p. 10)*

People compare lymphoedema with other chronic conditions and cancer; and express their frustration about underestimation of their needs, not having similar privileges and empathy from healthcare providers (Barlow et al., 2014; Bogan et al., 2007; Greenslade & House, 2006; Ridner et al., 2012; Ridner et al., 2016; Williams et al., 2004).

> *…the thing that changed my life the most was lymphedema and they always give me the impression that I should be grateful that's all I had… (Greenslade & House, 2006, p. 168)*

Dwarswaard et al. (2016)'s review on chronic conditions shows that **peer support** is beneficial by presenting success stories, normalising living with it and decreasing related anxiety. Learning from the experience of others, termed 'vicarious experience', is one of the sources of self-efficacy (Bandura, 1977). People with lymphoedema express their desire to share their experience to help others (Bogan et al., 2007; Ridner et al., 2012), as well as the support they get from connecting with peer patients (Barlow et al., 2014; Jeffs et al., 2016; Meiklejohn et al., 2013).

> *Knowing there were others that had the same problem and were going through the same type of struggle that I was made a big difference because I felt I wasn't alone anymore. (Bogan et al., 2007, p. 219)*

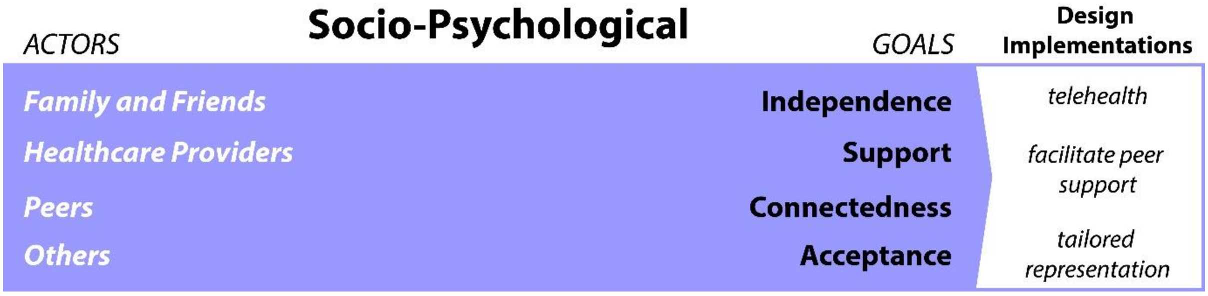

Figure 4 Socio-psychological aspects of lymphoedema self-management and related design implementations

Goffman (1959) explains how people choose to present themselves to **other people** around with a theatre stage metaphor: the impression created on others is guided by changing the way the individual looks and acts in the front stage of the theatre, while relaxed in the backstage. Hence, people control who can access their backstage and may misrepresent themselves to the others in order to fit in their "ideals" (Goffman, 1959).

Some people with lymphoedema think that their swelling does not fit to their ideal and want to hide their condition from others (Bogan et al., 2007; Fu, 2010; Greenslade & House, 2006; Jeffs et al., 2016; Ridner et al., 2012). One talks about her frustration about bandages: "You can't hide it when it's bandaged like this, it's in your face quite literally" (Williams et al., 2004, p. 284). Compression garments are also perceived as increasing the visibility of the swelling, which is a further barrier to wearing them (Barlow et al., 2014; Jeffs et al., 2016; Ridner et al., 2012).

> *My arm was massaged and wrapped several times a week. The swelling didn't go down. I was prescribed a glove and sleeve, which I wore religiously for quite a long time. But the appearance of my hand and constant comments about my sleeve became embarrassing to me. I quit wearing my sleeve.* (Ridner et al., 2012, p. 8)

Finding clothes and shoes to accommodate, and hide the swollen limb is a frustration (Bogan et al., 2007; Greenslade & House, 2006; Ridner et al., 2012), and when the swelling cannot be hidden, the reactions of other people to the affected limb can cause emotional breakdowns (Bogan et al., 2007; Williams et al., 2004). The idealised-self is expressed as "being normal" by many (Bogan et al., 2007; Greenslade & House, 2006; Jeffs et al., 2016; Meiklejohn et al., 2013; Ridner et al., 2012), while the route to normal life is suggested to be effective management of the condition (Bogan et al., 2007). Some people express how acceptance of having lymphoedema for the rest of life helped them gain control (Bogan et al., 2007; Jeffs et al., 2016; Ridner et al., 2012).

> *I suppose knowing that you've got to live with it, but it's a forever, ever and ever thing isn't it. (…) I think something clicked in the brain … got to accept it first, then tackle it and then get the results. (Jeffs et al., 2016, p. 5)*

Design implementations for the socio-psychological aspects are discussed in the following sections.

3.4.1 Telehealth

During face-to-face clinical assessments, lymphoedema specialists measure arm circumferences to evaluate the differences between two arms as well as keeping track of the progress. Galiano-Castillo et al. (2014) design and assess a telerehabilitation system to monitor arm measurements of breast cancer survivors. A telehealth system is utilised with the help of a caregiver to measure and log circumferences, while talking with the specialist is enabled via videoconference. The measurements were compared between face-to-face and telerehabilitation system and found to be reliable (Galiano-Castillo et al., 2014). Another telehealth application aiming to teach self-management to people with chronic swelling with mobility problems is well rated by participants (Faett, Brienza, Geyer, & Hoffman, 2013).

3.4.2 Facilitate Peer Support

Peer support is discussed to be a critical aspect of social and psychological support (Dwarswaard et al., 2016). The importance of building equality and mutual understanding between peers is emphasised for design implementations (Embuldeniya et al., 2013). Local lymphoedema support groups facilitate peer support and many people share their stories through social media.

3.4.3 Tailored Representation

Even if a product is beneficial and necessary in medical terms, people can be reluctant to use a feature if perceived to be stigmatising and not aesthetically pleasing (Wilkinson & De Angeli, 2014). Presentation of Self Theory (Goffman, 1959) discusses how people represent themselves in society. Consolvo, McDonald, and Landay (2009) considered the implementation of that theory in the design of a physical activity display. They emphasised the importance of aesthetics and the ability to control the outputs by its users if misrepresentation is desired (Consolvo et al., 2009). In the context of Lymphoedema, the look of compression garments and how people react to those is a frequently mentioned barrier (Barlow et al., 2014; Jeffs et al., 2016; Ridner et al., 2012). Sleeves with tattoo metaphors (Ercolano, 2012) have been demonstrated to be successful in changing the medical look of the compression garments and in facilitating individualisation. Another example of this is the purse that integrates an arm sling, to both help support the affected arm as well as camouflaging it in a fashionable way (Barnwell, Tullio-Pow, & Nyhof-Young, 2009).

4 Conclusion

A shift of care from clinics to homes are increasingly encouraged and necessary for many chronic conditions, including lymphoedema being the focus of this paper. The transition experienced towards effectively self-managing at home is discussed through a literature review of lymphoedema, behavioural theories, design approaches, studies related to chronic conditions and self-management. From the thematic synthesis of ten articles expressing the lived experiences of people with lymphoedema, multi-dimensional stages are distinguished, which are illustrated as a new preliminary framework in Figure 5. While some individuals proceed through those challenging stages, others fall behind in some aspects resulting in barriers to self-management. This understanding is important to facilitate the successful transition of people at the beginning of such periods and for the ones facing difficulties.

Obviously, this review has limitations in understanding the lived-experience of managing lymphoedema. Primarily, the thematic synthesis has been developed through secondary research, which prevents an in-depth understanding of the design needs of any new product. Seven of the ten articles reviewed in this study focussed on people with lymphoedema after breast cancer therapy, since the literature is limited for other types of lymphoedema. Yet, despite these limitations, the review has presented an opportunity to include the experiences of people from different parts of the world: USA, Canada, Australia and UK. The outcome describes the multi-dimensional stages people with lymphoedema go through for self-management. Future work will include a systematic literature review, and primary data collection by interviews and co-design workshops. Self-management is a critical component of care not only for lymphoedema, but also for other chronic conditions. Themes specific to other chronic conditions would be revealed by future investigations.

Guidance for design is provided by discussing design approaches in relation to how to assist the transition from clinical treatment to effective self-management. Ten design implementations matching those specific themes are identified, and discussed with relevant product examples. This preliminary framework presents the great variety of lived self-management experiences, and the inadequacy of one-design-fits-all approaches. Not only the impact of lymphoedema and strategies to manage are different for individuals but also each day is different in this respect. Focusing on these multidimensional factors by considering their stages and ultimate goals, would allow designers to better understand and address the opportunities to alleviate self-management.

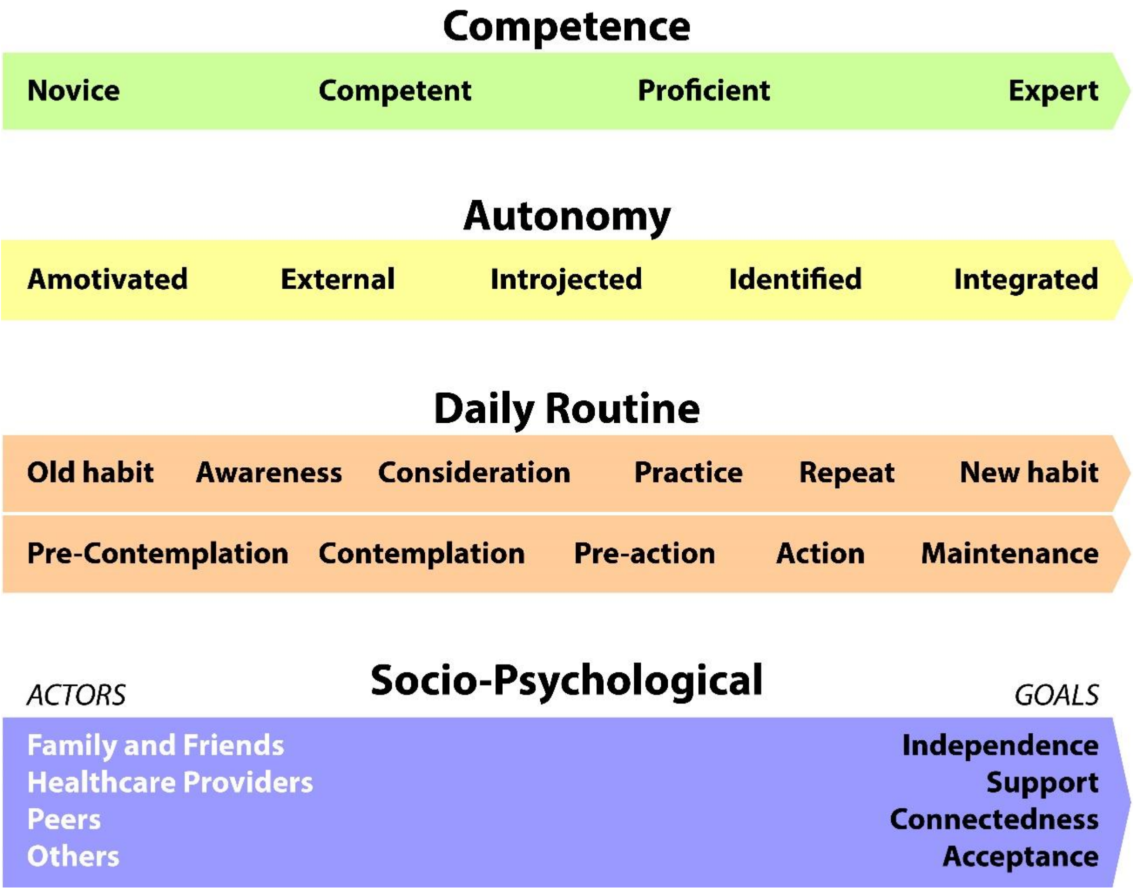

Figure 5 Multi-dimensional stages of lymphoedema self-management experience

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Toward a More Granular Management of the Calibration Process for Hearing Devices: the role of design-based knowledge translation

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This paper analyses a research and innovation action oriented toward creating various technologies to help people with hearing impairment in calibrating their hearing devices and examines how several design artefacts (e.g., sketches, mock-ups, motion graphic videos, prototypes) were used as a knowledge translation mechanism. In particular, the paper looks at how these design artifacts supported knowledge translation in a way that helped individuals with hearing impairment to better understand the calibration process of their hearing devices and to acquire a minimal but practical vocabulary to directly interact with their devices and communicate with the audiologist. Design-based knowledge translation increased the self-efficacy of hearing aids users and put them in the condition to carry out a fine-grained and more contextually-anchored calibration process and, consequently, to feel empowered to operate with a higher degree of autonomy.

hearing impairment, design for healthcare, knowledge translation

1 Introduction

According to the World Health Organization, over 5% of the world's population has disabling hearing loss, and due to an aging population, this number will probably increase[1]. While hearing aid technologies have dramatically advanced in the last 25 years, people's perception and use of these devices have changed relatively little. Digital hearing aids are now smaller and incorporate several functions that go far beyond the simple amplification and equalization operation performed by the traditional analog devices. On the one hand, these digital hearing devices can be calibrated in relation to a greater variety of parameters (e.g., compression, noise reduction, directivity) and this allows responding in a better way to the specific needs of each individual suffering from hearing loss.

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[1] http://www.who.int/mediacentre/factsheets/fs300/en/

On the other hand, the calibration process can be continuously adjusted by the individual with hearing impairment in relation to everyday activities and contexts. For example, the device can be calibrated in a specific way while the subject is sitting at a restaurant and wants to listen what the friend sitting in front of her has to say, and in a different way when the two friends leave the restaurant and go to listen to a concert. Equalization, volumes and other parameters of the hearing device can be re-adjusted in relation to the specificities of different environments.

However, the technological advancement of these new digital models of hearing devices is not always accessible or accessed by the population who have hearing impairments. The main reason is that the calibration process requires at least some basic understanding of key acoustic parameters and how these parameters can be adapted for different conditions of use (e.g., a concert, a noisy street, a phone conversation). If those with hearing impairments had a better understanding of these parameters, this would help both the initial calibration of the hearing device (that is generally done under the supervision of a professional audiologist) and the later continuous re-calibration of the device that the user could autonomously do in relation to the various contexts of use. It is, of course, difficult to imagine that individuals with hearing impairment can have the same level of technical and medical knowledge possessed by professional audiologists or by experts in acoustics. This technical and medical knowledge needs to be translated into formats that can be more easily understood and appreciated by a wider, non-professional audience, which as a result can have a more prominent role in the management of their hearing devices. Individuals with hearing impairment could more independently decide where and how to carry out calibration processes.

This is one of the research avenues of the 3D Tune-In project (Eastgate, Picinali, Patel, & D'Cruz, 2016), which brings together a variety of partners: a hearing aid manufacturer, research centers specialized in computer science and acoustics, private companies developing solutions for healthcare, and hearing associations. In particular, since this group has expertise in various areas of design (from visual design to interaction design, all the way up to service design), one of the core areas of the project was the creation of a variety of design artefacts (e.g., mockups, infographic representations, prototypes), which presented ideas, concepts and viewpoints across multiple domains. For example, diagrams and early-stage mockups were created to visually represent some complex algorithms behind the core engines of some 3D Tune-In software applications. These design artifacts helped translating technical knowledge in acoustics and computer science into visual formats that (1) could be more easily disseminated to the wider public and (2) be appreciated also by people without a strong technical background. In 3D Tune-In, a variety of knowledge translation processes has been carried out where specialized, scientific, technical knowledge has been reformulated for layperson across various formats such as written summaries, visual diagrams, motion graphics videos and prototypes.

The potential of design artefacts to support translational processes among stakeholders speaking different languages and having different needs and wants has been already explored in literature, for example in relation to contexts such as academic entrepreneurship and open innovation (Simeone, Secundo, & Schiuma, 2017a, 2017c). However, the potential of design to support knowledge translation in healthcare remains understudied. This paper intends to offer a contribution in this direction, by examining if design-based translational processes can support the calibration process of hearing devices and, if so, how. The next sections will further ground this research orientation into existing literature and will present some reflections based upon the authors' experience within 3D Tune-In.

2 Theoretical background

2.1 The calibration process for hearing devices

To properly calibrate their digital hearing device, people with hearing impairment need to undergo a fitting process with the help of an audiologist. After a preliminary calibration in the audiologist's studio, it is only when the patients wear their hearing device in real contexts of use (at home, at their work place, etc.) that they can realize whether some further calibration is needed. This process might need several weeks and several trips to the audiologist.

The challenges of calibration processes for the new-generation of digital hearing aids have been highlighted in scientific literature (Hickson & Meyer, 2014). The increasing complexity of the current digital devices is one of the issues: the devices offer a variety of functions that can be highly personalized in relation to both the specific audiological profile of the people with hearing impairment and to the real acoustic ecologies, i.e. the specificities of the context of use (Pichora-Fuller & Singh, 2006). Another important issue is related to the psycho-social factors tied to hearing loss (Knudsen, Öberg, Nielsen, Naylor, & Kramer, 2010): individuals with hearing impairment might experience difficulties in accepting and coping with hearing loss (Jerram & Purdy, 2001) or they can minimize or deny the problem, also because of the stigma they perceive as associated with hearing impairment (Meister, Walger, Brehmer, Wedel, & Wedel, 2008). An area of particular interest for this study is that self-efficacy - the level of confidence that an individual has in their ability to manage and adapt to using hearing aids - is one of the most important factors for successful hearing aid use (Hickson & Meyer, 2014). A good number of related studies point to the importance of providing individuals with hearing impairment with information, training, and counselling on how to directly manage and adapt their hearing devices and, consequently, increase self-efficacy (Bertoli et al., 2009; McCormack & Fortnum, 2013). While some authors previously focused on how design artifacts such as interactive videos can support the user in accessing knowledge helpful for the calibration process (Ferguson, Brandreth, Brassington, & Wharrad, 2015), a more systematic analysis of how design can increase the user’s self-efficacy and support the various phases of this calibration process is still missing.

2.2 Knowledge translation and design

Knowledge needs to be translated in order for it to be interesting and relevant for a variety of audiences (Graham et al., 2006). Processes of knowledge translation are particularly important when an interaction occurs between service actors such as academia, industry and end-users (Grimshaw, Eccles, Lavis, Hill, & Squires, 2012), as it happens in 3D Tune-In.

Previous studies specifically explore design-based translation in relation to contexts such as academic entrepreneurship (Simeone, 2016), open innovation (Simeone et al., 2017c) or value creation in organizations that also use arts-based interventions (Simeone, Secundo, & Schiuma, 2017b). In these studies, we refer to design as a symbolic practice where the very act of designing, for example, a logo, a diagram, a prototype, a product or a service is a way to create meaning (Krippendorff, 2006). Design comprises a set of practices and methods – such as user research and user testing, rapid and frequent prototyping, visualization techniques, task-based scenario building, attention to the brand experience – which also mark a distinctive way of thinking, approaching, and solving problems (R. Buchanan, 2004). In a R&D project such as 3D Tune-In, typical outcomes of a design approach would be, for example, sketches, various visualizations (e.g., 3D renders, data visualizations, motion graphics animations and videos), and prototypes at various degree of refinement. The role of these design artifacts in supporting R&D development projects have been studied by various authors (Bogers & Horst, 2014; Gero, 1990; Leonard & Rayport, 1997; Rust, 2004, 2007). None of these authors, though, specifically focus on the construct of translation even though this concept is not new in design research. Some scholars employ the concept of translation when referring to translational processes among the languages of different design methods or techniques (Singh & Gu, 2012). Others adopt translation in another quite commonly used connotation, as to describe design processes and outcomes (such as sketches) in terms of “translation of ideas” (Leblebici-Başar & Altarriba, 2013; Lin, 2007; Yi-Luen Do, Gross, Neiman, & Zimring, 2000). The role of design in building brand value and product identity - also through semiotic processes of translation (e.g., translating the abstract core ideas behind a brand into a visually-designed identity) - is frequently praised (Borja de Mozota, 2003). These works tend to characterize the translation processes in terms of a linear and quasi-literary sense.

Other studies adopt translation in a more extended sense to describe situations where different stakeholders interact, often departing from concepts such as boundary objects that can “facilitate the translation mechanisms across different cultural configurations and contexts” (Star & Griesemer, 1989, p. 393) or from Actor Network Theory, where Michel Callon and Bruno Latour describe translation in these terms: “By translation we understand all the negotiations, intrigues, calculations, acts of persuasion and violence, thanks to which an actor or force takes, or causes to be conferred on itself, authority to speak or act on behalf of another actor or force” (Callon & Latour, 1981, p. 279). Other studies more particularly focus on how participation in design is tied to “problems of interpretation and translation of varying user and expert perspectives” (Reich, Konda, Monarch, Levy, & Subrahmanian, 1996, p. 177) and argue in favor of “increasing access to technical knowledge and its translation for equal participation in a dialectical process” (Reich et al., 1996, p. 174). Translation is seen as a complex process riddled with negotiations (Cooper, Bruce, Wootton, Hands, & Daly, 2003; Deni, 2015; Tomes, Oates, & Armstrong, 1998) wherein designers act as “intermediar(ies) between disparate ideas, viewpoints and even goals. Being able to translate in this manner is an essential precondition for being able to integrate many things” (Boyer, Cook, & Steinberg, 2011, p. 327).

2.3 Design for healthcare

Various authors have investigated how a design approach and design methods can be used in healthcare (Chamberlain, Wolstenholme, Dexter, & Seals, 2015; Tsekleves & Cooper, 2017). Some studies surveyed best practices in creating environments that enhance the quality of healthcare delivery with perspectives spanning from architecture (Anderzhon, Hughes, Judd, Kiyota, & Wijnties, 2012), to interior design (Marberry, 1997) and wayfinding (Miller & Lewis, 1998), all the way up to real estate design and management processes (Zwart, 2014).

Studies have also shown how within healthcare, design thinking and various design methods can support user research (Glasemann & Kanstrup, 2011), product development (Cheung, 2012) and innovative services (Bessant & Maher, 2009). Høiseth and Keitsch used phenomenological hermeneutics to gain understanding of stakeholders in healthcare contexts (Høiseth & Keitsch, 2015). Donetto et al. presented the Experience-based Co-design (EBCD) as a participatory research approach that builds upon design tools and ways of thinking to bring healthcare staff and patients together to improve the quality of care (Donetto, Pierri, Tsianakas, & Robert, 2015). Lee examined the design of ambulatory healthcare from a service design perspective (Lee, 2011). A variety of authors specifically focused on how human-centered design can be instrumental in developing information and communication technology for healthcare (Ballegaard, Hansen, & Kyng, 2008; Duarte & Guerra, 2012; Wildevuur & Dijk, 2011).

These are all important perspectives on the use of design in healthcare and, as such, are currently explored by dedicated labs and research groups (Reay et al., 2016)[2]. However, in spite of some preliminary attempts (Jones, 2013), comprehensive studies on how design can be used in relation to the specificities of various areas of healthcare are still missing (Bate & Robert, 2007). In the words of Koomans & Hilders:

> *as design thinking continues to evolve in its application for value creation, organizational change, and culture setting, the quest for value in healthcare has just begun: value-based healthcare as the foundation for patient-focused and outcome-driven value creation. Unfortunately, this process needs acceleration. We claim that it is necessary to adopt and learn from design thinking practices to identify meaning, purposeful thinking, and patient- oriented innovation (Koomans & Hilders, 2016, p. 43).*

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[2] http://centerforinnovation.mayo.edu/design-in-health-care/
https://www.id.iit.edu/design-healthcare-certificate/
http://cfchd.org/

The purpose of this study is to offer a contribution to the area of design for healthcare, by particularly focusing on translational processes supported by design.

3 Approach

The article is based on the case study approach (Eisenhardt, 1989; Eisenhardt & Graebner, 2007; Yin, 2009) wherein we examine the phenomenon with depth. Such an approach may be considered suitable for the exploratory nature of this research (Dell'era, 2010). Case studies enable the author to identify and analyze key insights which occur over time (Paré, 2004). This approach works especially well in situations where behaviorally-oriented questions regarding 'how' or 'why' are posed and when the focus of such a study is a contemporary phenomenon within a real-life context (Glaser & Strauss, 1967; Pettigrew, 1990; Yin, 2009) that is investigated using multiple sources of evidence (Robson, 2002). Case studies have been consistently and regularly used in organizational research for more than half a century (Berg, 1968) and more recently (Breslin & Buchanan, 2008; D. A. Buchanan, 2012). Researchers are also aware of the limitations of such a method (Dasgupta, 2015). In line with Yin's view (2009), a case study approach enables the researcher to accommodate single cases or situations with small numbers of experiences; to gather relevant, periodic feedback; to accommodate one's study to the presence of different types and forms of evidence; to review outcomes and experiment with new theories and challenge old theories; and to develop lessons which can be extrapolated to the some of the substantive themes within a domain.

Within the 3D Tune-In project, three separate stages for the involvement of end users and other stakeholders have been organized. The first stage focuses on participatory design, aiming therefore at engaging end-user stakeholders in the project, capturing stakeholder needs and requirements, and finally specifying the 3D Tune-In development requirements. This stage was based on semi-structured conversations and interviews with hearing aid users and audiologists, following both a bottom-up (e.g., incorporating end user characteristics, their scenarios of use and their requirements) and a top-down approach (e.g., considering the available hearing aid functionalities and the needs of the other stakeholders) for requirements generation. 18 hearing aid users were involved in this stage across UK, Spain and Italy. In addition, a questionnaire study was conducted with 20 audiologists to elicit information about processes and issues during the hearing aid selection phase with clients during sessions intended for adjusting these hearing aids.

The second stage focused on evaluations within the formative stage of development by adopting an iterative design to feed results into the technical development as soon as possible. The formative evaluation was divided into two separate stages, one in the middle of the project and one at the end of the third quarter. Two separate groups have been involved: experts and general stakeholders (adults and children, both with and without hearing aids, and audiologists). Considering the latter group, 93 subjects were involved in the two stages. Interviews were carried out with adult and children participants in UK, Spain and Italy. For hearing aid users, a short questionnaire was also administered to collect information about the type of hearing aid users wore; how well they could hear with a hearing aid; situations they find it difficult to hear in when wearing their hearing aid; and their use of digital games. The whole questionnaire took approximately 5 minutes to complete.

The final stage, a summative evaluation of the final outcomes of 3D Tune-In with regards to enhancing social inclusion in society and improving quality of life, is currently in progress and already produced preliminary results.

A target of 75 participants for each application has been set. This final summative evaluation stage aims at measuring the 3D Tune-In success by assessing engagement, acceptance, usability, attitudes towards the final applications and perceived usefulness of the apps by adult and child hearing aid users, audiologists and children without hearing loss. To assess these factors, we are considering the use of custom questionnaires, interviews, and standardised questionnaires (e.g. Speech Spatial Qualities questionnaire) as needed once the main functionalities in each app have been fully implemented.

Within all these stages, data has been mostly collected through ethnographically-inspired methods such as participant observation, semi-structured conversations, and archival research. Surveys, user testing sessions, and interviews with audiologists and individuals with hearing impairment have also been conducted in various moments of the project to validate the initial user requirements and two iterations of the software applications. Two of the authors were part of the 3D Tune-In consortium and had the chance to directly participate in these activities.

4 Findings

Within the course of 3D Tune-In, a variety of software applications were developed including 3D virtual environments and videogames with hearing aid and hearing loss simulators (Levtov, Picinali, D'Cruz, & Simeone, 2016; Picinali, D'Cruz, & Simeone, 2015). By using the core audio engine developed within the project, named the 3D Tune-In Toolkit (Cuevas-Rodriguez et al., 2017), developers can create applications/videogames which allow users to test various functionalities of their hearing aids and to calibrate them within simulated environments that recall real world situations (e.g. at a concert, in a restaurant, on a street, at a train station, in a classroom). Although high-end models of hearing aid devices allow people to calibrate their devices directly through a connected mobile application, the 3D Tune-In Toolkit mostly operates using a hearing aid simulator within 3D virtual environments. Key characteristics of the 3D Tune-In Toolkit are:

Audio spatialisation. This allows the positioning of virtual sound sources around the listener, emulating different distances and different environmental acoustic characteristics. The spatialisation can be performed for devices other than hearing aids, such as headphones (employing the binaural technique) and loudspeakers.

Hearing loss simulator. A given hearing loss can be then simulated within the virtual environment, causing the listener to hear sounds filtered through the hearing loss model. This includes dynamic equalization, multi-band compression/expansion, non-linear distortion, and degradation of temporal and spatial resolution.

Hearing aid simulator. The emulation of a hearing aid can be then added at the end of the processing chain. This includes functions such as selective amplification, high/low pass filters, dynamic equalization, directional processing, dynamic range compression/expansion, and signal re-quantisation.

Applications developed using the Toolkit allow the users to calibrate functions such as directivity (e.g., the hearing aid amplifies more sounds from the front rather than from the back), tone control (high, mid and low frequencies), compression (amount, attack and release), noise control, etc. The 3D Tune-In Users are generally not familiar with this medical and technical knowledge. A series of design artifacts in 3D Tune-In helped the user in better understanding by translating this medical and technical knowledge into formats that could be more easily understood and appreciated. Such artifacts include:

- Sketches, visual diagrams, infographics representations, motion graphic videos (Figure 1)
- Impactful and easy-to-use interactive interfaces where patients (and their relatives and, more broadly, people not suffering from hearing loss) could play with various acoustic parameters and see in real-time how their hearing changes
- Videogames where users were immersed in designed 3D simulated environments where both hearing loss and virtual hearing aids are implemented and can be calibrated (Figure 2)

Figure 1 Still frames from motion graphics videos created by 3D Tune-In, where key technological and acoustic concepts are translated into cinematic sequences

Figure 2 Virtual environment where users have to perform some hearing-related tasks in various contexts (restaurants, noisy street, living room). Users also have to calibrate a virtual hearing aid in these different conditions of use.

Figure 1 shows an example of a design-based translational process where knowledge related to key technological and acoustic features of hearing devices is translated across different semiotic systems: starting from the medical knowledge – as codified in the technical and scientific literature from which 3D Tune-In departed – into a cinematic sequence that worked as an external communication material that also speaks to non-expert and non-academic target audiences.

The 3D environments such as the one represented in Figure 2 go a step further. The translational process here still starts from quite technical knowledge (e.g., how to calibrate various functions of the hearing device in different conditions of use) and goes across semiotic shifts as to become a material re-adaptation, i.e. a gamified virtual environment where the user is immersed into and is asked to perform activities such as guessing the right word, locating a sound source or modifying the directionality of her virtual hearing aid. These virtual environments simulate either typical daily life situations (e.g., talking to a friend while sitting at a restaurant or while walking in a noisy street) or unusual and magical situations (e.g., talking to a flying wizard in a magic garden). A variety of environments and game goals, increasing levels of difficulties while progressing the game and a scoring system as a reward mechanism are the mechanics behind the user engagement.

The translational process here goes beyond the intent to better communicate or disseminate. The latter could, potentially, also be done by simply paraphrasing or re-writing medical or technical knowledge in a simplified form as to be better understood by layperson. Conversely, the specific role of design in 3D Tune-In is that translational processes are strictly grounded into what the semiotician Umberto Eco would term as variation of 'matter' (Eco, 2003), where a certain specialized knowledge in audiology – typically codified into written or spoken words - is translated across multimodal semiotic systems (visual, auditory, graphic, tactile) as to engage the audience in an immersive and actionable environment. A constant use of various forms of design (including graphics, motion graphics, interaction design, and service design) is what allowed a continuous material articulation and re-adaptation of project results in a way that individuals with hearing impairment could better understand and appreciate as strictly tied to their medical needs.

5 Discussion and conclusions

At the moment of writing, 3D Tune-In is still carrying out an extensive summative evaluation that involves individuals with hearing impairment, their families and audiologists. Preliminary results show that design-based knowledge translation supported various phases of the calibration process (Table 1).

Table 1. Phases of the calibration process for hearing devices and role of design-based knowledge translation

Phases	What happens in this phase	How design-based knowledge translation supported this phase
Diagnosis	Health impairments (e.g., difficulty in hearing in specific situations) motivate the patients to understand certain fundamentals about their condition. Typically, patients meet the audiologist and have hearing tests. *Challenges for this phase*: the patients might not have the same medical knowledge as the audiologists. Their meetings can be troubled by differences in language and vocabulary.	Specialized medical knowledge was translated into diagrams and motion graphics videos and embodied into specific software applications for patients and their families as to allow them to grasp the meaning of basic audiology vocabulary and, consequently, better interact with the audiologist.
Choice of the device and preliminary fitting	Once the problem has been identified, a hearing device must be chosen and calibrated. The patient is generally guided by the audiologist in the choice of a hearing device. The preliminary fitting (initial calibration of the hearing device in relation to the specific hearing problems of the patient) is performed by the audiologist in his or her studio. *Challenges for this phase*: a variety of hearing devices are available in the market and they generally have differences in technical features and costs. Understanding these different technical features (e.g., different algorithms for noise reduction) can be quite difficult for the patient.	3D Tune-In developed a virtual environment where the users can experiment with a virtual hearing device and related key sound parameters. This specific process was oriented towards translating medical conceptual models of how hearing works into a virtual environment where the individuals with hearing impairment and their families could directly experiment with various acoustic parameters and form their own (simplified) conceptual model of how these parameters influence hearing.
Finalization of fitting	After the preliminary fitting, the patient goes back home and starts wearing their hearing aids in their daily life. By wearing their device in their typical environments (e.g., at work or in a noisy street), the patients may realize that the preliminary calibration needs to be tweaked. The patient typically goes back to the audiologist and reports problems and the audiologist performs the calibration. The entire	The 3D Tune-In virtual hearing aid was also used to create videogames. Individuals with hearing impairment and their families were asked to enter different virtual 3D environments with different sound conditions (noisy streets, restaurants, concert halls) and perform some

	process might need the patient to go back to the audiologist several times. *Challenges for this phase*: while wearing the hearing device in real contexts of use, the patients might feel that there is still something to tweak, but they do not generally have the working vocabulary to precisely report to the audiologist (e.g., a patient would rarely be able to report a problem with the directivity while listening to a female voice in a restaurant with high pitched background noise). At the same time, the audiologist might feel frustrated because they cannot grasp what exactly the patient needs.	calibration actions. The design was intended to further enrich the (simplified) conceptual model that a non-professional has in relation to how hearing works and to equip the individuals with hearing impairment with a richer vocabulary to interact with the audiologist. Typically, in this phase, users would understand the benefits of changing the calibration of their device in relation to the environments in which they typically live.
Continuous calibration of the hearing device	After the fitting is finalized (i.e., the hearing device is calibrated in relation to the specific needs of the patient), the patient will still need to periodically recalibrate the device. The new-generation devices can be continuously recalibrated by the patient in relation to specific contexts of use (e.g., the patients can change some parameters when they go to a concert, or when they are in a particularly noisy room and want to hear the voice of a speaker in front of them). *Challenges for this phase*: this continuous calibration should be performed autonomously by the patient. This means that the patient should be in the condition of understanding key parameters that can be calibrated and have some basics notions of acoustics. Moreover, user interfaces of hearing devices might not always be user-friendly.	For this final stage, as already described for Figure 2, a variety of videogames were developed to show people with hearing impairments that a continuous recalibration of the hearing device is needed in relation to different sound environments. This calibration can be done also autonomously and without the continuous support of the audiologist even in spite of complex user interfaces.

Table 1 illustrates how various design artifacts supported knowledge translation in a way that helped individuals with hearing impairment to better understand the calibration process while acquiring a minimal but practical vocabulary to communicate with the audiologist. In particular, what the audiologists have historically lacked is clear information on what happens when people with hearing impairment go back to their life after the calibration of the hearing devices in the audiologists' studio. How can this preliminary calibration be better tuned keeping in mind the specificities of the sound environments experienced by individuals with hearing impairment (e.g., specific work or leisure environments, specific areas of the city, etc.)?

Until now, this process has been troubled by knowledge gaps. For example, the individual with hearing impairment can sense that when she sits at the restaurants there is something that needs to be tweaked on her hearing device, but she cannot explain exactly what. She cannot describe the acoustic characteristics of the restaurant either. Processes of knowledge translations such as the ones supported by the design artefacts of 3D Tune-In can not only provide the individuals with hearing impairment and their families with a vocabulary to better understand how to describe the nuances of acoustic processes and report to the audiologists. Knowledge translation can also put the people with hearing impairment in the conditions to know how to directly and autonomously recalibrate their devices in the very moment in which these devices are used in specific contexts and sound environments. Early results from workshops and testing sessions show how individuals with hearing impairment felt an increased self-efficacy, a greater level of confidence that they could manage and adapt their hearing devices on the go and according to the specificities of the moment.

Currently, the process of calibration is mostly anchored to the studio of the audiologist as a pivotal element. Increasing the self-efficacy of hearing aids users means putting them in the condition to manage their hearing devices with a different level of granularity. We see this as a fine-grained and more contextually-anchored calibration process where patients feel empowered to operate with a higher degree of independence.

The case of 3D Tune-In shows how this self-efficacy and more granular management of hearing device was supported by processes of knowledge translation. In these processes, design was used to create a variety of artefacts, which could be easily circulated (e.g., diagrams), understood and appreciated (e.g., motion graphics videos) and which could immerse the individuals with hearing impairment and their family into emotionally and cognitively engaging virtual environments (e.g., simulators and videogames).

All this comes with some challenges, which are currently emerging when the audiologists use the 3D Tune-In apps. In particular, some of these audiologists are worried that the individuals with hearing impairment might feel that they do not need their professional support for the calibration process. These audiologists are convinced that a constant communication between patient and the professional remains a central element of the calibration process: increasing the self-efficacy of the individuals with hearing impairment might change established dynamics and put at risk validated medical protocols. In a way, the knowledge translation processes activated by 3D Tune-In might challenge the conventional power relations and the authority of the audiologist, echoing Callon and Latour’s points about power dynamics and negotiations in the act of translation (Callon & Latour, 1981).

At this stage, all this remains an open area of investigation, which will be further explored in the next months when the summative evaluation of 3D Tune-In comes to an end.

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Encouraging Physical Activity and Self-Enhancement in Women with Breast Cancer Through a Smart Bra

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Physical activity (PA) can have a substantial benefit in the prevention, treatment and rehabilitation of (breast) cancer. Wearable devices offer possibilities to monitor PA, to provide feedback and to set targets. Although the market for PA related wearable devices is booming, the impact of these wearables is questionable. One of the main concerns is the limitations to address individual needs of users, among which specific groups such as women with breast cancer. Through design, we see opportunities to stimulate for self-enhancement while encouraging PA after cancer treatment. Following a constructive design research approach, Aymée was designed. Aymée is a smart bra that changes its pattern based on the amount of PA. Through this interaction, Aymée aims to reinforce women recovering from breast cancer to feel good about themselves and to be (more) active. In this paper, we describe both the design approach in co-creation with former breast-cancer patients, as well as first results. We also discuss implications for designing intelligent systems that address PA encouragement.

physical activity; breast cancer; constructive design research; self-enhancement

1 Introduction

1.1 Breast cancer, body changes and PA

Worldwide, one of the most common cancers among women is breast cancer (Ma & Jemal, 2013). This cataclysmic event not only affects the health of the woman but also disrupts her daily life significantly. Bodily self-perceptions often deteriorate due to body changes (e.g., weight-gain, mastectomy, lumpectomy, hair loss) (Brunet, Sabiston & Burke, 2013), and physical activity (PA) levels may change due to physical barriers (e.g. mobility restrictions, lack of energy, fatigue, pain) (Brunet, Taran, Burke, & Sabiston, 2013).

Weight gain is a common disadvantageous effect of breast cancer treatment (Demark-Wahnefried et al., 2001; Demark-Wahnefried, Winer & Rimer, 1993; Goodwin et al., 1999) and is related to poorer survival in many studies (Holmes, Chen, Feskanich, Kroenke & Colditz, 2005). Even though this is an effect due to treatment, in general women are tended to feel a personal responsibility for their weight gain (Tiggemann & Rothblum, 1997) as a result of control failure. This might be reinforcement as women in treatment may struggle with feeling less in control over their bodies (Hefferon, Grealy, & Mutrie, 2010) due to other changes in their body, such as mastectomy, lumpectomy, hair loss. Additionally, research suggests that for a significant portion of women, in the early months after being diagnosed with breast cancer, these body changes negatively affect body-image (Fobair et al., 2006). Even long after the mastectomy operation, self-image is still often influenced negatively (Polivy, 1977). Due to the effects these body changes have on breast cancer patients, Brunet et al. (2013) state how important it is to be aware of these negative body-related emotional experiences, which even continue when cancer treatment is finished.

By use of make-up and the wearing of scarves, prosthetics, clothes, and wigs, women indicated that they were able to camouflage visible changes to their body affected by breast cancer (Brunet et al. 2013). Not only did these strategies camouflage the visible changes, but they also helped with self-enhancement and dealing with the negative emotions towards their changed body (Brunet et al. 2013). These strategies even persevered a long time after the end of the treatment. This suggests that the negative feelings towards body changes due to the cancer treatment are not erased for a long time.

Physical inactivity is a growing public health concern (World Health Organization, 2016) and it leads to a rise in non-communicable diseases (Blair, 2009; Blair et al., 1989; Chakravarty et al., 2012). Even though there are more physical barriers to be physically active for cancer patients, a growing number of studies provide evidence for the benefits of PA in cancer prevention, treatment and rehabilitation (McNeely et al., 2006; Monninkhof et al., 2007; Speck, Courneya, Måsse, Duval & Schmitz, 2010). One of the most important benefits is reducing the risk of death from this disease (Demark-Wahnefried et al., 2001). Moreover, a relation between lack of PA after diagnosis and weight gain has been found (Demark-Wahnefried et al., 2001) which in many studies is also related to poorer survival (Holmes et al., 2005). The positive effects of PA are not only influenced by strength and conditioning training, but also by daily activities such as walking (Holmes et al., 2005; McNeely et al., 2006).

1.2 Monitoring PA through wearable technology

In recent years, the consumer market for PA related monitoring devices has exponentially grown (Vos, Janssen, Goudsmit, Lauwerijssen & Brombacher, 2016). This increase in low-cost technology related to PA is consistent with more general trends such as the use of mobile computing and communication technologies in health care and public health (Fiordelli, Diviani & Schulz, 2013), and the self-monitoring of health outcomes (Swan, 2012). Wearable technologies have the potential to improve personal health outcomes and offer possibilities for early detection and monitoring of (chronic) diseases, remote care and self-management (Vos et al., 2016; Vos, 2016).

Well-known wearables brands such as Jawbone, Fitbit, Misfit, and Garmin have raised the public awareness of PA. Their wearable devices track daily activity on a 24/7 basis and provide feedback through accompanying smartphone apps. Nutrition, as well as sleep quality, are sometimes even included to sketch a complete picture of one's state of well-being. By creating cognitive awareness about the current lifestyle of the users, they try to persuade people to adopt a more active and healthy lifestyle (Shih, Han, Poole, Rosson & Carroll, 2015).

These innovations in smart wearable body sensors have created possibilities for people to become 'experts' in self-monitoring of PA on a 24/7 basis (Vos et al., 2016). Notwithstanding the above-mentioned opportunities for the domain of PA, many challenges need to be overcome. Although there is a general acceptance that people are different, most of these available consumer devices are still mainly based on underlying data models and design propositions following a 'one size fits all' approach in which, generic, standardized solutions will successfully address the needs of individual users (Vos et al., 2016). Furthermore, they seem to apply that ‘the numbers will tell the tale’. However, most people are not good at thinking statistically (i.e., quantitatively) but are good at thinking in stories (i.e., qualitatively) (Swan, 2014; Peeters & Megens, 2014). Moreover, standard approaches will not likely increase people’s motivation to be physically active. For example, studies have shown that people’s intrinsic motivation to exercise was not higher while training with a virtual coach, compared to people training without a coach (IJsselsteijn, de Kort, Bonants, de Jager & Westerink, 2004; Westerink et al., 2005). Hence, the impact of these wearables is questionable.

1.3 Design Opportunity

As current wearables do not address the needs of individual users, we aim to investigate whether it might be desired to design a more personalized approach of giving meaningful feedback about the PA level for former breast cancer patients. Brunet et al. (2013) have shown that wearables, such as clothes and scarves, provide strategies to feel better about body changes and to support self-enhancement. Hence, a design opportunity would be to create a wearable that, through self-enhancement of a garment, encourages PA. In this paper, we describe a constructive design research process that focusses on self-enhancement through a wearable that monitors PA. Within the discussion, we elaborate on opportunities to increase PA.

2 Design Process

In the next sections of this paper, the different steps of the constructive design research (Koskinen, Zimmerman, Binder, Redstrom & Wensveen, 2011) process are elaborated, explaining the different decisions that were made. First, a design exploration was made supported by a review of literature and an ideation session. Second, interviews were held with three former breast cancer patients and one breast cancer patient to learn about their experiences with breast cancer and being physically active. Third, a second design exploration was made to be tested in real life by one of the authors. Fourth, a co-creation session with three former breast cancer patients was held to indicate what preferences the final prototype should have. Fifth, the final design, Aymée, was realized and finally, Aymée was tested by two former breast cancer patients.

2.1 First Design Exploration

The start of the design process was to ideate different possibilities that aim to both encourage physical activity and positively the way the woman feels about herself and her body. Supported by a review of literature, different ideas were generated, such as an intelligent prosthesis that reassured the wearer that she can move without moving the prosthesis, or a bra whose strap would enlarge when there is no activity measured for a long period. However, neither ideas could contribute to positively influencing the way the wearer feels about herself. These iterations did include the use of a bra, probably due to its direct relation with the changed body affected by mastectomy or lumpectomy. As previous research indicates this relation to body changes is important to be aware of, the use of a bra seemed a suitable garment to design for. Previous work by Almeida et al. (2016) shows promising results in how the use of underwear can be an opportunity for intimate body-worn interactions.

The final chosen concept was a bra that changes its pattern based on the PA level, where a high activity level represents a more detailed and/or colourful pattern. This concept was further elaborated by doing several explorations on how to realize a changing pattern with the use of diffused LED, feathers, fabric movements and thermochromic inks. To avoid designing a bra with a high-tech feeling, it was essential to search for a pattern change that can be realized in a subtle and refined way. This was best realized with the use of thermochromic ink, a material that when applied to fabric becomes, becomes transparent if heated to a specific temperature. By mixing thermochromic ink with textile ink, it becomes possible to let the colour of the textile ink appear slowly by heating the fabric. Thermochromic ink can also be applied on fabric that already has a pattern; this makes it possible to hide the pattern but revealing it when heating the fabric. The tipping point of the thermochromic ink determines when the ink will become transparent. When using different thermochromic inks with different tipping points, the possibility arises to let colours and/or patterns appear one by one on a piece of fabric.

To realize a bra with a controllable changing pattern, a first design exploration was made (Figure 1). The elements that needed to be integrated within the bra, besides applying the pattern with use of thermochromic and textile ink, were a battery pack and a heating element to heat the fabric. Making this design exploration made it possible to communicate the final concept through a prototype.

Figure 1 First demo of Aymée. Left: cup before change of pattern, right: cup after change of pattern.

2.2 *Interviews*

Interviews were conducted with four respondents: three former breast cancer patients and one women who has breast cancer. A semi-structured format with an interview guide was used. All interviews were recorded and transcribed verbatim. The interview guide consisted of open-ended questions regarding the respondents' personal experiences with breast cancer and their perceptions about PA and wearables. The transcriptions of the interviews were manually coded based on a coding framework that was developed inductively. The coding frame and the content analyses were checked by the different members of the research team.

In the interviews, the personal impact of breast cancer was addressed. The interviewees emphasized that cancer did not only affect their physical well-being (lower energy level, weight-gain, mastectomy, hair loss), but also it affected their emotional well-being. The struggles of feeling like a patient instead of feeling like oneself were mentioned. One of the respondents stated:

> *I didn't feel like myself anymore. I'm not [interviewee name], I am a patient. That was the worst part…I'm not myself anymore, I had to give up my identity. (P1)*

Next, respondents indicated they used strategies, such as make-up, clothing, perfume, and lingerie, to feel feminine and beautiful, more after their experience with breast cancer. Why feeling feminine and beautiful became more important was explained by one of the respondents:

> *I have accepted it (about mastectomy), but I don't think it's pretty, I believe pretty is something different. (P1).*

One of the other respondents mentioned:

> *Mainly because your body is damaged, your body has changed, that is why it is even more important for me to look good. (P2)*

During the interviews, the importance of emotional well-being was confirmed, which is in line with previous research by Brunet et al. (2013), in which the importance of strategies that deal with negative emotions and that are used for self-enhancement are indicated.

At the end of the interviews, a demo of the first design exploration was presented to evaluate the first thoughts about a bra whose patterns transform based on the PA level. The concept to additionally encourage self-enhancement was not elaborated to avoid influencing the participants in the evaluation process. Based on the demo, the participants found it very hard to imagine what such a bra could mean to them as they were not able to wear the bra. Therefore, the decision was made to concretize the concept, so the participants were able to experience the bra.

2.3 Testing and Exploring

In the first design exploration, a bra was designed with a controllable pattern. However, this pattern was only controllable by turning it on/off via connection to the battery pack. A second design exploration had to be developed to make the pattern controllable based on the PA level. Because our aim is to stimulate daily PA, the bra should be able to measure the amount of PA throughout the day. Hence, a small microcontroller with an integrated accelerometer, Light Blue Bean, was implemented.

During the second design exploration, the limitations of small usage of thermochromic ink became evident. In theory, it is possible to create many variations in patterns when using thermochromic ink as it is possible to vary in different tipping points and control the heating elements to specific temperatures. However, due to the available variety of thermochromic ink tipping points (27°C, 31°C, and 47°C), real-life testing was necessary to experience which thermochromic ink already became transparent due to the effect body temperature has on the bra. The only ink that did not become transparent due to body temperature had a tipping point of 47°C. So by adding additional warmth (next to body temperature) with use of heating elements, the thermochromic ink became controllable. Unfortunately, this limited the possibilities in the variations of patterns and/or colours to only one change. Therefore, the bra will only change its pattern when the number of steps during the day is higher than the goal that was set up front.

The bra was tested in real-life conditions by one of the authors of this paper to calibrate the electronics (translating the data of accelerometer in a number of steps), and experience whether the heating elements are still comfortable when heated to 47°C. Furthermore, to enable the wearer to be in control of the heating elements, an interaction needed to be implemented so the wearer could indicate when she wants to see whether the goal is achieved or not. So even when the wearer already achieved her goal during the middle of the day, the pattern should not appear until the wearer indicates she wants to see it. During this first test in real-life conditions, different interactions with the bra were explored that considered several practicalities, such as accessibility and ease of use.

Integrating all these elements within a bra made it possible to monitor PA. The wearer of the bra could see whether her PA goal is achieved, by pushing a button which let the microcontroller turn on (or stay off, depending on whether the goal is achieved) the heating elements. As a consequence, the thermochromic ink becomes transparent, and the pattern and/or colour on the bra will appear.

2.4 Co-creation

In co-creation sessions with the three former breast cancer patients, user requirements were defined (Figure 2). The participants were presented with three different design sketches that vary in garment (bra, sports bra, and tank top), pattern (lace, animal print, and geometrical print) and the way the patterns transitioned (new print, asymmetrical, and filling in the pattern). The three sketches were discussed, to gain insights into the individual designs. While comparing the different designs, the participants immediately began to talk in terms of ‘preferences’. Different combinations of design and shape were thought of as the ‘ideal’ wearable that represented their PA level. Evidence for the importance of using this technique, before realizing the prototypes, was found when the three participants indicated different preferable combinations in design, shape, and transition. Two of the participants indicated a preference for a bra; the third preferred a tank top. It was decided to design two different bras due to practicalities of integrating technology and heating elements.

Figure 2 co-creation session with former breast cancer patient.

2.5 *Aymée*

The final design was Aymée, a personalized bra that encourages former breast cancer patients to be more physically active by additionally stimulating the wearer to feel good about herself (Figure 3). When the wearer reaches her desired PA level and wants to reflect upon this, Aymée will change from a 'normal' dark bra to a bra that reveals a beautiful pattern.

The transformation within Aymée aims to stimulate reflection moments on the daily PA level. However, by linking the PA level with a pattern on a bra, which is directly associated with the place of the cancer, a psychological effect is pursued: Aymée aims to complement the overall appearance of the wearer and stimulates the feeling of self-enhancement by encouraging her to feel proud of her achievement.

As the Light Blue Bean was a valuable approach to measure PA during the real-life testing, this microcontroller was also implemented in Aymée. For the pattern change, two black thermochromic inks were used with two different tipping points. The first tipping point was at 31°C and the second at 47°C. Before wearing the bra, the bra appears to be entirely dark. After wearing it for the entire day, the parts that are covered with the thermochromic ink with the tipping point at 31°C would already reveal a part of the pattern. When the wearer wants to see whether she achieved her daily PA goal, she pushes a button in the centre of the bra and the microcontroller will turn on the heating elements (if the PA goal is reached). By doing this, the thermochromic ink with the tipping point of 47°C will become transparent and reveal the last parts of the pattern.

Figure 3 two variations of Aymée worn by former breast cancer patients; P1 on the left, P2 on the right.

2.6 User Evaluation

To evaluate whether the transformation of Aymée contributes to how the wearer sees herself and how this affected her PA level, Aymée was worn for five days in a row by the two former breast cancer patients (Figure 3) with a preference for a bra. One of the participants (patient 1 –P1) was 57 years old, survived from breast cancer twice and wears a prosthesis due to a mastectomy. The other participant (patient 2 –P2) was 50 years old, recently survived breast cancer and had a reconstruction. To compare the monitoring of and feedback on the PA-levels by Aymée with a traditional wearable providing feedback through numbers and graphs on a smartphone, the patients also wore a Jawbone Up2. The patients were told this wearable was used to calibrate the electronics of Aymée to avoid influencing the participants up front.

Interviews were conducted with the two participants. A semi-structured format with an interview guide was used. All interviews were recorded and transcribed verbatim. The interview guide consisted of open-ended questions regarding the respondent's experiences with Jawbone Up2 and Aymée. The transcriptions of the interviews were manually coded based on a coding framework that was developed inductively. The coding frame and the content analyses were checked by the different members of the research team.

2.6.1 Pride

One of the first aspects addressed in the interviews was pride. Both participants were very positive about the use of the bra to receive feedback about the level of PA. Their feeling of pride was reinforced due to the change of pattern on the bra. A possible explanation for this can be found in the intuitive connection between the goal (being active) and why it is so important (prognosis cancer). The respondents stated:

> *If I hadn't been sick and I would have only worn a wrist wearable, I still would have been proud. Yet, I believe proud in a different way and fulfilled as how I felt with the bra. Because this is linked to my illness. (P2)*

> *It is nearby because it is on your body, it's more like: that's something I did … you feel like: I was able to make it (Aymée) change its colour (P1)*

This intuitive connection contributed the wearer in accepting her new body but also in converting this feeling into pride. Feeling proud to conquer cancer and being able to be active again. The following extract describes this view:

> *I don't have to be embarrassed about anything. I've been through something hard, so I can be so proud of myself that I look the way I do. (P2)*

2.6.2 Shift of Goal

The respondents indicated that they checked the application on the smartphone (connected to the Jawbone Up2) during the day to see if they had reached their activity goal. Within this application, a graph of the PA level is presented. This helped the participants reflect upon their PA level but when they saw they reached their goal, 'nothing' additional happened. The participants mentioned making Aymée change its pattern was considered as a goal itself. So there was a shift of goal: from trying to be active, to being active to change the pattern. One of the respondents explained:

> *Look, this graph says nothing to me. I mean look, you only check whether you have reached your goal or not. But this (Aymée) is a goal on its own, that it will change of colour. (P1)*

As this shift of goal was achieved, Aymée had an influence on the participant's mood. The feeling of joy and disappointment was considered bigger when (not) reaching the daily activity goal, as appears from the following extracts:

> *This (Aymée) had an impact on my entire mood. Primarily feeling proud and fulfilled…This is more personal than something on your wrist. Because this is really addressing femininity. This has way more impact when it doesn't work (change of colour) than Jawbone has. (P2)*

2.6.3 Personal

Jawbone Up2 was considered stand-off and generic. Moreover, due to its visibility, it raised questions from people around the participants about the function of the product. The participants continuously referred to Jawbone Up2 as a 'pedometer'. The interviewees expressed it as follows:

> *With such a wearable (Jawbone) everybody thinks, o yes that's a pedometer. But this (Aymée), nobody will, this is just for me. (P1)*
>
> *This is more personal (Aymée), that is more distant (Jawbone). The bra is more intimate. (P2)*

These extracts also indicate the increased intimacy level of Aymée. The participants had a feeling it was closer to their body than Jawbone Up2. This is probably again related to the placing of the product and Aymée's connection with the illness itself (i.e., bra and breast cancer). The following extract describes these perceptions:

> *Actually, I feel it is a really beautiful way to show how important being active is. And precisely because it's a bra, I was maybe even more conscious of this. A wrist-wearable, for me this (Aymée) feels more special to achieve that goal. (P2)*

3 Discussion

The aim of the study was to investigate if self-enhancement can be achieved among former breast cancer patients by use of a more personalized approach to giving meaningful feedback through a wearable that monitors PA. As previous research has indicated current wearables that monitor PA lack personalization (Vos et al., 2016). Thus, addressing individual needs of former breast cancer patients should be considered important due to the awareness of negative body-related emotional experiences (Brunet et al., 2013). In this study, we have seen that by addressing these individual needs it is possible to design interactions in a different and distinctive way, and a wearable that takes that into consideration has promising results for self-enhancement.

Providing feedback on PA level through a pattern change on the bra resulted in a goal shift among the participants in the study. Instead of the familiar way of using numbers and graphs as feedback on PA level, the pattern change of Aymée, based on PA level, allowed the wearer to experience this kind of feedback differently. Where PA monitors ask you to interpret graphs and statistics, Aymée asks the wearer to look in the mirror and see the result of that day, both on the bra but also on your body. This shows the potential and importance of context related wearables that combines feedback with the individual needs of the users, where being physically active becomes a means to an end.

By giving the feedback on the PA level on a bra, Aymée also increased the intimacy level in its interaction with the wearer. The feedback of Aymée is, therefore, more personal and intimate, and only available to the wearer. This affected their mood and how they felt about their PA level more directly. For example, they felt a great sense of achievement when their daily goal was reached. On the other hand, this could also result in a greater disappointment when the goal was not achieved during that day, as the first test also showed. Both are a result of the interactions in such a personal and intimate way.

In this study, a constructive design research approach was used. Typical for this kind of design research is that the prototype (or a different construction) is the centre and starting point of constructing knowledge (Koskinen et al., 2011). By doing this, it was possible to communicate the final concept better and therefore enabled the possibility of co-creation. With this approach, the individual needs of the users could be addressed and implemented in the final designs of Aymée.

Some limitations and questions for further research can be highlighted. The user testing of Aymée was limited to two former breast cancer patients based on which we cannot generalize our results. However, for both women in our study, several themes appeared to be of importance, which might indicate promising results. Another limitation was the use of semi-structured interviews to gain more insight into the influence of breast cancer on the women's self-esteem. A validated instrument, such as The Rosenberg Self-Esteem Scale (Rosenberg, 1965), could have provided more detailed information. However, due to the vulnerability and sensitiveness of the subject, we decided to use interviews (Baumeister, Campbell, Krueger & Vohs, 2003).

Changes of the bra are dependent on the taste of the wearer. If a wearer already dislikes the pattern, it is hard to reach a positive effect on self-enhancement and eventually on the PA level. In this study, the main goal was not to seek for a pattern that suits most people but to examine the effect of such a pattern change, based on PA level, can mean on the wearer. By use of co-creation sessions, their preferences became clear. When designing for a larger group of participants, it will be more difficult to implement all these preferences. However, it shows the potential of the use of this kind of products for PA wearables as they can be just as diverse as current bras. This is contrary to the 'one size fits all' principle used within the current consumer wearables.

In the current design of Aymée, one reflection moment about the PA level is stimulated at the end of the day whereas, for most wearables that monitor PA level, it is possible to reflect upon the PA level every moment of the day due to the accessibility of looking at the application. Aymée, therefore, limits the wearer to only one reflection moment and affects whether the wearer can already anticipate on her PA level throughout the day. Further research should be conducted to provide more reflection moments to the wearer.

Our design showed a promise for designing interactions and feedback of daily activity in a different and distinctive way compared to most consumer available wearables. The user evaluation also provided evidence for a more personal interaction with its users. The question that arises is whether this first step can lead towards (sustainable) behaviour change related to physical activity. In this paper, we described a constructive design research approach of a wearable aimed at self-enhancement. The assumption that is in question here is whether this self-enhancement leads to physical activity over time. To investigate this assumption, a longitudinal study with a baseline measurement is required to measure whether this effect will arise. This asks for a more robust prototype that can be used autonomously for a longer period. We see opportunities to develop these kinds of prototypes and evaluate them in such a longitudinal study through living labs or experiential design landscapes approaches (Peeters, Megens, Hummels, Brombacher & IJsselsteijn, 2013).

Furthermore, although within this study we only focused on former breast cancer patients, we do also see the promises of self-enhancement through PA for other groups of people, as this type of feedback proves to be more personal and motivational than the current standards. New studies and design processes are needed to develop these new kinds of design proposals.

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A Qualitative Study on Turkish Medical Device Manufacturers and the Attention They Place on Human-Centred Design

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Turkey has a rapidly growing medical device industry, yet the domestic market is mainly dependent on import trade products. It is also claimed that there is a prejudice against 'Made in Turkey' branded medical devices both in the domestic and Global market. In this research, it was hypothesised that the problem could be caused by the limited attention paid on human-centred design among Turkish medical device manufacturers; because the importance of human-centred design is drawing more attention in Today's healthcare industry. For this purpose, semi-structured interviews were carried out with manufacturers in Expomed 2017 Medical Devices Fair. Due to the fact that human-centred design is an umbrella term covering several aspects of good design, six of its important topics related to medical device designs were examined: Medical Device Usability, Patient Safety, User Interface, Use Errors, User Experience, and Ergonomics and Human Factors. The results suggested that although the manufacturers had an overall understanding of human-centred design, they mainly take its important aspects into account as much as the regulations oblige.

medical device design, human-centred design, Turkish medical device market

1 Introduction

The medical device market is one of the fast developing and competitive markets in the world. The global market is led by the USA with a market share of 49%; and Japan, German, China, France and the United Kingdom are other important competitors with their important manufacturers (The Ministry of Health, 2016). Although the size of the market also grows steadily in Turkey, it accounts only for the 1% of the Global medical device market (The Ministry of Health, 2016). According to "The Action Plan and Strategic Document of Turkish Medical Device Sector" published by the Ministry Health of Turkey, there are around 1000 medical device manufacturers in Turkey; however, most of them produce low-tech products, while the high-tech systems or materials are mainly imported from the leading countries. Besides, the domestic market is also mostly dependent on import trade products that cover the 85% of the overall market (Gumustekin, 2017).

Although Turkish medical device regulations are harmonised with the regulations of the European Commission, which means that a medical device produced in Turkey also needs to acquire a CE mark and then can be freely sold all through the EU market (The Ministry of Development, 2014), there is still a prejudice against the medical devices 'Made in Turkey', even within the domestic market. Design-related shortcomings could be an important cause of this issue; because it is hypothesised that currently medical device development processes are mainly engineering-oriented, and therefore, design-related improvements are necessary to change this negative image into positive in time. Supportively, the Technology Development Foundation of Turkey (in their report on medical devices sector of Turkey) also emphasises the importance of industrial design to provide products with high added value, yet argues on its undervalue within the R&D processes among manufacturers (Kiper, 2013).

On the other hand, as suggested by Buckle et al. (2003), when the medical system and its users are understood clearly, design can significantly enhance safety of both clinicians and patients. They also add that this helps the industry to add value and differentiate their products by providing good and safe designs (Buckle, 2013). Human-centred design comes into prominence in this respect; and as suggested by Harte et al. (2014), manufacturers with a lack of adherence to human-centred design during their development processes might even encounter product recalls due to unexpected device outcomes or product-user interaction problems. Therefore, human-centred design could be a key requirement to enhance the image and potential of Turkish medical devices industry; because a previous qualitative research conducted with medical device retailers in Turkey, which focussed on the usability aspect of Turkish production medical devices, also provided supporting results that manufacturers do not pay sufficient attention to usability when developing their medical devices, whereas the end users regard it as an important factor (Cifter & Eroglu, 2013). However, usability is only one aspect of human-centred design, which is an umbrella term covering several inter-related aspects of good design (Harte, 2014). As a part of this research, a literature review study was carried out in order to identify the other topics that are critical for designing medical devices; and six main topics in total were identified as: Medical Device Usability, Patient Safety, User Interface, Use Errors, User Experience, and Ergonomics and Human Factors. These aspects are shortly introduced in Table 1 with their relation to designing medical devices:

Table 1: Six human-centred design aspects for designing medical devices that are focussed within the scope of this research.

Medical Device Usability	As suggested by Wiklund et al. (2011), the general usability of medical devices is directly related to device safety, and usability testing enables identifying the use-related hazards, which is important for the overall risk management procedure. In this respect, IEC 62366-1:2015 Medical Devices – Application of Usability Engineering to Medical Devices (IEC, 2015) provides a good process model and valuable guidance to designers and manufacturers of medical devices. There are several studies in the literature, focussing on the usability aspects of medical devices. For example, a study performed by Fung et al. (Fung, Igodan, et al., 2015; Fung, Martin, et al., 2015) on the usability of positive airway pressure devices for the treatment of sleep apnea revealed that lay users with physical and/or sensory impairments experience many design-related difficulties while using the devices; and such interaction problems may result in increased frustration for patients. Similarly, Schaeffer et al. (2015) identified several usability problems for lay users in their studies with infusion pumps, and they recommended that human factors methods be implemented in the design process to optimise device usability before product commercialisation. As could be seen, usability inspection is an important aspect of the medical device development procedure. Usability testing is also linked with hazard analysis that is also a topic of regulatory obligations for manufacturers of medical devices.

Patient Safety	Patient safety is a board concept, which not only covers reducing and mitigating medical errors, but also aims to improve wellbeing of clinicians (Carayon, 2014); because it is related to optimising their physical, cognitive and behavioural/social performances (Karsh et al., 2006). Under this topic, it is also critical to take into account the diverse needs of users, the range of scenarios and the environments in which the device will possibly be used (NHS, 2010). With the emergence of home use medical devices, all these aspects have become a challenge for designers (Gardner-Bonneau, 2011). In this respect, the design of the system is critical in reducing adverse outcomes, and a range of factors including "patient", "task", "technology and tool", "environmental", "organisational" and "external environment" (which means that any environment outside but related to that system) factors are important to take into account during the design process (Karsh et al., 2006). In addition, evidence-based design strategies, which mean using the design input from the best credible research available, are also recommended to ensure the patient-centeredness of the design outcome (Henriksen, 2014). There are many product adverse event reports caused by design related problems, which are available in MAUDE database of FDA, and that could be useful for designers as an input in their design processes.
User Interface	According to FDA (2016), user interface covers “all points of interaction between the user and the device, including all elements of the device which the user interacts (i.e. those parts of the device that users see, hear, touch)” (p. 1). Therefore it covers both physical and digital aspects of medical device designs. User interfaces are also closely linked with environmental factors and device users (FDA, 2016). In general, the users of medical devices can provide considerable information about present problems with products that emerge from the misfit between their capabilities and the device features such as their controls, displays and their arrangement in relation to each other (Henriksen, 2012). In this respect usability testing could provide valuable information about the design of the interface. For example, the research of Fairbanks and Caplan (2004) on the design evaluation of defibrillators presents a case study which highlights the importance of user interface design in the field of medical devices, in which they identified several usability problems directly related to user interface designs. User interface design is also linked with use errors and ergonomics and human factors aspects of medical devices.
Use Errors	There are three types of errors; i.e. slips, lapses and mistakes (ISO 14971, 2007). A slip occurs when the action is not conducted as intended, while lapses means misses of actions due to memory or attention failure (Kohn et al., 2010). On the other hand, mistakes happen when the action proceeds as planned but fail because it is the wrong action to achieve the intended outcome (to err is human). There are also violations, which are caused by deliberate deviations from safe operating practices (Vincent et al, 1998). On the other hand, as highlighted in ISO 14971, user interface design features such as physical design and layout, ergonomic features or hierarchy of operation can also contribute to the use errors if they are insufficiently cared during the design process. As recommended by Israelski and Muto (2014), “use error can be addressed and minimised by the device designer and proactively identified through the use of techniques such as usability testing and hazard analysis” (p. 477). Hazards could be categorised under three categories as use related hazards, device failure hazards and overlap hazards covering both failures; and they need to be assessed as a part of risk management procedure during medical device development processes (FDA, 2016).
User Experience	User experience design covers both short and long term experiences and should become a regular requirement for all medical products and services (Mival and Benyon, 2015). Thanks to the increase of home use medical devices in the healthcare market, today the users of medical devices are very diverse (Cifter, 2011); and all these users may have different expectations from the products they use. Negative user experiences may result in stigmatisation or frustration of patients (Harte et al, 2014), which might

	result in decreased motivation in their treatments. As suggested by Wiklund & Weinger (2011), the “devices that are easy to use, as well as appealing to view and touch will engender greater user satisfaction” (p. 21). In this respect, the concept covers the needs and requirements of both professional users (e.g. doctors and nurses) and lay users (e.g. patients and nurses). The research of Lang et al. (2013) on PEP devices provides a good example of the significance of user experience in medical device industry, in which device designs are evaluated regarding their satisfaction among adolescent users and they recommend that design of the device should also support the socio-cultural and psychological needs for higher user satisfaction of their users.
Ergonomics and Human Factors	Hignett et al. (2013) argue that the human factors and ergonomics techniques have been increasingly applied to healthcare contexts since the past decade, and this provided an improved understanding and knowledge of the significance of the topic in relation to patient safety. It is also highlighted in medical device regulations of the European Parliament and of the Council that ergonomic features of medical devices must be paid attention during their design and development processes (EC, 2017). As suggested by Carayon et al. (2014), "many patient safety incidents are related to human factors and ergonomics (HFE) in the design and implementation of technologies, processes, workflows, jobs, teams and socio-technical system domains" (p. 196). They recommend four mechanisms to improve patient safety by implementing human factors and ergonomics into the process: (1) errors and hazards are likely to occur if a work system is not designed in accordance with human factors and ergonomics principles; (2) performance obstacles in a system can reduce the performance of clinicians and might prevent them from delivering safe care for patients; (3) resilience of the system is necessary in order to assist its users to detect, adapt to, and/or recover from errors, hazards and other negative disturbances; and (4) human factors and ergonomics cannot focus on one element in isolation, because the other components of the system are also likely to affect patient safety (Carayon et al., 2014). It is also important to work closely with clinicians and sustain long-term partnerships to understand the complexities of the system and shape it together (Hignett, 2013).

As it can be seen from the table, all these six aspects are interlinked with each other, and in many cases, it is not possible to ensure one without taking the others into account. Although the relevant literature highlights the importance of these topics in relation to the human-centred design of medical devices, their levels of implementation during medical device development processes are not clear in Turkey. In this respect, this paper present the results of a study of semi-structured interviews with a group of Turkish medical device producers and evaluate their understanding of human-centred design by using these six aspects.

2 Study Method

Currently, there are limited written resources available, focusing on Turkish medical device domain from a human-centred design perspective; therefore, this research adopts a qualitative approach in an effort to reveal tacit knowledge. Face-to-face semi-interviews were considered to be appropriate for this research; because the main intention was to collect in-depth information (Tracy, 2013) directly from medical device manufacturers. Semi-structured interviews were used; because the interviewer had a list of questions, but in certain cases, modified or changed the order of questions based on the flow of the interview (Robson, 2011). This is a flexible approach and generally used in small scale researches where the interviewer is also the researcher (Robson, 2011).

All of the interviews were conducted in Expomed Eurasia 2017 Fair (29 March-2 April 2017 / TUYAP Istanbul). Expomed is one of the biggest fairs of Turkish healthcare industry, and this year there were 34,086 visitors,4,972 of which were international visitors coming from 86 countries (Expomed, 2017). In order to select the interviewees, four criteria were sought:

- Manufacturers were expected to be located in Turkey
- 50% of their products were expected to be of their own production
- An authorised person who had detailed knowledge about the R&D procedure of the company was required to be available
- Agreed to take part and share up to 30 minutes for the interview

Based on these criteria, face-to-face interviews were performed with 17 manufacturers, and it took around 15-20 minutes for each. Due to the predetermined criteria, purposive sampling was used as the main sampling method in this research (Robson, 2011; Yildirim & Simsek, 2016). During the interviews, the researcher took detailed field notes on ready-prepared interview templates prepared for each participant. Due to the fact that this research adopted a qualitative descriptive approach, thematic analysis was utilised for data analysis.

The list of companies and their details (sizes and production lines) are presented in Table 2. One of the companies did not agree to share information about their company size. In order to ensure the anonymity of the participant manufacturers, a unique code starting with “C” is given to each of them. Their sizes are determined with the number of people working in each of the participant company; i.e. Micro: 1-9; Small 10-49; Middle: 50-250; Large: 250+. As could also be seen from the table, the production lines of the companies cover a diverse range of products.

Table 2 Company sizes and production lines of participant manufacturers

CODE	SIZES	PRODUCTION LINE
C1	Medium	Wound & burn treatment
C2	Large	MRI machine
C3	Small	Anaesthesia devices, ventilators, surgical tables
C4	Small	Operating room integration systems, urodynamic systems
C5	Large	Surgical tables, operating room lighting systems, medical aspirators
C6	Small	CPAP device, sleep apnea detection devices, medical aspirators
C7	Small	Sterilisation devices
C8	Small	CPAP device, medical aspirators, nebulisers
C9	Medium	Intensive care and new-born units
C10	NA	Sterilisation devices, surgical tables, operating room
C11	Micro	Wearable ECG device
C12	Micro	Pulse oximeter, inhalers
C13	Small	CPAP device, ventilators
C14	Medium	ECG device, medical aspirators, nebulisers
C15	Medium	CPAP device, inhalation devices, defibrillator, surgical tables
C16	Medium	Sterilisation devices, surgical aspirators
C17	Medium	Surgical tables, medical lighting systems, surgical aspirators

3 Results

The open-ended questions enabled the collection of data in four areas, i.e. (1) the company structures of the participant manufacturers, (2) their considerations on the value given to industrial design in Turkish medical device industry, (3) their general product development processes, and (4) their understanding of human-centred design with respect to the six topics focussed in the scope of this research. These aspects are discussed separately in this section.

3.1 Company Structures of the Manufacturers

The results suggested that 11 out of the 17 participating manufacturers (65%) had an internal R&D Department and 4 of those also had an internal Design Department for their product development.

On the other hand, only 4 of the companies employed at least one in-house industrial designer. Seven manufacturers stated that they worked with local and/or international design consultancies in order to meet their design related requirements. Other companies expressed that their design activities were carried out either by their engineers who were not gathered under a departmental establishment (3 participants) or company owners who had the product idea and were entrepreneurs themselves (3 participants). As it can be seen from the results, an important percentage of participants did not incorporate designers in their product development processes and rather adopted an engineering oriented approach.

3.2 Value of Industrial Design in Medical Device Sector in Turkey

The participants were asked about the value of industrial design in Turkish medical device sector and their responses were coded and gathered under 6 categories, which can be seen in Figure 1.

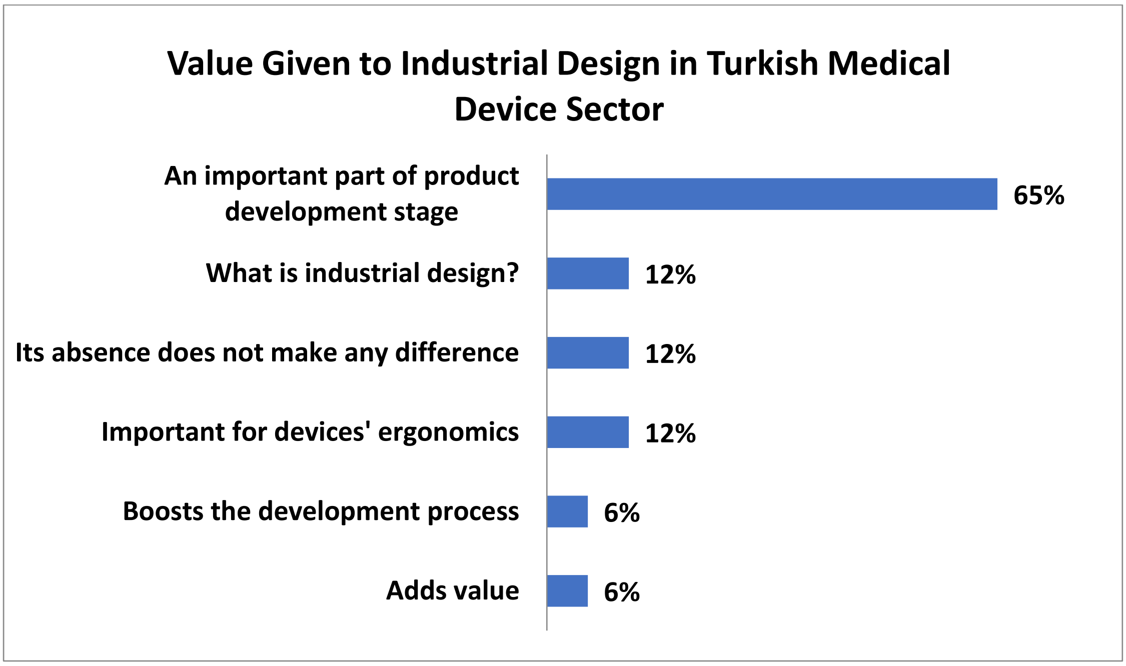

Figure 1: The value given toindustrial design in Turkish medical device sector

The results suggested that more than half of the respondents qualified industrial design as an important part of the product development stage of medical devices. A number of manufacturers also highlighted the importance of design activity in their processes, because they thought that designers provide multifaceted solutions that are important in such a highly competitive and global market. They also indicated that a structured design process also reduces the time required for their products to get into market.

On the other hand, two respondents argued that industrial design was not an important aspect of a medical device development process when compared to engineering requirements and its absence did not make much of a difference. Surprisingly, two other respondents were not even aware of what industrial design was and asked about it to the researcher.

The results showed that the number of manufacturers preferred cooperating with design consultancies outnumbered the manufacturers that employed an in-house industrial designer. According to the results, the reasons are summarised below:

- Cooperating with design consultancies provides richer design solutions
- There is a lack of competent designers working in medical device sector
- Due to the fact that designers get involved in the product development processes only at certain stages, it is more cost effective to cooperate with design consultancies

As it can be seen from the results, the value of industrial design still requires further improvements in the sector and more competent design consultancies are needed to support this.

3.3 Product Development Processes of the Manufacturers

The companies were asked to summarise the stages of their product development processes and based on their responses; six common stages were identified as:

- Identification of user requirements
- Field research for developing design specifications
- Design and Development
- Design testing
- Design evaluation and verification
- Validation

Figure 2 presents the percentages of manufacturers that each of these stages applicable to their own product development processes.

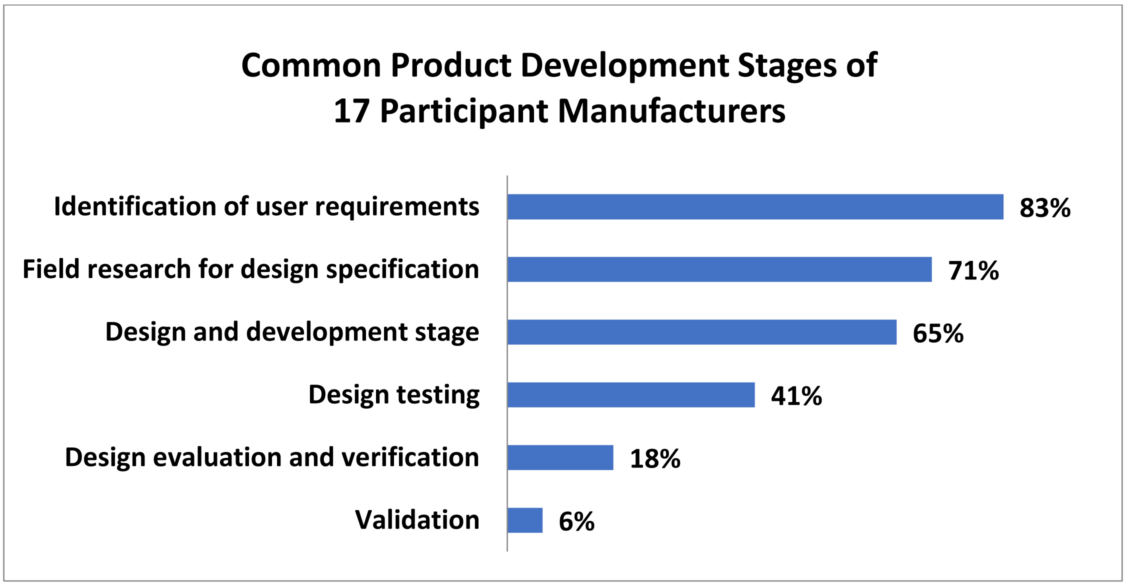

Figure 2: Common stages of product development of participant companies and their percentages

As it can be seen from the Figure, most of the companies expressed that they put effort in identifying user requirements as a part of their product development processes. For this purpose, they stated that they carried out user research activities (such as interviews) and market analysis as the first stage of their processes. They also expressed that in some cases, the product development started with a demand coming from medical professionals emerging from their professional requirements.

Field research for developing design specifications was also the second most mentioned stage by the participants; which means that the manufacturers valued collecting information directly from the context in which the device is intended to be used. Respondents mentioned that they worked closely with clinicians as consultants and observe their practices in this stage. As an outcome of this stage, they combine the information gathered from user research, market analysis and field research, and generate design specifications for their product development activity.

From the interviews, it was learned that participating the design and development stages of the manufacturers cover industrial design (N: 7/17), software development for electronic devices (N: 5/17), product engineering development (N: 8/17) and prototyping (N: 6/17) activities. The results suggested that most of the manufacturers did not treat industrial design as a specific stage of their product development processes.

It was seen that the design testing stage covered the introduction of a functional or semi-functional prototype to a limited number of clinicians and getting their feedback. This was not a clinical trial stage, instead could be considered as an extension of design and development stage. This stage was mentioned by less than a half of the manufacturers during the interviews.

Three manufacturers also expressed that they had an evaluation and design verification stage, in which they assess whether they met the predetermined design criteria. This was mentioned by only 3 participant manufacturers as a specific part of their own product development processes.

Finally, only one manufacturer mentioned that they carried out a validation activity, which was highlighted as a unique stage of a medical device design development process in the relevant literature (FDA, 1997; Alexander et al., 2001).

As it can be seen from the results, although most of the manufacturers stated that they valued user requirements and carried out user and field researches as important stages of their product development processes, they mainly involved users at the initial part of their processes. Design testing, as a specific stage, was carried out by less than a half of the participant manufacturers, and user research and design/development stages were generally isolated from each other. This was considered to be the result of working with no designers/external designers (N: 6/17) and/or not being aware of the importance of human-centred design in this domain.

3.4 Human Centeredness of the Design Processes of the Respondents

In order to understand the human centeredness of the design processes of participant manufacturers, a specific question on each of the six human-centred design aspects was directed. Two of the interviewees did not answer these questions, because they argued that their design activities were completely carried out by external design consultancies. Therefore, they are excluded in the results in this section. The results regarding the percentages of manufacturers (N: 15) interviewed fulfilling each of these aspects "to a certain extent" are presented in Figure 3.

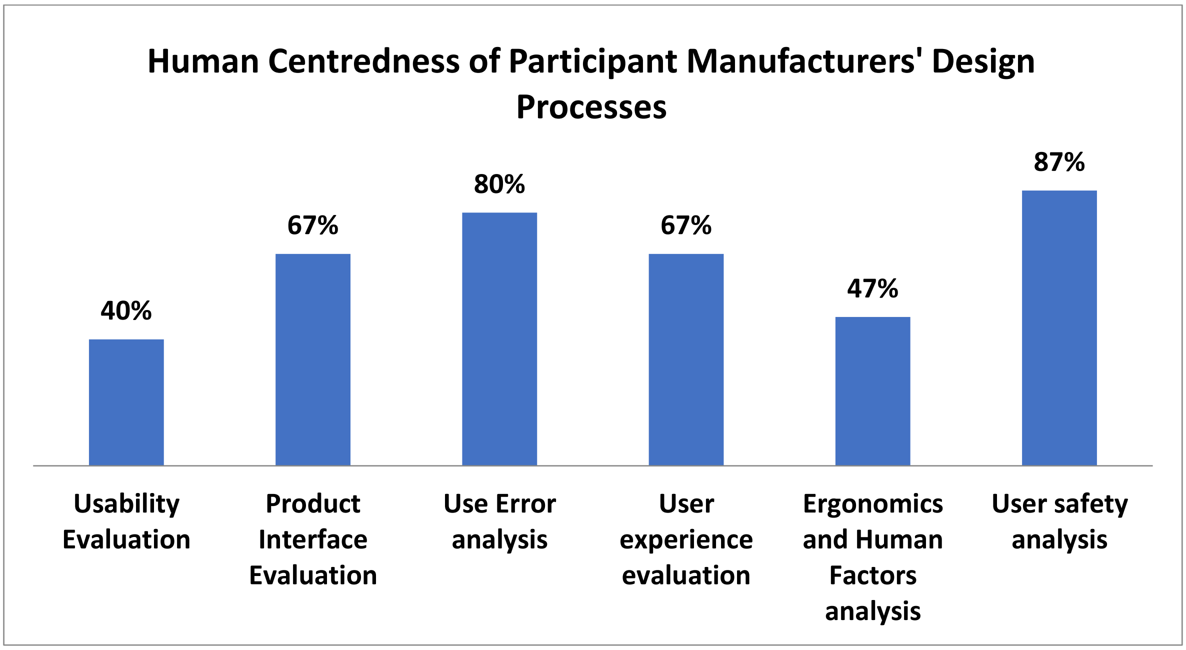

Figure 3: The percentages of manufacturers fulfilling each of the six aspects of human-centred design in their product development processes

As it can be seen from the Figure, most of the manufacturers claimed that they assessed their products in terms of user safety and use error. Regarding both aspects, the interviewees expressed that, as a part of the regulatory requirements, they had to carry out certain tests and analysis (such as clinical trials) and document them in order to obtain a CE certificate for their products. Only 4 out of the 15 participants stated that they conducted risk analysis activities. On the other hand, 3 participants mentioned that they provided user training activities for their customers to support prevention of use errors (C7, C15 and C16).

Regarding user experience, the participants expressed that they collected this data from the feedbacks of the users regarding the previous versions of the product, and used this information as a design input during the new product development process. 7 manufacturers also mentioned that they invited the potential users and got their feedbacks too. Similarly, for product interface evaluation, the manufacturers (N: 8) expressed that they kept in close contact with medical professionals (doctors, nurses and other hospital staff) who provide consultancy in the product development process and provide feedback based on their expert opinions. Only 4 participants (C5, C9 and C15) stated that they performed product interface evaluations, which are in fact conducted within the usability testing stage in an effort to meet the requirements of ISO 62366-1:2015 Medical Devices – Part 1: Application of usability engineering to medical devices. One of the problems emphasised for both user experience and user product interface evaluations was that it was not possible to test certain types of medical devices extensively with users before getting the necessary certification due to patient safety concerns. 5 participants stated that they sent “DEMO” products to hospitals and get feedback directly from the field after obtaining the certificate.

On the other hand, only 3 participants expressed that they conducted research regarding the ergonomics and human factors aspects of their products. Apart from this, other 3 participants stated that they took user and environment variety, as well as, possible diverse use conditions for their products into consideration during their processes.

Finally, the results showed that usability evaluation is the least met human-centred design aspect among the participant manufacturers. Only 5 participants expressed that they applied usability testing methods during their product development processes and this was for the purpose of meeting certain regulatory requirements for certification. 4 other participants stated that they inspected usability during clinical trials; however, they did not provide any hints of using specific usability inspection methods or a structured approach; therefore not included in the results.

4 Discussion and Conclusions

The marketplace demands medical devices that not only satisfy functional requirements but also user needs and preferences (Wiklund & Wilcox, 2005; Wiklund & Weinger, 2011), and this emphasises the importance of human-centred design in this sector. In this research, manufacturers from Turkish medical device sector were investigated in terms of their understanding of human-centred design and also to what extent they fulfil its requirements in their product development processes. For this purpose, six topics were identified from the literature, which were considered to be particularly important by covering critical aspects of human-centred design: i.e. Medical Device Usability, Patient Safety, User Interface, Use Errors, User Experience, and Ergonomics and Human Factors.

The results of the semi-structured interviews with 17 medical device manufacturers provided hints that the product development processes are mainly engineering-oriented in Turkey; and therefore, there is still a need for increasing the awareness of industrial design and its possible positive impacts within the industry. One of the critical issues of the sector is that there is lack of competent designers working in this sector, therefore very few manufacturers employ in-house designers. It was also seen that companies prefer working with design consultancies due to cost advantages, their experience in the field and rich design solutions they provide. For this reason, it could be inferred that design consultancies could play a vital role in increasing the awareness of human-centred design in medical devices sector of Turkey and change the prejudice against “Made in Turkey” branded medical devices by providing good and safe medical device designs to Turkish manufacturers.

Moreover, it was inferred that most of the manufacturers interviewed involve users and research into their requirements mainly in the initial stages of their design and development processes, and afterwards focus on technical solutions. In addition, although the participants had an overall understanding of most of the human-centred design topics questioned in this research, they mainly take them into account as much as the regulations oblige them. Particularly safety related issues are paid more attention. On the other hand, no structured approaches were uttered during the interviews with respect to user experience and user interface evaluation aspects in particular. Therefore, these efforts are considered to be far from being adequate. Besides, ergonomics and human factors analysis and usability evaluation were the least met topics among the participant manufacturers in their product development stages.

Based on these findings, a number of recommendations are made for not only for Turkish medical devices industry, but also for other countries with growing medical device markets, so that they can use human-centred design as a catalyst for providing patient centred products and competing better in the Global market:

- The product development process of medical devices is more than meeting regulatory requirements of the target market. A human-centred design approach is necessary.
- Human-centred design is not only a stage in the process, therefore needs to be applied throughout the product development process of medical devices.
- Design consultancies with the knowledge and experience in medical device can play an important role in increasing the awareness of human-centred design among manufacturers in developing markets.
- Medical devices that are appealing, usable and developed with diverse user requirements in mind can provide safer products and better user experiences, which is necessary for competing in the Global market of medical devices.

One of the limitations of this research is that the number of manufacturers interviewed was very limited. Also, due to the busy environment of Expomed 2017 Fair, the interviews were kept short to maximum 30 minutes; hence, it was only possible to collect the overall information about the current state. As a following research, it is proposed to conduct follow-up interviews with the manufacturers whom are considered having an understanding of human-centred design, and get more in-depth information about the current barriers and possible actions that could be undertaken to assist Turkish medical device manufacturers.

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Do-It-Yourself Medical Devices: exploring their potential futures through design fiction

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With ever increasing demands on healthcare around the world, ensuring adequate provision for patients is becoming more and more challenging. In this paper, we focus on future healthcare provision, specifically looking at how Do-It-Yourself (DIY) Medical Devices might become widely adopted. Our motivation is to move beyond current debates, which tend to focus on technological capabilities, and instead consider the *implications* of those technologies for future policy and regulation. Discussions around the future are often challenging, as people find it difficult to envisage how disruptive technologies make futures that stand apart from their current and previous experiences. To facilitate these discussions, we use Design Fiction to speculate about a multi-purpose DIY Medical Device which can support various medical conditions. Using Design Fiction in this way allows us to concretize and explore a future world in which DIY Medical Devices exist, and thus enable meaningful discussions around the social and ethical implications of such DIY medical cultures.

DIY medical devices; design fiction; making; design futures

1 Introduction

DIY Healthcare has become a significant topic of discussion in medical and financial forums as they explore the potential of smart and wearable devices to provide greater accessibility to health monitoring and facilitate care in the home (Pang, Zheng, Tian, Kao-Walter, Dubova & Chen, 2015). One of the drivers for discussions is the proliferation of wearable fitness trackers such as *Jawbone* and *Fitbit* which are able to monitor aspects of their environment and their users' lives, display real-time data, and also to share this data with other devices:

> *In the rest of our lives we're seeing the difference that innovative tech makes, and now the NHS will have a streamlined way of getting ground-breaking and practical new technologies into the hands of patients… frontline nurses, doctors and other staff. By doing that, we can transform people's lives. (Stevens, cited in NHS England, 2016, para.11).*

Whilst research investigating the use of body-worn technology to collect data has been ongoing since the 1970s (Riphagen, Hout, Krijnen, & Gootjes, 2013), scholars have recently taken to appropriating Wolf and Kelly's (2010) term 'quantified self' to describe such work. Quantified self research examines all aspects of participants' daily lives including gathering data regards the food they eat, their sleep patterns, changes in mood and biometric information such as blood pressure and heart rate. It has been argued that quantified self tracking not only allows individuals to learn more about themselves, but may also help them take action to become healthier and improve their lives (Lee, 2013). A quantified self approach to DIY Healthcare is thus primarily driven by the value associated with data collection (Dimitrov, 2016), which historically, has been fundamental to improving public health and patient care, whether it was driving sanitary reforms in nineteenth century Europe, or recent quality improvement in surgery (Carrera and Dalton, 2014).

Involving patients in data collection using commercial devices as part of their treatment presents considerable challenges to expected norms, regulations and practices, but the notion of patients developing their *own* DIY Medical Devices is even more radical. This is not a new idea though; in 1965, Frederick Fascenelli presented '*Electrocardiography by Do-It-Yourself Radiotelemetry*' a proposal to allow anyone with basic electronics knowledge to build their own electrocardiogram machine and transmit results to their doctor (Greene, 2016). Although his device never took off – primarily due to the complexity of creation and use – Fascenelli was driven by the same desire to improve access to high quality healthcare through technology that we currently see promoted through DIY Healthcare. More recently the interest and discussions around DIY Medical Devices has seen a resurgence through association with the so-called 'Maker Culture'. Maker culture is a grass roots technology centric culture in which participants aim to create new devices, repair and reuse old ones, or to simply tinker. This activity has been enabled by the decreased cost of componentry, increased access to experimental hardware platforms and new forms of fabrication technologies.

The term Democratised Innovation (von Hippel, 2005) is also used to denote practices whereby products and services are developed by the same people who ultimately use them. Within traditional proprietary innovation models, designers and manufacturers exploit internal assets and intelligence to develop standardised, 'closed' products. Contrastingly, when developed with Democratised Innovation principles, knowledge, resources and technologies relating to new products are diffused quickly, efficiently, and more often than not, 'freely' through networks of online and offline communities. This collaborative activity results in products which directly benefit those who created them and frequently also have positive impacts on society at large (von Hippel, 2005).

In the case of DIY Medical Devices, this form of innovation is evident in a variety of emerging activities such as the proliferation of access and availability of 3D printing through 'fab labs' and 'maker spaces' which have provided wearers of prosthetics with new opportunities for designing and modifying their own prostheses (Buehler, Branham, Ali, Chang, Hofmann, Hurst & Kane, 2015). Demonstrating a DIY mind set, the convergence of the insulin pump with easy and efficient ways of connecting devices to the internet has resulted in insulin-dependent patients, frustrated with their pumps' limitations, sharing their personal continuous-glucose-monitoring data and strategies for augmenting their own devices, through online communities. Perhaps the most notable example of this is *Nightscout*[1] which is an open-source platform developed and run by a global community of patients with type-1 diabetes. The platform combines a CGM (Continuing Glucose Monitor) device which provides constant updates on glucose levels, a DIY data transmitter, and freely available software which enables the CGM data to be shared across throughout the community via cloud data storage (Lee, Hirschfeld & Wedding, 2016).

Fostering visions of technologies, in particular DIY medical devices, as things that users have a role in *producing* – as opposed to simply *using* – is a powerful, egalitarian idea, however, such practices also

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[1] www.nightscout.info

carry forward risks associated with individuals taking technologies on which their life depends, into their own hands. Regulation pertaining to the production of medical devices is in place to prevent risk to patients from equipment that has not undergone a rigorous approval process. Currently in the UK, Medical Devices are classified under European regulations (European Commission, 2017) before undergoing a certification assessment relative to the class of device. Depending on its intended purpose, a medical device may be classified within Class I, IIa, IIb or III, with Class III covering the highest risk products (GOV.UK, 2017). The higher the classification, the greater the level of assessment required. Classification of a medical device will depend upon several factors including:

- how long the device is intended to be in continuous use;
- whether or not the device is invasive or surgically invasive;
- whether the device is implantable or active;
- whether or not the device contains a substance, which in its own right is considered to be a medicinal substance and has action ancillary to that of the device (Halliday, Kutty & Rakos, 2017).

Classification is primarily the first step towards conformity assessment and obtaining the CE mark (a logo placed on medical devices to denote that they conform to the requirements in the regulations). The CE mark shows that the device is fit for its intended stated purpose and that it meets legislation designed to ensure patient safety. Further, such approval signifies that a product can be freely marketed and sold anywhere within the European Union. In the UK, this activity is overseen by the *Medicines and Healthcare Products Regulatory Agency* (MHRA) which is responsible for regulating medicines, medical devices and blood components for transfusion in the UK.[2]

In the context of Democratised Innovation, fulfilling these classification requirements can be prohibitively expensive and hence severely restricts the participation of those with the technical skills to create or modify their own devices, and subsequently stifles community growth. If we are to move beyond this situation we need to first conceive a future which accommodates the potential for future DIY Medical Devices to be fully exploited. However, getting authorities to engage with futures is often difficult as they can get bogged down within discussions of the present, that are, in turn, more often than not based upon the past (Gonzatto, van Amstel, Merkle & Hartmann, 2013) In this paper, we use Design Fiction to explicate a future in which the widespread utilisation of DIY Medical devices plausibly exists. Although the design fiction methodology is becoming increasingly well established, one of its foundational tenets is the power of the 'diegetic prototype', a concept whose foundations include the realisation that fictional representations of medical devices can have a profound influence over the publics' perception of *real* medical devices (Kirby, 2010).

2 What is Design Fiction?

Design Fiction sits within a range of design practices known as speculative design which focus on the values embodied within a particular design artefact rather than the intended use of the artefact. The main attributes that these speculative practices share is that they are: free from the commercial constraints that might limit the design process; use prototypes as the main method of enquiry; present these prototypes within fictional alternate past, presents, or futures; and, often exhibit an irreverent or playful quality as a means of engaging the audience (Coulton, Burnett & Gradinar, 2016). These practices enable designers to not only to question how things might be, but to also unpack *why things are, the way they are*. Design Fiction is a particular form of speculative design which prototypes potential futures where emerging technologies have been widely adopted in order to understand what the potential broader ethical and societal implications of those technologies might be (Lindley, Coulton & Sturdee, 2017).

As a result of Design Fiction still being an emerging field, there remains a number of conflicting definitions of what it is and what it is for. To make our position clear within this research, we

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[2] www.gov.uk/government/organisations/medicines-and-healthcare-products-regulatory-agency

consider Design Fiction as a *world building activity*. Whilst the critical intentionality of Design Fiction distinguishes it from similar corporate endeavours which present futures commensurate with values of the corporation (Coulton, Lindley, Sturdee & Stead, 2017). the *means* of Design Fiction (the objects and artefacts produced by practice) are diverse and varied, yet the primary aim of Design Fiction is always the creation of a fictional world:

> *Design Fictions are collections of artefacts, that, when viewed together build a fictional world. The artificially built world is a prototyping platform for the very designs that define it, meanwhile those designs reciprocate in kind and prototype the world. (Coulton et al, 2017, p. 15).*

We propose two useful metaphors for considering how the individual artefacts relate to the world. Firstly, let us imagine a Design Fiction world as a distinct entity, one that we can see the overall shape of, but whose complex internal structure is hidden from view. What *is* in view, however, are a series of entry points. As shown in Figure 1, each artefact that contributes to the creation of the Design Fiction also plays its role as a metaphorical entry point to the fictional world.

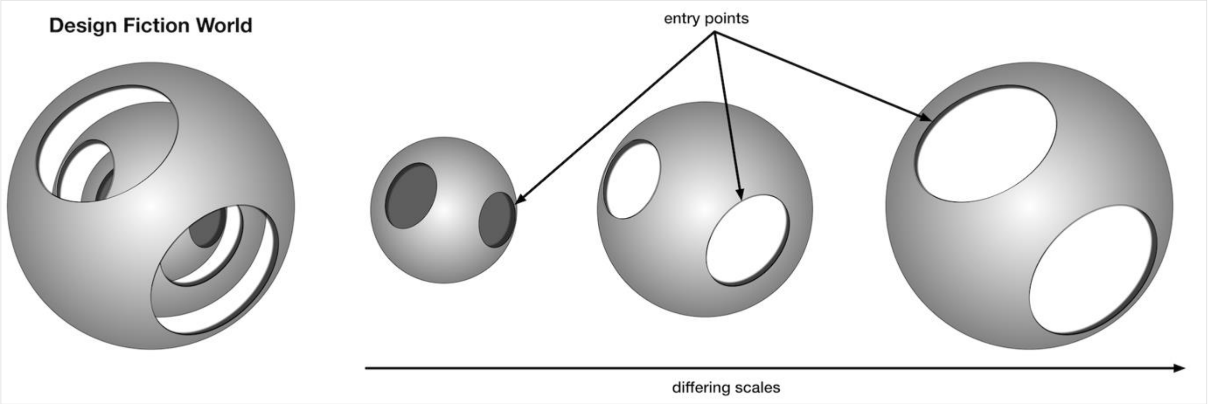


Figure 1 Design Fiction as World Building

The second metaphor, which works in unison with the first, is inspired by Charles and Ray Eames' iconic film about the relative size of things in the Universe, *Powers of 10*. The film shows our world from number of frames of reference (literally drawn as squares in the film) starting with a 1 meter squared section of an image that includes a couple sitting having a picnic. The camera then zooms out and increases the visible area by one power of 10 every 10 seconds. This changing scale is a device that encourages the viewer to constantly reconsider the scene being viewed. It is important to note that our use of such framing is not to suggest that Design Fictions adhere to the configuration 1 power of 10 per 10 second. Rather, we contend that the basic concept of shifting scale can be applied to the consideration of Design Fiction worlds and the artefacts that create them. We can think of each individual artefact that constructs the world as a representation of that world, but at a different scale (Coulton et al, 2017).

In the following section, we describe a Design Fiction as both a means to illustrate how Design Fictions are created, as well as to present a future world in which a DIY medical device might plausibly exist. Through the process of envisioning, designing and building this Design Fiction world, we create a reciprocal prototyping relationship whereby the designs create and test the world, and the world tests the prototype designs.

3 Do-It-Yourself Medical Device Design Fiction

Using the aforementioned concept of Design Fiction as world building, we present *HealthBand*. This Design Fiction uses a range of artefacts as entry points to its world and to represent that world at different scales. Each artefact also has a different focus, with the aim of facilitating multiple different 'readings' or interpretations of this future world. As the principle aim for Design Fictions is to enable, rather than shutdown, a wide a range of discussions as possible, these artefacts are presented in forms that are likely to be recognisable in relation to their audience's current experience. The aim is not to present the future as fantastical but rather as mundane, for it is through this mundanity that the audience's own lived experiences may come into relief. Further, such framing helps to realistically situate the artefacts within a plausible near future (Coulton et al, 2017). This mundanity gives Design Fictions a distinctly 'everyday quality', which in turn places our work in clear contrast to other speculative or critical design practices, whose artefacts are frequently intended for exhibition in galleries (Auger, 2013). In the following paragraphs, we design and present the artefacts created as part of the *HealthBand* Design Fiction.

3.1 Legislation

As previously discussed, present legislation overseen by the MHRA would prohibit the use of DIY Medical Devices such as *HeathBand* in a clinical setting unless these products can be proven to meet all the current regulation. Interestingly however, whilst the guidelines explicitly state that CE marks cannot be obtained for custom made health devices as they "must still meet the requirements in the directives and the type of device should be labelled clearly" (MHRA, 2016, para. 21), they also suggest it is not completely out of the question:

> *You don't need to get these checked by a third party to show they conform with the requirements but you need to draw up a statement to declare their compliance for custom-made devices, clinical investigations and performance evaluation devices.*
> *(MHRA, 2016, para. 22).*

This means that a change in the law, rather than a completely new law, would be a necessary component of any plausibly wide adoption of such a technology. In order to highlight this point, Figure 2 presents an extract from a fictional white paper. In the UK, white papers are policy documents produced by the Government that set out their proposals for future legislation. White papers may include a draft version of a Bill that is being planned to change existing law or introduce new legislation. This provides a basis for further consultation and discussion with interested or affected groups, and allows final changes to be made before a Bill is formally presented to Parliament. As white papers are aimed at facilitating discussions about the future, it would arguably make it the most appropriate artefact to engage those who are able to facilitate the changes in legislation required for DIY Healthcare and Medical Devices. As a white paper is particular to the UK, it would not necessarily make sense in the context of another country and thus highlights how the forms of a particular Design Fiction need to be chosen relative to their intended audience (Coulton, Lindley & Akmal, 2016).

3.2 Crownfunding Campaign

As part of the *HealthBand* Design Fiction we wished to address the question of how might the development of such devices be funded if the expectation is that it would effectively exist outside current commercial models for medical device production. Inspired by the way in which many Internet of Things (IoT) products services are being financed, we propose that such DIY wearables would likely be crowdfunded. Healthcare wearables are a popular trope of the IoT, thus appropriating the crowdfunding model lends plausibility to the Design Fiction, particularly if the audience is familiar with developments in IoT. This fictional frame is illustrated in Figure 3 which

22 **Legislating 'Do-It-Yourself' Wearable Health Devices**

Department of Health

The case for change

1.1 Rising aging populations living with chronic health conditions like diabetes, dementia and Parkinson's disease have put an incessant strain on the NDHS. Although it has been proven that these conditions can be successfully managed by patients using wearable health devices, due to abstruse health product legislation, too few devices have been made available to patients over the last decade. At the end of January 2027, 345 of the 418 local health authorities had put forward 'autonomous patient digital health' policies for consultation. Since then, the National Digital Health Framework has also published its report on 'home-made' wearable health devices,[20] as a means to fulfil the terms of service pledged by the NDHS in 2021.

1.2 Changes to digital health services have remained slow, expensive and bureacratic, with arguments about how many patients will be able to manage their own healthcare autonomously and what level of services are offered

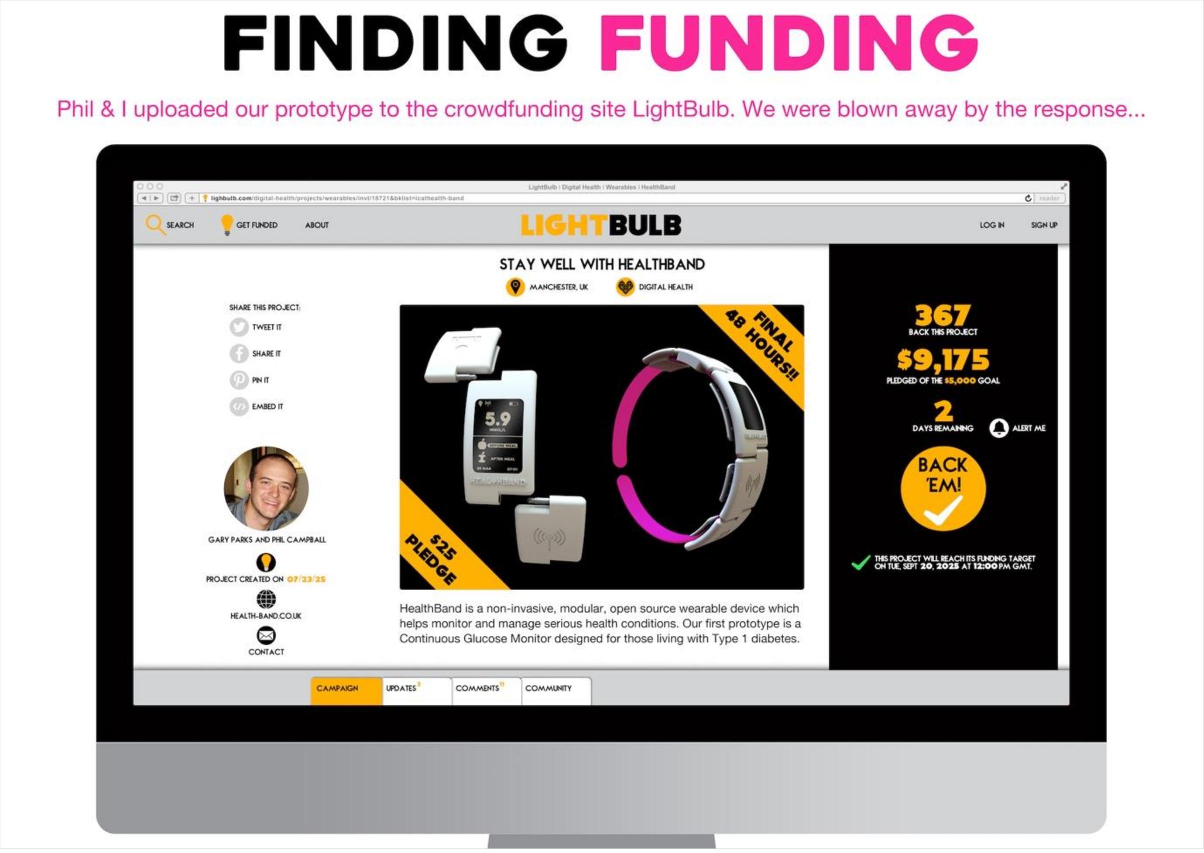
1.4 In response, this chapter sets out our proposals to reform health product legislation as well as identifying sufficient funding and expertise to make the most of the proposed changes; with community involvement to make the best outcomes for both 'autonomous citizens' and those continuing to use limited health services.

1.5 A number of the proposals build on consultantions and reviews conducted over the last year: the report of the Local Health Device Group; consultations on changes to the National Digital Health Framework;[21] frontline service reviews (the results of patient-led care trials at different sites across the country); and the National Patient Wearable Review also provided evidence.[22] The Government has taken account of responses to these consultations in deciding the way forward . A summary of the responses to each consultation is being published alongside this White Paper.

Getting tech in place

Making sure every UK citizen has access to digital technologies and

Figure 2 UK White Paper proposing changes in legislation that would allow DIY Medical Devices



FINDING FUNDING

Phil & I uploaded our prototype to the crowdfunding site LightBulb. We were blown away by the response...

LightBulb | Digital Health | Wearables | HealthBand

lighbulb.com/digital-health/projects/wearables/invt/18721&bklist=icathealth-band

STAY WELL WITH HEALTHBAND

HealthBand is a non-invasive, modular, open source wearable device which helps monitor and manage serious health conditions. Our first prototype is a Continuous Glucose Monitor designed for those living with Type 1 diabetes.

367 BACK THIS PROJECT

$9,175 PLEDGED OF THE $5,000 GOAL

2 DAYS REMAINING

✓ THIS PROJECT WILL REACH ITS FUNDING TARGET ON TUE, SEPT 20, 2025 AT 12:00PM GMT.

GARY PARKS AND PHIL CAMPBALL

PROJECT CREATED ON 07/23/25

HEALTH-BAND.CO.UK

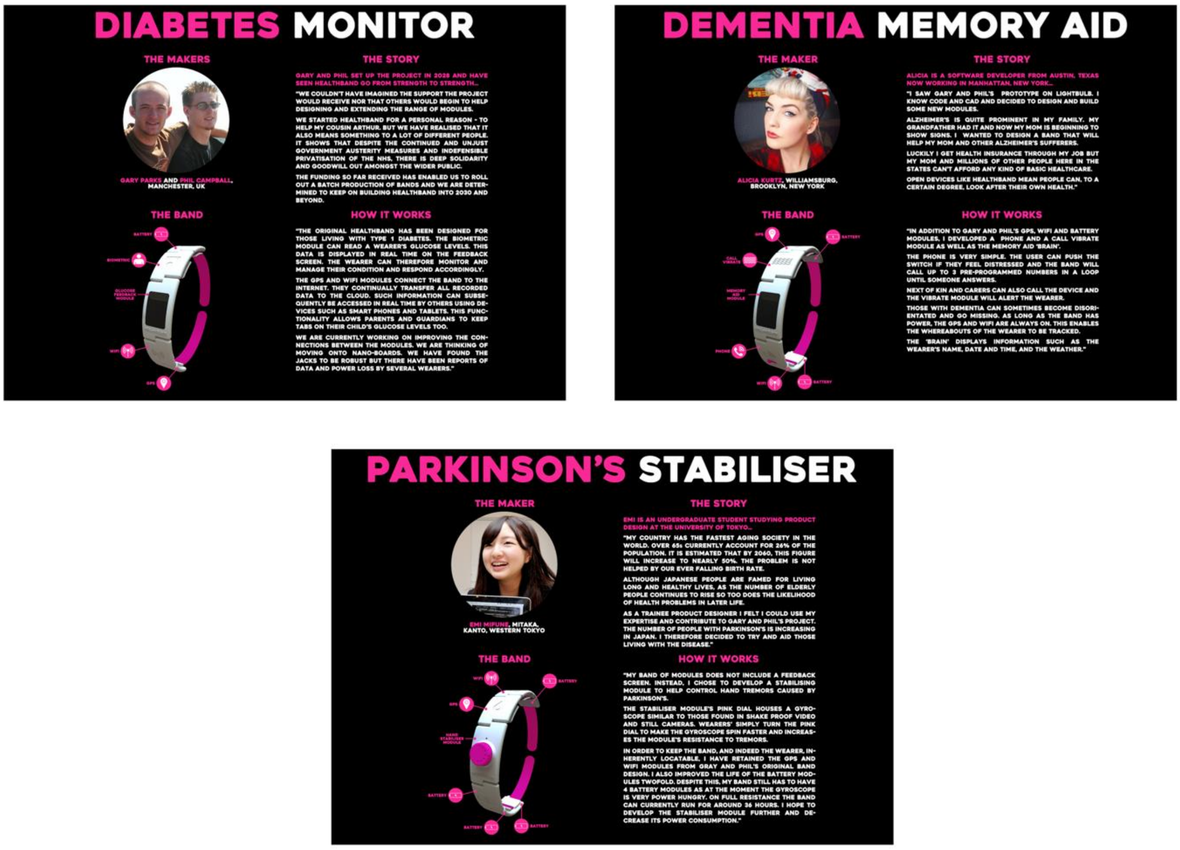
Figure 3 HealthBand Crowdfunding Campaign explains the origins of and motivations behind the product and discusses the success of a crowd-funding campaign which funded the production of the first three *HealthBand* prototypes.

The artefacts also detail how people can become actively involved in developing the project further by donating funds, creating new modules based on an open design template, or simply purchasing the device. Note, that whilst we created a fictional crowdfunding site *Lightbulb* for this fiction, in other work we have used existing organisations such as *Kickstarter* within the fictions as there is a strong argument that all the products and services that appear on these sites are indeed 'fictional' until they are successful in reaching their funding goal and the product and/or services are delivered to contributors.

3.3 Developer Stories

To illustrate the how and why it was created, each of the three *HealthBand* prototypes is presented in more detail in Figure 4. In the first *developer story*, Gary and Phil from Manchester in the UK, describe their original motivation for initiating the *HealthBand* project – to aid their cousin who has Type 1 diabetes – and the ensuing success of their crowdfunding campaign. Their story argues for the importance of personalisation, hence proposing a modular design, which encourages others to innovate on the *HealthBand* platform. This particular component of the design fiction draws inspiration from *Nightscout*, in that it focuses on self-monitoring of diabetes symptoms. It also seeks to extend the concept such that medical devices themselves become open-source hardware platforms.

The second story concerns Alicia from the USA who, having been excited by seeing the original diabetes monitor, decided to create memory aid and tracker modules. Alicia was inspired to design



DIABETES MONITOR

THE MAKERS

GARY PARKS AND PHIL CAMPBALL,
MANCHESTER, UK

THE BAND

THE STORY

GARY AND PHIL SET UP THE PROJECT IN 2028 AND HAVE SEEN HEALTHBAND GO FROM STRENGTH TO STRENGTH...

"WE COULDN'T HAVE IMAGINED THE SUPPORT THE PROJECT WOULD RECEIVE NOR THAT OTHERS WOULD BEGIN TO HELP DESIGNING AND EXTENDING THE RANGE OF MODULES.

WE STARTED HEALTHBAND FOR A PERSONAL REASON - TO HELP MY COUSIN ARTHUR. BUT WE HAVE REALISED THAT IT ALSO MEANS SOMETHING TO A LOT OF DIFFERENT PEOPLE. IT SHOWS THAT DESPITE THE CONTINUED AND UNJUST GOVERNMENT AUSTERITY MEASURES AND INDEFENSIBLE PRIVATISATION OF THE NHS, THERE IS DEEP SOLIDARITY AND GOODWILL OUT AMONGST THE WIDER PUBLIC.

THE FUNDING SO FAR RECEIVED HAS ENABLED US TO ROLL OUT A BATCH PRODUCTION OF BANDS AND WE ARE DETERMINED TO KEEP ON BUILDING HEALTHBAND INTO 2030 AND BEYOND.

HOW IT WORKS

"THE ORIGINAL HEALTHBAND HAS BEEN DESIGNED FOR THOSE LIVING WITH TYPE 1 DIABETES. THE BIOMETRIC MODULE CAN READ A WEARER'S GLUCOSE LEVELS. THIS DATA IS DISPLAYED IN REAL TIME ON THE FEEDBACK SCREEN. THE WEARER CAN THEREFORE MONITOR AND MANAGE THEIR CONDITION AND RESPOND ACCORDINGLY.

THE GPS AND WIFI MODULES CONNECT THE BAND TO THE INTERNET. THEY CONTINUALLY TRANSFER ALL RECORDED DATA TO THE CLOUD. SUCH INFORMATION CAN SUBSEQUENTLY BE ACCESSED IN REAL TIME BY OTHERS USING DEVICES SUCH AS SMART PHONES AND TABLETS. THIS FUNCTIONALITY ALLOWS PARENTS AND GUARDIANS TO KEEP TABS ON THEIR CHILD'S GLUCOSE LEVELS TOO.

WE ARE CURRENTLY WORKING ON IMPROVING THE CONNECTIONS BETWEEN THE MODULES. WE ARE THINKING OF MOVING ONTO NANO-BOARDS. WE HAVE FOUND THE JACKS TO BE ROBUST BUT THERE HAVE BEEN REPORTS OF DATA AND POWER LOSS BY SEVERAL WEARERS."

DEMENTIA MEMORY AID

THE MAKER

ALICIA KURTZ, WILLIAMSBURG,
BROOKLYN, NEW YORK

THE BAND

THE STORY

ALICIA IS A SOFTWARE DEVELOPER FROM AUSTIN, TEXAS NOW WORKING IN MANHATTAN, NEW YORK...

"I SAW GARY AND PHIL'S PROTOTYPE ON LIGHTBULB. I KNOW CODE AND CAD AND DECIDED TO DESIGN AND BUILD SOME NEW MODULES.

ALZHEIMER'S IS QUITE PROMINENT IN MY FAMILY. MY GRANDFATHER HAD IT AND NOW MY MOM IS BEGINNING TO SHOW SIGNS. I WANTED TO DESIGN A BAND THAT WILL HELP MY MOM AND OTHER ALZHEIMER'S SUFFERERS.

LUCKILY I GET HEALTH INSURANCE THROUGH MY JOB BUT MY MOM AND MILLIONS OF OTHER PEOPLE HERE IN THE STATES CAN'T AFFORD ANY KIND OF BASIC HEALTHCARE.

OPEN DEVICES LIKE HEALTHBAND MEAN PEOPLE CAN, TO A CERTAIN DEGREE, LOOK AFTER THEIR OWN HEALTH."

HOW IT WORKS

"IN ADDITION TO GARY AND PHIL'S GPS, WIFI AND BATTERY MODULES, I DEVELOPED A PHONE AND A CALL VIBRATE MODULE AS WELL AS THE MEMORY AID 'BRAIN'.

THE PHONE IS VERY SIMPLE. THE USER CAN PUSH THE SWITCH IF THEY FEEL DISTRESSED AND THE BAND WILL CALL UP TO 3 PRE-PROGRAMMED NUMBERS IN A LOOP UNTIL SOMEONE ANSWERS.

NEXT OF KIN AND CARERS CAN ALSO CALL THE DEVICE AND THE VIBRATE MODULE WILL ALERT THE WEARER.

THOSE WITH DEMENTIA CAN SOMETIMES BECOME DISORIENTATED AND GO MISSING. AS LONG AS THE BAND HAS POWER, THE GPS AND WIFI ARE ALWAYS ON. THIS ENABLES THE WHEREABOUTS OF THE WEARER TO BE TRACKED.

THE 'BRAIN' DISPLAYS INFORMATION SUCH AS THE WEARER'S NAME, DATE AND TIME, AND THE WEATHER."

PARKINSON'S STABILISER

THE MAKER

EMI MIFUNE, MITAKA,
KANTO, WESTERN TOKYO

THE BAND

THE STORY

EMI IS AN UNDERGRADUATE STUDENT STUDYING PRODUCT DESIGN AT THE UNIVERSITY OF TOKYO...

"MY COUNTRY HAS THE FASTEST AGING SOCIETY IN THE WORLD. OVER 65s CURRENTLY ACCOUNT FOR 26% OF THE POPULATION. IT IS ESTIMATED THAT BY 2060, THIS FIGURE WILL INCREASE TO NEARLY 50%. THE PROBLEM IS NOT HELPED BY OUR EVER FALLING BIRTH RATE.

ALTHOUGH JAPANESE PEOPLE ARE FAMED FOR LIVING LONG AND HEALTHY LIVES, AS THE NUMBER OF ELDERLY PEOPLE CONTINUES TO RISE SO TOO DOES THE LIKELIHOOD OF HEALTH PROBLEMS IN LATER LIFE.

AS A TRAINEE PRODUCT DESIGNER I FELT I COULD USE MY EXPERTISE AND CONTRIBUTE TO GARY AND PHIL'S PROJECT. THE NUMBER OF PEOPLE WITH PARKINSON'S IS INCREASING IN JAPAN. I THEREFORE DECIDED TO TRY AND AID THOSE LIVING WITH THE DISEASE."

HOW IT WORKS

"MY BAND OF MODULES DOES NOT INCLUDE A FEEDBACK SCREEN. INSTEAD, I CHOSE TO DEVELOP A STABILISING MODULE TO HELP CONTROL HAND TREMORS CAUSED BY PARKINSON'S.

THE STABILISER MODULE'S PINK DIAL HOUSES A GYROSCOPE SIMILAR TO THOSE FOUND IN SHAKE PROOF VIDEO AND STILL CAMERAS. WEARERS' SIMPLY TURN THE PINK DIAL TO MAKE THE GYROSCOPE SPIN FASTER AND INCREASES THE MODULE'S RESISTANCE TO TREMORS.

IN ORDER TO KEEP THE BAND, AND INDEED THE WEARER, INHERENTLY LOCATABLE, I HAVE RETAINED THE GPS AND WIFI MODULES FROM GRAY AND PHIL'S ORIGINAL BAND DESIGN. I ALSO IMPROVED THE LIFE OF THE BATTERY MODULES TWOFOLD. DESPITE THIS, MY BAND STILL HAS TO HAVE 4 BATTERY MODULES AS AT THE MOMENT THE GYROSCOPE IS VERY POWER HUNGRY. ON FULL RESISTANCE THE BAND CAN CURRENTLY RUN FOR AROUND 36 HOURS. I HOPE TO DEVELOP THE STABILISER MODULE FURTHER AND DECREASE ITS POWER CONSUMPTION."

Figure 4 HealthBand Developer Stories

the memory aid module both due to the prevalence of Alzheimer's in her family, and a in response to the difficulties faced by many in the USA of obtaining health insurance. In terms of the Design

Fiction it draws from health reports from the Alzheimer's Society[3] who highlight that Alzheimer's is the most common cause of dementia, affecting 62 per cent of those diagnosed with the syndrome. There are currently 850,000 people with dementia in the UK, with numbers set to rise to over 1 million by 2025 and are further expected to soar to 2 million by 2051. Introducing the USA perspective not only highlights that Dementia is a global issue, but also emphasises that individual countries have particular problems with access to healthcare, in this case access to affordable, comprehensive medical insurance in the USA.

The final story features Emi from Japan which highlights the issue of their increasingly aged society. Indeed, Japan's population is expected to see the number of over 65s to grow to nearly 50% by 2060 (McCurry, 2016) while also experiencing a declining birth rate (Soble, 2017). In this story, Emi has developed *HealthBand* modules which are specifically designed to stabilise hand tremors which are a common symptom of Parkinson's disease. We contend that his story, in part highlights that symptoms exhibited by patients vary from individual to individual which in turn emphasises the need for a flexible and reconfigurable design solution.

3.4 Modular Design

As previously discussed, individual patients' needs and symptoms can be quite varied, particularly when treating complex conditions such as dementia which unfortunately often develops alongside a range of other challenging health issues. Further, as dementia is a degenerative illness, the needs of a particular patient will vary over time. Technological solutions should seek to address different aspects of a condition and the platform should therefore be flexible enough to allow devices to be configured and reconfigured in order to meet the dynamic needs of users.

Figure 5 depicts an exploded view of the *HealthBand* prototype and illustrates how each of its modules connect together via 3.5mm jacks. The modules each have a rear 'clip' which must be used to secure them to a fuchsia 'Snap-On' wristband. In the fiction, the band is said to be comprised of a flexible metal strip coated in a layer of durable but soft to touch silicone. This feature means that the design is versatile, in that it would be able to fit a wide variety of wrist sizes.

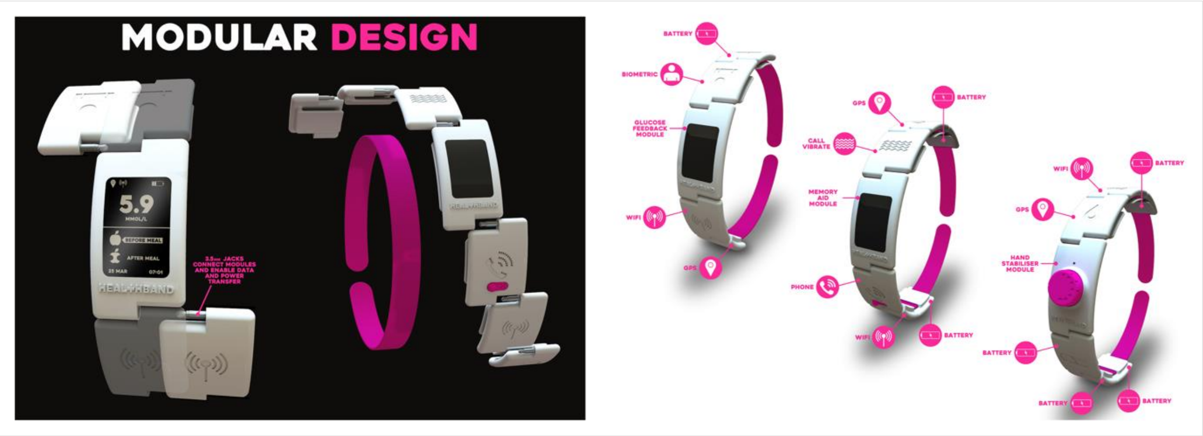


Figure 5 HealthBand modular design

The modularity of the *HealthBand* prototype was partly inspired by the *Blocks* modular smart watch which was first developed during the *Intel Make It Wearable Challenge 2013*. After being selected as one of the finalists and receiving $50,000 funding from Intel, the team behind the product then sought further capital via the *Kickstarter* crowdfunding platform (Charara, 2016). Despite numerous release dates being announced since early 2016, the device has yet to be released with the current estimated date being the 1st quarter of 2018. Given the continual delays, there is possibility that Blocks may suffer the fate of ultimately becoming *vapourware* (Coulton and Lindley, 2017).

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[3] www.alzheimers.org.uk

3.5 *Fabrication Permit*

The example of *Blocks* is quite representative of the current volatility across development of the IoT, in that it is a constantly evolving landscape with devices, services and companies entering and leaving the market at a rapid rate. Whilst this precariousness may be acceptable for early adopters of these technologies, it is unlikely to instil confidence in those responsible for healthcare provision. This suggests that while we may wish to take advantage of Democratised Innovation in the creation of such devices, there is likely a need to consider how we can facilitate trust in those creating such devices and ensure some level of accountability amongst device developers, health service providers and legislators. Such a task is of course highly complex and whilst we are not realistically suggesting this as a solution as part of the Design Fiction, to begin considering notions of accountability, we have created a device fabrication permit.

The permit draws upon present day medical device certification processes (MHRA, 2015) and also introduces the notion of linking a particular condition to the permit in a similar vein to how devices are currently classified. In this way, the risk to patients can be handled in a more nuanced manner and links directly to a developer's experience, as opposed to a simple, blanket legislation which might grant universal permission to fabricate medical devices.

NDHS

PERMIT No. 3874531

DOMESTIC FABRICATION PERMIT

NAME: WANDA OJABOE
SEX: F
D.O.B: 28/07/1965
ADDRESS: 1 CHART WAY
CLAPHAM
LONDON
SW4 9IJ
CONDITION: DIABETES T1
ISSUED: 12/02/2035
EXPIRY: 11/02/2038

I HEREBY CERTIFY THAT THE PERSON PRESCRIBED THIS PERMIT IS AUTHORISED TO FABRICATE A WEARABLE HEALTH DEVICE IN ACCORDANCE WITH THE 2032 DOMESTIC WEARABLE HEALTH ACT.

Derrick Hensley

DERRICK HENSLEY - CHIEF MEDICAL OFFICER

Figure 6 Domestic Fabrication Permit

3.6 *Guide to Obtaining Device Certification*

In proposing something as radical as DIY Medical Devices we are aware that the experience of healthcare professionals would become profoundly different. It is crucial that nurses, doctors, and other allied health professionals have confidence in the widespread use of such devices and the health-critical data that they collect:

> *While many healthcare wearables can be positive feedback tools and motivational aids, doctors ultimately want clinically proven products whose data they can use to make clinical decisions (cited in Wall, 2016, para.22).*

With this in mind, the last artefact we present for the Design Fiction is a pamphlet (Figure 7) which highlights a set of actions which device developers need to undertake before their device might be considered and put forward for clinical trials. Whilst the pamphlet follows similar requirements currently defined by the MHRA, it also introduces new requirements such as ensuring the software and hardware are open for both modification, the need for any data to be handled in a secure and ethical manner, and that devices would be considered by a specialised professional service before it could move on to the next stage of certification. As with the fabrication permit, this is not being offered as the solution to certification but rather providing a starting point for deliberations on what the actual requirements of a new certification process might be.


Department of Health

NDHS

A patient guide to gaining home-made heath wearable certification

Helping you deliver the **best** in care

To see all of our current patient information leaflets please visit www.uhb.ndhs.uk/patient-information-leaflets.htm

Starting a health wearable patient trial

SInce the Government passed the *Domestic Wearable Health Act* in 2032, the NDHS has outsourced health wearable research and development to third party developers.

If you are a third party developer and are looking to gain certification for your device, you must submit your prototype to testing via a series of patient trials.

The next 5 steps explain the first patient trial process:

1 Visit the NDHS website and complete the initial device sign up process - www.uhb.ndhs.uk/devicesignup

2 If your prototype passes the sign up process, it will be listed along with its CAD templates and operating software on the NDHS Open Wearable Database. All UK patients can access this database free of charge at anytime.

3 For its first trial, your device must be selected by a minimum of 6 patients and trialled for a minimum of 3 months by each of them. They must download, fabricate and operate the device themselves in accordance with your submitted instructions.

4 As per the *NDHS Wearable Hardware/Software Design Guidelines*, your device must transmit all patient usage data at all times to the NDHS data centre.

5 The patient data will be analysed by NDHS health tech specialists who will determine if your device can be put forward to the next stage of patient trials.

PI_1449_01 Devices and Patient Trials | 5

Figure 7 Device Certification Guide

4 Reflections on HealthBand World Building

What is evident when creating Design Fictions is that whilst the artefacts are fictional, if they are to facilitate meaningful questions around the futures they portray, they need to be conceived with the same commitment to detail as if they were actually being designed and produced. Further, we argue that it is the world building approach which allows such detail to be developed and which can address some of the associated complexity which emerges during the transition from an emerging technology with interesting potential to one capable of reaching widespread adoption in a variety of sectors. Crucially, the aim of the Design Fiction is not to present solutions to this complexity but rather to ensure that there is discourse that considers what factors may need to be addressed during this transition. Although the design process of creating the *HealthBand* Design Fiction has been discussed in this paper, we have, as yet, only had preliminary discussions with healthcare professionals, patients and carers with experience of the relevant conditions. It is imperative therefore to further reflect on these artefacts in terms of how they might extend to particular discussions.

Initially we considered that legislation would be the most contentious factor in enabling DIY medical devices, however, healthcare is an area that undergoes constant innovation with regards to medicines and devices. The challenge is thus: how can Democratised Innovation be facilitated within the existing frameworks which have been set-up to mitigate risk. The artefact itself implies that these risks can be overcome and establishes a case for change but how such risks could be mitigated and how liability may be addressed are not explored in any depth. We posit that these issues could perhaps be addressed to a further degree within the fiction by presenting potential opponents to the envisioned changes to legislation allowing DIY Medical Devices. Such opposition might take the form of reports from health policy *think tanks*, healthcare practitioners concerned with risks to public safety, medical ethics committees and competitors, that is, corporate medical device manufacturers, who currently must spend large sums of capital to develop medical devices which meet stringent design/production regulations. Legislatorial reform may also lead to a reduction in manufacturers' share of the medical device market and subsequently reduce their ability to increase profits.

When we created the crowdfunding campaign for *HealthBand*, it was primarily an artefact through which we chose to emphasise the patient initiated innovation and provide a frame in which the individual developer stories could highlight the factors leading people to advocate for DIY Healthcare and DIY Medical Devices. In many respects to those familiar with crowdfunding and creating IoT devices, here the fiction perhaps lacks detail that might produce more meaningful discussions. For example, what would be a realistic funding goal to achieve the creation of a new device? What exactly would users get for their investment? Given that a number of crowdfunded IoT devices have obtained funding but not met initial delivery targets, or drifted towards vapourware, would the ethical requirements placed on those developing DIY Medical devices through these crowd funding platforms need to be different from those say developing products and services for the home entertainment market?

In terms of the modular design of the *HealthBand*, this aligns strongly with the current emphasis on providing greater focus on the needs of individual patients rather than particular conditions and how these needs are likely change over time. This modular aspect is also particularly useful for extending the scope of the more fictional DIY Medical Device world to include other conditions which may present very different challenges than those currently envisioned.

The permit is primarily a means of linking current medical device certification with potential ways of how this might be adapted to allow Democratised Innovation and medical device production on a more individual level. There are subsequent challenges that the permit leaves unanswered, for example, how is the permit obtained and what are the requirements for applicants regards fabrication qualifications, liability, insurance etc. As it is a fabrication rather than developer permit, it also suggests that designs might be outsourced to certified individuals, or even machines, to be built thus allowing innovations to be disseminated through open-source practices. As with other previously discussed artefacts, it primarily presents a positive perspective and other, more negative questions might relate to whether a black market for permits and devices might emerge and how such actions might be addressed.

The device trials pamphlet introduces the requirement for clinicians to have confidence that the devices have proven benefit that would draw from, rather than be separate to, existing practices. This might be a useful starting point for discussions with those involved in medical trials as to how such practices might potentially operate. Such insights could then be used to initiate future iterations of, or additions to, the fictional world depicted by this design fiction. Further evolution of this work may result in a dynamic prototype usable by policy makers, community-based makers, patients, and technology developers to understand the safety challenges around widespread adoption of DIY Medical Devices, as well as the economic and health centric opportunities.

5 Conclusions

Whilst DIY Medical Devices are garnering considerable attention in the media, academia and industry, they are drawing from a design-maker culture that is challenging current manufacturing practices which are often less complex than the practices relating to the production of real medical devices. Presently the fiction only explores one example of a possible future – that of the three developers who we can describe as 'lay users'. Envisioning how healthcare professionals might become involved with the *HealthBand* concept could no doubt provide other interesting points of entry into the fictional world. For example, might doctors and nurses also begin to fabricate DIY products to cater for specific patient needs? Indeed, if we wish to progress the ideas initiated by the *HealthBand* fiction beyond their exciting potentiality, we need to further explore the implications of DIY Medical Devices from multiple perspectives and highlight the issues that would need to be addressed if they are to develop to a point of widespread adoption. Crucially, the fiction is built upon our own – the authors' – subjective interpretations regards the subject. While it is beyond the scope of this paper, real-world evaluations and interpretations regards *HealthBand* by a range of key stakeholders such as patients, healthcare professionals, regulators and medical device designers may well provide a rich source of insights which can in turn be used to instil the fiction with more rigour and criticality.

Despite the fiction's outlined limitations, we argue that Design Fiction is a highly useful way to address the implications for adoption of DIY medical devices as it is a speculative design practice specifically aimed at engaging with such a challenge. The paper illustrates the process of envisioning, designing and building a Design Fiction world – a reciprocal prototyping relationship whereby the designs create and test the world, and the world tests the prototype designs. We believe this creative practice has much to offer those considering the futures of emerging technologies, in particular for the healthcare sector, or other sectors that must make similarly complex and safety-conscious judgements.

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Does Feedback from This Device Change Unhealthy habits? Lessons from my PhD project

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Feedback from digital technology has often been used to support people in changing undesired, unhealthy habits. As yet, there has been little research into the efficacy of these designs. In my PhD project, I evaluated the acceptance, sustained use, and effect of four designs that provide feedback on undesired habitual behaviour through digital technology. Findings are that the disruptive effect of feedback on undesired habits has been proven, and there is some evidence that feedback may have a lasting effect on behavioural change. (Sustained) use of digital designs that provide feedback is moderated by motivation, age, goal-related aspects, and user experience. The necessity of high motivation to use a device poses challenges for the acceptance of and sustained engagement with designs for behaviour change that rely on feedback. Further challenges concern privacy and the quality of the evaluations of our designs.

feedback; digital devices; behaviour change; health behaviour

1 Introduction

Undesirable habits can be very hard to change. In recent years, we have seen a growing number of digital designs that claim to provide a solution. Many of these designs (automatically) record our behaviour and give us feedback on our performance. Evidence of the efficacy of designs that provide feedback on behaviour is slowly accumulating but remains limited to academic outlets that are historically less accessible to non-behavioural scientists, such as HCI researchers, designers and design researchers (Hekler, Klasnja, Froehlich, & Buman, 2013). This paper aims to provide designers and design researchers with an accessible overview of my PhD project, which contributes to answering the question whether feedback through digital technology is effective to change habitual behaviour. To do so, the paper provides a summary of a recent analysis of the current literature, and an evaluation of four existing designs for behaviour change that provide feedback on undesired habits.

In literature, habits are commonly defined as "behaviour (...) prompted automatically by situational cues, as a result of learned cue-behaviour associations" (Wood & Neal, 2009, pp. 580; Gardner, 2014, p.1). They help us to come to terms with the enormous complexity of everyday life, by taking away the burden of conscious deliberation from many uncritical decisions. Unfortunately, many of our habits have adverse effects on our own health and that of the planet we live on. The rigid cue-response-chain of a strong habit overrides contradictory behavioural intentions (Verplanken & Faes, 1999; Verplanken & Wood, 2006). This may lead to undesired results when habits have a satisfying short-term effect but damaging health consequences in the long run, as with snacking, a lack of physical activity, or alcohol abuse. Furthermore, since habits do not take into account current context, changed circumstances may render habits unproductive for contemporary life, even though the behaviour may have led to rewards in the past.

The major benefit of habitual behaviour is that it circumvents active consideration of the current context, but this also makes it very hard to change habits using interventions aimed at controlled processing, e.g. through persuasive messages related to the consequences of behaviour (Verplanken & Wood, 2006) or changing behavioural intentions (Sheeran, 2002). A more successful way to disrupt undesired habits is to bring habitual behaviour and its context to (conscious) awareness. Self-monitoring, the procedure by which individuals record the occurrences of their own target behaviours (Nelson & Hayes, 1981), enables perception of our own behaviour and adaption to the current context. This leads to a decrease in unwanted behaviour (Quinn, Pascoe, Wood, & Neal, 2010). Unfortunately, self-monitoring is difficult for even the most motivated individual (Wilson, 2002). There is often a discrepancy between self-reported and actual performance in health behaviours such as calorie intake and physical activity (Lichtman et al., 1992),

Accurate self-monitoring is greatly improved by personalized information from external sources (Kim et al., 2013; Li, Dey, & Forlizzi, 2010). The advent of mobile and interactive media has given us an unsurpassed opportunity to support people in self-monitoring, by providing them with tailored feedback. Feedback has been defined as "actions taken by (an) external agent(s) to provide information regarding some aspect(s) of one's task performance" (Kluger & Denisi, 1996), on their behaviour. Digital technology can offer constant, real-time updates, powered by sensitive measurement devices, often worn on the body. Besides data generation, digital technology can offer habit-disrupting cues such as light and sound signals, buzzes, and push messages. Digital technology is not only useful to present users with evaluations of past behaviour ("reflection-on-action"); because of the ubiquity of wearables and mobile devices, feedback from digital technology offers an unprecedented opportunity for "reflection-in-action" (Schön, 1984): the analysis of behaviour as it occurs. This could greatly increase people's efficacy in self-managing healthy behavioural change.

1.1 *Solutionism or smart solutions?*

The rapid rise of the technological possibilities has been matched by a similar rise in the number of designs on the market that make use of these possibilities. Wearable activity trackers (cf. Kooiman et al., 2015) give us feedback on whether we walk enough; sleep monitors monitor our sleep (e.g. Ogihara & Eshita, 2016); smart devices track our eating habits (e.g. Zandian et al., 2009), an app can warn us about situations in which we are likely to smoke a cigarette (e.g. Naughton et al., 2016) and a growing number of devices tell us (and others) what emotions we experience in cases where we are unable to do so ourselves (e.g. Van Dijk, 2017). This increased attention in health design practice is closely followed by a growing body of literature in design research and human-computer interaction research in the past decades (e.g. Darby, 2001; Fischer, 2008; Frohlich, Findlater, & Landay, 2010; Ludden, 2013; Hänsel et al., 2015; Gouveia et al., 2016). By far the biggest part of this literature researches the different channels, modalities, and other properties of feedback through digital technology: how to optimally design the feedback technology.

Considering all this attention, it may come as a surprise that there has been relatively little research into whether all this feedback on health behavioural is as effective as we implicitly presume. After all, the rise in designs and research based on these designs may very well be a case of technocratic solutionism (Morozow, 2013): we have sensors and actuators, especially in smartphones, and we have wearables. Now that we've been provided with these hammers, we suddenly see nails everywhere. But are these really nails?

1.2 When we build it, they will change?

In my PhD project, I investigated whether feedback through digital technology is an effective way to support people in changing their undesired, unhealthy habitual behaviour. Theory supports this hypothesis; with Control Theory (Carver & Scheier, 1985) delivering the best explanation: reflective behaviour change resembles a thermostat. When looking to change their behaviour, people compare their performance to a behavioural goal. When a discrepancy between goal and performance is noted – given enough motivation, opportunity, and the right abilities – people will attempt to reduce this discrepancy. This process depends on conscious scrutiny of behaviour and its effects. Knowing that habitual behaviours are mostly automatic, and thereby outside of conscious scrutiny, the strength of feedback lies in delivering exactly that cue that is needed to make automatic behaviour available for conscious deliberation. Feedback may also increase motivation to change the target behaviour (Northcraft, Schmidt, & Ashford, 2011): feedback places the target behaviour higher on a hypothetical list of priorities. When given feedback on the number of steps we take, we may prioritise walking over other modes of transportation or other physical activity choices, because feedback diverts our attention towards this behaviour.

The question is, of course, whether practice follows theory. To find out, we [1]examined the available evidence from literature, to evaluate whether current literature provides an answer to the following questions:

- Is feedback through digital technology an effective way to change habitual behaviour?
- Is feedback through digital technology effective for each user in every context, or are there intrapersonal (e.g. character traits, psychological states such as motivation) or interpersonal (contextual or systemic) moderators? What feedback properties are most effective in different circumstances?

To provide further answers to these questions, we then evaluated 4 existing designs for behavioural change. Inclusion criteria for the designs were: a) the design addresses habitual behaviour, b) the design uses feedback on behavioural performance as its (primary) behaviour change technique, c) the design can be tested in real-life conditions (beyond the lab). To obtain valid results, we only included participants who could reasonably be expected to be motivated to change their behaviour, for instance because they chose to purchase or download the design of their own accord. The first design we evaluate in this paper is a physical activity tracker which is currently available in the market; the second design is a commercially available app that gives feedback on water drinking. The third is an online solution (web-based platform and app), currently available from a public institution, that gives feedback on the nutritional content of meals. The evaluations of these three designs help answering questions about what determinants and design properties enable the design to be effective for what audience. The fourth design is a 'smart' fork that registers eating rate and gives feedback when you eat too fast. This evaluation contributes to answering whether feedback is an effective way to durably change undesired behaviours.

2 Literature review: The efficacy of feedback technology for habit change

To evaluate current practices and the state of the art, we reviewed the available scientific evidence for the effect of feedback through digital technologies on habitual behaviour. A combined search in a range of scientific and design- and HCI- oriented databases, and auxiliary ancestry searches, yielded a set of 69 original papers (with a total of 72 studies) that matched our inclusion criteria: digital technology that delivers *tailored feedback* by an *external agent* to provide information regarding *task performance*, aimed at *automatic (habitual) behaviour*, with an analysis of the design's efficacy.

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[1] All research projects have been performed together with a range of partners from academia, hence the 'we'.

The included studies covered a range of dependent variables, varying from energy consumption to motor skills and physical activity. We thematically classified target behaviours of the intervention, feedback technology, feedback characteristics (content (feedback sign, comparison, and level of tailoring), timing, modality, frequency, duration, data source), and the availability of visual examples of the design and provided feedback. For each intervention, number of participants, independent and variables, analysis method, results, and possible methodological concerns were assessed. A complete overview of the search terms and analysis of the interventions is available in Hermsen, Frost, Renes, & Kerkhof, 2016.

2.1 Feedback disrupts habitual behaviour

Our analysis showed strong evidence for the idea that feedback disrupts habitual behaviour, making it available for conscious scrutiny. 59 of 72 studies show a beneficial effect of feedback on disrupting habitual behaviour. Of those 13 studies that did not find this effect, 4 suffered from a lack of statistical power for the type of analysis performed. Their null finding may very well be due to small sample sizes, since descriptive results in all four studies did point towards a small positive effect of the reported interventions. Where feedback did not lead to disruption of current behaviour, this was sometimes due to misunderstanding of the design's purpose. Other studies showed contrary effects, such as in a study on taking breaks at work, where participants used a design providing social activity feedback not to take part in social activities, but to avoid colleagues, or to find empty rooms for meetings (Kirkham et al., 2013).

However, current literature does not (yet) provide evidence for lasting effects of this disruption on behaviour. Two causes underlie this: as yet, there has hardly been research into lasting effects of this type of feedback on behaviour change; and research that has been performed so far, often suffers from methodological shortcomings. Either the research designs lack statistical power for the type of analysis performed in the study, which leads to a greater chance of false positives and inflated effect sizes, or the research designs had no strategies to deal with demand characteristics ("I have this beautiful design for you, and now I'm going to watch you use it. Does your behaviour change yet?").

2.2 Conclusions from our review

Our review enables us to at least partially answer our first question: yes, feedback from digital technology is able to disrupt undesired habits; but whether this leads to lasting behavioural changes remains unclear. To test this, we need research with higher quality research designs, data gathering, and analysis than what is currently common; be it qualitative or quantitative, or action research (such as the different flavours of research-through-design), which all have their relative merits to add to our knowledge. Furthermore, our review showed that there is hardly any evidence about what moderates sustained use of digital feedback technologies. The question who uses these technologies in which circumstances to which effect still needs to be answered.

> *Conclusion I: feedback from digital technology can disrupt habitual behaviour, but evidence for lasting behaviour change is lacking.*
>
> *Challenge: we are in need of better evaluation methods of our designs.*

Interestingly, our review shows that the disruptive effect of feedback on undesired habits occurs independently from modality (e.g. visual, auditory, or tactile feedback), timing, frequency, and medium (e.g. mobile phone apps, websites, or wearable devices). This is probably the result of optimisation and iterative user testing in the design phase, which led to choices for feedback modality, timing, frequency, and media which fit the target behaviour and user needs. For instance, in the case of modality, the target behaviour often rules out specific feedback modalities. In driving a car, the visual channel is more often than not occupied by keeping track of traffic. Visual feedback on driving behaviour is more often than not dangerous instead of supportive, as anyone who has ever attempted to text while driving will realise. At the dinner table, both the visual and the auditory channel are occupied, and a designed artefact which relies on visual or auditory feedback on eating behaviour needs to deal with the social practices of eating, which, for many people, has an important social function as well. Disrupting this social aspect with feedback messages on eating behaviours can be perceived as rude, and such designs are likely to be abandoned.

> *Conclusion II: there are no general guidelines for choosing optimal feedback properties. These depend on the design's context of use and the target behaviour.*

3 Design case I: Physical activity tracker

Evidence (Couper et al., 2010; Funk et al., 2010; Donkin et al., 2011; Perski et al., 2016) shows us that lasting engagement with a design is essential for behaviour change. Unfortunately, our literature review revealed that we hardly know anything about what factors (be it states, traits or context) drive sustained use of our designs, and how this differs for individuals across different contexts. Even the expected uptake of designs for behavioural change is as yet under-researched, let alone how long we can expect people to keep on using a design. The only evidence available as yet comes from industry whitepapers (Fox & Duggan, 2013; Chen, 2015), which claim abandonment rates of 30–80% in the first weeks, depending on technology.

3.1 711 Fitbit Zips moving about

To find out more about patterns in who will succeed in using designs that give feedback on behaviour long enough for the behaviour change to occur, we performed an explorative study among 711 participants from four urban areas in France. They received an activity tracker (Fitbit Zip) and gave us permission to use their logged activity data for 320 days. They also filled out three Web-based questionnaires: at start, after 98 days, and after 232 days to measure a range of potential determinants of sustained use: demographic and socio-economical, psychological, health-related, goal-related, technological, user experience-related and social predictors. We determined the relative importance of all included determinants on the duration of tracker use by using machine learning analysis techniques. Providing a detailed overview of the rationale, method, analysis, and results of this study would go beyond the scope of the current paper, but can be found in Hermsen, Moons, Kerkhof, Wiekens, & De Groot, 2017.

3.2 Slower attrition than expected

The data showed a slow exponential decay in physical activity tracking, with 73.9% (526/711) of participants still tracking after 100 days and 16.0% (114/711) of participants tracking after 320 days. On average, participants used the tracker for 129 days. This decay is exponential, but slower than may be expected from what little literature exists on the topic. Most important reasons to quit tracking were technical issues such as empty batteries and broken trackers or lost trackers (21.5% of all respondents of our third questionnaire, 130/601). Major determinants of tracking duration were age (the under 25 kept up tracking less long than older participants) and user experience-related factors (those who liked the design and user interface of the Fitbit more and found it easier to use, tracked longer than those who liked it less and found it more challenging). Other, smaller determinants were mobile phone type (iPhone less than others), household type (single parents less than others), perceived effect of the Fitbit tracker, and goal-related factors (having 'adjacent' goals such as healthy eating and quitting smoking decreased Fitbit use, when compared to 'central' goals such as increasing activity). Interestingly, many determinants had a smaller contribution to sustained use than may be expected from literature, or no effect at all. Perhaps this means that in real life, determinants such as education, character traits, income, and profession play a much smaller role than in isolated lab conditions.

> *Conclusion III: User experience and the evaluation of the user interface are important determinants for engagement with and sustained use of a design; technical failures are the most important reason for abandonment*

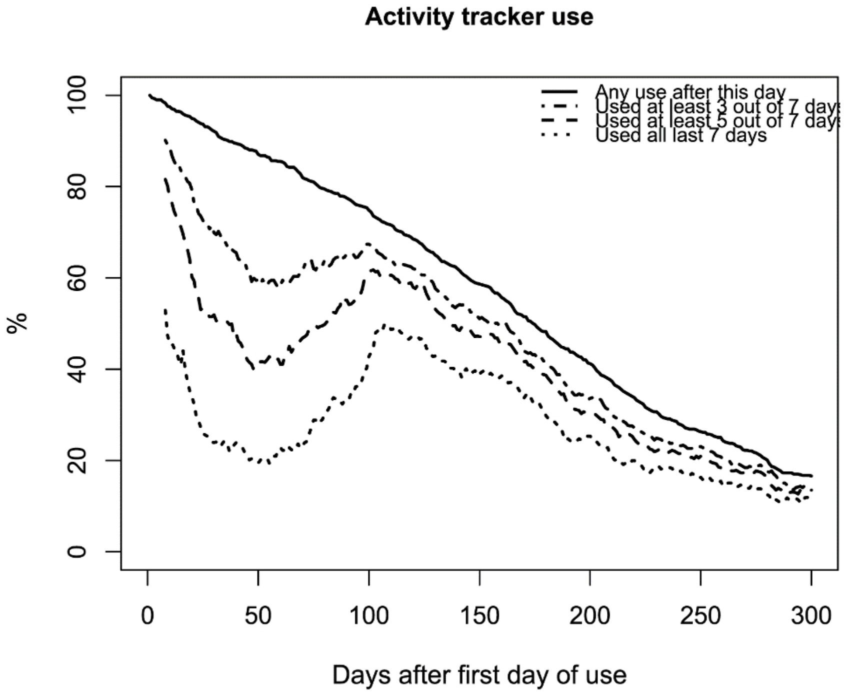


Figure 1: Usage decline of the Fitbits. The horizontal axis shows the number of days since the first day of use. The percentage of participants who used the activity tracker for any number of days after a particular day is indicated with a solid line. The other lines indicate habitual use: the percentage of participants who used the tracker for at least 3, 5, and 7 days in the preceding 7 days

It may not come as a surprise to designers and design researchers that user experience, aesthetic preferences, and ease of use matter, but many other stakeholders such as commissioners and the scientific community are relatively unaware of this importance. The latter tend to put more faith in underlying general working mechanisms and neglect user experience design (Hermsen, Van der Lugt, Mulder, & Renes, 2016) which may lead to clunky designs.

4 Design case II: An app that gives feedback on water drinking

To shed further light on potential moderators of sustained use and engagement of designs providing feedback, we performed two smaller studies with mobile apps. In the first study, we adapted an existing mobile app which gives users feedback on their water consumption and attempted to influence sustained use by manipulating the kind of feedback participants received. In a second study, we interviewed long-term and novice users of a mobile app which gives feedback on the nutritional value of your meals.

In the first study, we looked at moderators of sustained use of an app in which participants could register the amount of water they drank. The app then gives feedback on their water consumption. We recruited 538 participants through the online iOS app store. After downloading and installing the app, all participants completed a questionnaire about their motivation to record and change their water drinking behaviour, their perceived self-efficacy in doing so, and the appropriateness of five potential goals for their app use (Rooksby, Rost, Morrison, & Chalmers, 2014): documentary ('how much water do I drink?'), diagnostic ('has my water drinking an effect on fatigue?'), behaviour change oriented ('I want to drink more water'), reward-oriented (comparison to others, badges, etcetera), and 'fetishized' (interest in gadgets for their novelty value).

We randomly assigned all participants to one of five conditions: app-as-is, negative feedback on behaviour, positive feedback on behaviour, feedback aimed at competition against other app users, feedback aimed at cooperation with other app users (common goals). Participants recorded their water drinking behaviour using the smartphone app. as they saw fit, with no requirements on duration and frequency of use.

The trial lasted for 68 days, but no participant made it that far; 23.8% (128 participants) downloaded the app, but never used it. A further 23.6% (127 participants) only used the app a single time. Only 129 users (24%) made it past the first week. These findings are in line with what little evidence that exists about the expected duration of the use of mobile apps for health. An 80% attrition rate in the first week is quite normal (Chen, 2015), and people are likely to keep downloading different apps until they find one that fits their needs.

All participants were highly motivated to use the app in the first place ($\mu = 5.38$, $SD = 1.36$ on a seven-point scale), but it took a very high motivation and the goal to change drinking behaviour to actually start using the app. Once in use, age (older more than younger), motivation (extremely high more than very high), and having the concurrent 'documentary' goal influenced sustained use. Interestingly, our experimental manipulations did not affect sustained use whatsoever (a full overview of experimental methods and results is provided in Hermsen & Frost, 2018).

Conclusion IV: A digital feedback design must have a close fit with user needs and goals.

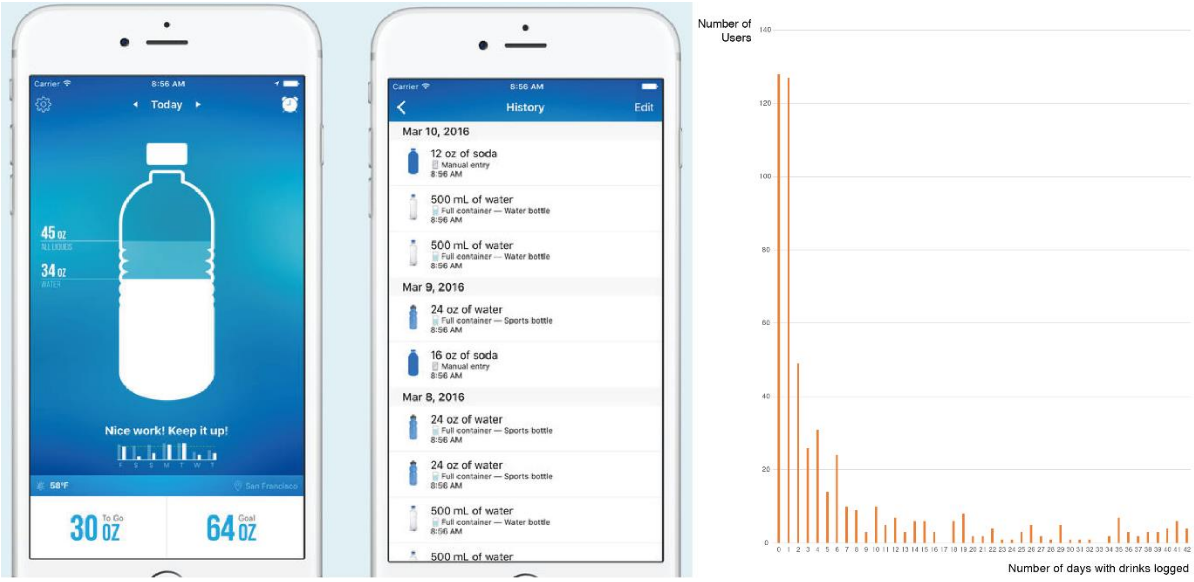
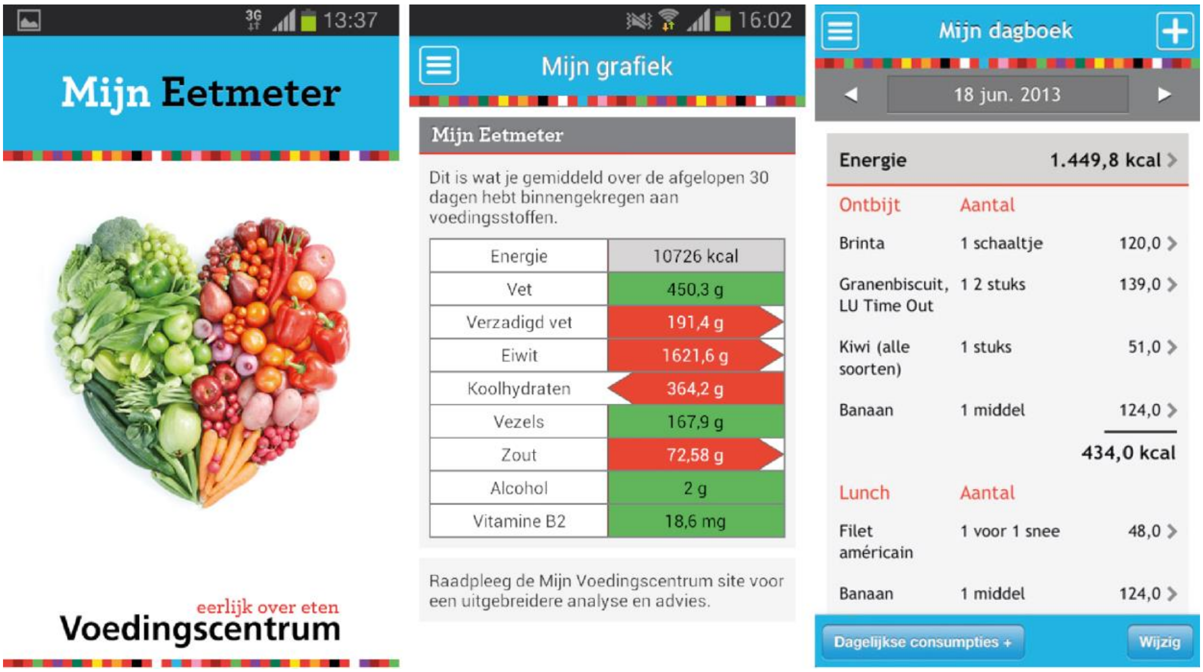


Figure 2: Screens from the water drinking app, and a graphical display of the percentage of users that stopped logging on a particular day

5 Design case III: An app that gives feedback on nutritional content of meals

In a second, qualitative study, we interviewed 20 long-term users and 8 novice users of Eetmeter, an app that provides feedback on the nutritional value of your meals. This app has been developed by the Netherlands Nutrition Centre and has a steady following of tens of thousands of active users. Once again, initial motivation to use the app, documenting the nutritional value of participants current diet, and motivation to change eating behaviour were the main drivers for app use. Social influence and integration with other dietary interventions (diets, consults from dietary professionals, etcetera) did not appear to have an effect on the use of the app at all (a full overview of the research method and results will be provided in Hermsen & Van Eijl, 2018).



Mijn Eetmeter

Dit is wat je gemiddeld over de afgelopen 30 dagen hebt binnengekregen aan voedingsstoffen.

Energie	10726 kcal
Vet	450,3 g
Verzadigd vet	191,4 g
Eiwit	1621,6 g
Koolhydraten	364,2 g
Vezels	167,9 g
Zout	72,58 g
Alcohol	2 g
Vitamine B2	18,6 mg

Raadpleeg de Mijn Voedingscentrum site voor een uitgebreidere analyse en advies.

Energie		1.449,8 kcal
Ontbijt	**Aantal**	
Brinta	1 schaaltje	120,0
Granenbiscuit, LU Time Out	1 2 stuks	139,0
Kiwi (alle soorten)	1 stuks	51,0
Banaan	1 middel	124,0
		434,0 kcal
Lunch	**Aantal**	
Filet américain	1 voor 1 snee	48,0
Banaan	1 middel	124,0

Figure 3: Screens from Eetmeter, an app to determine the nutritional value of your meals

5.1 *Motivation is the key*

Our studies indicate that when people are sufficiently motivated to change their behaviour, they need some kind of 'scaffolding' to support and shape their behaviour change attempts. For some people, this takes the form of a mobile health app, even if this involves some rather annoying self-reporting of eating and drinking behaviours which would drive most people away from the app. For others, digital technology that gives feedback on their behaviour is not the kind of motivational and practical support they need to reach their goals; they are better off using other interventions or designs that combine feedback with other behaviour change techniques.

This finding, that highly motivated people use the designed intervention as a sort of 'scaffolding' to support and shape their behaviour change process, is in line with previous literature that sees feedback technology as lived informatics, i.e. the idea that people will actively select those resources that best support the behavioural change they seek, rather than with literature that follows the idea of 'persuasive technology', i.e. the idea that technology is capable of driving behavioural change itself (Rooksby et al., 2014). The notion of lived informatics also comprises the variety of uses and motivations that people have for the design. Some people will see tracking their behaviour as a social, collaborative process and will find more use for designs that encourage relatedness; others track to achieve autonomy and self-determination and will find use for designs that encourage those (Gouveia, Kapanaros, & Hassenzahl, 2015; Kapanaros, Gouveia, Hassenzahl, & Forlizzi, 2016).

> *Conclusion V: only those who display extreme motivation to persevere show lasting engagement. People with less than extreme motivation are likely to abandon the intervention before it has a change to affect behaviour.*
>
> *Design Challenge: how do we engage people who are not already extremely motivated to change their behaviour? This is a severe problem that concerns all designs for behavioural change. When should we opt for 'broader' interventions, with different components for people with the need for relatedness or autonomy, and when should we restrict ourselves to designing for a target group who has goals and use styles that fit our design?*

6 Design case IV: A fork that vibrates when you eat too fast

To contribute to the existing knowledge on whether feedback through digital technology can change undesired habits in the long run, we performed a range of studies that evaluate the acceptance and efficacy of a design to slow down eating rate. This is a deeply engrained habitual behaviour, which is strongly associated with stomach disorders and overweight (Robinson et al., 2014), which in itself causes a range of debilitating health issues, such as diabetes type II and some forms of cancer (Berenson, 2012). Because of its deeply automatic nature, eating rate is put-near impossible to change by will alone. The solution may lie in using a 'smart' fork, equipped with sensors and actuators to provide real-time feedback on eating rate; in other words, the fork vibrates when you eat too fast.

6.1 User experience evaluation

To evaluate the usability and acceptance of this fork, which is available on the market under the name 10sFork, we asked 11 participants to eat a single meal with the fork in our laboratory, and then take the fork home for three days and use it as much as possible. After the laboratory meal and upon returning the fork, we interviewed the participants. The fork proved an acceptable tool: users reported enhanced awareness of their eating rate and felt comfortable using the fork in social settings. However, none of the participants felt the fork was 'for them', even though they did recognise the need to slow down their fast-eating. This self-perceived target group membership, and the incapacity of the fork to take meal characteristics into account, may be issues affecting acceptance of the fork as an intervention for healthy eating in real life (full report in Hermsen et al., 2016).

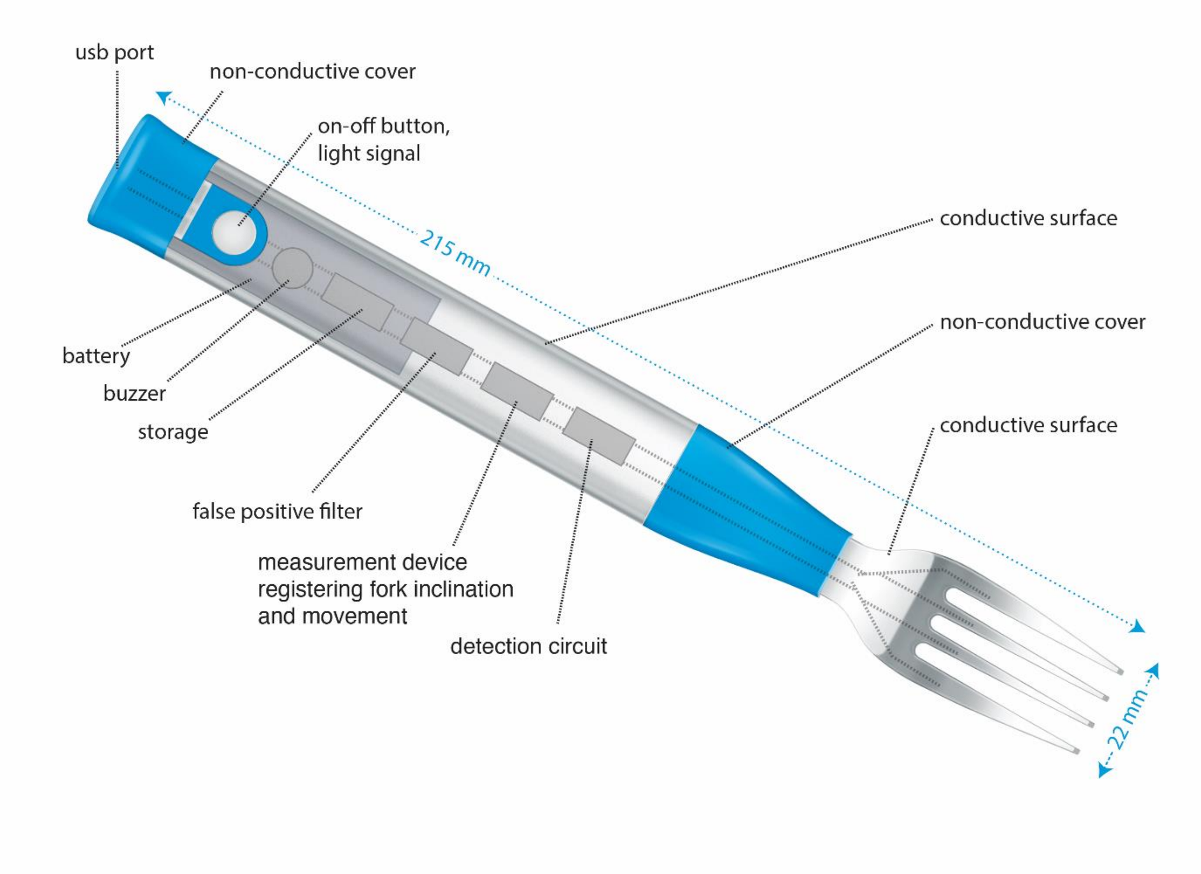


Figure 4: The 10sFork, produced by SlowControl, Paris, France

6.2 Lab study on effect

To test the effect of the fork on eating rate, we invited 114 self-reported fast eaters to our lab. They were randomly assigned to the feedback condition, in which they received vibrotactile feedback from their fork when eating too fast (i.e., taking more than one bite per 10 seconds), or a non-feedback condition, where they ate with the fork without feedback. To control for demand characteristics, we told all participants about the importance of eating slowly, and that the fork would record their eating speed. Participants in the feedback condition ate at a slower eating rate and took fewer bites per minute than did those without feedback. A slower eating rate, however, did not lead to a significant reduction in the amount of food consumed or level of satiation. This may have to do with the artificial setting of the meal; uncertainty about norms in a social setting are known to cause people to 'revert' to generally accepted ideas of portion size (Higgs, 2015). Alternatively, a slower eating rate may take more meals to start having an effect on the amount of food we eat (full report in Hermans et al., 2017).

6.3 Field study on real-life use and effect

Finally, we performed a field study, to learn more about the effect of using the fork in everyday life. We enlisted 150 participants, all self-reported fast eaters. To make sure all participants were well motivated to change their eating rate, we invited only participants currently under treatment of a dietician for complaints related with their eating rate, such as overweight and stomach complaints. All participants used the fork for one week without feedback to establish their baseline eating rate. Then they were randomly assigned to one of three conditions: eating as many meals with the fork as possible for one month, without feedback; same, but with vibrotactile feedback; and same, but with vibrotactile feedback and access to an online dashboard that provides retrospective feedback on eating rate. After this one-month training period, they once again ate with the fork without feedback for a week, to establish the effect of the training. This one-week measurement was repeated two months later.

The study revealed that people who received vibrotactile feedback managed to decelerate their eating, with a lower eating rate and a higher success ratio (percentage of bites that have at least 10 seconds between them). This effect remained after two months. Even more surprisingly, people in the experimental conditions managed to lose a bit of weight because of eating with the fork, where people in the control condition remained at the same weight. After two months, this weight loss persisted. This result shows that feedback from digital technology indeed has the potential to change undesired behaviours in the long run. However, the impact on BMI was small. For people to really lose weight, more 'holistic' approaches are needed, in which dietary interventions are combined with physical activity plans and eating behaviour interventions (full report in Hermsen et al., 2018).

> *Conclusion VI: our findings confirm the conclusions from our literary review, and also show that in certain cases, feedback from digital technology can lead to lasting behaviour change.*

These effects, albeit small, give confidence in the potential effect of feedback from digital technology on undesired habits that until recently proved put-near impossible to change. But new challenges also emerged. Both in our user experience evaluation study and in our lab study, participants did not particularly feel the need to change their eating rate. Even after receiving information about the detrimental long-term effects of eating too fast on our health, they did not feel motivated to slow down. In general, it is very hard to get people to accept the gravity of a problem, and even harder to convince them to accept solution as being 'for them'. How do we get people to start engaging with our feedback? We have seen previously that motivation to use a design needs to be very high, but people also need to realise both the problematic behaviour and the severity of its consequences.

> *Design challenge: How can we design a product or service in such a way that people understand that they are the target group, and in such a way that motivates uptake, without discouraging users by scaring them off or triggering cognitive dissonance reduction?*

7 Further challenges: measurement and privacy

7.1 Where do the data for the feedback come from?

In the past years, we have seen a steep increase in designs that provide feedback on a range of behaviours. Many of these rely on machine learning principles to signal events that warrant feedback: there are designs that predict influenza (Barlacchi et al., 2017) and depression (Merothra, Hendley, & Musolesi, 2016) from human activity patterns, and it is now possible to reliably predict when people who just quit smoking are in danger to start again (Naughton et al., 2016). These developments broaden the scope of potential designed solutions that provide us with feedback on our behaviour. However, many behaviours and human practices are (and will be for quite some time) too complicated to measure. For instance, the automatic analysis of nutrition is not yet feasible, even though the first products that claim to do so have already appeared online (e.g. Fitly, 2017). To obtain feedback on eating behaviour, the user still has to painstakingly provide their own data.

This can be expected to have a detrimental effect on sustained use and may form part of the explanation for why only a small segment of users of the water drinking app made it to the second week. Similarly, it is as yet very hard, if not practically impossible, to reliably detect human emotions. Yet, there are many products that claim to do just that (e.g. Sensoree, 2015; Bonte, 2017). This practice of introducing designs to the marketplace before they are technologically feasible is questionable, because it will kindle hope in people in need of such solutions, which will then inevitably lead to disappointment.

> *Design challenge: Automatic generation of data for feedback on behaviour can greatly increase engagement with a design by taking away the frustrating task of self-monitoring. However, this is at this moment only possible for a small range of behaviours. How can we develop ways to measure more and more complicated behaviours?*

7.2 Where do the feedback data end up?

Machine learning techniques and other forms of automatic measurement of behavioural data have their advantages, but they also come at a cost. Literature has described these forms of self-tracking in Foucaultian terms, where subjects willingly regulate, govern, and optimise themselves (Whitson, 2014). There is indeed a fine line between beneficial self-regulation through feedback, and the use of automatically generated behavioural data to subject people to standardisation and regulation. In order to give feedback, most products rely on data analysis that takes place on the vendor's servers, and visualisation of feedback through online and mobile applications. This process gives rise to concerns about privacy. Who owns the data that is generated by measuring your behaviour? Who guarantees that this data remains within the closed loop of measurement - analysis - feedback - measurement, and does not get transferred on to third parties? Is your data accessible? The 10sFork in the vibrating fork project registers each and every bite with a unique time stamp. This data is then used for direct, vibrotactile feedback, and for retrospective visualisations of your eating rate patterns. However, this data set was until recently unavailable for users of the fork. Similarly, many activity trackers will tell you how many steps you have taken, will show you historic trends in your activity and how you compare to others, but the entire data set with every registered step remains unavailable, stored in the vendor's server park for who knows what use.

> *Design challenge: As yet, there are no best practices of designs that use feedback for behavioural change that satisfactorily address privacy concerns. We need solutions that*

provide open, usable data for their users which remain closed off to anybody else. In other words, we need to start designing for privacy, or at least for privacy awareness.

8 Conclusion

This paper aimed to answer two questions: does feedback through digital technology have an effect on undesired habitual behaviour, and what determinants and feedback properties enhance the efficacy of the feedback? We have seen that feedback from digital technology can disrupt the automatic cue-response-pair of habitual behaviour, which makes that behaviour available for conscious scrutiny. All this does not necessarily mean that we can expect the technology and the feedback itself to lead to behaviour change. Current evidence allows us to see feedback through digital technology as a vehicle for behaviour change, but not (yet) as a driver (Patel, Asch, & Volpp, 2015). The vibrotactile fork project, however, shows that in specific cases, where people are adequately motivated to choose the design that provides the feedback as their vehicle, feedback on undesired habits can be an effective behaviour change technique.
Our second question: which determinants or feedback property enhance the efficacy of feedback designs, proved harder to answer. Our research shows that user experience and engagement play an important role. Challenges lie in keeping users engaged long enough for behaviour change to occur, and in guaranteeing users' privacy.

Unfortunately, although research presented in this paper shows the potential efficacy of designs that provide feedback, we are currently a long way from firmly establishing in what cases feedback through digital technology can sustainably change behaviour, and from finding out what works for whom in what contexts. This state of affairs is not helped by current methodological standards and reporting traditions in design research and HCI. These are insufficient to generate generalisable knowledge about the efficacy of our designs for behavioural change. To get there, we need to overcome one final challenge: improve the way we as design researchers report our designs. We need to put more effort in evaluating our designs, be it through qualitative or quantitative measurements of its effects, or by more thorough reporting of the design process and its iterations. Only then can we make more generalised conclusions about what works when and for whom.

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Section 22.

Design for Subjective Wellbeing

DRS 2018 Design Research Society 2018 Catalyst

University of Limerick
25th – 28th June 2018

Editorial: Design for Subjective Wellbeing

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1 Introduction

SIGWELL is the Design Research Society's Special Interest Group (SIG) focusing on Design for Wellbeing, Happiness and Health. The SIGWELL community has an interest in advancing knowledge, and the development and application of design research in the broadest sense to improve the personal and societal health, wellbeing and happiness of people.

Our SIG is managed by an international board (including the authors here, and in addition – Marc Hassenzahl and Matthias Laschke from the University of Siegen in Germany, Leandro Tonetto from Unisinos, Brazil and and Tiiu Polma from Montreal University in Canada.) Together we represent research in design for subjective wellbeing, experience design, positive design and participatory design across a range of domains from industrial design, engineering, psychology, interaction design and architecture. In 2017 we launched a research manifesto putting forward our vision for our SIG at the World Design Summit in Montreal (Petermans 2017).

2 From DRS2016 to DRS2018

In the 2016 conference, the SIGWELL themed tracks included papers on both 'Design for Health' and 'Design for Wellbeing' (Cain et al 2016). Two years ago, we were starting to see more research on subjective wellbeing, and the methods and approaches being reported were highly user-centric, participatory and sometimes critical and speculative. The distilling of design knowledge into frameworks and tools for designers was a popular deliverable of the research.

This year, following the call for tracks, we saw the distinction between the two areas growing, with a large community proposing tracks around design for health(care) and a smaller community proposing tracks around design for wellbeing – particularly subjective wellbeing. Therefore, this year there are two distinct thematic areas for SIGWELL themed sessions at DRS2018, representing the growth and increasing differentiation between Design for Wellbeing (our focus here) and Design for Health (with sessions chaired by Emmanuel Tsekleves). Design for Wellbeing in our context has a particular focus on Subjective Wellbeing, experience design, positive design and design for happiness.

The SIGWELL Design for Wellbeing themed session is an important opportunity to showcase emergent thinking and research from a highly international design community. We see evidence of the growing trend in moving away from designing physical objects and "more stuff" to designing for meaningful experiences, where it is the act of designing which can also contribute to a meaningful experience and improved subjective wellbeing rather than the outcome of the design activity per se. Increasingly, the methods to do this are participatory and lead to interesting and timely questions about the role and experiences of co-designers, and the effects of involvement on their own wellbeing.

3 SIGWELL: Design for Wellbeing papers

For DRS2018, authors were asked to contribute papers in the general area of subjective wellbeing. Five papers met the quality threshold for the conference and it is interesting to observe that these showed some convergence around two key themes:

Three of the papers used participatory design in a more applied, therapeutic context, focusing on the involvement of people with either specific mental health issues and conditions such as dementia (Garde et al 2018), vulnerable youths (Hong et al 2018) and postnatal depression (Warwick et al 2018). The other two papers played into a more exploratory, theoretical space, looking at how new frameworks and philosophical framing of concepts, e.g. play (Legaard 2018) and somaesthetic practice (Heekyoung and Stahl 2018) could be used to design new meaningful and pleasurable experiences, and so by their nature increase subjective wellbeing.

3.1 Theme 1: Using participatory design in a therapeutic context –

Starting with the theme of how involving people with mental health issues in design impacts upon them, Warwick et al (2018) in their *paper "Co-designing wellbeing: the commonality of needs between co-designers and mental health service design uses*" analysed how the design process impacted on co-designers of a new perinatal mental health service. The co-designers were new mothers, who drew upon their own personal experiences to create a new service 'Mums Matter'. The authors compared these impacts with the eventual service users of the service. Most notably, their paper reveals potential pressure points in the design process and raises important questions about how the risks around these should be mitigated to protect a co-designer's wellbeing. Most pertinently, how should designers' roles expand to explicitly manage a co-designer's wellbeing during the design process?

Warwick et al (2018) point towards an emerging issue in design for wellbeing research: that of the blurring between participatory design as a means to create a design outcome which enhances wellbeing (e.g. a service, product or experience) and participatory design as a therapeutic process in itself. In this respect, the act of participating in a design process can promote feelings of wellbeing through for example, the co-designer feeling they are being listened to, and the social interaction that comes from taking part in these types of co-design activities.

Hong et al's (2018) contribution *"Co-creating Happy Moments: A Case Study of Designing for People with Mental Health Challenges"* builds on this theme further. They explored a participatory design approach to engage with and design meaningful experiences for two groups of mentally - marginalised participants - a community in Norway that supports mental health and a group of youths in Finland. They used participatory design to enable the involvement of individuals and catalyse a positive change – though this change is observed rather than formally measured. This research raises some interesting questions around the blurring of boundaries between participatory design and art therapy. Interestingly, Hong et al (2018) also observed that they found their own involvement in the research as researchers also made them feel happy.

Continuing with the participatory design theme Garde et al (2018) in their paper titled "*Design probes for people with dementia*" developed a particular type of design probe to be used by people with dementia and reflected on the outcomes of using them as a source of inspiration for designers. Their aim with the probes was to "develop insight into the perspectives and life of people with dementia to enable a more empathic design approach and to identify needs, opportunities and ideas for mindful design interventions". Intriguingly, the authors found that more defined assignments (versus open-ended) had more value for designers as the defined assignments led to more sharing of personal details, and hence insights. They reflected that this contradicted other researchers' work who had found that the less instructive the probe tasks were, the more reflective and insightful the outcomes were. In terms of benefits to the participants, in the same way as both Warwick et al (2018) and Hong et al (2018), it was the act of participating which provided pleasurable benefits, allowing for personal reflection and enjoyment in doing the activities. Furthermore, the authors suggested that the participants felt empowered by using the probes because they felt they were helping with research

3.2 Theme 2: New theories and frameworks

Moving on to the second theme, where the final two contributions move into a more exploratory, theoretical space, we see new framings for designing meaningful and pleasurable experiences. Firstly, Legaard (2018) in their paper titled "*The road to happiness is paved with playful intentions*" start with the position that play activities, like meaningful experiences emerge when the activities of the experience comply with the interests, goals and passions of the person having the experience – thus linking meaningfulness to intrinsic motivation. The paper provides an understanding of the components of a play experience through the introduction of an evolving 'Play Blueprint', which draws upon the theoretical foundations within play, experience design and positive design. Through this, the paper explores the relationship between meaningful and playful experiences, calling for designers to use the characteristics of play and playfulness to increase the intensity of an experience.

Finally, the contribution by Heekyoung and Stahl (2018) titled *"Soma-Wearable Design: Integrating Somaesthetic Practice and Fashion design for Somatic Wellbeing"* introduces a new concept – that of soma-wearable design for somatic wellbeing. As the authors explain, "*Somaethetics is a branch of philosophy that grounds the meaning of human experience in the bodily presence*". They propose that somaesthetic practice and fashion design have a meaningful overlap with their focus on body consciousness. Their paper describes how they conducted a design workshop with 14 fashion juniors to introduce the soma-wearable design approach and then observed how the approach was interpreted by the students. They point to some interesting future directions for the research, for example in investigating the link between somaesthetic reflection and self-perception and performance, e.g. through soma-wearables for mood change.

4 Looking to the future

Despite the SIGWELL theme containing a smaller number of accepted papers this year, the prevalence of participatory design as an underpinning methodological approach in the majority of the papers is noteworthy. However, perhaps one issue of debate, and of interest to explore further through discussion at the conference is the blurring of the boundaries between participatory design and art therapy. We see this emerging when it is the acts of involvement in participatory design which carry the therapeutic benefits and enhance subjective wellbeing, rather than the design outcome per se. In these situations, it is also interesting to reflect on how participation in designing for subjective wellbeing, can also have an emotional effect on the researchers involved – both positively through engagement in a meaningful experience, but also in raising more challenging questions of how designers are trained to work with people in sensitive scenarios around mental health.

Perhaps another challenge faced by researchers in the area of design for subjective wellbeing is that of scale. Many examples (both in this session, but also in the design for subjective wellbeing literature more generally) are individual case studies, relating to very specific populations, contexts and scenarios. From a methodical research perspective, the challenge lies in validating these approaches across other settings with other groups of people, so we start to build and converge on approaches for designing for subjective wellbeing supported by an evidence-base of their successes and failures. This challenge will be explored further through a SIGWELL workshop (Ozkaramanli et al 2018) also to be held at DRS2018, "*Victories and Defeats: Current Practices in Design for Wellbeing*".

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Co-designing Wellbeing: the commonality of needs between co-designers and mental health service users

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This paper considers the potential impact of the co-design process on the wellbeing of stakeholders involved in mental health service design. The findings presented here are drawn from semi-structured interviews conducted with both co-designers of a perinatal mental health service, who previously had issues with their mental health and acted as experts by experience, and the service users who accessed the designed offer. These have subsequently been analysed using a General Inductive Analysis approach (Thomas, 2006) to understand the factors that impacted on a participant's wellbeing in both circumstances. Our findings highlight that there are similarities between the factors that impacted on the wellbeing of the co-designers and those that impacted on the wellbeing of service users accessing a mental health service. This paper suggests ways in which the design community might learn from the mental health sector to manage, and potentially improve, co-designers' wellbeing during the co-design process. It also suggests how the role of the designer might need to expand to explicitly consider and manage the wellbeing of co-designers during a project.

co-design; wellbeing; service design

1 Introduction

As the Design profession has moved from designing for people to designing with people (Sanders & Stappers, 2008, 7; Brown, 2009; Blyth & Kimbell, 2011), designers have adopted new roles that allow stakeholders of an issue to play a central part in the design of a solution (Sanders & Stappers, 2008, p. 7). Involving stakeholders in the creation of a service or a product is commonly defined as *co-design*. This term is often used as an umbrella term for participatory or open design processes, but this research understands co-design to involve a group of stakeholders who come together to work creatively through the entire design process; from the definition of the problem space, through to the design of the potential solution (Sanders & Stappers, 2008, p. 7).

Co-design groups are generally comprised of those who can offer expertise on the issue being considered, including professionals, front-line staff, and previous or potential users (Steen, Manschot, & De Koning, 2011, p. 53; Visser, Stappers, Van der Lugt, & Sanders, 2005). However, the members of the group, known as *co-designers*, place the experiences of users at the centre of the decision making (Steen et al., 2011, p. 53). Co-design research to date has predominantly focused on the positive impacts of involving stakeholders in this way, including the: higher quality of ideas; improved knowledge about users' needs; and more successful innovations (Steen et al. 2011, p. 58).

However, much of the research focuses on the impact on the *outcomes* of the process (service, system or community, etc.), and there has been little exploration of the potential impacts of co-design on the *co-designers* (Vink, Wetter-Edman, Edvardsson, & Tronvoll, 2016). Those impacts that are discussed are usually outcomes of stakeholders continued involvement in a project or programme, for example, feeling more empowered (Manzini, 2010) or gaining new skills (Wolstenholme, Grindell, & Dearden, 2017). There is little research into how being a co-designer impacts on the individual at different points in the process, or how being a co-designer could have a negative impact on an individual's wellbeing.

The concept of wellbeing is one that is heavily described, but historically ill-defined (Dodge, Daly, Huyton, & Sanders, 2012, p. 222). The term is frequently used interchangeably with 'quality of life' and other similar phrases, without a common, detailed understanding of what it means. For this research, the authors have drawn on Dodge et al.'s (2012, p. 230) definition of wellbeing as "the balance point between an individual's resource pool and the challenges faced". When an individual faces more psychological, social or physical challenges than they have psychological, social or physical resources, this balance is lost, having a potentially negative impact on their wellbeing (Dodge et al., 2012; Kloep, Hendry, & Saunders, 2009). Similarly, not receiving adequate challenge, can also result in a reduced sense of wellbeing, as our resources can 'stagnate' (Dodge et al. 2012, p. 230).

Considered in very simplistic terms, being a co-designer can be viewed as a 'challenge'; this could be seen as a positive challenge, which could help the co-designer to 'flourish' (Keyes, 2002). Equally, as a novice, the stakeholder may not necessarily have the 'resources' to draw on to navigate or enact aspects of the design process, thus adversely impacting on a co-designer's wellbeing.

The issue of wellbeing in the context of co-design is particularly important when working to create new health and social care services, where the issue being focused on could be sensitive or distressing, just as in the case considered in this research. Here, the authors analyse how the design process impacted on the wellbeing of co-designers of a new perinatal mental health service, who had drawn on their own personal experiences to create a new offer, 'Mums Matter'. These impacts are compared and contrasted with interviews conducted with the eventual service users of the co-designed service. The paper presents the aspects of the design process that can have impact on a co-designer's wellbeing, and what can be learnt in this respect from the way mental health services manage wellbeing of service users.

This research offers two contributions to academic and practitioner audiences: firstly, the findings suggest the potential pressure points in the design process and how these might be mitigated against to protect a co-designer's wellbeing. Secondly, the authors suggest how designers' roles might need to expand to explicitly manage a co-designer's wellbeing during the design process.

2 Related Work

An exploration of literature related to this issue has identified two main gaps: firstly, there is no research that explicitly discusses a designer's role in managing the wellbeing of co-designers. Secondly, there is little research that discusses the impact that design can have on wellbeing, particularly the potential negative impacts of being involved in the design process. These issues are discussed in the following sections.

2.1 Designer’s role in co-design

Sanders and Stappers’ (2008) depiction of the evolution of co-design and co-creation describes designers and users swapping roles, with the designer acting as a facilitator to the process, and the user taking on a more prominent role in decision making. As a result of this shift, the profession has continued to see the development of a new set of roles, distinct from the traditional definition of designer as “a person who plans the look or workings of something prior to it being made” (The Oxford English Dictionary, 2017).

Recent research has identified the ‘expanding roles’ of design practice (Tan, 2012; Yee, Jefferies, & Tan, 2013). Yee, Jefferies and Michlewski (2017, p. 18) identified seven roles to drive change by design: cultural catalyst; framework maker; humaniser; power broker; friendly challenger; technology enabler; and community builder. All of these investigations have established that designers can adopt multiple roles in a project, often simultaneously, in order to involve as effectively as possible stakeholders in the design process (Tan, 2012; Yee et al., 2013; Yee et al., 2017). However, none of these have talked about a designer’s role in managing a co-designer’s wellbeing during the process.

2.2 The impacts of co-design on wellbeing

There is a small amount of literature that discusses co-design impacts that can be linked to an individual’s wellbeing. Much of it describes the positive outcomes of co-design, including objects, services or systems that improve wellbeing. For example, Zanetti and Taylor (2016) note that “co-creation has shown to improve health outcomes with regard to multiple health conditions”. Camacho Duarte, Lulham and Kaldor (2011) similarly noted their co-design project improved “community well-being and safety”.

Co-design literature also frequently describes an empowered community as an outcome of co-design, although it is not always anticipated. Research suggests that stakeholders can be empowered by co-design as it is an “active engagement process” (De Couvreur & Goossens, 2011). Such engagement results in “empowered people who take more responsibility for their own well-being and the future” (Szebeko & Tan, 2010). Others describe this empowerment as resulting in ‘happier’ consumers (Pera & Viglia, 2015). For service design projects in particular, outcomes such as a sense of “community affiliation” (Pera & Viglia, 2015) and “a shared vision of the future” (Reay et al., 2016) can also be linked to wellbeing.

The opportunity provided by design to ‘make’ something - whether it’s social change, or something more tangible - is also seen as having a positive impact on wellbeing (Szebeko & Tan, 2010). Prototyping activities, including designing, making and using, are “framed as sources of happiness, which lead to engagement, new challenges, fruitful relationships and sense of accomplishment” (De Couvreur, Dejonghe, Detand & Goossens, 2013, p. 68).

Despite the claims of positive wellbeing detailed in the literature, “existing research on co-design seems to focus mainly on wellbeing outcomes at the micro or meso-level” (Vink et al., 2016, p. 396). Vink et al. (2016) also describe how there is not yet a clear analysis of how the design process influences wellbeing across levels, entities, types, outcomes, intentions and transformation. The negative impacts of the process on wellbeing are also overlooked in co-design literature, “as a result, conversations about how to reduce and mitigate negative impacts of the co-design process are absent” (Vink et al., 2016, p. 396). Steen, Manschot and Koning (2011) also acknowledge the need to consider “whether the intended benefits are indeed realized”, and the “risks of co-design.”

There are many aspects of the design process that might feel challenging to non-designers, as they are a departure from standard ways of working and might require a new set of ‘resources’. For example, Design frequently addresses ‘wicked problems’ (Rittel & Webber, 1973; Buchanan, 1992), which are inherently complex, with indeterminate outcomes. This amount of uncertainty can impact on stakeholders, who may be uncomfortable with ambiguity and open-endedness. Depictions of the design process also frequently describe ‘a fuzzy front-end’ (Sanders & Stappers, 2008), where designers use divergent thinking to explore all potential factors related to an issue. The multiple directional changes in the ‘fuzzy front-end’ could also feel alien to co-designers. Designers also have to consider what could be, rather than simply build on what exists (Manzini, 2010; Tan, 2012). However, imagining an alternative future is a difficult task for a non-designer, particularly the shift from the familiar inductive or deductive logic, to the use of the unfamiliar ‘abductive reasoning’ (Martin, 2009).

There is a need to make clearer the role of co-design in affecting wellbeing and developing the dialogue around the impacts. Vink et al. (2016) suggest opportunities for “designers to better optimize the total value created through co-design”. This can be achieved through “considering and managing not only the impacts of what is being designed, but also the impacts of the design process, designers can work to enhance the overall influence of co-design on well-being” (Vink et al., 2016). Vink et al. (2016) believe this is approached by a number of steps, including understanding all impacts of co-design on wellbeing and a “deepening exploration of how co-design contributes to different types of wellbeing”.

This paper aims to build on the fourth of Vink et al.’s (2016, p. 398) proposed expansions: “Monitoring co-design’s negative outcomes related to wellbeing and discussing opportunities for mitigating or reducing these outcomes.” It will do so by considering the factors that impact on a co-designer’s wellbeing, and how we can learn from mental health support in how we might mitigate against them.

3 Research Methods

A case study research design was chosen as it “defines topics broadly not narrowly, cover contextual conditions and not just phenomenon of study, and rely on multiple and not just singular sources of evidence” (Yin, 2003, p. 33). This study aims to explore the gaps in knowledge in relation to the impacts of being a co-designer on wellbeing, and as such, this dictated an exploratory design (Yin, 2003, p. 3). An embedded, multiple-case design was chosen, to compare and contrast two different projects that reported impacts on wellbeing, to understand any commonalities and differences between the cases (Yin, 2003, p. 45).

The first case chosen aimed to uncover the impacts of being involved in a co-design process on participants; and the second, to understand the impacts of the co-designed mental health service on the service user. Although both activities had very different purposes (to design an effective service, and to improve a participant’s wellbeing), the reflections of both groups appeared to be very similar, and allowed the authors to reflect on what could be learnt about the management of wellbeing from both contexts.

The research was qualitative by nature, in order to explore “well-grounded, rich descriptions and explanations of processes in identifiable local contexts” (Miles & Huberman, 1994, p. 3). For context, an overview of each case is outlined below:

3.1 Case study one: Co-designers

In June 2015, Mind, a federated charity that aims to improve the mental health and wellbeing of people living in England and Wales, embarked on a project to co-design a service for women with poor perinatal mental health. This was part of Mind’s broader programme, Service Design in Mind (SDiM), which aims to embed service design techniques and methods into their network of local Minds that deliver mental health services (Pierri, Warwick & Garber, 2016, p. 580).

Up to 20% of women will develop a mental health problem in the perinatal period (from pregnancy to the child’s first birthday), including problems such as: antenatal and postnatal depression, obsessive compulsive disorder and postpartum psychosis (Bauer et al., 2014). Mind wanted this work to be led by women with lived experience of perinatal mental health problems, “experts of their experience” (Visser et al., 2005), to help shape what their organisational response should be. They advertised on social media and received 100 applications from women who wanted to participate, and from this, they selected five women to be part of the co-design team who were paid for their work on the project. Each of these women was from a different area of the country and had a different experience of mental health support; one was supported in a hospital environment, one had private treatment, one received counselling, one accessed cognitive behavioural therapy and one was treated with medication.

These women were also joined by representatives from two local Minds, who had expertise in delivering mental health services for this target group. A service designer from the SDiM team (also an author) was appointed as the facilitator to guide the co-designers through the design process, and the manager from Mind’s Products programme (for which the service was being designed) was present to manage the overall project.

The co-designers led every aspect of the design process from defining the design brief, to detailing the final service concept. The SDiM team acted only as facilitators of the process; planning the workshops that introduced the possible design tools and methods, and the co-designers had the power and permission to make all decisions about the service’s purpose, look and feel.

The co-designers were brought together once a month for a workshop; five in total, one for each stage of the SDiM methodology (see Figure 1).

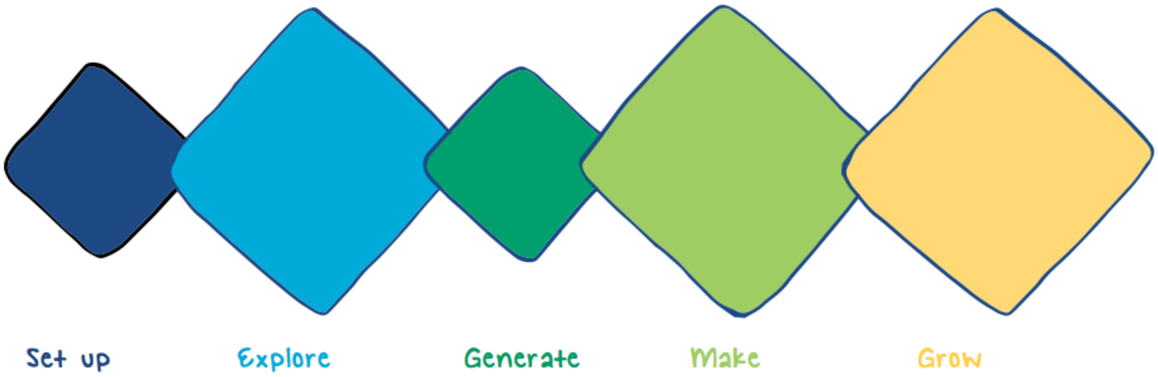

Figure 1: The five stages of the Service Design in Mind methodology (Pierri et al., 2016, p. 581)

In the *Set-up* workshop, the co-designers shared their own experiences of support they received and used this to create a research brief, which guided the work in the early stages. The facilitator introduced the design research process in detail and the co-designers tried out tools and methods, to increase their confidence and familiarity with the process.

In the *Explore* workshop, the facilitator supported the co-designers to create example discussion guides and test them on each other, before finalising the questions to ask research participants. Following the workshop, the co-designers interviewed 20 women with lived experience, 1 relative and 11 experts. Each co-designer reflected on the interviews they conducted to identify the insights that they felt should influence the next steps.

In the *Generate* workshop, the co-designers shared their key insights from the Explore phase. The facilitator helped to map and group similar findings to identify themes and patterns that were then used write a new design brief. Following the workshop, the co-designers used the design brief to generate ideas about ways Mind could meet those aims, describing their best ideas in a storyboard.

At the *Make* workshop, the co-designers shared their storyboards, reflecting and critiquing them to take forward the aspects of the ideas that they liked. The co-designers combined these to create the ideal service offer, which the co-designers named ‘Mums Matter’, that was then mapped out step-by-step with the facilitator’s help. After the workshop, the facilitator created a storyboard to describe how Mums Matter would work. Each co-designer then showed this to the women they interviewed to get their feedback on the concept.

At the *Grow* workshop, the co-designers used the feedback from the interviewees to create another iteration of Mums Matter. The facilitator then helped the co-designers to think about the key messages for the service and how Mind would reach out to the women who need support.

In May 2016, following the completion of the workshops, a mental health practitioner with specialist perinatal mental health expertise used the co-designers' design outputs to create the session content for Mums Matter.

3.2 Case study two: service users

At the end of the workshops, the final design for Mums Matter was an eight-week course, which would introduce key content on: how to manage the everyday; dispel myths; and nurture themselves.

Service users could self-refer to access this course, but awareness was also raised through healthcare professionals and other community groups and spaces. Service users were brought together in groups of no more than eight to discuss their feelings and learn about ways to improve their mental health. The service users had access to a fully paid-for crèche, so that they had time and space to share their emotions without needing to look after their children.

In weeks seven and eight, the service users and facilitator met up in an informal setting e.g. a local cafe, to help them get used to supporting each other with their children around.

There was also an optional session, separate to the course, for supporters of the mums (this could be a partner, relative or friend) to learn more about perinatal mental health and how to help them.

Once a mental health specialist created the course content, Mums Matter was run as a live prototype in two local Mind organisations. Prototype one began in October 2016, and prototypes two and three began in February 2017. Key primary care professionals, including health visitors and GPs, referred service users to access Mums Matter. Each potential service user was assessed for their willingness and readiness to attend the service using accepted mental health measurement models. They then attend eight sessions: six in a community building, and two in an informal setting e.g. a local cafe.

3.3 Data collection

In both cases, the primary research method was semi-structured interviews (Robson, 2011), in order to gather rich, descriptive stories from the participants. All co-designers and service users were invited to participate in the research.

The co-designers were invited to take part in an interview after the project had concluded to contribute their views on the process and how it had impacted on them. Four out of the five women involved consented to an interview.

In the case of the service users, each of the mums that attended were asked to share their experiences of the service one month after the service had concluded. Ten out of fourteen service users consented to be interviewed.

For each set of interviews, a discussion guide was created that broadly focused on: what was good about their experience, what could be improved and what were the positive and negative impacts on them, if any. None of the questions asked about wellbeing explicitly, but instead drew out in the discussion details of how the experience (of being a co-designer, or a service user) had affected the participants' psychological, social and physical resources, in relation to their psychological, social and physical challenges, as per Dodge et al.'s (2012) definition.

The same independent researcher conducted all of the interviews with the co-designers and the service users. Each participant gave their informed consent for their interviews to be audio recorded, transcribed and analysed. All of the women were also asked if they felt well enough to take part in the interview before it commenced.

4 Data analysis

As this research was both qualitative and exploratory, the authors adopted a General Inductive Analysis approach (Thomas, 2006) to build theory directly from the data, without being influenced by pre-defined hypotheses (Scriven, 1991, p. 56). This approach is similar to a Grounded Theory approach (Glaser & Strauss, 1967), but does not require the researcher to be independent of the activity being analysed (Thomas, 2006). As one of the authors was both practitioner and researcher in this study, it was appropriate to draw on this alterative inductive-based approach.

The research data went through four distinct stages:

- data-cleaning;
- first-stage coding;
- building multiple coding collections;
- and identifying themes and patterns.

To clean the data, the interviews were all first transcribed and put into a common format to aid reading of the text. They were then read several times, with hand codes made amongst the text (Glaser & Strauss, 1967, p. 106). Each excerpt of text related to a psychological, social or physical impact on the participant was copied onto a Post-It note, to continue the manual analysis of the data.

Using the Post-Its, quotes were grouped based on perceived commonality. These created multiple coding collections (Tan, 2012, p. 79; Yee, 2010), which were then assigned a title that summarised the meaning or theme of the group. Looking across all these groups then allowed the researchers to identify a set of factors that impacted on wellbeing. With each of the factors, a process of correlating the theory with existing literature, as well as reflecting back on the original data, helped to ensure their plausibility. Aspects of the patterns were also validated with key members of Mind's team to check inter-rater reliability and ensure accurate interpretation of data and outcomes.

5 Discussion

All of the women interviewed reported improved wellbeing, either as a result of being involved in the co-design process, or accessing the Mums Matter service. The co-designers primarily related an improved sense of wellbeing to using their own previous, often negative, mental health experiences, to create something positive for others; using an existing resource to meet a new challenge. Whereas, the Mums Matter service users felt that the skills and knowledge they acquired during the course resulted in improved wellbeing outcomes; providing new resources to meet an existing challenge.

Although the women's positive wellbeing outcomes were attributed to different activities, the women described a number of similar factors that had impacted on their ability to maintain or readdress their wellbeing balance during the course of the co-design project, or the Mums Matter service. These factors are outlined below:

5.1 Commonality of experience

The first notable factor that impacted on the women's wellbeing was meeting others with a shared experience.

All of the women interviewed enjoyed being brought together with women who had experienced the same mental health issues. In the service users' interviews, women described that learning that they were not alone in their experience was crucial to their recovery: "meeting other mums who were in the same position, knowing that there were other people who were feeling the way that you do and it's not that you're a bad person."

Although both the co-designers and service users knew that they would meet women with this shared experience, in the case of the co-designers, they had not anticipated how much this would improve their wellbeing. Each of the co-designers interviewed said that they had not met women who had shared their experience to such an extent. They found this particularly empowering as it helped to ‘normalise’ their feelings; “I was so relieved that other women who are capable intelligent women in every respect went through mental health problems in that time. I felt less abnormal.” As all of the co-designers were all ‘recovered’ from their mental health issues, the design team had also not anticipated this impact, nor deliberately chosen co-designers who had not accessed peer support, but it proved to be a crucial factor in improving their wellbeing during the process.

In both cases, what was critical to the positive impact was that they were provided with a platform to express their experience without being judged. Within the service context, this was both anticipated and expected, but within the co-design context, co-designers were unsure if they would be drawing on their own experiences directly. One co-designer commented that “the first things we talked about was our experience of perinatal mental illness, so there was never any shyness or awkwardness”. For the service users and the co-designers, they felt this opportunity to share, and to be listened to, helped improve their wellbeing, and contribute to positive group dynamics. Explicitly in relation to co-design, this sharing of experiences was attributed to feeling ‘valued’ and able to contribute something of worth. By being viewed as “experts of their experience”, the co-design process helped to provide an opportunity for a negative experience to be seen in a positive way.

5.2 Group dynamics

The second, related, factor that impacted on both co-designers’ and service users’ wellbeing was group dynamics. As a result of this shared experience and attending the course together, service users formed bonds that often continued once Mums Matter was finished. In some cases, the entire group bonded: “we've set up a WhatsApp group so we talk on there”. For some cohorts, more one-to-one friendships formed, with a few examples of two individuals meeting up regularly: “I met one girl and we now see each other quite regularly so that’s quite nice, I think I got on well with her”. The continuation of relationships outside of the service environment has helped to provide sustained peer support for the mums, which many felt would form a part of their continued recovery.

Conversely, in other cohorts of service users, there were tensions amongst the group, and this impacted on wellbeing throughout the service delivery. Some women described feeling that they did not have the opportunity to share their opinion or experience. One mum felt that her group was often dominated by one person: “there was a girl when we did it who talked a lot and I think if you're not somebody who talks a lot it can feel a bit like a one man show sort of thing”. A similar situation was described in another cohort where a mum said that “there were people that had bigger personalities in the group”. In both cohorts, mums that had noticed this had felt that this detracted from their wellbeing as it left them frustrated, and unable to participate in the way they wanted.

Similarly, in the co-design group, one co-designer described feeling that her experience had been dismissed on occasion by another member of the group: “there was a woman in the group who I had quite an opposing view to on one aspect of recovery”. She went on to describe that an idea she had proposed at the idea generation stage had been ‘dismissed’ by one person who “rolled her eyes”. She commented that the facilitators probably had not noticed this, and she did not want to complain about the incident, as she felt that in general she had a strong connection with the group.

However, all of the co-designers generally felt that they had bonded very well, and that this had helped them to develop a cohesive service in the timeframe as they had a shared sense of purpose and aim. For example: “it felt like we were just one team all on the same level, all equally having a say, it didn't feel like any one person's opinion was more important than anyone else.” Whilst giving everybody the opportunity to contribute equally is an understood principle of good facilitation, co-designers found that the opportunity to supplement a working relationship with personal relationships formed over lunches and breaks was particularly important. In parallel to the service users, they found this became a form of peer support, which has continued post-project: “there was that empathy for each other as we had all been through something, certainly with me they were all so supportive and encouraging”. Recognising that the community needs to bond in multiple ways is important to promote positive impacts on wellbeing in a co-design context, as it can provide social resources to help address new challenges.

5.3 Facilitation

The importance of facilitation in a co-design context (Sanders and Stappers, 2008; Yee, Jefferies and Tan, 2013) and mental health (Repper, Ford & Cooke, 1994) is well established, in order to encourage participation and help manage the aforementioned group dynamics. However, the data shows that the relationship between the women and the facilitator was of equal importance.

In Mums Matter, the facilitator’s primary aim was to improve the mental health of the service users, and so it was anticipated that this role would be an important factor in the wellbeing of the service users. One mum said, “I trust her which is a big thing, I don't trust anyone really, [but] I trust her, I can tell she's genuine”. Another commented that “her being an open, genuine person is fairly integral to a course like that succeeding”.

The Mums Matter facilitator had been recruited and trained with a focus on the personal skills that would be required in this context, whereas the co-design facilitator had not received any mental health-specific training. However, a similar theme was still apparent in this case, with the personal skills of the co-design facilitator being valued over their design abilities. The co-designers remarked on how the co-design facilitator had been ‘encouraging’, ‘positive’, ‘trust-worthy’, ‘patient’, ‘professional’ and ‘relaxed’. Of particular importance was the perceived empathetic nature of the co-design facilitator, with one mum describing her as “very sensitive and considerate of any sensitive areas and emotional issues”. All of the co-designers described trusting the facilitation team; both to deliver the best possible outcome, but also as people they could share their honest thoughts and feelings with.

The Mums Matter facilitator was also in contact with the service users between the sessions of the service to provide support and encouragement to keep them attending. Service users thought this was key to maintaining their wellbeing between sessions. Similarly, one of Mind’s facilitation team spoke to each co-designer between the workshops to see how they were managing with their design activities. Although the ‘check-ins’ were primarily to support the co-designers with the design activity, the women felt that this was also key to maintaining their wellbeing during the process as they prevented them from becoming overwhelmed and helped them to feel valued, again providing a vital social resource.

Although both the Mums Matter facilitators and co-design facilitator played key roles in maintaining and improving the wellbeing of the women they supported, only the mental health facilitator worked with that primary aim. The co-design facilitation team considered the wellbeing of the women in relation to the activities they were asked to complete, but it was no one person’s main responsibility or focus.

5.4 Structure

In both cases, the co-designers and service users talked about valuing the structure provided by the service or co-design project.

In the case of the Mums Matter service, this was not surprising as it had been designed to take the women through important topics in a logical order. None of the service users interviewed felt any content should be removed, or moved to a different part of the course. They all talked about the content being critical to help them to progress in their recovery and provide the resources required to rebalance their wellbeing.

Although the structure of the co-design activity wasn't focused around improving wellbeing, nevertheless, it was an important factor that helped the co-designers to maintain their wellbeing during the process. Understanding what was going to be achieved overall, and within each session, was incredibly important to help them feel confident about their tasks. One co-designer noted that:

> *"[The facilitator] recapped and said 'this is what we have done in this section, we've finished this bit and this is how we are going to do the next bit', so it was really structured. It certainly really helped me feel confident in the process because you knew you were making progress and achieving what needed to be achieved".*

This was particularly important in relation to the activity between sessions. Having activities clearly explained with examples and frameworks to support them, helped the tasks to become a positive experience, rather than a focus of their anxiety.

Several co-designers did discuss the difficult timing of one activity, as they were asked to generate ideas over the Christmas period, and it became difficult to manage this around other commitments. Although they had been reassured about how much work they needed to do, they all felt a responsibility to achieve as much as possible, which had the potential to result in a negative impact on their wellbeing. Similarly, the service users in the first cohort of Mums Matter were given activities to do at home that were part of their continued learning about their mental health and wellbeing. These were rarely completed, mainly to do with the pressures of life at home. Service users described feeling 'guilty' about not having completed 'homework'. As the facilitator detected this issue during the sessions, this aspect of the service had been changed for cohorts two and three. However, this correlation does demonstrate the need to share and manage expectations of activity between co-design sessions to reduce this potential point of anxiety.

For both co-designers and service users, the perceived flexibility within the structure was equally important. Despite the focused timeframe, the co-designers described feeling that they had time to contribute, and they felt listened to, which was very important to their wellbeing. One co-designer remarked that despite the structure, sessions were not 'formal' and so "it made you feel really comfortable to be able to say whatever you thought". In a similar vein, the service users found that they had the opportunity and space to share their feelings, and they were not rushed onto the next topic.

Designers therefore need to consider the project structure not just from the point of view of achieving the desired outcome, but also in relation to mitigate negative impacts on co-designer's wellbeing.

5.5 Management of the beginning and the end

As well as the importance of structure, the beginning and the end of both the service and the co-design project provided opportunity to considerably impact on the women's wellbeing.

In both cases, the beginning of the service and co-design project commenced with a one-to-one meeting between the mum and the facilitator. For the co-design project, this was a formal one-to-one interview process to select the co-designers, but it proved to be an important stage in setting expectations of the project and forming relationships with the facilitator.

For Mums Matter, the facilitator met with the potential service user in order to assess her suitability and readiness for the course. However, it also proved to be important to gain an understanding of their mental health and wellbeing, and potential triggers that might impact on the mum during the service. Conversely, the co-designers shared some of their mental health experiences as motivation for participation in the project, but there was no discussion around how the co-design activity might impact on their wellbeing.

Data shows that meeting the facilitator before Mums Matter began helped the service users to feel more comfortable with the idea of attending: "because I had already met [the facilitator]… she was like, well done for coming". Many of the service users still talked about feeling anxious before attending the service for the first time: "because I suffer from anxiety everything goes to my head so at first I was thinking am I going to look stupid?" The co-designers expressed similar emotions in relation to this stage of the projects; they said that they felt excited about the co-design project, but they were still anxious about meeting the other co-designers for the first time.

Likewise, the ending of the co-design project and service delivery was a factor that could have a detrimental impact on the wellbeing of the women involved. The participants in both the co-design project and Mums Matter service were in regular contact and had a purpose for meeting. In both cases, when this ended, the women described a sense of loss. For the service users, this had been predicted, and the end of the formal service model was followed by two additional sessions that took place in the community.

In the case of the co-designers, the impact of the end of the project was not predicted or managed. The co-designers said they felt "sad it was over", and wanted to continue to have a way to contribute to the project. Unlike many co-design projects, the service, and co-designers, were not local to a particular area, and such an opportunity was not possible. However, it proved important to the co-designers that they had an application for their new 'resources'.

Managing both the beginning and the end of contact are key to maintaining wellbeing, to ensure that a sense of balance is retained or attained during and post-project. Further research would help us to understand the impact of the pre- and post-project phases in detail, to provide guidance as to how this might be achieved.

6 Conclusion

This research has found that being involved in co-design projects may have an unplanned impact on co-designers' wellbeing. Furthermore, there are clear similarities between the factors that had impact on the co-designers' wellbeing, and those that had an impact on mental health service users' wellbeing, outside of their simple involvement in the project or service.

By drawing comparisons between a service focused on improving wellbeing, and a co-design project that unintentionally impacted on wellbeing, it is hoped that readers can gain insight into the factors that influence wellbeing within the co-design project. Also, how negative factors might be mitigated or managed in the future based on how these factors are managed in a mental health setting. This directly builds on one particular aspect of Vink et al.'s (2016) earlier findings, which stated the importance of understanding negative outcomes and how these might be reduced. A summary of the factors found through this study to impact on a co-designer, and how these could be managed, is presented below (Table 1).

Some of these factors have been discussed in literature in relation to successful co-design projects, for example, the importance of facilitation (Burns, Cottam, Vanstone & Winhall, 2006; Tan, 2012; Light and Akama, 2012), the impact of sharing experience (Battarbee, 2003), and the dynamics of group behaviour (Light and Akama, 2012; Van Mechelen, Zaman, Vanden Abeele & Laenen, 2013). However, none of these have been found to relate specifically to a co-designer's wellbeing before, or correlated with mental health practice.

This paper does not suggest that people with lived experience of sensitive issues should be excluded from co-design teams; on the contrary, it is crucial that those with expertise and skills to offer continue to be involved in the co-design process. However, it suggests that designers need to be more explicit in their management of wellbeing during such co-design projects. Moreover, as current statistics suggest that one in four people will suffer from a mental health problem during their lifetime (McManus, Bebbington, Jenkins, & Brugha, 2016), it becomes even more vital that designers are aware of the impact the process can have and how they can manage both these intended and unintended impacts, regardless of the focus of the work.

Table 1 How to mitigate against factors that negatively impact on a co-designer's wellbeing

Commonality of experience	• Allow opportunities to share their experiences in a non-judgemental space.
Group dynamics	• Create opportunities for the community to 'bond' on a personal level. • Allow everyone to contribute and be listened to. • Ensure no one dominates the group.
Facilitation	• Create relationships with each co-designer to establish lines of communication and possible triggers for their wellbeing. • Recognise the importance of your inter-personal skills, over your design skills. • Gain co-designers' trust in your ability to deliver outcomes. • Gain co-designers' trust that you understand and empathise with their experiences. • Check-in between workshops to establish co-designers' general wellbeing, as well as the progress of the design work. • Ensure one member of the team has a responsibility to consider and monitor the wellbeing of the co-designers.
Structure	• Explicitly outline and re-cap on activities to provide reassurance about achievements. • Build in regular opportunities for people to share their thoughts and opinions. • Negotiate the timing of co-design activities so they don't have unintended impacts for the co-designers • Manage co-designers' expectations in relation to each activity.
Management of the beginning and the end	• Meet co-designers in advance to establish general wellbeing, triggers etc., as well as set expectations for the project. • Consider ways to keep the community involved post-project. • Keep lines of communication open post-project so co-designers remain informed.

Just as recent research has called on the design profession to change and adapt the roles it plays to maximise user input (Yee, Jefferies, & Tan, 2013; Tan, 2012; Burns et al., 2006), this paper suggests that designers also need to extend their responsibility, to simultaneously enable and protect the co-designer during the process. This prefigures a new duty of care for the co-design process. Practitioners need to plan and craft their project, including co-design group composition, design activities and project structure, in relation to the 'co-designer's experience', as much as the desired outcomes.

Although further research is required to extend the knowledge of these wellbeing impacts and the best ways for these to be managed, these findings are presented as a starting point for designers working in this context. Also, the research is presented as a call for the design profession to recognise their potential impacts and to learn from other sectors who have expertise in managing mental health and wellbeing in a composite and integrated caring manner.

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Soma-Wearable Design: Integrating Somaesthetic Practice and Fashion Design for Somatic Wellbeing

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With advanced technologies and raised expectations for the quality of life, research and design attempts are increasing to promote wellbeing. While data-based reflective practice and behaviour change have been a main strategy in supporting technology-mediated wellbeing, we bring the perspectives of somaesthetic practice and fashion design to complement this research scene. Assuming that body consciousness could positively influence self-perception, presentation and performance through clothing, we propose *soma-wearable design* as an alternative approach to explore qualities that elaborate and promote somatic wellbeing. First, we conceptualize constructive links between design for reflection, somaesthetic practice, and style-fashion-dress; and re-interpret the core qualities of somaesthetic appreciation (Höök et al., 2016) for soma-wearable design: 1) transient space for reflection with the body, 2) sensory prompt synched to context, 3) body modification for subject formation, and 4) learning through bodily experience. We articulate these qualities based on the survey of selected fashion objects; apply the soma-wearable design approach to a workshop with fashion design students; and discuss implications about forms, materials and experiential qualities of soma-wearables.

soma-wearable design; somaesthetic practice; somatic wellbeing; style-fashion-dress

1 Introduction

With advanced technologies and raised expectations for the quality of life, public interest in wellbeing is growing, expanding related design opportunities from reactive healthcare to proactive self-care. Human-Computer Interaction (HCI) disciplines have mainly taken data-based approaches to make positive behaviour changes by tracking personal activity and biometric data. However, the efficacy of tracking applications is questionable with data overload and user disengagement in reflective practice (Jung et al., 2016); and attention to bodily movement and reflection is growing (Höök et al., 2017), demanding for different approaches to promote mind-body integrated wellbeing. Somaesthetics is a branch of philosophy that grounds the meaning of human experience in the bodily presence (Shusterman, 2008), and could provide complementary perspectives to research and design for wellbeing in line with other research motivations that bring the bodily lived experience into human-computer interactions, including affective computing (Picard, 1997), embodied interaction (Dourish, 2014) and bodily imagination through digital media (Loke et al., 2014). We propose that somaesthetic practice and fashion design have a meaningful overlap with their focus on body consciousness; explore their intersection to frame out a design space for *soma-wearables*; and speculate about desired experiential qualities and related design dimensions for somaesthetic wellbeing through wearables. Specific questions that motivate this study include:

1. How to support somaesthetic practice and somatic wellbeing through wearables?
2. What kinds of experiences could be unfold through soma-wearables for somatic wellbeing?
3. What may be the qualities and design dimensions to define soma-wearable design?

This study draws three approaches to speculate about the questions above: 1) literature review of related perspectives—1-1) design for reflective practice, 1-2) somaesthetic practice in HCI, and 1-3) fashion for subject formation and material speculation with the body, 2) articulation of formal and material qualities of selected fashion objects in relation to somaesthetic reflection and wellbeing, and 3) workshop to explore potential design concepts and implications of soma-wearables. By linking the three perspectives of reflective practice, somaesthetics, and fashion, we conceptualize *soma-wearable design* as an approach to promote somaesthetic reflection. Based on this conceptual foundation, we analyse selected fashion design examples by articulating how their forms and processes may mediate somaesthetic practice and wellbeing, what may be desired experiential qualities of soma-wearables, and what may be specific design dimensions and attributes to consider in creating those qualities. Lastly, we conduct a workshop to introduce the soma-wearable design approach, explore possible design concepts, and discuss the workshop process and findings.

2 Conceptual Foundation: linking three perspectives

Advancement in information and communication technologies has brought innovations in personal healthcare practice and ecosystems but also introduced new problems including information overload, anxiety and stress (Pickert, 2014). Attempts are increasing in HCI research and practice to explore alternative perspectives in making technology applications including *calm technology* (Weiser, 1999) for seamlessly weaving technologies into everyday contexts, *slow technology* (Hallnäs & Redström, 2001) for applying technologies for reflective purposes beyond productivity or efficiency, and *positive computing* (Calvo, 2014) for making positive changes in individual and social behaviours through computing. This study is in line with these humanistic approaches to contextualize technologies for wellbeing, to support technology-mediated self-care and reflective practice. In this section, we build conceptual links among the three perspectives relevant to the design for wellbeing—1) design for reflective practice, 2) somaesthetic practice, and 3) style-fashion-dress—to propose the soma-wearable design approach as a means of elaborating and promoting somaesthetic reflection and wellbeing.

2.1 Design for Reflective Practice

Reflective practice is thinking about one's actions and learning from them to change one's practice for personal and professional development (Schön, 1983). It requires *critical attention* to the practical values and theories which inform everyday actions (Fook, 2007) and *conscious engagement* in a process of continuous learning from experience by asking what happened, why does this matter and what are the next steps (Rolfe et al., 1988). Data-based reflective practice to reveal and change one's behavioural patterns has become a mainstream strategy in the design for wellbeing in HCI. Although the number of consumer products is increasing for tracking one's activities (e.g., steps), biometric data (e.g., heart rate), and other meta-data (e.g., location), criticism about their efficacy is also growing by addressing that activity data collection does not result in intended behaviour changes without the user's intrinsic motivation and conscious effort for learning (Baumer et al., 2014; Slovák, 2017). It has been also criticized that those products overly compete for consumer attention, often causing technology addiction and anxiety from data overload (Leslie, 2016). And there are more human performances and felt senses that cannot be tracked yet with current technologies (Tholander & Nylander, 2015). As the notion of wellbeing pervades diverse activities beyond healthcare, concerning with various qualities of life from an integrated perspective, it has become more critical to support individuals' subjective goals and particular patterns of reflection instead of imposing standardized goals of wellbeing such as more fitness activity, work productivity, social connectivity, etc. As an alternative approach to currently dominant data-based reflective practice, we aim to explore how to support conscious reflection and embodied wellbeing from the perspectives of somaesthetics and style-fashion-dress.

2.2 Somaesthetic Practice

Somaesthetics, as a discipline related to bodily perception, performance and presentation, concerns appreciating and cultivating the body as a subject that perceives and learns aesthetic qualities of experience (Shusterman, 2015). Related concepts and methods related to somaesthetic practice could be applied to embrace the qualities of bodily movement, reflection and imagination in design object as well as process. For example, *body scanning* and *body mapping*—which will be further described in the workshop section—reinforce mind-body association by sensitizing individuals to attentively listen to their mind and body (i.e., soma) from an integrated perspective and make sense of their experience through *focusing* and *articulating* felt senses (Pacheco & Loke, 2017). Based on this shifted focus to one's somatic being (compared to physical or mental being), we could expand the notion of wellbeing to *somatic wellbeing*, a status of being appreciative of the qualities of one's somatic presence and experience in accordance with the rhythms of one's environment; and speculate about corresponding design approaches to promote noticing and making sense of mind and body association as a critical skill for self-care and reflection (Feldenkrais, 2009). HCI researchers have explored how to engage body consciousness and support somaesthetic practice with interactive systems. Höök et al. (2016) defined related experiences as *somaesthetic appreciation* and investigated its core qualities to consider in design with interactive technologies: 1) subtle guidance directing attention inwards, 2) making temporal, interactive and spatial spaces for reflection, 3) intimate correspondence with feedback and interactions that follow the rhythm of the body, and 4) providing means to articulate the experienced bodily sensations. These qualities provide a constructive foundation for exploring how interactive systems could guide body and mind reflection and creating new contexts and ecosystems to promote subjective wellbeing.

2.3 Style-Fashion-Dress

Fashion affects individuals' body consciousness as a personal and social medium through which to perceive and present the body. Fashion, beyond producing clothes and appearances, but also negotiates subject positions (e.g., gender, ethnicity, class) by navigating through power relations with multiple dimensions: fashionable dress vs. fixed costume, global vs. ethnic, the future vs. the past, time vs. space, agency vs. structure, dressing to belong vs. dressing to differentiate, mainstream vs. street style, production vs. consumption (Kaiser, 2013). Individuals mix and match different elements to formulate temporary expressions about who they are or are becoming by fashioning their body. According to Tulloch (2010), *style-fashion-dress* is a complex system that recognizes the parts and wholes of processes and concepts: *style* is a social process in which narratives of the clothing choices are collectively in flux with time, and also an agency in the construction of self through the assemblage of garments, accessories, and beauty regimes; *fashion* encompasses more than clothing style, spanning food and furniture preferences, popular culture, language, technology, or other dimensions of culture and change; and *dress* is material forms of body modifications and body supplements. The system of style-fashion-dress pervasively influences one's subject formation as well as lifestyle in the web of broader social and cultural values, shaping the notion of wellbeing. In particular, the material processes and symbolic values of style-fashion-dress could inform the soma wearable design approach with their impact on self-perception, performance and presentation, which will be further elaborated in the next section.

The conceptual foundation for the soma-wearable design approach, which is built across the three perspectives above, sets out the following assumptions of this study:

1. Body consciousness—*awareness of one's condition through the lens of mind and body association*—can be the first step toward self-reflective practice for wellbeing.
2. Articulating felt senses and their meanings could be part of reflective practice for wellbeing, potentially influencing self-perception, presentation and performance in social context.
3. Somaesthetic reflection requires sophisticated skills and training for *noticing* and *articulating* what one feels in their body in relation to the environment and what it means to oneself.

3 Toward Soma-Wearable Design Approach

In this section, we review fashion theories and selected fashion objects to further elaborate the soma-wearable design approach. We speculate how the metaphor of the body is continuously fashioned and refashioned as a compelling and revealing means for subject formation and how related qualities of bodily experience could conceptualize soma-wearable design for self-reflection.

3.1 Implications from Fashion Theories and Objects

We first review the influence of fashion on subject formation, its creative ecosystem and provocative impact in (re-)constructing the body from physical, social and cultural perspectives.

3.1.1 Influence on Self-Perception, Presentation and Performance

Clothes in contemporary society have been developed from a practical asset that protects the body to a social marker that affects the way we see ourselves as well as present ourselves to others. Fashion and style elements are critical in wearable design, often more than utilitarian values, in terms of how wearers perceive and present themselves through clothing choices in their social and cultural contexts. *Enclothed cognition* is a term to describe the effect of clothing on cognitive process (Adam & Galinsky, 2012): when a wearer understands the symbolic meaning of the clothes and physically wears them, the clothes can impact the wearer's emotion and performance, putting the wearer in a different psychological state. The concept does not fully explain how it came about, but it suggests that it will be worth exploring various ideas (Blakeslee, 2010). Some practical tips are shared to select clothes to change the way people think as intended, for example, suits to power up, casual wear for creativity, gym clothes for healthy behaviours, uniform for a particular task performance (i.e., white lab coat effect), luxury goods to show political status, dress or accessories with fun graphic details for positive thinking (Sarda-Joshi, 2016; Gowans-Eglinton, 2017), and more. We need to understand more about how clothing choices affect our self-image, performance and the impression that we convey to others and in turn, the way in which people behave towards us.

3.1.2 Driven by Changes and Remixed through Creative Ecosystems

Fashion design is largely driven by trends from haute couture industry, artists and celebrities influence, and labels associated with social class. A desire for the next new change drives fashion industry. Fashion design does not only support new expressions of desired self-images, but also creates new experiential values with novel expressions, challenging the modern design mantra of *form follows function*. In fashion industry, style and performance (i.e., form and function) are inseparable, creating synergetic influence on the wearer's perception of self-image and performance. Many sportswear companies acknowledge the fashion side of experience with sport (Mellery-Pratt, 2015), and often collaborate with athletes and celebrities to embrace their performance and achievement in the style and symbolic meaning of fashion products (Yotka, 2016). The style aspect of a fashion product is often criticized as a superficial image that could misguide or deceive its functionality. We aim to demystify the biased notion of style and fashion by investigating the synergetic relationship between form and function of wearables. Although fashion styles are largely driven by the quest for newness, some form factors are repeatedly used to satisfy certain functions, reified as iconic elements for certain genres of activity wear (e.g., leggings for yoga, laced top and layered skirts for ballet). These style elements, not only supporting the performance of physical activities, also influence ritual qualities that condition the wearer's mind, making the experience more engaging. Iconic style elements are remixed with other design elements, creating new fashion trends or labels that make a statement on certain lifestyles. The changes in fashion styles further speed up today, expanding through creative ecosystems of connected user experiences across different product categories and communication platforms. Collaborations between fashion designers and artists, architects and celebrities create unique symbolic and style values to fashion objects with greater impact on popular culture and product ecosystems.

3.1.3 Material Speculation for Re-imagining the Body

Wearable forms and styles, with their intimate and expressive influence on the body, reimagine our bodily presence in the world with new material and fabrication technologies. Many fashion designers question relationships between the body and the society through exploratory material processes and expressions. Hussein Chalayan performs stories of clothing that transforms identities through precise objects that are very body conscious or create an alternative (Bateman, 2016): e.g., six models wearing chadors of varying lengths—from fully clothed to totally nude—as a statement on the oppression of traditional clothing on Muslim women in SS98; a coffee table transformed into a dress as an experiment with cutting techniques[1] in AW00 (Figure 1) (Stansfield, 2016). Joanna Berzowska explores a wider range of material properties in the development of wearable, physical computer interfaces beyond screen or wrist interactions. Her work embraces the soft, playful and magical aspects of electronic textiles, so as to better adapt to the contours of the human body and the complexities of human needs and desires, even speculating about gender dynamics and energy generation through the body[2] (Berzowska, 2010). Iris Van Herpen is well known for her use of materials as diverse as metal umbrella ribs, industrial yarns, woven metal, leather strips, and transparent acrylic[3]. Credited with introducing 3-D printing to fashion, she blends hi-tech processes with traditional handwork, creating imaginative sculptural garments (Kapfunde, 2015).

Figure 1 Coffee Table Skirt by Hussein Chalayan in AW00 (Photo Courtesy of ©Chalayan)

With the approaches of these fashion designers, we intend to highlight that 1) material and technical experiments in fashion design are interweaved with speculative narratives about physical, social, cultural and political dimensions of the body and 2) those experiments rest at the intersection of art, engineering, architecture and science. Their integrative approaches allow them to construct composite textiles with complex functionality and sophisticated behaviours and explore a broad

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[1] Coffee Table Skirt by Hussein Chalayan. http://oxot.com/table-skirt/ and http://chalayan.com/about

[2] Captain Electric and Battery Body by XS Lab. http://www.captain-electric.net

[3] Crystallization by Iris Van Herpen. http://www.irisvanherpen.com/haute-couture/crystallization

range of computational expressions by blending them with traditional handwork. Their works using emerging technologies are proving that the basis of fashion technology is more than just blinking lights but freeing designers to use their materials in ways never imagined, for example, by bringing architectural approaches to composite textiles and create shapes, folds and scales of clothing. Fashion design, as an integrative form of creative experiment, offers unique perspectives to explore soma-wearables with its focus on body consciousness through material speculation.

3.2 Core Design Qualities of Soma-Wearables

Articulation, a method in cultural studies, enables understanding of subject formation through the system of style-fashion-dress, a process of navigating alternative self-perceptions and presentations through clothing (Kaiser, 2013). The method of articulating involves breaking down a whole, which may appear harmonious, and identifying differences, contradictions or fractures in the whole by considering new possibilities and formations (Grossberg, 2010). We apply the method of articulation to rearticulate unique formal and material qualities of selected fashion objects as potential qualities of soma-wearables by speculating how they could provide alternative bodily experiences. Although the selected examples were not designed for the purpose of somaesthetic reflection, their alternativeness allows creative reinterpretation of their forms and meanings for such context. The following qualities and design dimensions are not definitive or exclusive to each other. Instead, by specifying those formal and experiential qualities of the examples, we intend to conceptualize the soma-wearable design approach and further discuss its implications for research and practice.

3.2.1 Transient space for connecting reflection and expression: hiding or revealing

A space for reflection is one of the core qualities in somaesthetic appreciation design, enabling and guiding attention inwards to focus on one's bodily sensation with minimal distraction. The scale of wearables affords a limited but transient space around the body by connecting inward focusing and outward expression of perceived sensations. The personal boundary set by clothing can be adjusted with transformative structures, extending the self-reflection to self-presentation in public context, which would influence back on self-perception and performance according to the theory of enclothed cognition (Figure 2). The transient space could be designed somewhere between closed (private) and open (public) through different clothing forms to hide or reveal one's reflection status—its instant or accumulative effect—through soma-wearables.

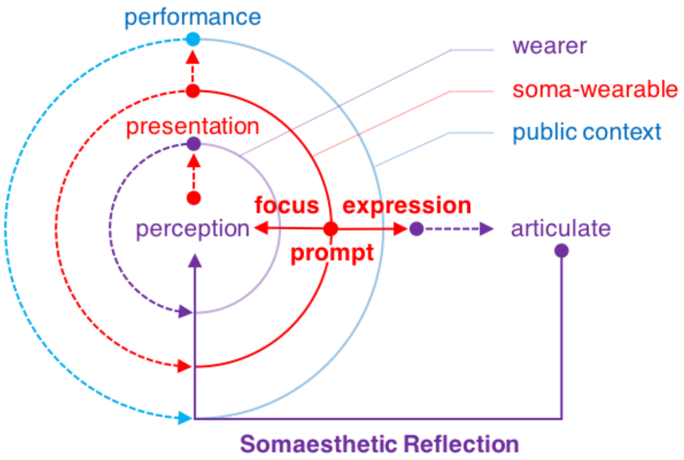

Figure 2 A conceptual space for somaesthetic reflection through soma-wearables: the status and effect of focusing inwards could be expressed outwards in wearable forms, affecting back self-perception, presentation and performance. This would reframe the reflective practice into a reciprocal process for noticing one's bodily sensation in relation to the environment and articulating their instant or accumulative relationship through wearables for intended perceptual/behaviour changes.

3.2.2 Sensory prompt synched to context: stimulating, alleviating or responsive

The quality of guiding attentions inwards could be combined to different sensory prompts for *stimulating*, *alleviating* or *responding to* the wearer's physiological or contextual condition. For example, *Kino*[4] (Deahl, 2017), a kinetic accessory roaming on clothing, can stimulate the wearer's inward focusing as a tactile prompt traveling on the body; *Sensewear*[5] (Rhodes, 2015) can alleviate sensory disorders by engaging the wearer in interacting with simple shapes and textures of the clothing (Figure 3); and *NADI X*[6], smart yoga pants, can respond to the wearer's posture for fitness guidance and feedback (Feitelberg, 2017). Some wearable applications display the effect of perceived sensations, further affecting the wearer's emotion or performance: *AWElectric*[7] animates emotionally charged goose bumps and shares the thrill with visual and vibrotactile feedback (Neidlinger et al., 2017); *Facebook Vest* inflates according to the number of likes received on Facebook posts (Wainwright, 2010). Physiological and psychological impact of sensory prompts on mood changes—either instantly or accumulatively—needs to be further investigated with different sensory prompts and display elements embedded in wearables.

Figure 3 Sensewear (Photo Courtesy of Emanuela Corti and Ivan Parati). Corti and Parati are faculty members at Ajman University, College of Engineering (UAE) and founded Witsense srl, a start-up to develop smart wearables with embedded sensors for collecting vital data and actuators for activating garments and accessories.

3.2.3 Body modification for subject formation: supporting, constraining or augmenting

Body modification and supplement is a fundamental function of clothing, serving various purposes from body protection to decoration. Sometimes bodies are modified through purposeful training over time as in the case of ballerina's feet and toes. Pointe shoes is critical in ballet practice as an extension of dancers' bodies and an essential tool of expression (Kaufman, 2017). They equip the wearers to do what no human is designed to do by constraining their body shapes or movements for particular training. Purposes and approaches for body modification become diversified with advanced technologies. *GS3*[8] holds up an injured spine and flexibly adjusts to its recovery status beyond statically supporting it (Chaya, 2017); prosthetics can augment human perception and performance with new physical additions to the body, as in the cases of *Sonifica*[9], the implanted instrument to make sound performance with the body (Goldemberg & Zalcberg, n.d.) and *the third thumb*[10] to see what it may be like to live with an unusual body part (Wilson, 2017).

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[4] Kino: Kinetic, "living" jewelry for dynamic fashion. https://vimeo.com/224797586

[5] Sensewear Clothing by Crvnd Design Collective. http://sensewear.clothing

[6] Wearable X | Fashion technology company building future of clothing https://www.wearablex.com

[7] AWElectric | SENSOREE. http://sensoree.com/artifacts/awelectric/

[8] GS3: Graduated Spine Support System. http://youreshape.io/reshape-17-graduated-spine-support-system/

[9] Viktoria Modesta. http://www.viktoriamodesta.com

[10] The Third Thumb Project. http://www.daniclodedesign.com/thethirdthumb

3.2.4 Learning through the body: improvised performance or practiced skills

Body modification is not only about static, passive addition to the bodies, but also involves changes in bodily skills and abilities through the interplay between the bodies and the wearable (or implanted) artefacts. Any bodily experience involves movement—small or large, internal or external—that has both reflective and performative aspects. While some interactive systems for somaesthetic appreciation like the Soma Mat and the Breathing Light (Höök et al., 2016) support stable self-reflection (and learning about one's somaesthetic perception) with minimal movement and distraction for inward focusing, the notion of soma-wearables aims to explore dynamic bodily experiences that involve learning through alternative and conscious movements: e.g., *Sway*[11], a mindfulness app with a movement tracker, transfers the qualities of Tai-Chi to an interactive experience for practicing mindful movement (Cheng, 2017); *hipDisk*[12], a set of two layered disks worn around the waist, enables the wearer to discover new body-space relationships by generating sound according to the wearer's movement in the space (Wilde, 2012); and *Bubble Jumper*[13], an augmented body suit, creates a new kind of sport play and related rules and skills by boosting the wearer's strength and protecting players when they crash into each other (Kim, 2017).

We elaborated potential experiential qualities of somaesthetic appreciation through the lens of wearables based on the selected examples—e.g., being attentive to one's bodily sensations through sensory prompts for reflection, being synched to one's environment and other entities for harmonious presence, experimenting with unfamiliar body modifications or movements, exerting to practice unique bodily skills and develop somaesthetic knowledge, and ultimately expanding one's perceptual and experiential horizon through body consciousness (Höök, 2010). These qualities collectively consolidate the definition of somatic wellbeing, a status of *being appreciative of the qualities of one's somatic presence in accordance with the rhythms of one's environment*, and elaborate the soma-wearable design approach to support it accordingly. In the next section, we report the process, outcomes and implications of a design workshop that we conducted to see how the soma-wearable design approach could be applied in design practice.

4 Soma-Wearable Design Workshop

We conducted a design workshop with 14 fashion design juniors to introduce the soma-wearable design approach with its desired qualities, and observed how the approach is interpreted by them. The workshop consists of three parts: 1) body scanning and mapping for individual sensitization, 2) orientation of the soma-wearable design approach, and 3) group ideation and discussion. The students were asked to complete the first part individually before attending the workshop, provided with an audio script for body scanning and a template for body mapping. The soma-wearable design approach was introduced afterwards (for about 1 hour) so that its concepts and examples would not influence the students' ideation. After the orientation, the students shared their thoughts about body scanning and mapping and ideas for soma-wearables by sketching and body storming (for about 2 hours).

4.1 Body Scanning and Body Mapping

Body scanning is a method for listening to one's mind and body through a guidance for directing attention inwards in an environment where distraction is eliminated. The method, similar with meditation, could be applied for conditioning oneself for creative practice and design ideation (Lee, Lim & Shusterman, 2014). Richard Shusterman derived the following principles for body scanning from Feldenkrais methods (Feldenkrais, 2010): 1) divide body parts, 2) focus on one part at a time, 3) question about a felt sense, 4) contrast sensations felt from different body parts, 5) relate the position and movement of the body to felt senses (i.e., proprioception), and 6) associate felt senses with related experiences. We provided the students an audio script that guides body scanning to

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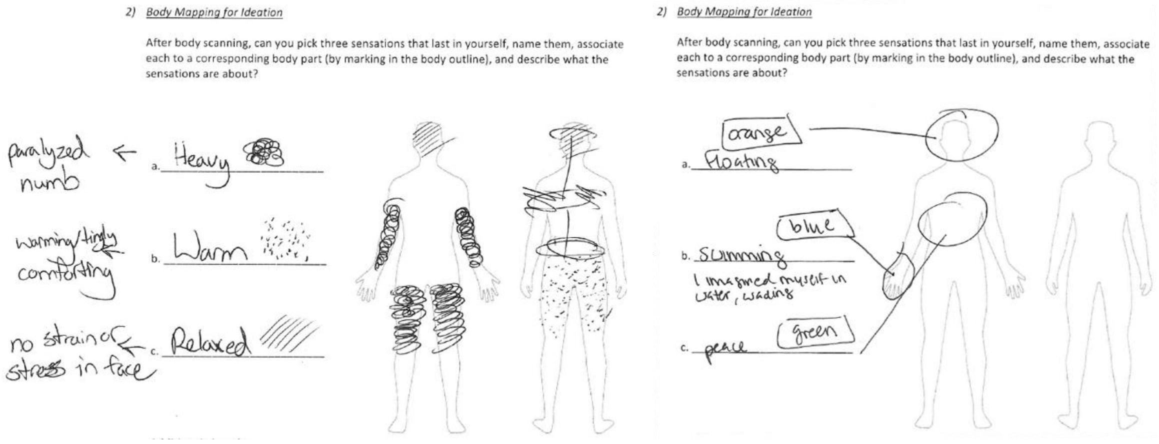
[11] Sway | Mindfulness in motion. http://www.pauseable.com/sway/

[12] hipDisk -augmenting the moving body with sound. http://www.daniellewilde.com/swing-that-thing/hipdisk/

[13] Bubble Jumper. https://youtu.be/ddH-DiGWioM

inspect their body parts separately from bottom to top, let sensations emerge from each part, and make sense of them as inspirations or narratives for reflection as well as ideation. Body mapping is used as a means for articulating felt senses from body scanning. The students were asked to list three senses that lasted in their body and associate each to a corresponding body part by marking them in the body outline (Figure 4).



2) *Body Mapping for Ideation*

After body scanning, can you pick three sensations that last in yourself, name them, associate each to a corresponding body part (by marking in the body outline), and describe what the sensations are about?

paralyzed numb ← a. Heavy

warming/tingly comforting ← b. Warm

no strain or stress in face ← c. Relaxed

2) *Body Mapping for Ideation*

After body scanning, can you pick three sensations that last in yourself, name them, associate each to a corresponding body part (by marking in the body outline), and describe what the sensations are about?

orange

a. Floating

blue

b. Swimming

I imagined myself in water, wading

c. peace green

Figure 4 Examples of body mapping in the given template.

We observed what kinds of felt senses the students came up with after body scanning and how they associated those senses with different body parts and develop wearable concepts. The students used the following descriptors to articulate their felt senses: tingly, buzzy, crawly, loose (fingers, legs), pulsing, ringing (head, chest), pouring out, caved (chest), tense, pain, ache (shoulder, back), floating, swimming, sinking, synching, falling, heavy, comforting, peaceful, relaxed (whole body), numb, warm, cool, etc. Many of the students described some changes in their sensations felt before and after body scanning, for example, from relaxed to tingly to numb, from cold to warm, from comforting to sinking and heavy, and so on. It is hard to generalize the pattern of changes, but it is noticeable that even in a short and static body scanning session, individuals went through dynamic feelings in different parts of their body, reflecting varying depths of their focusing and articulation. Many felt senses are associated with some narratives in relation to specific environments or material qualities (e.g., felt like swimming, floating, sinking in water) and background sound in the guide script (e.g., pulses felt through the body following the rhythm of the sound, chest felt like caved by the resonating sound). It was common for the participants to focus on negative feelings such as pain, stress or shaking (from fatigue), especially around the neck, shoulder and back. Few mentioned about emotion-free descriptors like colours or temperatures.

4.2 Ideation and Discussion in Groups

After describing and sharing their felt senses, the students discussed in four groups about how to convert those sensational qualities to wearable design and what they would mean in terms of somaesthetic reflection and wellbeing. Because they are trained fashion design students, hand drawn or Photoshop sketching and body storming methods were efficient enough for them to ideate and communicate initial concepts without using tangible, craft materials. Design concepts explored were categorized into three themes: 1) sensory stimuli for therapeutic experience, 2) material imagination for body support, and 3) fidgeting through the body.

4.2.1 Conceptual theme 1: sensory stimuli for therapeutic experience

Providing sensory stimuli (e.g., heat, gentle pulse, electric shock) for therapeutic or meditating experience was one of the recurring concepts. This theme reveals that many students naturally focused on sensations related to stress, fatigue, pain or headache after body scanning. Most ideas were about embedding static sensory prompts (mostly heat) into specific parts of clothes (e.g., a jacket with heating pads embedded around the shoulders, head warp with heating/cooling effects, electrotherapy through clothing), which seem to be largely influenced by the principle of *division* in body scanning. By focusing on a specific body part at a time, the students were able to *compare* and *contrast* different senses felt in each part of the body, identified which parts they felt more or less stressed, tired or painful; and applied rather direct interventions to corresponding areas of clothes.

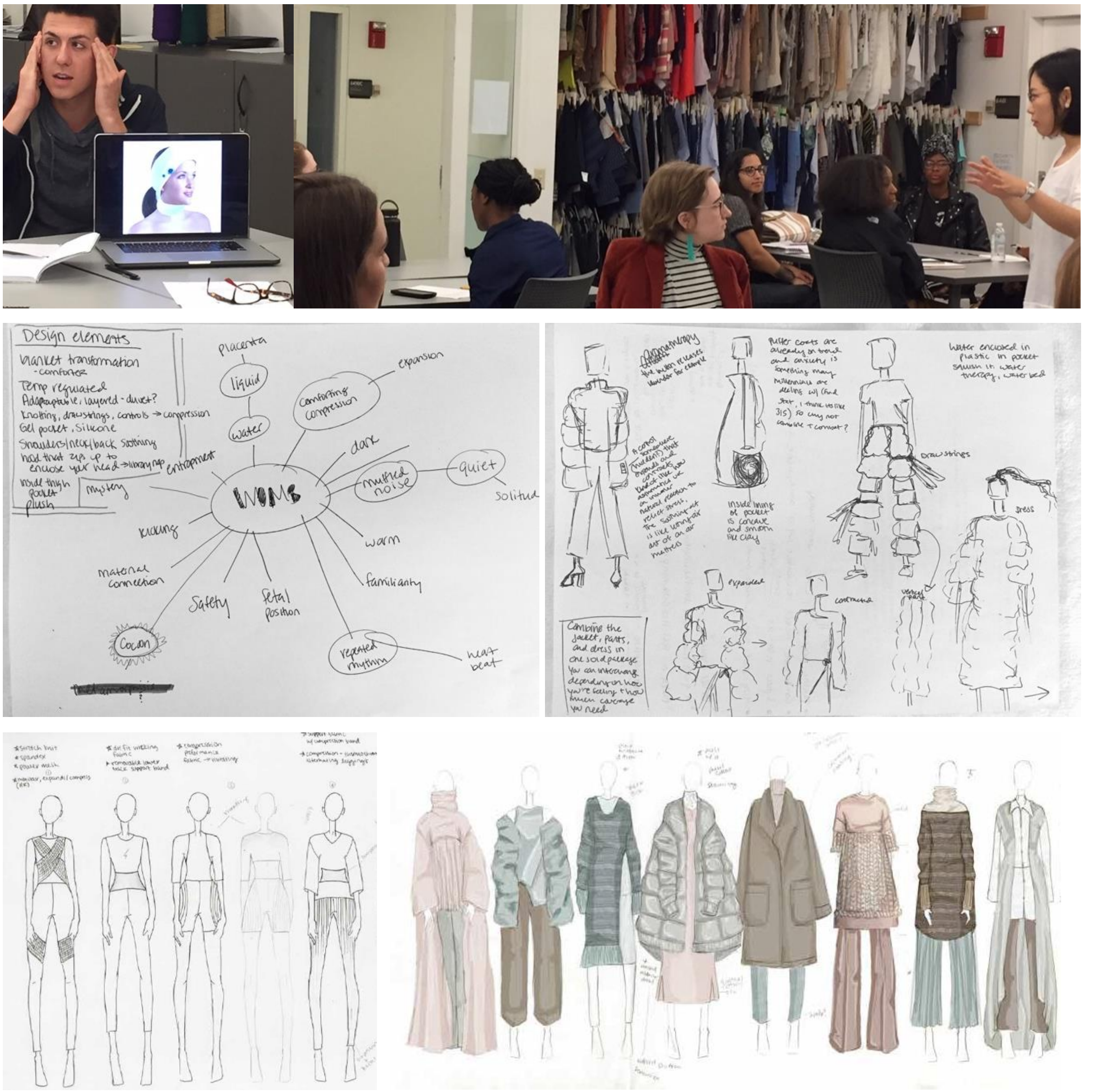


Figure 5 Soma-wearable ideas explored in the workshop: Photoshop sketch of head wrap for stress release (top-left; sketch by Nathan Haberthy), mind mapping for ideation (middle-left), jumpsuits with strips for fidgeting (middle-right; sketch by Niyah Jackson), multiple layers for the feeling of compression (bottom-left), and oversized clothes with soft materials for the feeling of comfort (bottom-right; sketch by Sarah Elliott and Julie McGrath).

4.2.2 Conceptual theme 2: material imagination for body support and pain relief

Supporting a desired body posture or relieving pain was another conceptual theme. As briefly mentioned, many students focused on negative sensations, such as chronic pain (mostly in the back and neck), sore muscles or joints (around shoulders, arms, and legs), headache and shaking hands; and immediately thought of physical interventions such as body supporting structures and/or layers that could simulate the feelings of compression, expansion or massaging. Some ideas were discussed about how to connect different parts of the body (e.g., head and shoulder, back and thighs). It is noticeable that different formal patterns and structures were explored by *graphically dividing and connecting multiple parts of the body* (e.g., a head wrap that goes across the temples, a neck support that connects the head and the shoulder, a jewellery in between neck and chin) for the effect of *redirecting or distributing the pain* from one part to relatively stable and relaxed parts. Other ideas were discussed regarding how to simulate a corresponding *material experience* through wearables, for example, how to make the wearer feel like sinking in or synched to water, gently compressed like human hugs, moving through clay by wrapping the knee joints with manoeuvrable textiles (solid but flexible), etc. Similar ideas include a body wrap that reduces and absorbs back pain, a compression shirt that helps the wearer to keep the upright posture, and gloves that help alleviate arthritis.

4.2.3 Conceptual theme 3: connecting and fidgeting through the body

In relation to the first and second themes, the concept of making *a transient space* for bodily reflection and expression was explored in different wearable forms, simply from oversized clothes to multiple layers, inflatable clothes, transformative hoods, and strips to expand and collapse clothing layers. These transformative elements define the third conceptual theme that divides different parts of the body and re-connects them to enable unusual and un-purposeful movements around the body, which are easily associated with fidgeting for releasing stress and anxiety. Specific wearable concepts include a jumpsuit with fabric strips that connect arms with legs, concavity in pockets back of thighs, snuggle layers under thighs, some weights between outer and inner layers, heat up by kinetic movement, and jewellery or tassels to play with.

4.3 Reflection

Due to the limited time of ideation and the specific background of the students in fashion design, most ideas were discussed around the first and second themes that directly build upon their felt senses after body scanning to respond to them with therapeutic interventions. Still it was interesting to observe how imaginations and narratives emerging from body scanning drove material speculation for wearables by elaborating on particular experiential qualities (e.g., sinking in water, walking through clay). The students shared their reflection that the body scanning principles of *division* and *contrast* introduced them alternative ways of thinking about the connection between multiple body parts and opportunities for playing with and moving around their body through clothes. In group discussions, questions were raised regarding how to *abstract* the sensations that they felt from body scanning (instead of literally simulating them or responding to them with therapeutic interventions), how to make others experience similar sensations that they felt through clothing, and how clothing could enable new bodily movement, reflection and performance. Although the questions were not fully answered, the discussion revealed potentials of the soma-wearable design as an approach to embrace the body as a source for design ideation as well as an object for reflective and expressive fashion. While this first workshop mostly resulted in discussions about wearable forms and materials that make a space for reflection and provide sensory prompts for somaesthetic appreciation, their influence on self-perception, presentation and performance need to be further investigated later.

5 Discussion and Conclusion

This study proposes the soma-wearable design approach to complement current behaviour tracking approaches in the design for wellbeing. Assuming that body consciousness could positively influence self-perception and performance through clothing, we integrated the perspectives of somaesthetic practice and fashion design to conceptualize the soma-wearable design, and elaborated desired qualities of soma-wearables and corresponding design dimensions by re-articulating selected fashion objects in the context of somaesthetic reflection and wellbeing. The four qualities—1) transient space for reflection, 2) sensory prompt synched to context, 3) body modification for subject formation, and 4) learning through the body—frame out a design space to promote somaesthetic wellbeing through bodily reflection, experiment and learning. Different wearable design concepts were explored from the workshop with fashion design students, mostly around the qualities of transient space for reflection and sensory prompt. The result and student feedback indicate that the other qualities of body modification and performance to augment one's experience horizon are relatively new design dimensions and hard to be explored only within a limited time in this workshop context. We see this as a meaningful opportunity to further investigate, especially about the constructive loop between self-reflection and subject formation through body consciousness.

Although fashion design can bring useful perspectives to contextualize somaesthetic practice with intimate and direct material influence on the body, we also understand that superficial style elements and too much attention to public presentation of the body could prevent one from getting into a deeper flow of self-reflection and subject formation. In this vein, the conceptual qualities and design dimensions need to be further investigated in terms of sophisticated wearable forms and styles that are *neutral* (i.e., not implying any subject stereotypes) and *ordinary* (i.e., not too sculptural like special costumes), but still *evocative* of bodily experience and reflection.

We expect the soma-wearable design approach would envision a promising potential of somaesthetics and fashion perspectives in the design for wellbeing by elaborating and promoting somatic wellbeing through material speculations. We plan to conduct more soma-wearable design workshops with diverse groups beyond design students to explore more soma-wearable concepts by refining the proposed methods and intended qualities. In addition, we will also conduct a longer study to investigate the constructive link between somaesthetic reflection and self-perception and performance with specific application scenarios (e.g., soma-wearable for mood change).

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The Road to Happiness is Paved with Playful Intentions

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Through exploring the relation between designing for happiness and designing for play experiences, the paper proposes key elements that constitute meaningful play experiences. The paper proposes that designing for playfulness may also lead to more meaningfully engaging experiences. Meaningful experiences emerge when the activities of the experience comply with the interests, passions and goals of the person having the experience, by which meaningfulness is naturally linked to intrinsic motivation. This is true also for play activities, which are typically defined by e.g. being voluntary activities. Building on conditions for meaningful experiences, the author addresses the element of playfulness as a key to separate what can easily be good and meaningful experiences from experiences of play. The contribution of this paper is to provide an understanding of the components of a play experience and the relation between meaningful and playful experiences. The paper introduces the Play Blueprint, a framework depicting the key components of play experiences, intended as a valuable tool in designing for play(ful) experiences.

play, experience, meaningfulness, playfulness

1 Introduction

A fundamental argument for this paper is that, in order for an activity to be play, it needs to not only be meaningful, but it also needs a grain (or more) of playfulness. This argument also poses the basic condition that all play experiences must be meaningful. Since the emergence of experience design (see eg. Hazzenzahl, 2010 or Jensen, 2013) and positive design (see eg. Desmet & Pohlmeyer, 2013) design research has gained increased focus on, and understanding of, what meaningful experiences are and how they can be designed for. We know that meaningful experiences are those that relate to a person's motives, interests and desires (Hedegaard, 2017) which resemble the drivers in play as a voluntary activity that we engage in exactly because it holds meaning for us at that moment. Boswijk (2007) derived 11 characteristics of meaningful experiences such as heightened concentration and focus, timelessness, and emotional engagement. These aspects are all inherent in play activities (see e.g. Huizinga 1955, Sutton-smith 1997, Sicart 2014 or Hedegaard 2017) supporting the argument that play experiences are inherently meaningful. Although play activities do not have a specific purpose or outcome, the activities in themselves are meaningful and driven by intrinsic motivation.

The second part of the argument; that a play activity also needs to be playful, is supported by the fact that not all meaningful experiences are play. Many meaningful experiences are directed at specific outcomes and has a purpose and goal in real life, i.e. beyond the activity in itself. If I were to spend time helping families who lost their home in a tsunami, it would be meaningful for me because it supported my beliefs and sense of virtue. But it would not be play. A condition for entering the play space is to accept that it is indeed detached from real life, and as such it has its own rules, boundaries and an absence of immediate consequences for 'real life'. One of the most commonly mentioned features of play is exactly this bracketing of the play activity in a time and place of its own, detached from 'ordinary' life (see e.g. Gordon, 2009)

We also see that objects in play are typically 'pretend' objects, just as the play setting is a 'pretend' setting in which everything is possible. This leaves the definition of the play space and boundaries up to the imagination of those who participate in playing. The layer of imagination is one of the characteristics that constitute playfulness, supporting the argument that a play experience needs playfulness in order to be play. The imaginative nature of play was also emphasized by both Huizinga (1955) and Vygotsky (1978), underlining the dependency between playfulness and play experiences.

In order to examine and design for play experiences, the author proposes a framework that aims at operationalizing the components of play experiences. Through the descriptions of the proposed framework it is the intention to further enable a discussion about playful experiences as something that builds on, but is not completed by, meaningful experiences. As a consequence, many experiences that would often be considered play (building with LEGO bricks for example) may not be defined as play experiences, although some of the basic characteristics (such as voluntariness) are present. 'Building' (instead of 'playing') also indicates a specified outcome, which further disputes if it should be considered play, although for many it will still be a meaningful activity. Adding playfulness, however, such as imagination (building a castle where a king lives), pushes the building activity towards a play experience.

2 The Play Blueprint

The 'Play blueprint' is a framework focused on operationalizing the inherent components and structure of meaningful play experiences. The Play blueprint does not include temporal aspects of an experience, but aims at defining the play experience through its components, following the definition of an experience by Gadamer (1975) as a unity of meaning.

A play experience is structured around activities that take place in the play space and is always directed at (and motivated by) the intentions of the persons playing, here described as motive orientations. The term motive orientation (following Hedegaard, 2017) is preferred over alternatives such as 'motivation' or 'intention' because it underlines the directedness of the user's focus towards something desirable.

Play experiences furthermore incorporate elements of playfulness as described above, leading to the definition of three basic categories for describing play experiences in the blueprint; Activities, Motive orientation and Playfulness. There are numerous definitions of what play is (see e.g. Huizinga (1955), Vygotsky (1978), Caillois (1961) or Sutton-Smith (1997)). Focusing on the three basic categories of a play experience offers a perhaps more operational definition of play:

Play is an intrinsically motivated experience centred around explorative activities, igniting a sense of playfulness in those who participate.

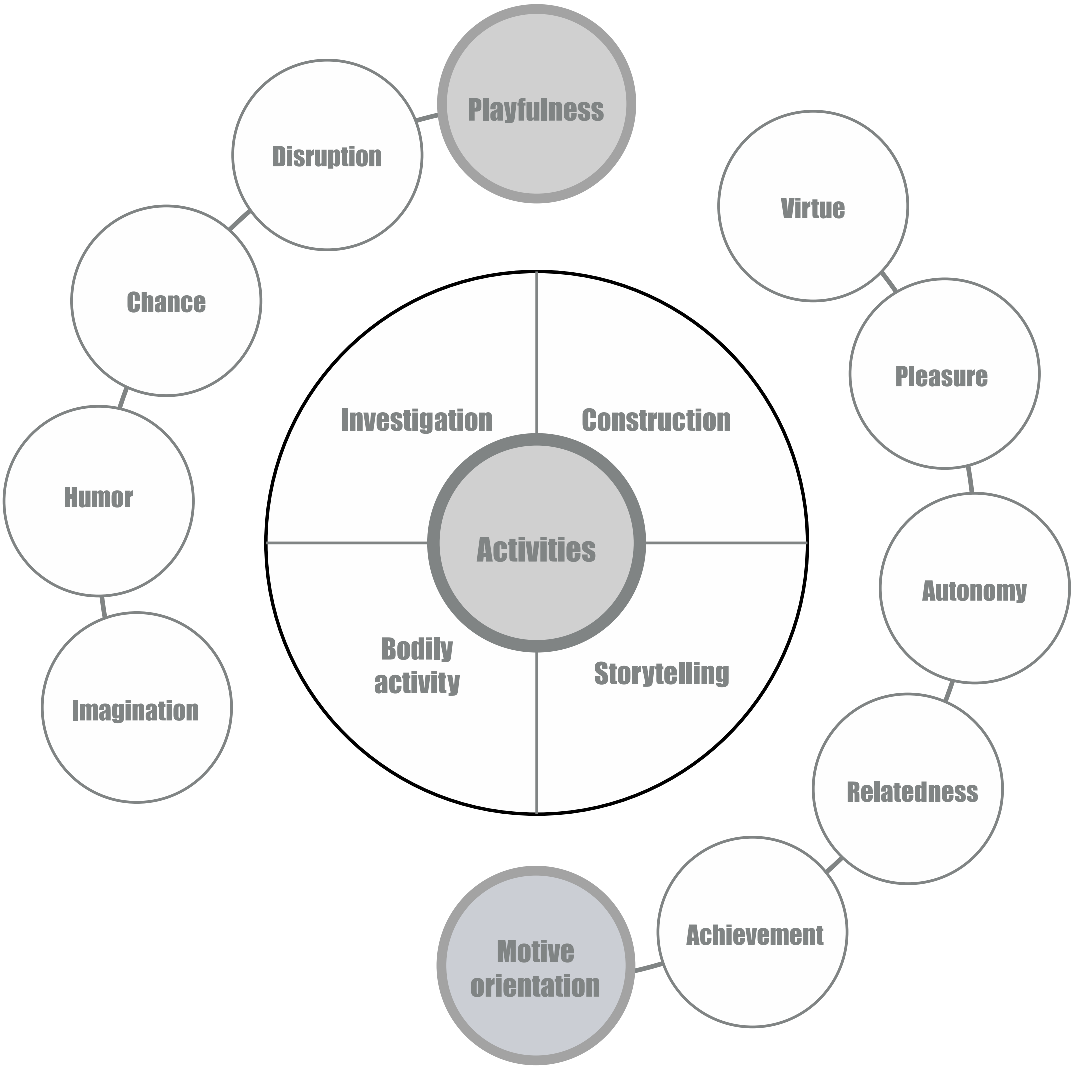

Figure 1: The Play Blueprint

The Play blueprint was developed by firstly aligning and comparing relevant research on play experiences, building also on basic theories from experience design and positive design. It was secondly refined through empirical studies within the Play User Lab (PUL) project, where it was used as a tool to firstly explore and understand playful experiences, and secondly for developing new designs aimed at specific intentions for new play experiences. The Play blueprint was furthermore used as a tool to analyze and design artefacts for new play experiences by 16 students from the MA programme in 'design for play' at Design School Kolding.

The PUL project consists of a series of workshops planned and facilitated by designers and researchers from Design School Kolding with the aim of aiding the participating companies to gain better understanding of, and be able to design for, play experiences. The participating companies work in the fields of play and learning, e.g. toy manufacturers, manufacturers of playground equipment or developers of school interiors. 18 different companies have so far participated in the project, which has also provided a sound basis for empirical research. Each company participated in a series of 8 full-day workshops over the course of 4 months. Some of the workshops involve children both as users in observation sessions and as active participants in the design process.
The Play blueprint was trialled and refined during some of the sessions with the participants in the PUL project. Using the Play blueprint allowed them to pinpoint weaknesses in the play experiences currently offered, and start developing ideas about how to, for instance, increase the possibility for achievement as motivational factor. Discussion with participant about the blueprint following the

workshops as well as observations of their process of working with the blueprint, helped refine it to the final version presented here.

Figure 2: Workshop in the PUL project

The framework is called a blueprint because it is intended to be used as a scaffold for understanding particular play experiences through explicating its components, hereby becoming a tool for both analyzing play experiences retrospectively and designing for new play experiences.

In the following section, I will describe each of the three main categories in the framework.

3 Activities

The many theories about play provides us with a smorgasbord of play types (see e.g Caillois, R., 1961; Hughes B., 2002; Fagen, 1981) but for the sake of simplification, these are distilled to four different activities: Investigation, Construction, Bodily activity and Storytelling.

They are considered activities rather than distinctive ’types’, because a play experience is rarely restricted to one unique ’type’ of play, but rather a combination of activities. Constructing with bricks for instance is rarely only about construction, but typically includes a very important element of storytelling.

The four activities were defined by comparing and distilling theoretical groundwork of play theory, and by empirical research in the PUL project. The data obtained in the PUL project stems from both observations of children’s play activities in schools, kindergartens and playgrounds, and from exercises where children were directly involved, developing new designs with the participating companies. In both cases the participating companies structured and distilled the components and activities of the play experiences, which in each case supported the described structure with the four main play activities.

The activities provide a basic structure for a play experience, and a focal point around which the play experience evolves.

3.1 Investigation

Babies and small children are particularly prone to this activity, for instance biting or objects. We do this investigation when we encounter something that is new to us. For small children, it is focused on simple, basic investigations of the characteristics of different objects, but for larger children and adults it becomes more complex, typically focused on the relation between things or investigating social relations between oneself and others.

The concept of investigation is not to be confused with exploration, which is a basic condition for all play activity (De Valk, Bekker & Eggen, 2015). Investigation aims at examining an object or relation, narrowing in on a specific understanding of it, whereas exploration does quite the opposite, opening the experience towards whatever happens, allowing the experience to take new paths (Jensen, 2013).

3.2 Construction

Construction refers to an activity where those playing manipulate their environment to create things. A typical example of a construction activity is building with bricks. But all ‘hands-on’ exploration through combining and manipulating materials to construct something new are considered construction activities, so other examples could be building sand castles on the beach, or making drawings on a piece of paper.

The act of personalizing the play experience can often lead to incorporating construction activities into the play experience, for instance colouring a plastic sword to give it a more personal expression.

3.3 Bodily activity

Play activities that take place on playgrounds are typically very physically intense, leading to stimulation of the senses and challenging one’s gross motor skills. These activities are for example running, jumping, swinging, climbing and other types of physical play.

An example from observations of children at a local playground illustrates how the play activities within a play experience tend to overlap. A group of children were playing on a pirate ship. They would swing from the ship out on a little island using ropes, with the intention of avoiding the enemies who were boarding their pirate ship. So, their bodily activities were founded on the storytelling of the play situation.

3.4 Storytelling

The fourth activity is storytelling, i.e. building and developing the imaginative layer that is inherent in most play activities. I use the term ‘storytelling’ instead of the term imagination to underline the active development of the story, rather than being just a static imaginative space. Storytelling as activity is part of developing the play space and story amongst those playing. Telling a story can also be play, if the story is developed (thought up) together, where each person in the play activity actively contribute to the story. This is the main difference to imagination in relation to playfulness, which similarly provides an imaginary space one might enter, but in that case, not necessarily take part in developing.

4 Motive Orientations

The motive orientations describe the intentions (of the player) that the play activity is directed at, as stated by Hedegaard (2012: 10) who writes that “in a specific situation a child's motive can be seen as an orientation in the activity setting. A child's motive orientation is expressed in his intentional activities and his wishes”. She (ibid: 11) further writes that “an activity can be motivating if it relates to children's already-developed motives”, meaning that motivation needs to come from something that complies with the intentional desire of the person playing.

Karoff (2013) provides an example where two children, Aske and Olivia, are playing. Olivia is very concerned with how the peasant family in her play activity drives the production, how the children in the family are doing in school and ensuring that the house is clean and tidy. She lets the family pack a large wagon of vegetables and travels to Askes country to sell the vegetables. In the meantime, Aske is planning an ambush against Olivia. He takes over the business and threatens the family on their lives.

In this example, there is a quite obvious discrepancy between the motive orientations of Olivia and Aske. Olivia is driven by making the family succeed in a way that supports her feeling of virtue. In her play activity, she aims to do something morally good. Aske has a different motive orientation. He is less concerned with the aspect of virtue, but wants to succeed as a warlord. He is motivated by the accomplishment of gaining power and wealth.

The Motive Orientations were extracted from literature such as Karoff (2013), Hedegaard (2012 / 2017), Desmet (2013) and Ryan (2000), and was furthermore confirmed through studies in the PUL project.

4.1 Achievement

In Self-determination theory (Ryan and Deci, 2000) there are three vital components believed to be the main drivers of intrinsic motivation. The first of these components is ‘competence’, comparative to what Deterding (2011a) describes as mastery. In game design (as in play) the player needs interesting challenges that comply with, and build upon, his skill level. They must be both difficult (prone to lead to failures) but also (at some point) achievable (Chikszentmihalyi, 1990), it is a very important aspect of motivation.

In the Play Blueprint, the word ‘achievement’ is used instead of the terms ‘competence’ or ‘mastery’, because these two words do not imply a reason why, i.e. they miss the direction that supports motivation. (We are motivated to build our competence/mastery because it allows us to reach new achievements).

4.2 Autonomy

The second component in the Self-determination theory is ‘autonomy’, i.e. doing things in your own way. Autonomy relates closely to the characteristics of play experiences as being free and explorative (Deterding, 2011b). In our studies in the PUL project, we found all three components of the self-determination theory to be present both in the observations of children, and in an exercise, we did with the adult participants. In this exercise, they were asked to build a domino effect chain, and were given challenges to incorporate for instance a bridge or a pendulum in their solution. They noted especially three things in the reflection afterwards that had motivated them in the task; Achievement, autonomy and collaboration. They wanted to make a spectacular domino chain, challenging themselves to achieve a result to be proud of, so many groups added additional challenges, for instance making the pendula start not just one but several rows of dominos. They also appreciated the setup, where they, although they had been given a specific task and had been told where to start and stop, they were free to create the chain and add fun effects to it as they wanted to. We had provided a bunch of different materials – such as cardboard, paper, strings, but also balls and toy-cars for them to pick freely from. Through that setup their experience of autonomy was well supported. The third aspect that had been particularly motivating for them in the exercise was the collaboration with others, leading me to address the third motive orientation stemming from the three components of the self-determination theory; Relatedness.

4.3 Relatedness

In the domino exercise the participants were divided into groups of 2-3 people, each of them being tasked with constructing a specific part of the domino chain, connecting it all in the end as one chain.

The collaboration they had internally in the groups was mentioned as a motivating factor, but also the opportunity to tease and challenge the other groups was important. So, it was evident that the social aspect of the exercise was important for their motivation in different ways.

Relatedness is also connected to achievement and the challenges a person (or group) takes on, because we often do such things in order to be acknowledged, in some cases even admired, by others. Relatedness addresses all these factors – collaboration, teasing, challenging, showing off and other aspects of playing that are defined by the relations between those playing.

Figure 3: Domino building exercise in the PUL project.

4.4 Pleasure

As described by Desmet and Pohlmeyer (2013), a key element in design for happiness is the notion of pleasure. The concept of pleasure covers for instance aesthetic pleasure of a product considered to be beautiful, or embodied feedback as mentioned by Sicart (2014), similarly to what Gabler et al (2005) describes as juiciness (in digital game design). Juul and Begy (2016: 1) further describes ’juiciness’ as “additional redundant feedback that is not necessary for communicating the game state to players, but rather gives players common superfluous feedback in response to their actions”. I, personally, experience pleasure by the feedback I get when the magnet in the power plug for the mac computer makes it ‘magically’ snap into place. Buxton (2007: 129) similarly describes a positive experience he had with an orange squeezer that added more emotional appeal to the product by the interaction, writing that:

> *...my pleasure is due to the feel of the action when pulling the lever down. there is a cadence in the action that is almost musical. This is something that no drawing or photograph can capture, since it has to do with feel, and it takes place over time.*

If I perform an action that gives me pleasure just once (with a purpose), it is part of a good experience. But if I repeat the action (for instance pulling the plug out simply to put it back in), it becomes a playful action without any other purpose than experiencing this type of embodied feedback again.

Sicart (2014: 4) furthermore notes that “play can be pleasurable when it hurts, offends, challenges us and teases us, and even when we are not playing. Let’s not talk about play as fun but as pleasurable, opening us to the immense variations of pleasure in this world”.

4.5 Virtue

The fifth motive orientation is virtue. Virtue is described by Desmet and PohlMeyer (2013) as being a morally good person. Virtue can for instance be expressed by doing certain things in order to take responsibility for the environment, but it can also be helping one’s parents by doing the dishes. For a child, virtue is often related to having a meaningful role in the family and taking part in the responsibilities within the family.

You could question whether virtue – as something that in many cases leads to a real and beneficial outcome, for instance getting the dishes done, is still play? But virtue in play is slightly different in that it refers to the imaginative space of the play activity. Being a white knight that saves a princess from a dragon for instance.

We see examples of play-related virtue when children play superheroes or playing house that involve virtuous values of how the members of the family acts in different situations. The evolvement of moral values is inherently tied to culture and as described by Bruner (1996), children learn about culture through play. He writes that:

> *Children show an astonishingly strong "predisposition to culture"; they are sensitive to and eager to adopt the folkways they see around them. They show a striking interest in the activity of their parents and peers and with no prompting at all try to imitate what they observe. (ibid: 47).*

In their research on behavioral change in relation to enforcement of policies, Shove, Pantzar, and Watson (2012) draw out similar motivational factors such as personal values – linking to virtue - and social practice – linking to relatedness. They (ibid: 142) note that there are two classic strategies for, for instance, promoting more sustainable ways of life, ”one is to persuade people of the importance of climate change and thereby increase their green commitment; the second is to remove barriers obstructing the smooth translation of these values into action. ”

BJ Fogg (2009) proposes a similar division between what he describes as motivation and availability. The Play blueprint refers specifically to the first concern - building motivation – due to its focus on meaningfulness of a play experience, whereas the second concern (availability / removing barriers) relates to the basic premise of making the experience available, ensuring a suited threshold for engaging in the experience.

5 Playfulness

As stated in the beginning of this article, playfulness is considered a vital ingredient for an experience to be considered ’play’. But playfulness in itself is not necessarily play, and can be added as a component in other types of experiences, hereby making experiences with a purpose playful. Sicart (2014: 26) describes playfulness as an attitude and further as “a projection of characteristics into an activity” in which case it lacks the autotelic nature that is characteristic of play experiences. Playfulness, in that case, preserves the purpose of the activity it is applied to, relating it to the concept of gamification (see e.g. Chou, 2015).

If we unfold the concept of playfulness using the ESF model by Jensen (2014), we can illustrate the difference between playfulness in relation to open-ended experiences (relating to the term omni-directed in the ESF-model) and goal-directed experiences that are aimed at a specific outcome. As illustrated in the model, this is a significant difference between gamification and play, due to the characteristic of play to be free/open-ended without a pre-defined outcome and, as mentioned above, autotelic. The model also illustrates how the commonly mentioned characteristic that play does not have consequences outside of the play situation relates only to the direct (immediate) experience, seeing that play will always have derived consequences such as developing skills or making friendships.

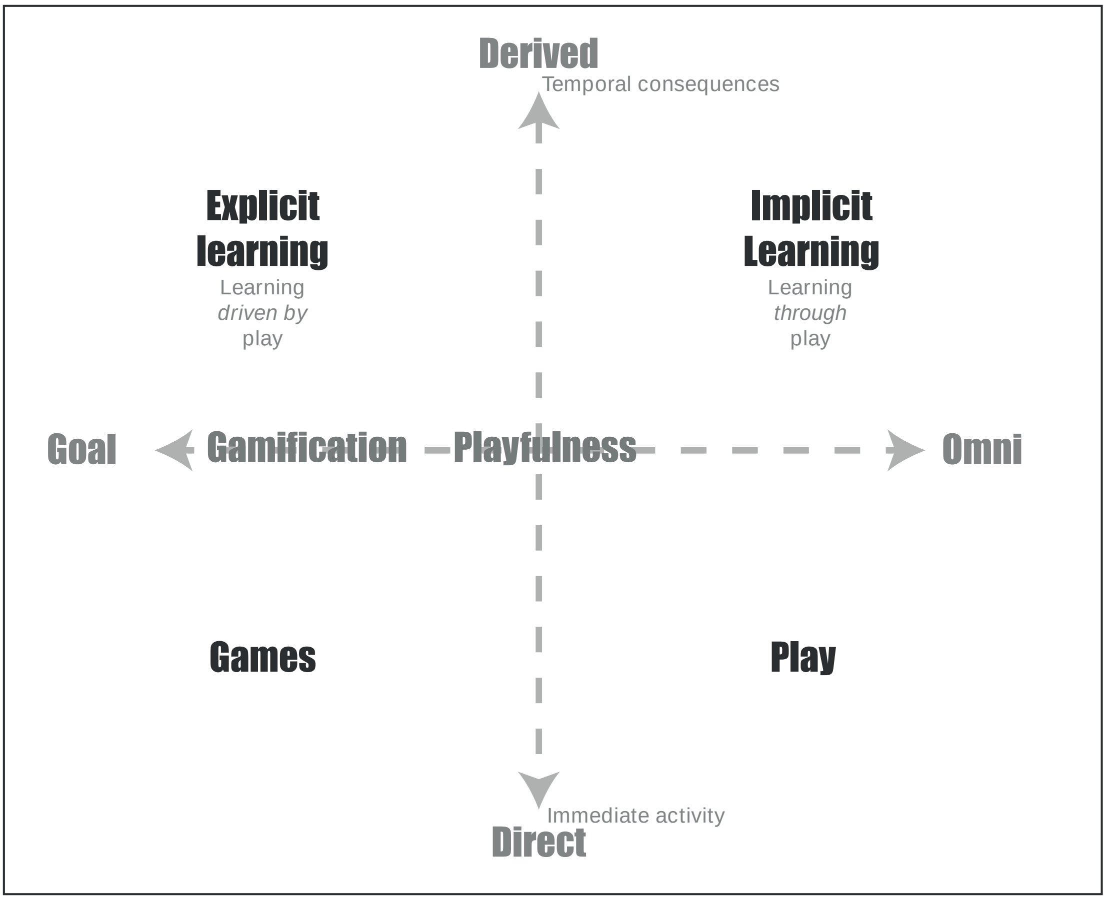

Figure 4: The ESF model with focus on playfulness.

While I will not dive into the aspects of learning in this article, it is interesting how the model also places games and play experiences in relation to implicit and explicit learning respectively, explicating the difference between them, considering learning/development to be a derived outcome of any experience. The term ‘implicit learning’ was coined by Reber (1967) as learning that produces unconscious knowledge, whereas explicit learning is the opposite, i.e. learning with a specified (often quantifiable) goal.

The research by Overbeeke et. al. (2002) underlines the importance of playful aspects in order to create joyful interactions, stating that ‘joy of use’ is not the same as (and in some cases, even opposite to) ‘ease of use’, suggesting a counterpoint to usability. They (ibid: 9) advocate for creating a fuller user experience, writing (about the designer) that “it is his task to make the product’s function accessible to the user whilst allowing for interaction with the product in a beautiful way. Aesthetics of interaction is his goal.” They (ibid: 9) further write that:

> *Interfaces should be surprising, seductive, smart, rewarding, tempting, even moody, and thereby exhilarating to use. The interaction with the product should contribute to the overall pleasure found in the function of the product itself. The experiential is assumed to lead to joy of use.*

These considerations refer to two of the four components of playfulness in the play blueprint; Chance (the element of surprise) and Imagination (transferring human traits such as moodiness to a product personality). Sicart (2014) likewise mentions serendipity (chance) and imagination as vital parts of playfulness, and adds that playfulness is also disruptive. The disruptive nature of a play experience relates to the freedom inherent in play experiences, and the need to push the boundaries when playing. Beyond these three; Chance, Imagination and Disruption, Humour is also considered an important component of playfulness, building on the research by e.g. Yue, Leung and Hiranandani (2016) and Barnett (1990). While playfulness, as described here, can take part in many types of experiences, I consider it a vital part of a play experience because it encapsulates the attitude of play behaviour. Barnett (1990: 319) underlines the close relation between play and playfulness by proposing that “rather than regarding play as what the child does, the better way is to focus on play as an internal predisposition to be playful”.

5.1 Chance

The characteristic of play as an exploration suggests inherent opportunities to make new discoveries, finding something unexpected or making new connections, in order to maintain interest in the play experience. These aspects can be ignited by a degree of randomness, i.e. a potential for something unexpected to happen. Play has an intrinsic insecurity about where it is taking us, and what is going to happen. Sicart (2014) mentions how serendipity can force us to experience something with playful astonishment. Many board games incorporate the element of chance by including the roll of a dice in the gameplay. We also see chance and surprises in digital products, often described as Easter eggs, i.e. hidden elements that are not part of the function or gameplay but can be uncovered by performing specific actions. In 2009, for instance, Google maps would suggest that you kayak across the Pacific Ocean, if you asked for directions from New York to Japan.

5.2 Imagination

Play demands its own space, bracketing the play activity as separate to ordinary life. Whereas most experiences can be difficult to define in time and space, a play experience has a well-defined time and space. The play space typically unfolds in an imaginative world where everything is possible. If children for instance play with LEGOs (playing, not just building), they can create settings for imaginative play to happen, where princesses and trolls are natural inhabitants.

This creation of a meta-reality within which the play experience unfolds is a typical trade of children’s play (see e.g. Huizinga, 1955 or Hedegaard, 2016), but it also often appears when adults play. We saw this in the previously mentioned exercise in the PUL project, where the adult participants created a domino-brick setup. One of the groups had included a little toy car which would run down a slope to make a jump, hereby hitting the next domino brick. But they had also build a small garage where more of the small toy cars were put because, as they explained, if the first driver doing this extremely dangerous stunt did not survive, a replacement driver would need to be ready.

So instead of considering the toy cars as just a functional mechanism bringing the motion of the domino setup to the next point in a more interesting way, they saw it as a meta reality with a brave little driver, who had been given the task of doing this stunt.

5.3 Humour

In the PUL project, a group of children (aged 11-12) were developing an imaginative land inhabited by unicorns. One of the ideas that would make them giggle each time they told someone about it, was the ability of the unicorns to shoot rainbows out of their rear ends when farting. Such humorous ideas were abundant in the work of the children, and appeared to be a valuable source for energizing their playfulness.

Albeit humour is essentially a social construct (elicited through the interactions and dialogue of people, as in the example above), in-animate objects can also inspire and support humorous situations.

Humour in relation to objects often builds on quirkiness, exaggeration and humanization. At Design School Kolding we developed a new co-creation lab, in which we made movable workstations designed as oversized chairs, because making things out of scale adds playfulness through both imagination and humour. Sicart (2014: 20) also notes that a typical approach to playful interface designs is to make them “quirky and with personality”, hereby humanizing them.

5.4 Disruption

Sicart (2014: 4) notes that “play is always on the verge of destruction, of itself and of its players, and that is precisely why it matters. Play is a movement between order and chaos”. An important characteristic of play is this balancing inside and outside of the boundaries of the play activity, providing openings for non-destructive disruptions. Sicart (ibid: 26) writes that:

> *Playfulness always respects the purpose of the activity for its own integrity to exist. This does not mean that playfulness cannot be disruptive. In many cases, a playful attitude will result in a relative disruption of the state of affairs, though without destroying it.*

Disruption is for example seen when my little son, who is 2 years old, decides to use a hammer to play the piano. It becomes playful because he is doing something unintended to see what the effect will be. This action also supports his feeling of autonomy, because he is disrupting the play experience in his own way, exploring the consequences of doing something unintended.
The example illustrates the close link between disruption and creativity, because disruption pushes the exploration process to (and beyond) the edge. Trying out things that were not intended, making new connections, and increasing ones understanding of actions and reactions.

6 Implications for Design

This paper focuses on designing artefacts for play experiences by breaking the experience up in more operational concepts, guided by the ’Play blueprint’ framework. While a designer’s intentions are never directly transferable to a user’s intentions, this approach to the design process may guide the designer to achieve a better link between intention and the resulting experience. I trialled the model in the PUL project, where participants were asked to use the model to guide the design process. In this case the participants started by defining the different parameters by how they would ideally want the resulting play experience to be like, for instance “initiating but not restricting children’s imagination” or “building competences by making it easy to use but hard to master”. These statements were then used for idea generation, formulating opportunity spaces such as “How might we initiate but not restrict children’s imagination through the product aesthetics?”.

Some of the characteristics of the play experience are, by the very nature of the concepts, very difficult to design for. How do you, for instance, design for disruption? How can a design initiate unintended use if the designer does not know what that unintended use will be? Designing that leaves room for imagination, exploration and playfulness is also difficult. Suggestions to take on these challenges often revolve around the levels of ambiguity in the design.

Design for disruption can be considered a design of open possibilities, leaving room for ‘wrong’ ways of doing that turn out to be interesting twists instead of breakdowns of the experience. Designing towards an openness of user adaptation may at the same time entice the user to immerse in playful exploration.

So, when we use the Play blueprint as a guide in designing for play experiences, some of the concepts can be addressed directly, whereas others are concerned with designing possibilities, providing opportunities for disruption and exploration.

Figure 5: Play installation in Copenhagen. The design aesthetics sparks imagination without defining if it is a squid, a melting Darth Vader, a space ship or something else entirely. It is an interesting example of ambiguity in design aesthetics.

6.1 Student projects – designing play mutants using the Play blueprint

The sixteen first-year students from the new Design for play Master's programme at Design School Kolding did a project entitled 'play mutants', where the idea was to analyse a child's play experience and use the elements from it to mutate an everyday situation/object into a play experience.

The students started the project by observing children playing in a nearby schoolyard, using the Play blueprint to draw out specific characteristics of the play experience. They focused on the activities it contained, the motive orientations of the children, and on which elements of playfulness were present. One of the students had observed a group of classmates in a sandbox, who were touching and exploring the sensory feeling of the sand while building. She noted how pleasure (e.g. letting the sand run through the fingers) worked as a motive orientation, how they explored imaginatively what the sand might become when constructing 'things' with it, how social relations affected their motivation by building something the others liked, or making up exciting stories about what they were building. In many cases the stories had a humorous angle, further enhancing the playfulness of the experience.

These observations were transformed into design principles, e.g. using materiality to enhance the sensory experience, allowing people to build and share something, and supporting imagination and humour. She designed a physical map of Design School Kolding which used different textures for sensory experiences. It was made possible to place different physical elements on the map, hereby building stories about the spaces and different situations people have experienced at the school. You could also move the rooms around, connecting them in new ways, for instance combining the rooms the person used the most, to imagine how the space could be.

The map as such was probably not very helpful for guests at the school, but it was a canvas for sensory investigation and a play space for sharing personal stories in relation to the physical spaces at the Design School.

The other students likewise observed play experiences to create new design principles for, for example, a waiting room at a doctor's office, tools for language learning, or principles for communication on social media. While the focus of their 'mutations' were very different, they all used the Play Blueprint as a focal point, enabling them to better understand the important aspects of the play experience and transform it into new play experiences. These steps allowed the important abstraction from object (e.g. sand) to principle (e.g. sensory experiences) and to a new object (e.g. the map) – a process that Jensen and Coxon (2013) describes as the transition of knowledge. As the example shows, it is not the idea to use all the components described in the blueprint, rather it is valuable to pinpoint which are important and combine those in the new design.

7 Conclusion

The article introduced the 'Play Blueprint' framework, describing what are considered to be the main components of play experiences, building upon theoretical foundations mainly within play, experience design and positive design. Although the proposed framework is not necessarily fully comprehensive, I argue that it covers the essential components of meaningful play experiences. As such it provides a foundation for designing meaningful play experiences, but also for incorporating playfulness in other joyful experiences.

Gordon (2014: 240) establishes a link between play and long-term happiness by noting that "the pleasure engendered by attuned play in the first year of life provides a foundation for life to be joyful". Furthermore, the characteristics of play as something personally engaging (due to being an experience entered voluntarily and experienced in a personal (autonomous) way based on one's own inherent intentions) also infuses the play experience with high levels of authenticity. These aspects were also described by Freud (1955), who regarded the child's play as expressive of personality patterns and internal desires. And as Tuber (2008) mentions (drawing upon the work of D. W. Winnicott) authenticity (the ability to be and act according to one's real self), is a hallmark of mental health.

The title of this paper - 'the road to happiness is paved with playful intentions' – refers to these important connections between play and happiness, encouraging designers to utilize the characteristics of play and playfulness to increase the intensity of an experience. As stated you have to enter a play activity voluntarily and do it in your own way, based on your own intentions and ways of doing. So, it always becomes personally engaging when we enter a play-space. Such experiences can never be designed in themselves, but we can design with the intention of eliciting meaningful and engaging play experiences. The Play Blueprint introduced in this paper can be a valuable tool in that process.

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Co-creating Happy Moments: A Case Study of Designing for People with Mental Health Challenges

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We all have to consider the importance of mental health, which just as with physical health can cause us to feel ill, unwell and ostracized from our community. However, the stereotypes and prejudice that result from misconceptions about mental problems appears to form an impassive and invisible barrier between the people with mental health challenges and the public who is less willing to interact with them. As three researchers respectively from service design, visual communication and art education, we undertook collaborative interdisciplinary design as a strategy, in order to explore a participatory approach to engage with our participants, namely, an anonymous community in Norway that supports mental health and a group of 27 youths in Finland. The aim of our project was to create pleasurable and meaningful experiences for the mentally marginalized individuals, thus potentially having a positive impact on their subjective wellbeing. We conclude the paper with a discussion of how participatory design enabled the participation of those mentally marginalized individuals and eventually catalyzed a positive change.

subjective wellbeing, participatory design, interdisciplinary design, positive design

1 Introduction

Summarizing mental health issues presents a wide range of challenges for those who are affected, for instance, major depressive episode, generalized anxiety disorder, panic disorder and alcohol dependence (Keyes, 2005). Mental health is further seen as one of the leading factors to almost 800 000 suicide deaths in 2015, within which depression – a mental health disorder – is estimated to affect 311 million people worldwide (Vos et al., 2016; WHO, 2016a). Some argue towards removing mental illnesses from the category of illness and suggests that “*they be regarded as the expressions of man’s struggle with the problem of how he should live*” (Szasz, 1991, p. 21). However, the majority of people with mental health difficulties seem to have to struggle with the symptoms of the disease itself; moreover, they frequently encounter public stigma and may suffer from self-stigma, which turn them against themselves, and lose self-confidence (Rüsch, Angermeyer & Corrigan, 2005).

Therefore, mental health has been regarded as an important factor in the evaluation of a person's wellbeing and assesses how the quality of life is affected in regard to the researcher of wellbeing and care practice (Albrecht & Devlieger, 1999; Hendriks, Dreessen & Schoffelen, 2016). The basis of comprehending mental health problems should be built on understanding the organic base of impairments and the social model of disability (Albrecht & Devlieger, 1999), which collectively do affect quality of life.

Just as a flu can spread from person to person, Gladwell argues how little things can make a significant difference and then lead to a tipping point where the whole situation can be changed (Gladwell, 2006). Similarly, reducing social stigma attached to mental health problems and making the mentally marginalized individuals feel part of the larger society can both lead to such tipping point.

Although it might be difficult to bring significant and effective changes to those objective factors resulting from health issues and social environments, there has been considerable interest in providing a positive impact on individuals' level of happiness, that is, designing for subjective wellbeing (SWB) through creating pleasurable and meaningful experiences for people with mental health challenges. There are several variations in the wording of SWB (Deci & Ryan, 2008; Diener, 1984; Okun & Stock, 1987), while the literature generally agrees that SWB includes various affective evaluations of moods and emotions and cognitive judgments of life satisfaction (Desmet & Pohlmeyer, 2013; Diener & Lucas, 1999).

Theoretical efforts have provided explanations to understand the enhancement of quality of life among individuals with mental health challenges and the interventional efforts designed to enable positive impacts and empower these individuals. According to the National Mental Health Development Unit, however,

> *Two thirds of people with mental health problems live alone – four times more than the general population; more than 50% of people with mental health problems have poor social contact, as defined by the Oslo Social Support Scale, compared with six per cent of the general population; people with mental health problems see fewer friends regularly – between one and three in an average week, compared with the four to six friends reported by the general population. (Campbell & Davidson, 2012, p. 57)*

The anonymous community involved in our project was the image of the society of Oslo in microcosm. Therefore, advocating an institutional agenda on helping the marginalized community in the context of Nordic visual environment, we undertook collaborative interdisciplinary design for a consistent disciplinary framework in understanding emergent complex forms of design practice (Dykes, Rodgers & Smyth, 2009) as a strategy. By utilizing and integrating our diverse knowledge, we explored a participatory approach in order to engage with our participants, namely, the mental health service users in the anonymous community in Oslo, Norway and the 27 youths in Porvoo Art School in Finland. Our proposition is that social engagement and care giving will enable positive changes on those who are challenged by mental health issues.

2 Designing for participation

2.1 Forms of Participation

Many efforts have been made to better understand people with mental challenges and find ways to improve their illnesses. For many years, suicide mortality rates in the Republic of Korea have been high compared to other high-income countries, but with intervention the suicide rates have decreased recently. The statistics appeared in Korea have shown that it is effective to have community interventions (WHO, 2016b), improved health care (WHO, 2008), and training and surveillance activities as part of the social care strategy (WHO, 2017). In this regard, the importance of updating both theoretical and physical practice as part of an overall social care strategy has been highlighted.

Participatory design (PD), as a powerful catalyst, has been utilized in practice to address problems faced by marginalized and vulnerable groups in our society, for example, the LAUGH project applied an inclusive participatory methodology to develop playful artefacts that can contribute to non-pharmacological personalized approaches to caring for people living with late stage dementia in residential care (Treadaway et al., 2016); four different participatory workshops were designed to discover ways to deepen Namibian children's appreciation of literature, and aimed to co-create a stimulating and engaging reading environment for them with different stakeholders (Itenge-Wheeler, 2016); PD workshops were sought to enable ageing people to articulate their core values in relation to their experiences of ageing with others and in the broader communities they inhabit (Leong & Robertson, 2016).

In our case, we chose PD as a development approach for two reasons. One being that PD is a key approach to build understanding and extended by involving our participants and co-designing with them to the initial objective, so that their voices are heard and they have the right to make concrete choices (Bratteteig & Wagner, 2014) in the whole process. For another, the above case practices show that most of PD outcomes are related to either tangible results for users in early PD projects or non-tangible ones in recent development (Kyng, 2010; Whittle, 2014). When seeking for our PD goal of creating pleasurable and meaningful experiences to participants, we explored different design tools and methods to engage with our participants, such as interviews, storytelling, persona, storyboard, craft workshops and digital documentation. In this case, user participation throughout the process was not only emphasized, but also facilitated to enhance the possibility of mutual learning in-between different groups. In other words, the participants co-constructed a solution to open up a dialogue in the two communities in two different countries.

2.2 Incorporating Artistic and Cultural Views

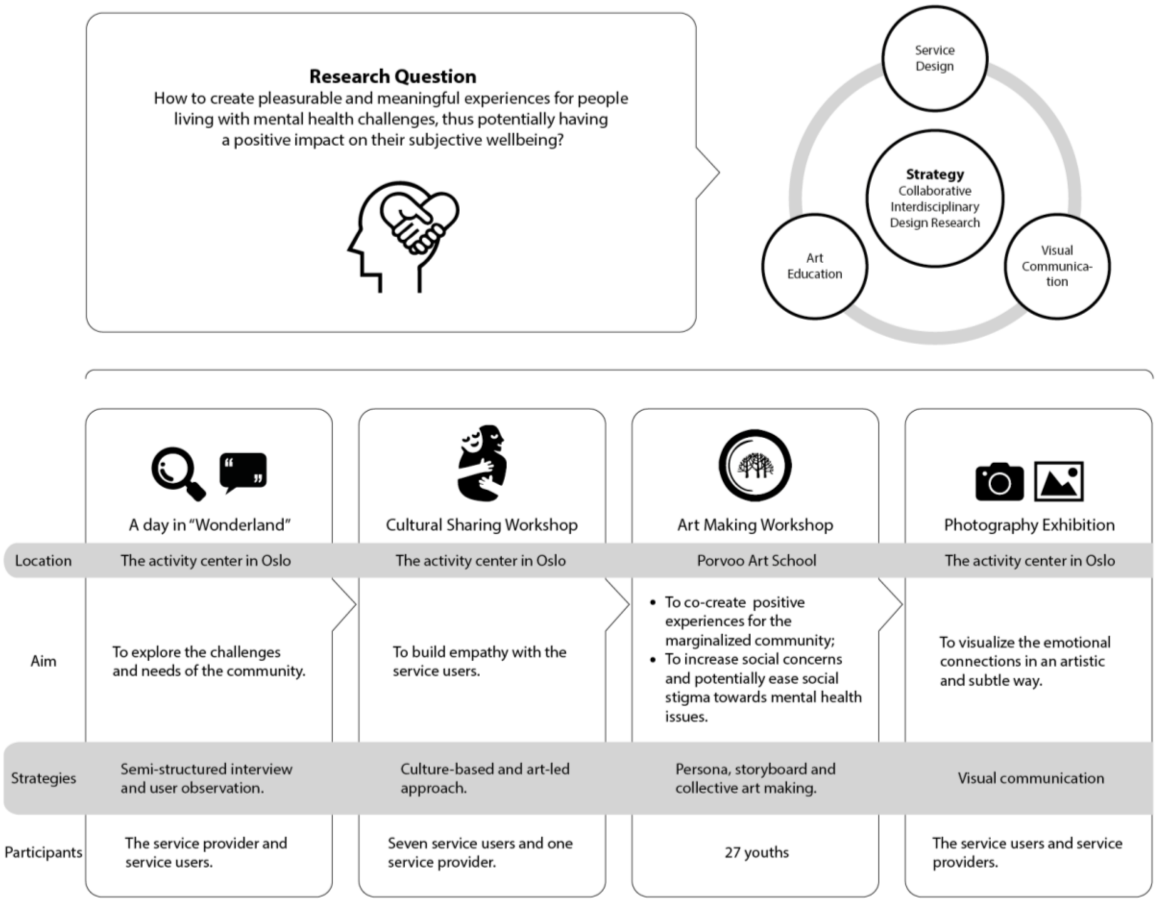
Some work highlighted the challenges for involving vulnerable participants in the design process, including narrow interests or social anxiety (Frauenberger, Good & Bright, 2011; Frauenberger et al., 2013; Makhaeva, Frauenberger & Spiel, 2016) adopted PD process to engage autistic children in developing their own smart objects. The aforementioned authors conducted the PD sessions along experiences with sensory objects and storytelling, which enabled connections to arise through equal participation in art making and shared storytelling. Leaving design space for the vulnerable group seemed to be effective as they did not have access or skills to use sophisticated tools at the time. They therefore pointed out how important to leave design processes open ended and the need to investigate creative potentials in autistic children during the sessions.

Considering the limitations of engaging vulnerable participants in PD process, a large body of research has been dedicated to utilizing both art and culture as pivotal catalyst and initial entry to bring positive impacts to vulnerable people in order to achieve better quality of life. Richardson and his colleagues have demonstrated that art therapy produced a statistically significant positive effect on negative symptoms of chronic schizophrenia (Richardson et al., 2007). An innovative art therapy program was delivered by *STEER*, a community-based mental health organization in Northern Ireland, to support their users in achieving mental wellbeing (Heenan, 2006). Grocke and her colleagues conducted a ten-week group music therapy project for people with a severe and enduring mental illness living in the community (Grocke, Bloch & Castle, 2009).

Focusing on the special needs of these people with mental problems highlights the limits of various topics to encounter the new group. Especially when our project involved people who were with mental challenges who were identified as a vulnerable group according to World Health Organization (WHO, 2018). We acknowledged from our observation that these participants were less willing to interact with new people and showed little interest in "participation". The situation, however, was completely different only when involving this community in an artistic or cultural environment in which alternative ways of being creative were positively encouraged. Thus, it was significant to infuse the initiatives with local views of art and culture in order to meet our design objectives. We therefore needed to create safe and customized conditions that could encourage, enable and motivate those with mental challenges to express themselves fully, explore creative potential as well as open their work for personal interpretation. For the youths in Porvoo Art School, our PD workshops developed from the core idea of co-creating positive experiences for the marginalized community in Oslo, in which collaborative design activities took place. The activities required a playful environment and the PD outcomes made use of physical objects to help make the initial objectives become tangible in the design process. Equipped with multiple PD methods, this case study was characterized by genuine commitments to incorporate community participation and local cultures, therefore infusing them in the design course.

3 The case study

In this section, we will present our project as a community-based case study with a series of design activities that were carried out (for an overview of the project, see Figure 1).



Research Question
How to create pleasurable and meaningful experiences for people living with mental health challenges, thus potentially having a positive impact on their subjective wellbeing?

	A day in "Wonderland"	Cultural Sharing Workshop	Art Making Workshop	Photography Exhibition
Location	The activity center in Oslo	The activity center in Oslo	Porvoo Art School	The activity center in Oslo
Aim	To explore the challenges and needs of the community.	To build empathy with the service users.	• To co-create positive experiences for the marginalized community; • To increase social concerns and potentially ease social stigma towards mental health issues.	To visualize the emotional connections in an artistic and subtle way.
Strategies	Semi-structured interview and user observation.	Culture-based and art-led approach.	Persona, storyboard and collective art making.	Visual communication
Participants	The service provider and service users.	Seven service users and one service provider.	27 youths	The service users and service providers.

Figure 1 Overview of the project

3.1 A Day in "Wonderland"

The anonymous community in Oslo was an activity center for supporting its users in achieving mental wellbeing. We approached to the community with an initial view to exploring its challenges and needs. Instead of offering psychiatric treatment or therapy, the community provides a wide range of artistic activities from media workshops and graphic workshops to providing textile rooms, art studios and galleries, as a relaxing way to engage with people who come to the community. It presents both ethical and aesthetic characteristics: to the public, it appears to be an art gallery; and to its service users, it provides an area for them to practice artistic expressions in different forms of tools and formats.

As outsiders to the community, we started with a semi-structured interview with a senior staff member to gain getting a close insight on understanding the community from an insider's perspective. The findings from the interview highlighted that there was a lack of "participation" in the community. In referring to "participation" in this context, we define it as a term of enhancing communication and interaction in the community, rather than increasing the amount of people to take part in activities in the most general sense. According to the staff, there were approximately 20-25 service users aged 40-60 who regularly participated in the activities provided by the center, on a daily basis. However, the service users spent most of the time in their own comfort zones without actively interacting with one another.

Due to the high ethical standards required in our project and the sensitivity needed towards the service users, it was challenging to directly engage them in normal social conversations, such as, "*what is your name?*", "*why are you here?*", etc. Thus, a soft way to build understanding with them was required. We then conducted an observation, where we randomly took part in some activities provided by the community, as if we were one of the service users. Interestingly, a number of the them initiatively started conversation with us, asking "*where are you from?*". Their curiosity was aroused by our exotic new faces in the community, this gave us entry to where we could utilize our Chinese identity in order to interact with them.

We noted from the observation that a majority of the service users took interest in arts, crafts and cultures. There were a number of weekly workshops facilitated by both local artists and professional art educators, where the service users could have the opportunities to enact their artistic expressions, through artistic engagements such as drawing, singing and sculpting (see Figure 2). In our eyes, the mental health service users were talented "artists" living in their own worlds, rather than a group of vulnerable individuals living with mental health challenges. Although marginalized by mental health problems, they showed great artistic passion and talented artistic expression in the community. Therefore, we intended to show our respect to those mentally marginalized individuals by addressing them as "artists" in this paper.

Figure 2 Examples of some artworks made by the service users in the community

3.2 *Cultural Sharing Workshop*

Having acknowledged that our exotic identity could arouse the artists' interest, we were inspired to engage them with a cultural sharing workshop, which was carried out in 2017 when Oslo was granted the title of *European Forest City*. In Chinese characters, three people (人) together become a group (众), three trees (木) together grow to a forest (森). Based on this concept about man and nature from Chinese ideology, the aim of our workshop was to build empathy with the artists through a culture-based and art-led approach, which was to learn several simple Chinese characters with regard to human and nature (see Figure 3) and to try to use traditional Chinese brushes and ink to draw a picture together. The idea of involving traditional Chinese brushes and ink was to make the workshop more playful and engaging through the use of exotic drawing tools that were new to the participants.

Figure 3 Chinese characters presented in the workshop

A total of seven participants including one staff member of the community took part in the workshop. We shifted our roles from being an observer to being a facilitator (Spinizzi, 2005). We started by introducing a foreign culture, e.g. Chinese characters, which was entirely new to the participants who then showed curiosity and passion for learning. In doing so, communication and interaction were opened up, as questions related to Chinese culture were coming fluidly and continuously from the participants.

During the workshop, the participants were encouraged to freely show their artistic expression by collaboratively drawing a picture using traditional Chinese brushes and ink provided (see Figure 4). In the end, each of the random and abstract pieces drawn by the participants collectively formed a complete picture, where different stories related to the participants' personal life stories were found, e.g., a magical tree from a Norwegian fairy tale told in childhood, alphabets in the shape of puzzle pieces from the puzzle games that were played in the community, new branches sprouting under some "bleeding" brushstrokes—which was seen as a metaphor for life.

The workshop closed with hugging (see Figure 5). Hugging, as a normal social interaction, was initially intended to express heartfelt gratitude to the participants for attending the workshop. Surprisingly, it revealed an unexpected scene where one of the participants was petrified and showed hesitation, more precisely, a complex mix of emotions. But finally, the participant decided to give a hug to us – the outsiders who were different from their language, culture and religion.

Figure 4 One participant was using the provided Chinese brushes and ink for his first practice and the final picture drawn collaboratively by the participants

Figure 5 Hugging one of the participants in the workshop

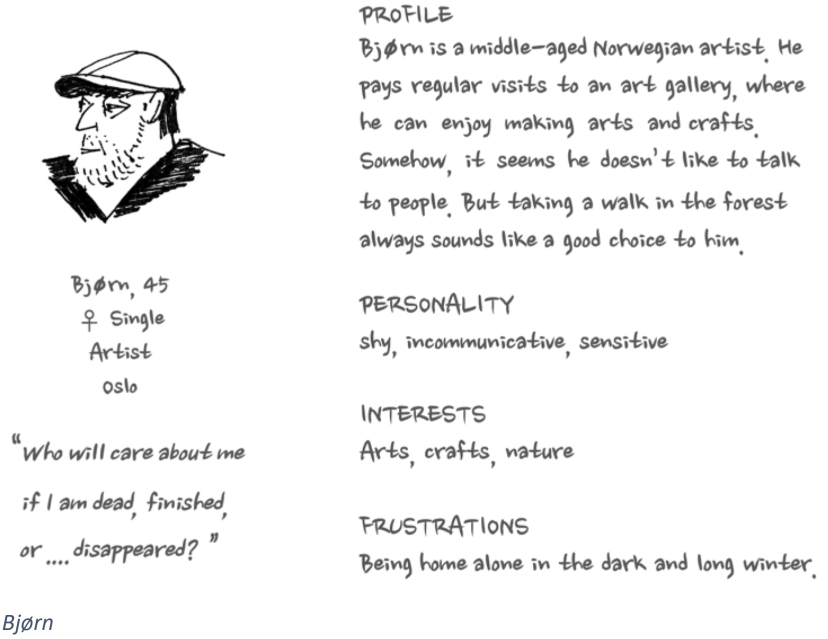
The biggest outcome of this workshop was that we built an empathetic connection with the participants and found there was an emotional need. The culture-based and art-led strategy served as an engagement catalyst, which triggered the participants' curiosity to learn those Chinese characters and to understand the exotic notion of human and nature behind those Chinese characters. Then they gradually and initiatively related their own personal stories on their nature – the Norwegian forest – as in this example: "*I spent my childhood in forest. It was very nice, but the house was sold*...". Interestingly, one of the participants even revealed jealousy to forests: "*They* [the Norwegian forest] *are always there, never vanish, but who will care about me if I am dead, finished, disappeared*...". This implied that the participants showed an emotional need of feeling being cared about, which then led us to the niche where we could utilize design to create pleasurable and meaningful experiences for them, and hence could potentially improve their SWB.

3.3 Collaborative Art Making Workshop

In order to respond to the artists' emotional need – feeling being cared about, we conducted another workshop where we engaged the workshop participants in co-creating pleasurable and meaningful experiences for the artists, so as to potentially enhance their SWB. The purpose behind the workshop was to increase social concern around mental wellbeing and build a better understanding in terms of those artists for the public.

The workshop took place at the Porvoo Art School in Finland. It was a one-month workshop consisting of a series of sessions, i.e. introduction, ideation and production. A total of 27 youths aged 12-16 took part in the workshop. Firstly, we introduced the anonymous community in Oslo to the participants. When it came to its service users, we did not address them as people with mental health challenges, but as talented artists. In doing so, we hoped to potentially ease public stigma towards mental health issues. Stigma related to mental health problems are not a rare event and are widely endorsed by the general public (Corrigan et al., 2001). Many people with mental health problems not only struggle with the symptoms and disabilities that result from the disease, but are also challenged by the stereotypes and prejudice that result from misconceptions about mental illness (Corrigan & Watson, 2002). As a result, there appears to be a social distance between people who have experience with mental health issues and the public who are less willing to interact with them (Martin, Pescosolido & Tuch, 2000).

To build an image of the artists for the participants to understand where the design problem was, we applied persona (see Figure 6) and storyboard (see Figure 7) as storytelling design techniques to outline a profile of a middle-aged Norwegian artist and visualize a day in his life. The character was Bjørn, a 45-year-old Norwegian artist who took keen interest in arts, crafts and nature, but did not feel happy about his life. The storyboard was made up of six scenes, starting from having breakfast in his single flat, going to an art gallery for a regular visit, painting in the gallery, having lunch with the other incommunicative artist in the gallery, going for a walk in the forest with mixed feelings and finally heading back to home (see Figure 7). The character was fictional while the stories we used to create both the persona and the storyboard were real, which was based on the research data collected from the community in Oslo. The profile of Bjørn gathered up the features of the artists.



"Who will care about me if I am dead, finished, or .... disappeared?"

PROFILE

Bjørn is a middle-aged Norwegian artist. He pays regular visits to an art gallery, where he can enjoy making arts and crafts. Somehow, it seems he doesn't like to talk to people. But taking a walk in the forest always sounds like a good choice to him.

PERSONALITY

shy, incommunicative, sensitive

INTERESTS

Arts, crafts, nature

FRUSTRATIONS

Being home alone in the dark and long winter.

Figure 6 Persona of Bjørn

Figure 7 Bjørn’s daily routine

After gaining an understanding of the artists through the persona and storyboard, the participants were encouraged to step into the role of designer, collaboratively working on tackling the challenge — how to make Bjørn and other artists like him feel happy? This was associated with our research question, namely, how to design pleasurable and meaningful experiences for people living with mental health challenges, thus having a positive impact on their SWB?

Our intention of giving this challenging task to the participants was not to seek a perfect solution, but to spark their creative insights on creating positive experiences for those vulnerable individuals. The participants were divided into several groups and discussed different ideas that would lead Bjørn to happiness. One of the ideas came from the storyboard, as in this example: “*His life looks so blank, we could add some colors for him*!” Another idea arose regarding a personal life event with a loved one, which was a reaction about gift giving: “*I don’t feel happy when my dad has to travel abroad for work because I don’t get to see him for a long time. But he always comes back home with a gift for me, and that makes me happy*.” Other ideas such as paintings, crafts, a herbarium book with a collection of plants were proposed, which were inspired by Bjørn’s interest revealed in the persona and storyboard.

Given we had built a deeper understanding of the artists through the conducted observation and culture sharing workshop, our role in this workshop was not just an idea facilitator, but also an idea generator. We joined in the discussion with the participants and contributed an idea of plates. This was inspired by our observation conducted in Oslo, where we noticed that lunchtime was a chance where the artists would get together and enjoy food in the community. This was also visualized as a scene in the storyboard.

The ideation closed with a proposal of crafting a set of colorful ceramic plates as a gift to the artists, where ideas of “colorful paintings”, “handmade crafts”, “gift”, “nature”, “plates” were combined together. As a sparkling signature for a gift from a Nordic neighbor, nature was proposed as a theme on the ceramics, where the creative outcomes i.e. the plates, could be customized and painted (see Figure 8).

Figure 8 The workshop participants painting on ceramic plates

Figure 9 A handmade ceramic plate with a note

After the ideation, a new phase began where the idea of making ceramic plates started to become tangible. The participants were introduced the instructions and safety precautions of making ceramics, and then they initiatively started to lead their own creative process. Over a series of sessions of shaping clay, firing clay and glazing ceramics, a set of 27 ceramics were created in the ceramic studio in Porvoo Art School.

At the last session of the workshop, we used a camera to record the moment of each pair of hands holding the ceramic plate handmade by the participant (for an example, see Figure 9). Every participant left a note with their ceramic plate, each telling the story of the image and also a message they were willing to deliver to the artist who received the ceramic.

3.4 Exhibiting the Emotional Connections

We then brought the ceramic plates with notes from Porvoo to Oslo. When the artists received the gift, we took photos of each pair of hands holding the ceramic plate they chose. In this way, the same ceramic plate was respectively held by two pairs of hands – one pair of hands belonged to one of the ceramists in Porvoo and the other pair belonged to one of the artists in Oslo (see Figure 10).

To present the connections of those photographs, we held a small-scale exhibition (see Figure 11) in the community in Oslo. The aim of the exhibition was to visualize the emotional connections between the ceramists and the artists in an artistic and subtle way. In doing so, our hope was to fill the emotional need of being cared about through those photographs, to express the emotions that are too difficult to put into words, and to deliver the message from the ceramists to the artists: "*You are not alone because we share the same Nordic nature with you*".

During the exhibition, the artists felt excited to see their hands in the photographs and they were also curious to find the paired hands that were holding the same plate. At the end of the exhibition, the staff proposed to take a group photo as a memorable moment of the community, and also empathized that anyone who did not wish to be in the photo was free to leave. It turned out that almost everyone felt willing to show their faces in the photo. The exhibition closed with laughter and hugs from the artists.

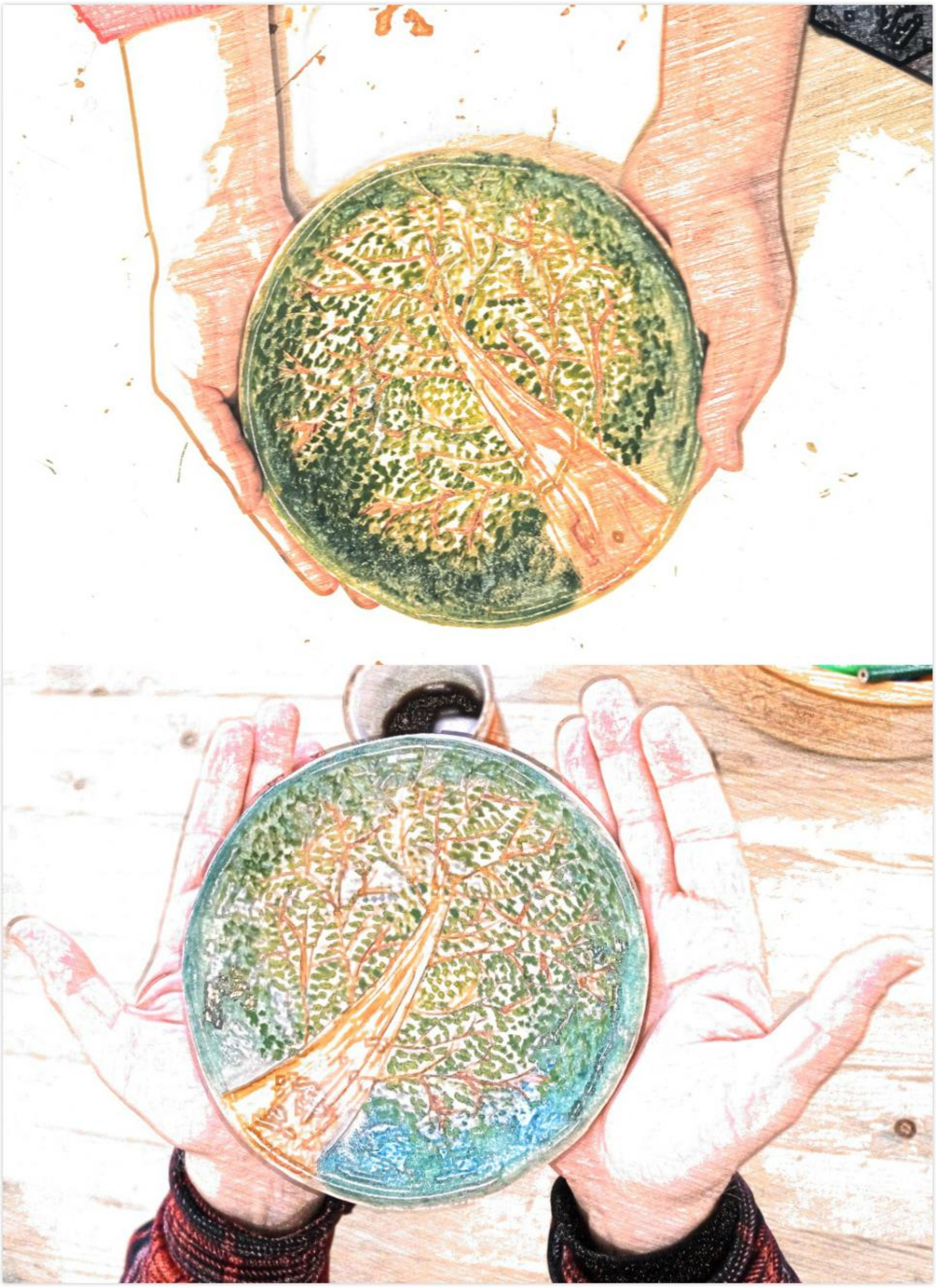


Figure 10 Two pairs of hands holding the same plate

Figure 11 A glimpse of the exhibition held in Oslo

4 Discussion

We have presented how we took an PD approach to create pleasurable and meaningful experiences for mentally marginalized individuals, and how our project had a positive impact on their SWB through building emotional connections between them and the public. In this section, we will discuss a number of takeaways of this case study. We hope our discussions will generate insight for designers and practitioners to undertake further actions on designing SWB for marginalized groups.

4.1 Catalyzing Happy Moments

The phrase "happy moments" in this context is defined as positive impacts. The term "happy" is used to express a positive emotional state and such positive emotions, e.g. joy, interest, contentment, love, etc., which have remarkable impacts on human beings (Fredrickson, 2004). Happiness is often used interchangeably with SWB in research literature. The level of how happy one feels can be used to measure his or her SWB (Diener, 1984). Our original intention was to utilize design as a catalyst in order to bring happy moments to the mentally marginalized artists so as to potentially improve their SWB. However, as the project progressed, we surprisingly noticed that our project not only had a positive impact on those artists, but also on the youths and even us, the researchers.

4.1.1 The Happy Moments for the Artists

The culture sharing workshop was said to be an engaging experience for the artists. Taking the culture-based and art-led strategy, we successfully utilized Chinese culture as something new to draw their attention, which catalyzed their initiative in the workshop. During the workshop, the artists raised questions around Chinese culture to the researchers, started discussions with one another, and also interacted with the staff who participated in the workshop. Taking a participatory approach, communication and interaction were enhanced, which therefore helped the artists improve their communication skills, and potentially enhanced their relationship with the mental health service provider.

Although the workshop was planned in an easy and simple way, the artists were happy that they gained some new skills, i.e. knowing how to write Chinese characters and to use Chinese brush and ink, which potentially helped boost their self-confidence (Li, 2016). Additionally, learning a new art, i.e. using Chinese brush and ink to paint, also provided a new way of expressing themselves, stimulated their creativity skills and enhanced their self-esteem (Staricoff, 2004).

Receiving the gift from Porvoo was also a happy moment to the artists. The ceramic plates handmade by the youths in Porvoo made a significant impact which enabled the artists to feel cared about by the public, as in this comment from one of them: “We had never received anything like this [holding a handmade plate in hand] in the last 40 years”.

The artists were very happy about the exhibition and were proud to be part of the exhibition. More importantly, when the staff proposed to take a photo at the end of the exhibition, most of them were happy to show their faces, as if they finally were a part of the community.

4.1.2 The Happy Moments for the Youths

In the collaborative art making workshop, every youth had a chance to step in the role of designer, giving their creative ideas and making them become tangible. The finalized proposal was combined with ideas coming from each group. The youths felt respected as every voice had been heard. Moreover, confidence was thereby enhanced as they were aware of their ability to contribute own ideas to the design process. In a PD process, it is important to note that every voice needs to be heard, so that participants can feel included in the problem definition, inquiry, discovery, findings and implementation (Pascale, Sternin & Sternin, 2010).

Although it was a slow and effortful process the youths had to spend their spare time to make the ceramics, they showed strong responsibility and were able to self-lead the making process. It was a joyful moment when the ceramics were finally done. The youths felt accomplished as their efforts had paid off. More importantly, they realized they had contributed their share to bring happy moments to the mentally marginalized artists.

4.1.3 The Happy Moments for the Researchers

From a starting point of positive design, we were able to combine our diverse knowledge and utilize PD as a catalyst to enable positive change – in sharp contrast to the early phase of our project, the artists spontaneously started to communicate, hug and laugh with us.

A lovely surprise for us was we received a card from the community after the project, saying they would always welcome us back to the community. Through applying interdisciplinary design to create positive experiences of pleasure, virtue and personal significance (Desmet & Pohlmeyer, 2013), we were no longer just outsiders to them, but who made the community become a better place for them and made them feel cared about by the public.

4.2 PD as a Learning Process

4.2.1 Situated Learning

PD enabled us to step into a learning process where empathy with the artists was able to be developed. As a cognitive definition, empathy refers to “*the attempt by one self-aware self to comprehend unjudgmentally the positive and negative experiences of another self*” (Wispé, 1986, p.318). This is associated with understanding and contextualizing user’s needs and experiences. The strategy of taking a culture-based and art-led approach enabled us to uncover the artists’ emotional need. Our strategy did not just come out from nowhere, but was inspired by the observation that we conducted in the community in Oslo. By putting ourselves in the artists’ shoes, situated learning enabled us to create meaning from the real activities of the artists’ daily lives (Stein, 1998), where many of the most useful hows were captured, not just the whats revealed in the semi-structured interview with the staff member.

4.2.2 Mutual Learning

As a key part in PD, mutual learning enables different groups of people to understand different ways of reasoning (Simonsen & Robertson,2012). In the culture sharing workshop, empathy was achieved during the process of mutual learning, where multi-stakeholders i.e. the artists, the service provider and the researchers, were all empowered to share on equal participation in drawing a picture and learning a new culture together. Learning the technique of using Chinese brush and ink enabled facilitating learning from one another. Additionally, using this new technique to collaboratively draw a picture not only enabled the stakeholders to work together, but also enabled deeper familiarization and better relationships among them. Such a mutual learning environment created a comfortable space where the artists were willing to share their personal stories and experiences – an emotional need of feeling being cared about was hereby acknowledged.

In the collaborative ceramic making workshop, the artists did not involve in directly, but were introduced through the form of persona and storyboard. This storytelling technique was an efficient approach to have the youths quickly learn from the key information embedded in the fictional character. In addition, the making process not only facilitated discussion, but also stimulated learning from one another and sharing of skills and knowledge. We did not teach the youths merely the knowledge of how to make a ceramic, rather, we engaged with them as an involved schoolmaster, to design with them and not just for them (Rahman & Lim, 2016).

4.3 Visualizing Emotional Connections

4.3.1 One-of-a-kind Nordic Nature as a Bridge

Norway and Finland are not only two geographically close Nordic countries, but also share the same love for nature. In our project, nature was utilized as a core medium and emotional catalyst in enabling the connectedness between the artists in Oslo and the youths in Porvoo. Taking a customization approach, the youths were able to make lifeless and ordinary plates become meaningful and symbolic to the artists, by painting a one-of-a-kind familiar element regarding Nordic nature on the ceramics (see Figure 12). Furthermore, in an aesthetic and non-verbal way, the implication behind those one-of-a-kind ceramics as a gift from the public was intended to bridge the social distance and to remind those artists – there is someone in the world who cares about you. Connections between them were visualized through exhibiting the photographs of different hands holding the 27 handmade ceramic plates. Through presenting two pairs of different hands holding a same ceramic plate, our exhibition built a virtual-bridge for the artists to feel emotionally connected with the youths.

4.3.2 Making the meaning behind the modes

Previous researches pointed out that multimodal techniques in PD research helped to rekindle participants' interests, and even helped designers/researchers discover not only the functionalities and attributes to the underlying motives behind design choices but also to the important values implied in the participants' outcomes (Derboven, Van Mechelen & Slegers, 2015; Halloran et al., 2009). In terms of the high ethical criteria in this project, multimodal thinking applied in our PD case allowed continual participation from the artists and revisits to the community, which corresponded to the PD methodological principles proposed by Spinizzi (2005). Furthermore, we approached the initial objectives through different modes, either in physical objects or tacit knowledge. The multiple methods went beyond simply reacting to the functionality of a design approach, but functioning to take on the appearance of the PD outcomes as well as catching the participants' full attention to the design details in the process.

The notion of multimodality was applied in our project in understanding mode and medium and their potential for creating emotional connection. According to Gunther Kress, the term mode is used "*for the culturally and socially produced resources for representation*", and the term medium is used "*for the culturally produced means for distribution of these representations-as-meanings, that is, as messages*" (Kress, 2005, p. 6-7). In the project, the youths made physical ceramics for the artists through identical plates, as modes. The shape, the material, even the colors carried by the mode i.e. plate constructed the message – there is someone in the world who cares about you. If we consider the plate in terms of the actual production from the youths, the action of passing their message to the artists is the medium. The physical modes, as material, created emotional connection, as non-material. The abstract theoretical message is within cultural and semiotic categories, and emerges in and materialized through the resources of modes (Kress, 2014). Some of the youths drew blueberries on the plates, while others used yellow to represent the sunshine or a warm atmosphere. Through these materialized forms they told their personal experiences with regard to nature. How they visually expressed themselves in the ceramic plates was the outcome of ceaseless semiosis as well as a transformation based on their impressions of nature. In this sense, these plates are material means for making meaning – socially shaped and culturally available.

Figure 12 An image of reindeer on the ceramic plate

4.3.3 Multimodality enabling the emotional connections

Obvious and less obvious modes were both considered in our project (Dicks, Soyinka & Coffey, 2006). In the first workshop, we used modes of hugs, gestures and speech. In the second workshop, the youths delivered their messages through physical materials in the modes of shape, size, texture and color, while facial expression, speech and gestures were repeatedly used in the exhibition, as a close of the project. In this case, we assumed that sensory embodied experiences could be perceived (e.g. through touch) in different modes (e.g. color), in that Pink suggests:

> *It is our assumed ability to perceive the world around us – and as such the modes of communication that produce meanings/representations in the form of media – through the five (differentiated) senses that is pivotal for multimodality scholars (Pink, 2011, p.263).*

Visual scholarship was employed to rethink the relationship between the meanings, the materials and the values in the workshops. We added values to the visual production i.e. 27 identical ceramics through bringing them from Porvoo to Oslo as a gift handmade by the youths. The intention behind this transnational behavior was to build invisible emotional connections between those two communities and to bring happy moments to the mentally marginalized artists through those tangible modes.

In this way, we found different expressions of sensory experiences in the community. For the artists, it is usually the case that linguistic communication about their embodied and sensory perception is never enough to fully express exactly what they had experienced. Therefore, other sensory routes bridged the possibility to communicate with tactile experience, such as drawing and hugging.

Emotional connections then became evident as the messages carried by the modes were easily shared between the artists and the youths, albeit without any textual message.

4.4 Ethical Considerations

From the very beginning of the project, we were aware that the artists were a particularly vulnerable group where ethical dilemmas could easily occur. As such, we have made our best effort to avoid potential ethical issues from arising. Firstly, before the research, we provided project consent forms which state the aim of the project including potential risks and benefits to them. Secondly, during the research, we informed the participants that they had the right to stop any interaction or engagement in the research at any time. Lastly, we discussed the feedback of research findings with both sides of the research participants before publication.

For privacy requirements and ethical considerations, the photos presented in this paper are edited original images that we took during the research. The artists' involvement is completely confidential, as is all their information such as faces, names, addresses is anonymized. The purpose behind conducting the second workshop across the country was also intended to protect their privacy. Furthermore, by addressing them "artists", we not only attempt to show our respect, more importantly, we hope to ease social stigma in terms of the mentally marginalized individuals.

On the other hand, we also acknowledge that there were nevertheless lingering ethical concerns with the approach we adopted. It is often advised to "*avoid close physical contact*" and "*maintain physical distance that is neither very close nor very distant*" (Davies & Janosik, 1991, p. 167) during the interaction with people with a psychological condition. This reveals the possible reason for the participant's hesitation towards a hug in the workshop, as either hugging or being hugged by an outsider could be somewhat unfamiliar and challenging to the participant. Our action of hugging the artists although seemingly naive, strengthened the bond, increased comfort and allowed each marginalized member to realize that they are a connected part of society, therefore positivity impacting their SWB.

5 Conclusions and future work

While we have vast differences in language, culture and religion, we all have emotions, such as the feeling of caring and being cared about. Our project built an emotional connection between the artists and the public. More importantly, our project brought joy, gratitude, laughter and connection to the community, which became a pleasurable and meaningful experience that could have a positive impact on their SWB and happiness. Thus, we believe such a positive impact can potentially catalyze empowerment in their lives, that is, a feeling of being part of the larger society. Handmade ceramics, although brittle, contain a plethora of emotion and are strong in terms of their story. We hope the strong bond forged in those ceramic plates can give the artists a hint of being cared about, by someone with whom they could feel emotionally connected over whatever distance.

Although the findings from our project are encouraging, we acknowledge that our work is limited by its short duration with a fairly small sample. Further study is needed to investigate if those positive impacts do or do not have a long-term or even lifelong positive impact on the majority of people living with mental health challenges.

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Design Probes for People with Dementia

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In order to include persons with dementia in the MinD project actively, design probes were developed to provide insight into their perspectives. We applied probes due to their exploratory character and participation through self-documentation. The aim of this paper is to reflect on the design of the probes in relation to the outcomes as a source of inspiration for designers. More specifically, we investigate the openness and tangibility of the probes, and their content relating to the past, the current or the future. The five participants completed the probes to a large extent. The openness of assignments influenced their completion and the resulting value for empathizing and inspiration for designers: More defined assignments led to more sharing of personal and sensitive information than very open ones. While crafty, tangible assignments were filled in more extensively than less tangible ones, the classical writing assignments resulted more often in more introspective and reflective information from participants. Furthermore, participants filled in assignments about past memories more extensively than those relating to future goals.

design probes; design for dementia; active participation; engagement

1 Introduction

The MinD project aims to use mindful design to support people with early to mid-stage dementia and their caregivers to increase their self-empowerment, confidence and wellbeing in social contexts. Dementia, often causing cognitive, behavioural and psychosocial difficulties, affects people in the social context with respect to recognizing, relating to and empathizing with other people. In addition, side effects of the situation of living with dementia might be potentially having to deal with its stigma – either imposed by others or self-perceived. These difficulties pose a challenge for engaging socially and reduce personal well-being. The MinD project employs mindful design to find ways of complementing existing care approaches to empower people with dementia in everyday social situations (Niedderer et al., 2017). The final aim is to develop solutions that enable self-empowerment and confidence of people living with dementia.

While knowledge about abilities and disabilities of persons with dementia is valuable information in developing designs, learning about user needs and preferences is even more important (Meiland, Dröes, Sävenstedt, Bergvall-Kåreborn, & Andersson, 2010). The majority of research published about dementia and their caregivers is quantitative in nature while in particular qualitative research has the potential to provide meaningful insights into experiences and values of people with dementia. (Carmody, Traynor, & Marchetti, 2015). Persons with dementia themselves are often excluded from research with the result that their perspectives remain underexposed (Carmody et al., 2015). Persons with dementia and their caregivers should be actively included through qualitative research and co-design, and be considered a source of lived experience and valid knowledge (Scottish Dementia Working Group, 2014) – this is the approach the MinD project takes.

To better include people with dementia and achieve the project's aim, the MinD project includes a data collection phase to gain insights from people with dementia and their caregivers, followed by the design development phase and an evaluation phase. The data collection phase comprised focus groups, interviews, and visual probes, which were conducted in three countries (The Netherlands, Germany and Spain). The study reported here is part of the data collection phase with people with dementia, and reports on the use of design probes (also called 'Visual Diaries' or 'Do Books') in the Netherlands.

Active participation of persons with dementia in the design process requires dedicated facilitation (van Rijn, van Hoof, & Stappers, 2010). In MinD, semi-structured interviews with people with dementia and caregivers and focus groups with caregivers have provided insights into the challenges people with dementia and their caregivers are facing regarding daily living, social engagement, decision making and the use of assistive devices (Niedderer et al, 2017). To gain additional insight into what persons with dementia consider as meaningful for their personal lives, what supports their decision making and empowerment, and what type of assistive devices they accept, we employed dedicated design probes. In this paper we report on the probe method that was developed for this aim and specifically on the results from experimenting with different types of probes as part of the data collection phase in the Netherlands during autumn 2016 and spring 2017.

The project aim and the development of the qualitative interviews and the design probes content were guided by our mindful design approach. Mindfulness values, drawing on a broad range of understandings from mindfulness and mindful design (Niedderer (2014), Ie, Nguyen & Langer (2014), Langer (2010)), include awareness and acceptance (e.g. of emotions and/or situations), reflection (e.g. on emotions and/or situations), reframing situations/perspectives, choice, empowerment (resulting from choice) and wellbeing. This approach was developed to offer different perspectives and choice. The interview and design probes content was targeted to ask specifically, directly or indirectly, for aspects of mindfulness in people's lives, including indicators for empowerment, decision making and wellbeing.

2 Design Probes

Probes have the ability to focus on the social, aesthetic and cultural environment of participants' lives as well as their needs, feelings, values and attitudes. By allowing participants to act on open tasks or questions and determine their own focus in their answers, design probes can provide deeper insights into people's experiences, concerns and values (compared to more researcher steered methods, such as interviews and focus groups) (Mattelmäki, 2006).

Probes are items that pose a number of evocative tasks to get inspirational responses from participants that usually are fragmentary. They have a playful nature and evoke a subjective approach. Probes, as they were originally developed by Gaver, Dune & Pacenti (1999), were not meant to gain comprehensive data on detailed research questions (Gaver, Boucher, Pennington, & Walker, 2004). They were developed as a design method to collect inspirational data from elderly in three countries they could not speak to directly (Gaver, Dunne, & Pacenti, 1999).

Since Gaver's contribution, probes as a method have been applied to various areas in HCI and design, also in the context of dementia: Van Rijn, van Hoof, and Stappers (2010) collaborated with relatives of people with dementia in later stages (instead of the persons with dementia themselves). Brown et al., and Brankaerts and Wallace et al. applied probes directly with people with dementia (Brankaert, 2016; Brown et al., 2014; Wallace et al., 2013a). Brown et al used a camera and two workbooks to have people take pictures of their daily life, describe them in the workbooks and rate the captured situations on an emotion scale. Their aim was to elicit deeper insights in the life of persons with dementia to aid the development of assistive technologies. The probes have a strong diary character but their design in relation to the types of responses is not discussed in detail in their article (Brown et al., 2014). Wallace et al on the other hand describe their very artistic and inspirational probes in more detail, but cannot reflect on a larger number of returned probes due to only one participating couple (Wallace et al., 2013a). In another project with elderly participants (presumably without dementia), Wallace and Lindley used probes as a design tool to think with, as a *"vehicles for conversation and relationship building when spending time with participants, rather than away from them"* (p. 78, Wallace & Lindley, 2014). Brankaert applied "playful probes" that included a game aspect with people with dementia to generate more interesting responses. However, in his research he does not reflect in detail on the impact of the probe designs on the responses generated (Brankaert, 2016).

The adaptability of the probes method implicates a need to describe and reflect upon the detailed use and appropriation of the method in the different contexts (Brown et al., 2014). With this paper, our aim is to explicitly report and reflect on the design of probes for persons with dementia, the process around distribution and recollection of the probes and the types of reactions and information our specific probes evoked. Particular focus is placed on the probes as a source of inspiration in relation to their openness, tangibility, and their content relating to the past, the current and the future.

3 Probe method for active participation of people with dementia

Our aim with the probes was to develop insight into the perspectives and life of people with dementia to enable a more empathic design approach (Koskinen, Mattelmäki, and Vaajakallio, 2014) and to identify needs, opportunities and ideas for mindful design interventions. We chose to apply probes due to their exploratory character and for more active user participation through self-documentation of persons with dementia. Our probes contain assignments that are ambiguous and in line with Gaver's original intentions, as well as concrete questions and even some assignments that have a strong resemblance to diary approaches in dementia research (e.g., Välimäki, Vehviläinen-Julkunen, & Pietila, 2007).

Our point of departure is that benefits such as mutual learning (Robertson & Simonsen, 2013) for all persons included in a design endeavour are essential to a participatory approach. With the probes, benefits for the participant were aimed at pleasure in doing the activities, enjoying personal reflection, the generation of something that they and their family can keep as a memory and, inherently, more active participation in the data collection phase of the design process.

The main advantage of probe assignments, offering an aspect of self-empowerment, is that they can be done in a self-directed manner, at the time the person with dementia wants to or feels best, in a way the person prefers to do it, as concise or elaborate as desired, by self-deciding what the focus of the answer should be, and even by deciding not to do it – which should be easier than being confronted with an interview situation which requires immediate focus and answers. As participants can do the probes in their own time and take their time to think about their contributions, we anticipated that their results would be preceded by reflection, leading to thought-through and comprehensive responses.

Moreover, design probes allow various ways of expression (e.g. writing, drawing, crafting and photographing). Qualitative research with persons with dementia poses certain challenges (Beuscher

& Grando, 2009) and probes potentially suit the abilities and preferences of people with dementia better than continuous concentration and eloquence by participants that is required in longer verbal communications such as interviews. To achieve these benefits, we put effort into making the probes aesthetically attractive. Also, we realized that we were taking precious time from the participants and therefore needed to be respectful by putting care and consideration into the probes. Inspired by Wallace & Lindley (2014), we moreover hoped that this effort, once perceived by the participants, would help us to build a relationship with the participants and we were trying to create the probes in a way that they could be perceived as a gift in return for the participants' efforts.

3.1 Probe design

There are two types of probes, inspiration oriented probes, like the probes by Gaver et al (1999), and information oriented probes (Boehner, Vertesi, Sengers, & Dourish, 2007). While our probes were a combination of both, in this paper we will focus on the role of probes as sources of inspiration and empathy to designers.

To serve the role as source of inspiration for design ideas, the design of the probes needed to consider comprehensiveness in relation to open-endedness as well as surprise potential for the specific target group they are developed for (Bredies, Buchmüller, & Joost, 2008).

Working with persons with dementia, the probe design paid special attention to the type of the topics covered, the technical presentation of the assignments, and the mood they conveyed: As the abilities of persons with dementia vary a great deal, variation was introduced in the technical presentation as well as the required mode of expression for the assignments. To facilitate independent completion of the assignments, questions and instructions were formulated in short sentences and clear wording. All assignments were designed to minimize learning, feel familiar, not take away control, and reassure the user. For writing activities, the writing space was always limited to prevent participants to feel pressure about how much they were expected to write (Wallace, McCarthy, Wright, & Olivier, 2013b). We also did not opt for traditional diary keeping, which involves much writing and might make participants more aware of their diminishing writing skills (Bartlett, 2012).

The focus of the probes was to gain more insight in the processes of change going on in participants' lives and the potential support of design herein. The probes therefore addressed the participants' awareness of change (decline and gradual loss of control) as well as their hopes and needs for preservation and enhancement. In line with the interviews, these overarching questions about change were addressed with respect to activities of daily life, leisure activities, social engagement and overall wellbeing as well as artefacts used.

The probes consisted for every participant of specially selected maps and envelopes that contained lose leafs with the assignments and additional material needed to do the assignments such as stickers, cards, mini photo albums, etc. The envelopes could either be given to the participants one by one or a few at a time or all at once. This was to be decided by the person with dementia in consultation with the caregiver.

We had writing activities varying from open questions that invited to write short episodes to simple list making. To generate visual content we had photographing assignments, for which an instant camera was used in combination with places in the probe sheets that pictures could be pasted to. The rationale was that pictures taken could be immediately put into order and place (affordance) to lower the risk that people would take pictures and later on not remember the rationale for it, as such problems have been reported from other photo projects with participants with Alzheimer's (Shell, 2014). Other activities were crafting related, such as using stickers to label or decorate paper objects. For this paper, we selected 10 of the 26 probe assignments to analyse. The selection was based on the inclusion of assignments from different topics (e.g. goals, living situation, wellbeing) and categories – open and less open assignments, assignments including more tangible items, as well as all the different activity types that were provided (see table 1).

Table 1 Overview of the probe assignments (colour codes: green = open, red = not so open, blue = about the past, orange = about the future).

Assignment	**Focus point**	**Activity type**	**Tools**	**Openness with respect to format**	**Openness with respect to content**	**Tangibility**	**Past, present, future**
1) What do you feel are the most important things that you've done in your life?	Goals	writing/list making	writing space	medium open, suggests list making	medium - things can be everything	No	past
2) What would you like to do or achieve in the future?	Goals	writing/list making	writing space	medium open, suggests list making	medium - things can be everything	No	future
3) Please use this object to tell about what home means to you personally. What makes your home your home and what makes your home beautiful? Feel free to draw on/inside the object, stick things onto it or change it in any way you see fit. (Wallace et al., 2013a ; Wallace et al., 2013b)	Living situation	handicraft/ writing	Abstract 3D pop-up paper house, pens, stickers	very open	open	yes, 3D	today
4) In which situations do you feel emotionally strong? And in which situations emotionally vulnerable?	Wellbeing	writing/list making	Writing Space	medium open, suggests list making	not so open - situations is more specific	No	today
5) In which situations do you feel physically strong? And in which situations physically weak?	Wellbeing	writing/list making	Writing Space	medium open, suggests list making	not so open - situations is more specific	No	today
6) If you could capture anything (for instance any moment, sound, song, smell, view, object, place...) and preserve it in this jar for you to relive what would you choose? (Wallace et al., 2013b)	Memory, preservation	handicraft, write	Paper with pictures of preservation jars and stickers to write on and paste on the jars	less open	open	yes, 2D	past
7) Please take 3 photographs of the things you tend to take with you when you go out of the house. Why do you like to take them?	Environment/access	take photos, write	Camera, photo album sheet, with assignments, spots to paste the polaroid pictures and writing space	partly open, requires pictures	not so open	Yes	today
8) Please tell us about some things you would like to be acknowledged for. (Wallace et al., 2013a)	Capabilities	Handicraft, write	paper with pictures of trophy cups and stickers to write titles on and paste on cups	less open	medium - things can be everything	yes, 2D	today
9) Which activities or daily tasks do you not like to delegate? Why?	ADL	writing/list making	Writing space	medium open, suggests list making	not so open - tasks is specific	No	today
10) Which ones are you happy for someone else to do for you? Why?	ADL	writing/list making	Writing space	medium open, suggests list making	not so open - tasks is specific	No	today

3.2 Examples of the different types of probe activities

In this section, we describe examples of probes of the different activity types.
Probes one and two comprise writing or list making activities about achievements and future plans. They ask “What do you feel are the most important things that you have done in your life? “ and “What would you like to do or achieve in the future?”. These questions are provided on two sides of an A3 sheet in combination with lineated writing space and an illustration (see Figure 1).

Wat zijn voor jouw gevoel de meest belangrijke dingen die je gedaan hebt in je leven?

[redacted]

Wat zou je willen doen of willen bereiken in je toekomst?

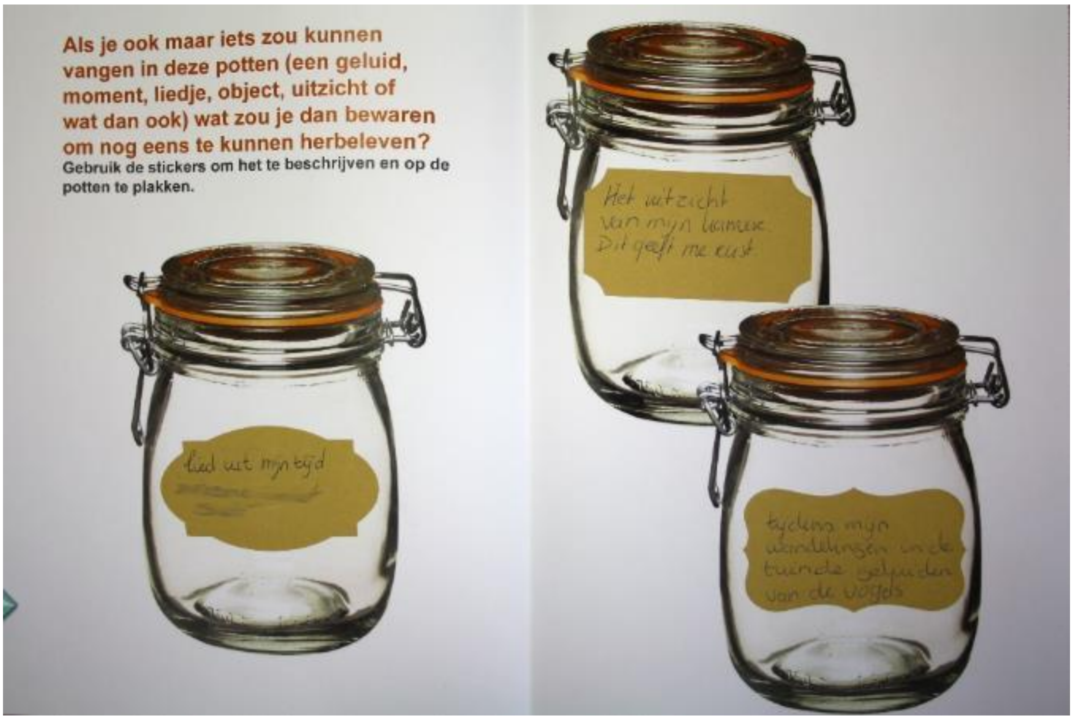
[redacted]

Figure 1 Assignments 1 and 2 about achievements and plans for the future, Dutch version. Handwritten entry blurred to protect privacy.

Probe three was an A3 folded sheet that that revealed a pop-up house when folded out. This assignment was based on an assignment by Wallace et al. (2013b), who used a wooden house object as probe with the instruction *“Please use this object to tell about what home means to you personally. What makes your home your home and what makes your home beautiful? Feel free to draw on/inside the object, stick things onto it or change it in any way you see fit”*. Our house came with a set of stickers, which could be used to modify the house. It is primarily a three-dimensional handicraft activity.

Figure 2   Assignment 3 about what "home" means, photographed during the interview with the participant. Dutch version, this one includes a handwritten description by the participant and use of many of the stickers.

Assignment six comprised pictures of preservation jars and labels that could be written and pasted onto the jars. This assignment was also based on an assignment of Wallace and McCarthy and their question *"If you could capture anything (for instance any moment, sound, song, smell, view, object, place...) and preserve it in this jar for you to relive what would you choose?"* (Wallace et al., 2013b). It is a handicraft assignment, similar to the pop-up house, albeit only two-dimensional.



Als je ook maar iets zou kunnen vangen in deze potten (een geluid, moment, liedje, object, uitzicht of wat dan ook) wat zou je dan bewaren om nog eens te kunnen herbeleven?
Gebruik de stickers om het te beschrijven en op de potten te plakken.

Het uitzicht
van mijn kamer.
Dit geeft me rust.

Lied uit mijn tijd
[redacted]

tijdens mijn
wandelingen in de
tuinde geluiden
van de vogels

Figure 3   Assignment 6 about preservation of memories, filled in by Dutch participant.

Assignment 7 included a photographing activity with an instant camera. The assignment was to take 3 photographs of the things participants tend to take with them when they go out of the house. This was accompanied by the request to explain in writing why they like to take them and an illustration.

Maak drie foto's van de dingen die je meeneemt als je de deur uit gaat.

Waarom neem je deze mee?

BOODSCHAPPENTAS-

OM INKOPEN IN TE DOEN

BEURS.

GELD VOOR BOODSCHAPPEN ETC

LIPPENSTIFT.

REGELMATIG LIPPEN STIFTEN

Figure 4 Assignment 7 with Photo task, filled in by Dutch participant. Pictures blurred to protect privacy.

3.3 Process around handing out and getting back

Five probe sets were handed out to participants in the Netherlands. The five participants were selected by case managers of a care centre in the Eastern part of the Netherlands. Applied selection criteria comprised recently diagnosed, living at home, and daily presence of care giver to support participation.

All probe sets would remain property of the participants after completion. However, with the consent of the participants, we took photos for analysis after a period of approximately four weeks. Participants were given an information and consent form saying that any information they would add to the probes map would exclusively be used for analysis and scientific presentations, and that they would stay the owners of the probes. This included "process consent", i.e. participants could decide to not to use them or not share them with the researchers in the end (Dewing, 2007).

Of the 5 handed out probe sets, 4 returned nearly completed in their entirety. One was abandoned after working on 7 out of 10 assignments analysed here. The probe sets were discussed with the participants during interviews of about an hour each. These interviews were introduced with an open request to provide some general feedback about the probes. After that, the interviewer and the participant reviewed the completed probes to discuss each assignment.

4 Method of Analysis

The probe sets were collected as photographs of the completed probes. These photographs were accompanied by transcripts of the interviews about the probes.

For the purposes of this paper, the probes and interviews were analysed with two foci: (1) to collect design ideas and identify areas for design intervention and (2) to find out which types of probes worked best for this purpose. In this paper, we report in detail on the second focus. This paper does not include details on the thematic analysis with regard to the actual content of the answers to the probes.

Our method of analysis for the second focus comprised of three steps, (1) coding of the probes, (2) coding of the accompanying interviews and (3) comparison between different probe types:

1. Each assignment in each probe set was coded to indicate if it was done, in which way it was filled in (e.g. in whole sentences or just words), how extensive it was executed, the level of personal details that were shared, and the attitude of the participant that could be elicited from the content the participant had generated (positive or negative view). Each of these aspects had several codes. In the case of personal details we coded whether participants had filled in personal information. We also coded whether participants described things in relation to interactions/relationships with others, one example being a participant who described as a future goal that she wants to keep a good relation with her son, daughter in law and the grandchildren. This was discerned from descriptions of the effects of dementia *on* interactions/relationships with others, e.g. someone describing being retired early due to sickness and therefore losing the contact with his colleagues. We also coded if emotions were expressed, for example when a participant described her happiness when, at some point, she was not any longer dependent on a professional caretaker for showering after the recovery from a fall accident. We coded that sensitive information was shared in case participants freely showed their own weaknesses, needs or regrets. An example is a participant who wrote that she would like to be acknowledged for what she means to her partner. We also specifically coded whether participants told anecdotes or shared motivations for their statements, deeds, choices etc.
2. The interviews were also coded but in a different way: The coding was focused on a direct evaluation of the diaries or the assignments. We coded to which assignment a statement referred or if it was a general statement about the whole probe set. Next, we discerned codes for emotional reactions, ratings of assignments as like, dislike, assignments being described as easy, difficult, inspiring, dull, or not applicable. Moreover, descriptions about how the assignments were done by the participants, were identified.
3. We compared the coding outcomes for tangible probes with intangible probe assignments, assignments that were open with respect to the content participants could fill in with less open probes as well as probe assignments that were more open with respect to the format participants could use to express themselves with assignments with less open formats. We also distinguished probes that were referring to the past (memories) with probes that were pointing to the future (plans).

5 Outcomes

5.1 Overall appreciation of probes and assignments

The interviews provided important information about how the design probes were completed and perceived: In four out of five cases the probes were completed in cooperation with the caregiver (mostly the spouse), because it was too difficult for participants to do it on their own, as was stated in the interviews. This shows that we might still have overestimated the capabilities of the participants. One person thought the work with the probes in general – unrelated to dementia - was difficult because some of the questions were hard to answer, in the sense that after a long lifetime there are many things to remember and to choose from to document. However, participants stated that the probes were filled in according to their own wishes and therefore we are confident that the story of the persons with dementia themselves was told.

Most of the assignments were filled in by making lists or noting down phrases (with the crafts oriented assignments we also asked for short, written descriptions).

Three of the five participants stated in the interviews that, for different reasons, they did not like the probes very much. The person who had abandoned the probes after 7 assignments said the crafty assignments were not for him and were described as “childish” by him. We learned that he had had a quarrel over the probes with his spouse, because he did not want to accept any help: He had formerly worked in a job that required precise writing and had a hard time accepting the gradual loss of his skills. He said he would have preferred to just talk about these topics. A second person, although completing all assignments, did not like assignments that required confidence in his life achievements and skills. The third person told us that she felt aggrieved every time she had to work on the probes and that this had put undue pressure on her. She had filled in the assignments together with her spouse. They both discussed every item in detail, and then the spouse would document the essence of what they had concluded. During the interview, the spouse very eloquently explained everything they had filled in. In spite of negative perceptions, participants reported that they experienced benefits from completing them.They stated that the probes had been a way for them to talk about topics they would not get to talk about in daily life. Of the two remaining participants, one said that the probes were “nice”, and the other was indifferent about them. They both had someone who helped them by writing for them. No one indicated the probes to be dull and two participants even found inspiration in the probes in the sense that they stimulated to discuss topics they would not normally get into in daily life.

Some assignments were indicated as not applicable to individual participants. The assignment asking people to photograph and describe items they take with them when they leave the house was named twice in this respect. However, when questioned, it did not seem to be the assignment as such but it was particular aspects of the assignment that were found to be not applicable. These included the illustrative pictures of things people might take with them, such as a lipstick (see Figure 4), which the male participants explicitly referred to as not applicable. This shows that even small details can spark discussion, if they are not designed completely gender neutral.

When looking at which probes were especially disliked, there was not one that stood out. However, looking at which probes participants liked, the pop-up house that addressed the topic home was rated positively by two participants. The probe that asked people to tell what they would like to be acknowledged for was not filled in by three participants. This is striking, given that all other probes were filled in by at least 4 out of 5 participants. For this probe, one person just filled in general values, expressed by sayings, but did not specifically link these to herself. Hence, only one participant had completed the assignment with things he/she wanted to be acknowledged for. In the interviews, participants stated that they were modest and therefore did not feel the assignment fitted them, or that they could not see much value for their current abilities and needs due to the sickness.

5.2 Openness of probe assignments

We were interested whether the responses to open probe assignments were more valuable for empathizing by designers (Mattelmäki, 2006) and also higher appreciated by the participants. For this aim, two types of openness of an assignment can be distinguished (see also Table 1):

1. Openness with respect to the format: an open format leaves several options to the participant to express him/herself. An example is the home assignments, where people could use the pop-up house and the page it was attached to, to draw, write, place stickers or use other ways to modify it. In comparison, the assignment were people could write things they would like to preserve on labels and place them on conservation jars more restrictive in its format, because it prescribed one way of expression.
2. Openness with respect to content describes how open the assignment is formulated. As an example, the home assignment is not only open with respect to format, but also with respect to content: it just asks to describe what home means to the participant, it does not ask for anything specific like an artefact or feeling. The same applies to the assignment with the preservation jars, hence, even though this assignment is not open with respect to the format it is very open with respect to the content. On the other hand, asking people to take

photographs of things they like to take with them when they leave the house, is requesting very specific content.

The assignments with an open *format* led less often to the sharing of personal or sensitive information in our study than those which are more prescriptive with respect to format. The sharing of personal information happened nearly twice as often in assignments with less open format than in assignments with open format, the same applies to the sharing of sensitive information.
When looking at assignments with respect to openness of the *content*, the most personal and sensitive information were shared in assignments that were not open with respect to content. In the other categories, there was no significant difference between open and less open assignments.

5.3 Tangibility

An additional value of tangibility of design tools, and of using the hands in creative and learning tasks, is often claimed (e.g. (Papert, 1980)). Our probe sets consisted of several assignments with more tangible materials, such as the ones with photographing or using stickers as well as “not so tangible” assignments that used writing on a sheet of paper as only form of expression.

Overall, there was not much difference in the total percentage of assignments filled in between the tangible and not so tangible ones (16 out of 20 and 26 out of 30 assignments). However, there was a difference in how the assignments were filled in: The tangible assignments were filled in more extensively than the less tangible ones.

When looking at the sharing of personal information, there was no noteworthy difference between tangible and not tangible assignments. However, more emotions were shared in not tangible assignments. This might be due to the emphasis on writing, which might be an easier way to express differentiated emotions – easier than by drawing for example.

With respect to attitude, there were more neutral attitudes in the tangible assignments and more negative attitudes expressed in the not tangible assignments. This might be because there was less opportunity for participants to bypass topics in the assignments including writing, which could have led to upsetting feelings, causing a negative attitude.

5.4 Recalling past, present or pointing towards the future?

Dementia can be described as slow transformation from healthy cognitive functioning (for our participants in the past) to a loss of cognitive functions, in particular memory (for our participants in the future) (American Psychiatric Association, 1994). Besides looking at the form of the assignments, we therefore considered the different types of content, which the probes address to see whether assignments that relate to the past (memories, reminiscence) are perceived differently to those about the present or the future.

Amongst the assignments analysed, there are two that recall the past (A1: important things done in your life; A6: capturing something for preservation), and one that points towards the future (A2: “What would you like to do or achieve in the future?”). All three assignments were completed by each of the five participants. However, the future oriented assignment was filled in less extensive than the other two, the to-do list was in all cases shorter, than the “done” list (3.4 VS 1.6 items on average). This could be interpreted on the one hand as a reluctance to make plans for the future because of the prospect of the illness, and was characterised by statements such as: ”not many expectations for the future anymore” or because people feel they have done all the important things in their life and are content, e.g. “I am 78 years old”. There were no significant differences in the sharing of personal information and the attitude was mostly neutral.

6 Discussion

Even though some participants disliked parts of the probes, the interviews revealed that they completed them because of the perceived relevance and importance of the research. One could argue therefore that participants felt empowered by the probes because they felt they were helping with the research. Furthermore, indirectly, we learned a lot about living with dementia from the people who did not fully complete the diaries, just because there was more discussion and more trying to explain and reflection by them in the interviews.

Our participants were people in the early stages of dementia. Nevertheless, most participants had dementia related difficulties working on the probes by themselves, especially the writing posed problems. This points towards using more tangible assignments using other forms of expression than writing, which however led to less sharing of personal details. Moreover, tangible probes without writing require people to remember what they meant to say at the time they made the probes, which also can be an issue.

For several participants, the probes sparked deep conversations and discussions between spouses, which was not anticipated by us. Future probes could consider this in the design to focus more on both partners and their potentially differing perspectives (e.g. the perception of safety when a person with dementia is out and about on his/her own) and the relationship between the two.

The openness of assignments clearly influenced their completion and the resulting value for empathizing and inspiration for designers. More defined assignments led to more sharing of personal details, which provides important insights and therefore is most valuable for designers. This seems to indicate that people reveal this personal part of themselves only if explicitly asked to do so. In contrast, if assignments are open, people chose *not* to share personal and sensitive information. This finding is contrary to other researchers' work, who stated that the less instructive the probe tasks were, the more *reflective* and suitable the answers were for deducing inspirations for concrete design solutions (Bredies et al., 2008). The difference here might be in what is considered valuable information for design or what kind of topics the prescriptive probes address. We sought to learn about people's deeper needs, dreams and motivations, which is inspiring information that however does not directly lead to design ideas.

Assignments with open format or content were however more often filled in than closed assignments. This appears to indicate that more specific questions, which ask for specific information and a specific way to provide this information, are more polarizing and led more often to people rejecting them. The open format also seems to lead to more extensive answers, while for assignments with open content we cannot claim the same. Both open format and content also led more often to a positive attitude. Assignments with more prescriptive content were generally met with a more negative attitude, possibly because people could not circumvent topics that they perceived as difficult.

The more tangible assignments were filled in more extensively than "less tangible" ones and the attitude was more often neutral while the attitude with the less tangible assignments was more often negative. However, in order to generate introspective and reflective information (e.g. emotions) from participants, traditional writing might work better than the crafty assignments. Describing an emotion by drawing or photographing is experienced as more difficult. Therefore, it might be useful to request a written description of any tangible material made in the probes. This, however, undermines the intention to offer various ways of expression to participants with different preferences. Another option is to complement tangible probes with interviews, which however requires remembering what the probes intended to express at the time made. As we analysed only a limited number of assignments, more research about the connections between openness, tangibility and the value of the probes for inspiration and empathizing is needed.

From a first analysis of the content of the probes, it appears that our participants prefer to address memories and achievements from the past over making plans for the future. Provided it is considered important for mental health to have plans for the future, this is an interesting area for further investigation in the content analysis of the diaries in the MinD project as well as to explore the potential that probe design can have in this. Detailed analysis of the *content* of the probes will be presented elsewhere. See table 2 for an overview of the most remarkable results.

Table 2 Overview of how probes were filled in in relation to their openness, tangibility and relation to the past or the future.

	Sharing of personal details (incl. emotions)	Filled in extensively	Attitude of content filled in ☹ = negative ☺ = positive
tangible		√	
"not so tangible", mostly writing	√		☹
open content			☺
prescriptive content	√		☹
open format		√	☺
prescriptive format	√		
about past		√	
about future			

7 Conclusion

Most probes were completed in cooperation with the caregiver, because it was too difficult for participants to do this on their own. Making the probes and assignment formulations even simpler, however, may not be a solution, as the problem was not in understanding the assignments, but in developing adequate responses. Importantly, the interviews revealed that the process of completing the probes jointly led to conversations regarding topics they would not normally get into in daily life, which was perceived as enriching and inspirational. Cooperative work on probes to stimulate this effect could be a valuable goal for the future. However, to guarantee the perspective of the individual with dementia is taken into account, separate interviews about the probes with the person with dementia and the partner might be necessary.

Interestingly, we found that more open assignments do not equal more inspirational reactions by the participants. The most open assignments generally provided less personal information and less sharing of emotions and needs. To gain such kind of information, the assignments with prescriptive content and writing as technique worked best, most likely as there was less opportunity for participants to bypass upsetting topics. However, while classic writing assignments led to more sharing of emotions and sensitive information, more tangible assignments led to more extensive replies and are generally appreciated by the participants. This means that in order to receive inspirational, personal and sensitive data, prescriptive assignments and the writing technique need to be used, paired with more open, tangible assignments for more engagement. Further research is needed to understand how we can encourage people with dementia to consider their future, and what they can do (rather than what they can't), since the importance of doing things, including new things and being of help to others has been a strong thread throughout responses to interviews conducted as part of the MinD project.[*]

In summary, we can say about designing the probes that:

- Prescriptive format and content, employing writing is most useful for eliciting personal detail
- Tangible, open format assignments, and assignments about the past are most successful in eliciting more detailed responses
- Open content assignments and assignments about the future are most challenging in eliciting responses, and future work needs to be done to address this

While most assignments were completed, some of the output needed explanation by the participants to understand the meaning of and reasons for what they had made or written. Therefore, we recommend to always pair probes with a follow-up interview to get insight into

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[*] publication forthcoming

underlying needs and values, in particular in those cases where more in-depth inspiration is intended to be gained from probes.

With regard to providing a pleasurable experience to participants, even though the probe assignments were not greatly liked by all our participants, the assignments were completed in most cases. The reason for not liking them was that participants felt challenged in completing them. Moreover, the reflective character of some assignments was at times perceived as confronting. The main reason for completing them was that actively participating in the research gave the participants a sense of contribution, which is in line with the findings of the MinD project1 that it is important for people with dementia to still be able to help users and be useful. The dichotomy between challenge for and contribution by participants will be an issue for future research.

Finally, the study indicated that the more active participation in the research was beneficial in terms of both the ability to contribute and help as well as in facilitating enriching interaction between people with dementia and caregivers.

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