



Proceedings of the 6th Conference on Design4Health

Editors: Kirsty Christer, Claire Craig & Paul Chamberlain

Volume III

Proceedings of the 6th International Conference on Design4Health

Amsterdam, Netherlands, 1st - 3rd July 2020

Editors: Kirsty Christer, Claire Craig and Paul Chamberlain

ISBN: 978-1-8381117-0-0

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Volume 3



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Foreword

When the Design4Health Conference organising committee collectively chose ‘The Future is Now!’ as the theme for the 2020 conference we had not anticipated a future shaped by the emergence and ensuing devastation of COVID-19.

This would have been the sixth Design4Health Conference. In January, plans were well underway with Sabine Wildevuur and colleagues in Amsterdam, hosts of the event. With over 300 submissions from 30 countries, this would have been our largest conference yet. However, a few weeks after a successful review day we began to hear from friends and colleagues affected by the COVID virus. Our priority has always been the health and wellbeing of the wider Design4health community and we made the difficult decision to cancel.

In recognition of the time and effort that had been put into crafting submissions, we invited those with accepted abstracts to submit full papers, which would be published in online proceedings. The result is found here - 95 papers across 4 volumes.

The papers are an exceptional testament to the Design4Health community. Whilst many do not reference COVID-19 directly, the research themes they interrogate and their exploration of the role of design in creating solutions to societal health challenges are exceptionally relevant.

As we move forwards, we recognise the importance of continuing to create opportunities where researchers are able to transcend their own disciplines, to share research and create new intellectual spaces and paradigms. We feel confident, that in these extraordinary and unprecedented times the Design4Health community is well placed to make a difference.

On behalf of Lab4Living and the Conference organising Committee, welcome to these proceedings.

Claire Craig, Kirsty Christer & Paul Chamberlain (Lab4Living)

Reflections from Sabine Wildevuur – host of Design4Health 2020

In September 2018 the decision was taken that the sixth Design4Health Conference 2020 was going to be hosted in Amsterdam, the Netherlands. How happy we were as organizing committee, and started immediately to develop the conference planning in close collaboration with the initiators of D4H - Paul Chamberlain, Claire Craig, and Kirsty Christer - from Lab4Living, Sheffield Hallam University. A team of knowledgeable and enthusiastic people with very different academic backgrounds but all devoted to design for health, was assembled for the Academic Programme Committee and Review Committee.

The first milestone for the organisers was the deadline for submissions; the amount of submissions exceeded our wildest expectations. The UK-NL review committee joined forces in the review process. And on a special review day on 23rd of January 2020, in the historic anatomic theatre of Waag in Amsterdam, 20 members of the review committee divided into the teams red, white, blue (indeed, the Dutch flag!), and orange took the decisions on the 347 submissions. There was something in the air that day; a great vibe, a strong bonding feeling, and everyone was looking forward to the first of July 2020, when the official opening of D4H2020 would have taken place, and the D4H community would be (re)united in Amsterdam.

The rest is history. We would have loved to welcome you in beautiful Amsterdam. But in April 2020 we had to take the tough decision not to proceed with the conference this year. Keep on the good work on design for health, and remember: The future is now!

Special thanks to the members of the organising committee:

DesignLab University Twente (Anke de Koning), *Amsterdam University of Applied Sciences* (Somaya Ben Allouch and Nathalie Brommersma), *Lab4Living, Sheffield Hallam University* (Paul Chamberlain, Claire Craig, and Kirsty Christer), and *Waag|society&technology* (Paulien Melis). This committee collaborated with 4TU (*University Twente (UT)*, *Delft University of Technology (TU Delft)*, *Technical University Eindhoven (TU/e)*, *Wageningen University & Research (WUR)*).

Academic Programme and Review Committee

- Armagan Albayrak (TU Delft)
- Somaya Ben Allouch (*HvA*)
- Remi Bec (*Lab4Living*)
- Marina Bos-deVos (TU Delft)
- Daniel Bossen (*HvA*)
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- Peter Weijs (*HvA, VUMC-AMC*)
- Gemma Wheeler (*Lab4Living*)
- Sabine Wildevuur (*UT*)

All abstracts included in these proceedings were double blind refereed by the review panel, and expanded to full papers taking into account the referees' recommendations. The review panel further refereed full papers.

Particular thanks to Dr. Alison Mayne and Rebekah Di Maulo for their support in the final formatting of the work. Thanks to Graham Nesbitt for the D4H visual ident and cover design.

Themes of the conference

The overall theme of Design4Health 2020 was designing in the context of future health and healthcare with an aptly named title: The future is now!

The conference sought papers which considered:

- What will health look like in the future?
- Where will health and healthcare be enacted?
- How might our lives be configured?
- What will the future designer look like? What skills will they need?
- How might current research trends (e.g. personalisation, interdisciplinarity, circular design) translate into this future for design and health?

The papers contained in these proceedings were submitted in response to the call and they interrogate a number of areas. In addition to exploring methods, ethics and broader questions about ways we evaluate the impact of design you will see research that relates to:

- Designing citizen science and community-driven care
- Designing for urban vitality
- Care model design
- Designing personalised eHealth technology
- Care model design
- Health data design/digital self
- Sustainable health and wellbeing
- Wildcard Chindōgu. Designing dystopian futures
- Meta themes (methods, ethics, evaluation that cross linked across other themes)

Thank you to everyone who submitted papers and to your contribution to the broader discourse that is Design4Health. This is an exceptionally rich and comprehensive body of work and we very much hope that you enjoy reading the papers as much as we have enjoyed reviewing them.

Citations for the Proceedings

Christer Kirsty, Craig Claire and Chamberlain Paul, eds. 2020. *Proceedings of the 6th European Conference on Design4Health*, 1st-3rd July 2020 Amsterdam:

Sheffield Hallam University.

ISBN: 978-1-8381117-0-0

Citation for Paper in Proceedings (Chicago author-date): 11

Author Surname, First Initial. Second Initial. (Year). Conference paper title. In Christer K. Craig C. and Chamberlain P., eds. 2020. *Proceedings of the 6th European Conference on Design4Health*, 1st-3rd July 2020. Amsterdam:

978-1-8381117-0-0

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Collaboration in open innovation health initiatives: Working towards a sustainable healthcare system

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ABSTRACT *Open innovation initiatives in the health sector are considered spaces that can fuel systemic change. However, it is not clear yet how these initiatives contribute to the transition to a sustainable healthcare system. This research explores how actors in open innovation health initiatives contribute to a sustainable transition in healthcare by implementing the Quadruple Aim. The Quadruple Aim is a practical framework that helps organizations to innovate in healthcare. It consists of four aims: improving the health of the population, improving the work-life of care providers, enhancing patients' experience and reducing health cost. Sixteen interviews with professionals from different backgrounds working in health initiatives in the Netherlands, highlight that 1) improving the health of the population is the main aim, 2) not all initiatives are considering all four aims, 3) solutions to one aim can cause new problems, and 4) the Quadruple Aim is not assessed in a structured way. This indicates that the implementation of the Quadruple Aim is highly challenging. A suggestion for future research is to focus on how design can facilitate the implementation of the Quadruple Aim in open innovation health initiatives.*

Keywords: Quadruple Aim; open innovation; sustainable healthcare system; collaboration

Introduction

Open innovation is seen as a promising direction for fuelling systemic change in the health sector (von Wirth et al. 2019). With different open innovation initiatives emerging rapidly, little is known about how these initiatives support collaborating actors to reconfigure the health ecosystems they are part of.

Emerging diseases like COVID-19 and the increasing number of chronic diseases around the world are putting considerable pressure on the healthcare system. The cost of care is continuously increasing, making healthcare systems of many countries unsustainable (Porter and Lee 2013). Thus, many actors are currently working on transitioning towards a sustainable healthcare system.

One approach that seems promising for this transition is the 'Quadruple Aim'; it is a clear and practical framework that can be adopted by organizations to innovate in healthcare. It consists of four aims: improving the health of the population, improving the work-life of care providers, enhancing patients' experience and reducing health cost (Pannunzio, Kleinsmann, and Snelders 2019; DiMatteo et al. 1993).

These four aims challenge how the healthcare system currently works. The implementation of the Quadruple Aim is not exclusively assigned to care providers, but also requires the involvement of other actors, such as government officials, companies, designers, and patients. In this study, we explore how the Quadruple Aim currently helps actors with different backgrounds to innovate together in open innovation initiatives. The research question is: How do actors in open innovation initiatives contribute to a transition into a sustainable healthcare system by considering the Quadruple Aim?

A qualitative interview study among open innovation initiatives in the Netherlands was conducted to understand how actors implement the Quadruple Aim and which challenges they face. The following section presents a literature review on the Quadruple Aim and open innovation initiatives in healthcare. Then, four empirical observations regarding the implementation of the Quadruple Aim in open innovation initiatives are presented. The paper concludes with a suggestion for future research on how a design approach could contribute to implementing the Quadruple Aim in a more structured way.

Theoretical Background

The Quadruple Aim

Emerging diseases like the current pandemic COVID-19 and the increasing number of chronic diseases around the world are putting considerable pressure on the healthcare system, demanding more services, with higher quality and more efficiency. For example, due to COVID-19, hospitals in Spain have been forced to implement telehealth monitoring in a timeframe of two weeks (Bau 2020), resulting in a substantial economic impact for the hospitals. This example demonstrates how the cost of care is continually changing making the healthcare system unsustainable (Porter and Lee 2013).

In healthcare, an approach that can help transition towards a sustainable healthcare system has been defined, called the Quadruple Aim (Bodenheimer and Sinsky 2014; Spinelli 2013). This practical framework consists of four aims and is an improved version of the Institute for Healthcare Improvement's Triple Aim. The first aim, 'improving the health of the population' focuses on patients (and potential future patients). It is currently the core aim of care providers (Pannunzio, Kleinsmann, and Snelders 2019). The second aim 'improving the work-life of care providers', is currently underemphasized (Brik 2019), but should be considered equally important as, for instance, low levels of job satisfaction among physicians reduce work performance (DiMatteo et al. 1993). The third aim, enhancing patients' experience, could also improve patient satisfaction and health outcomes (Rimer et al. 2004). Finally, the aim 'reducing health costs' relates to all different actors of the health system, including patients, care providers, government, among others. Existing cases, like the one of Johnson & Johnson who saved millions of dollars on care costs by investing in wellness (e.g. helping employees stop smoking), demonstrates that preventive measures can help reduce the cost of care by having healthy people demanding less care (Porter and Kramer 2011).

These four aims are interrelated. For instance, attempts to simultaneously improve the health of the population, patients' experience and reducing health cost may have a negative effect on the work-life of care providers as it further complicates their already stressful work-life (Bodenheimer and Sinsky 2014). Besides, these four aims challenge the way healthcare systems currently work. Implementing the four aims demands great inter-disciplinary efforts as existing governance structures, roles and relations between actors, and their current ways of operating need to be redesigned. Hence, implementing the Quadruple Aim is not a challenge exclusively assigned to care providers, but involves multiple disciplines and organizations.

Open innovation in healthcare

Multiple disciplines and organizations can successfully innovate together through open innovation (Bergema et al. 2011), where actors with different backgrounds contribute with their unique perspective to solve a complex challenge. With this kind of collaboration, new ways forward can be discovered, and health practice can be strengthened. Existing research has also shown that open innovation provides a space for collaboration that can fuel systemic change (von Wirth et al. 2019).

The presence of different actors from society, government, industry, and academia, and alliances between organizations contribute to foster knowledge to improve health, to provide more effective health services and strengthen the healthcare system (Leydesdorff 2012; Stone and Lane 2012). In open innovation, actors are dependent on each other's outcomes, and they need each other's knowledge to fulfil their responsibilities (Bergema et al. 2011).

In recent years, the term 'open innovation' has been popularized, and with this, multiple open innovation initiatives have emerged globally. For this research, we focused on open innovation initiatives in the health sector in the Netherlands.

Method

The objective of this study was to explore how actors in open innovation initiatives approach the Quadruple Aim and find out which challenges they face. We wanted to gain a better understanding of their roles within the initiatives, their activities and how these allowed them to address the Quadruple Aim. A qualitative study with semi-structured interviews fitted well with this purpose (Patton, 2005).

We selected three different types of open innovation initiatives for this study: Innovation labs, Collaborative networks and Biotech spaces. Innovation labs focus on tackling complex societal challenges with an innovative approach and outcome (Brankaert and den Ouden 2017). Collaborative networks consist of organizations and actors that collaborate to achieve goals that they would not be able to achieve individually (Camarinha-Matos and Afsarmanesh 2005). Finally, Biotech spaces have the goal to provide space and equipment to start-ups or to other initiatives to accelerate their development process (Ledford 2015). A total of eight initiatives were sampled, by identifying the purpose and the type of initiative through desk research, filtering out descriptions such as ‘innovation network’, ‘collective design and production’, and ‘biomedical co-work space’.

Sixteen interviews were conducted; fourteen semi-structured interviews and two informal interviews. The interviews were designed to explore the purpose of the initiative and the role of the actors. Actors were asked to share examples of how they work on a project and the challenges they face, followed-up by questions regarding the four aims: improving the health of the population, improving the work-life of care providers, enhancing patients’ experience, and reducing health costs. For each initiative, one to three members with different roles and professional backgrounds were interviewed, to include different perspectives (Ravitch and Carl 2015). In addition, two people from an overarching subsidy program were interviewed (see Table 1). The interviews lasted between 40 to 90 minutes and were conducted face-to-face (7 interviews), through video call (6 interviews), or via phone call (3 interviews). All interviews were audio-recorded and transcribed verbatim except for the two informal conversations. The information was complemented by consulting the webpage for each initiative, reading papers shared by interviewees, and reviewing online publications.

Table 1. List of interviewees

Type of initiative	Role	Professional Background
<i>Innovation lab</i>		
I1	Program coordinator*	Industrial design engineering
	PhD researcher	Design for interaction
	PhD researcher	Industrial design
I2	Director*	Medicine
	Scientific co-director	Civil engineering

I3	Master student	Industrial design
I4	Designer & concept developer	Audiovisual and theatre
	Program developer	Psychology
<i>Biotech space</i>		
B1	Chief business officer	Biochemistry
B2	Director	Industrial Engineering
<i>Collaborative network</i>		
C1	Innovation manager	Business Information
	Innovation manager	Business innovation & entrepreneurship
C2	PhD researcher	Medicine
	Medical specialist	Medicine
<i>Subsidy programme</i>		
S1	Financial advisor	Social geography
	Project manager	Human geography
* Informal conversations		

The data analysis focused on how the Quadruple Aim is considered in each initiative. Hence, it was used as an analytical lens to explore what the initiatives deliver and miss regarding the four aims. For each interview, quotes related to each of the four aims were selected. The quotes per aim were then sub-clustered according to the type of activity or behaviour described. For example, for the aims 'improving the work-life of care providers' and 'enhancing patients' experience', sub-clusters such as 'health providers looking for data' and 'monitoring health through tools' were found respectively. Then, relationships between sub-clusters were explored. For instance, it was found that some innovations for the second and third aim were related to the roles of care providers (e.g. one relationship was labelled 'some innovations are creating new roles'). Based on the relations discovered, four observations of how open innovation initiatives address the Quadruple Aim were identified.

Findings

Our data highlight how the Quadruple Aim (improving the health of the population, improving the work-life of care providers, enhancing patients' experience, and reducing health costs) is used by actors of open innovation initiatives to make the transition towards a sustainable healthcare system. Four observations regarding the implementation of the Quadruple Aim are presented below.

1) Improving the health of the population is the main aim

The data showed that improving the health of the population is a priority for the initiatives in this study. All the initiatives develop innovations to help or support patients, and to improve the lives of people. For instance, the scientific co-director of an Innovation lab mentioned:

Last week we started a new project focusing on how to support young adults with autism to empower them to have more control over their lives and to explore how technology could eventually support them, together with the caregivers and the case managers.

Some initiatives measure the impact of their innovation with regard to this core aim. The chief business officer of a Biotech space considered counting the number of patients that are being treated a success factor. While all initiatives focused on improving the health of the population, the other three aims are tackled differently in each initiative.

2) Not all initiatives are considering all four aims

What stood out was that none of the initiatives currently tackles all four aims present in the Quadruple Aim. Most initiatives do not even consider them all. For instance, some actors focus their initiatives on patients but do not consider improving the experience of health providers a priority.

The overall aim is to find a solution for medical needs. Whether the solutions make the surgeons' life easier is not necessary. But of course, we try not to make things more complicated.

(Chief Business Officer, Biotech space)

Another case relates to the reduction of care cost. Some actors consider reducing the cost of care impossible, while for others, reducing the cost of care is a priority. For instance, a PhD researcher in a collaborative network expressed that some innovations are expensive; therefore, reducing the cost of care is not possible. In Biotech spaces, the approach was completely different. One actor mentioned that cost reduction is a requirement to start a new project. Their aim is not only to experiment but also to commercialize because it is a public-private organization.

3) Solutions to one aim can cause new problems

Solutions to successfully implement a particular aim often raised challenges for the implementation of other aims. For example, a few members of Innovation labs mentioned they focus on preventive innovation, which could allow them to work towards a reduction of care costs.

So, prevention is a very hard challenge because you need to do a lot of things that you don't normally do in the health domain. But it is also one of the models where you have the biggest chances for cost reduction.

(PhD, Innovation Lab)

Not only a preventive approach but also e-health was mentioned as a promising approach to reduce the cost of care. However, these approaches create new roles that did not exist before. With these new roles, new challenges emerge. For instance, an emerging need is to define who will be looking at data and how the new approach will affect the work-life of care providers.

4) The Quadruple Aim is not assessed in a structured way

Finally, the data also indicates that most initiatives do not assess the Quadruple Aim in a structured way, because they either lack a sense of awareness on the topic or because they do not consider it as a priority. In some cases, some aims are being tackled indirectly, as a side-effect.

That [improving the work-life of care providers], is sometimes a side effect. [...] I think it has to do with the fact that if we are involved in a project with healthcare professionals, I transfer some knowledge because I facilitate a lot of workshops [...]. So, I am introducing design thinking methods, and they can use it in their daily work. [...] But I am not there in the hospital to see if they have used some of these methods or the insights we have come across in the meetings. I think there is an impact, but I can't quantify it.

(Innovation manager, Collaborative network)

This example demonstrates that actors might be tackling more aims, but do not plan or intend this. It might be a consequence of another action realized. Hence, they do not always verify the impact of the aims because they might be tackled indirectly or unintentionally. Besides, in some cases, the impact does not come immediately, so the impact is difficult to measure.

Conclusion

This study presents four observations related to how the Quadruple Aim is used by innovation initiatives to move to a more sustainable health system: 1) Improving the health of the population is the main aim, 2) Not all initiatives are considering all four aims, 3) Solutions to one aim can cause new problems, and 4) The Quadruple Aim is not assessed in a structured way. These four observations show that although the Quadruple Aim is a promising approach to transition towards a sustainable future, the implementation is still highly challenging.

Future research on how design can facilitate the implementation of the Quadruple Aim is recommended. We suggest making use of design methods and tools that can facilitate the process in practice. For instance, by supporting actors in considering and implementing all four aims in a structured way and detecting the possible impact of each aim within their initiative. Besides, tools could also focus on measuring or more structurally keeping track of the impact of implementing the Quadruple Aim.

Acknowledgements

This study was made possible by the Design Management Network. We also thank the interviewees for participating in this study; both their time and their enthusiasm are much appreciated.

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Fashion, Organic Tanned Sheepskin, Biodiversity and Our Soil Health: Investigating the ecology of organic sheepskin, biodiversity and Fashion's relationship to living matter in our soil.

Sarah Morehead

Northumbria University, UK

[ABSTRACT only] This practice research approaches Sustainable Health and Wellbeing through a design lens from a holistic perspective. We are all intrinsically linked to our environments and ultimately the health of our land. Through farming practices and natural erosion our soils are rapidly losing their biodiversity and the capacity to grow crops for food and fibres, affecting our health and wellbeing. I explore this through making a replica Irvin WW2 jacket in organic sheepskin. Making the heritage garment involved investigating the myriad of natural processes that allowed the materials for the jacket to be 'grown' and also able to be composted back into the soil. These processes included creating a pasture, raising sheep, curing and tanning sheepskin and examining all components such as organic cotton thread and brass hardware. I have worked with specialists exploring possible ecological narratives for materials where agroecology practices could be Cradle to Cradle (Braungart and McDonough 2002).

Internationally, there is concern about the 24 billion tonnes of topsoil the planet is losing each year (Global Agriculture, 2019). Our soils are becoming increasingly degraded due to intensive farming practices and natural processes. As the layer of fertile topsoil thins, it gets increasingly difficult to grow crops. A productive soil microbiome enables biogeochemical cycling of both macronutrients and micronutrients essential for the growth of plants and animal life. Re invigorating our soils is one of the pressing concerns of our age, not just for crops, but also for their ability to help in the management of water and carbon sequestration.

In designing for the planet's health, as symbiotic creatures of the living earth, we are designing for our own health and well-being. This work starts to explore the complexity of how we work with the land to gain materials for design and making and how we manage end of product life that gives back to the soil.

Keywords: fashion agroecology, soil microbiome, designing with agriculture, carbon sequestration, cradle to cradle



Figure 1: Organic Tanned Sheepskin Replica WW2 Irvin Flying Jacket



Figure 2: The ecological circle of life; soil biome giving life to pasture, sheep, growing wool, meat and sheepskin and the making of a jacket. The garment decomposing giving new life to the soil biome.

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The Mismatch: A Model for Sustainable Medical Device Design in South Africa

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ABSTRACT *The medical device industry is one of the fastest-growing sectors of the global economy, however, it is dominated by high-income countries (HICs) such as The United States, Germany, Japan and China. Approximately 80% of medical devices in low-to-middle income countries (LMICs) are donated or imported (World Health Organisation 2011). Due to a mismatch between the design of these devices and the context in which they are used, approximately 40% are out of service, 70–90% never function as intended, and up to 98% are broken within five years (Presterio 2010; Malkin and von Oldenburg Beer 2013; Chan 2010). To overcome this mismatch, the World Health Organisation identifies local production as a possible way to increase the sustainability of medical devices in LMICs. South Africa's (SA) medical device development (MDD) industry is underdeveloped and approximately 90-95% of medical devices in SA hospitals are imported or donated (SAMED n.d., Mitchell 2017). Although MDD process models have been defined, none describe the SA MDD regulatory landscape and most describe the MDD process from an engineering or business perspective rather than a design point of view. The lack of appropriate, sustainable medical devices, particularly in LMICs suggests the need for a shift towards a more human-centred, design-orientated medical device industry, which promotes local manufacture. This paper explores a study that aimed to define a design process model for paediatric Medical Device Design (MDDes) in the South African context to better enable local industrial designers to participate in the field. This paper presents key case study findings in comparison to existing MDD process literature and introduces an MDDes process model more suited to arriving at sustainable medical device outcomes in the South African context.*

Keywords: Sustainability, Medical Device Design, Process Model, South Africa

Introduction

To be sustainable, a medical device (MD) needs to be appropriate for the context or setting in which it is intended and meet the needs of the people using and being treated by it. Despite the rapid development of sophisticated medical technologies globally, issues of centralised manufacture and the lack of human-centred design (HCD) methodologies in medical device development (MDD) processes, means that the majority of the world's population lack access to MDs that are appropriate for their specific epidemiological needs (Cheng 2003; World Health Organisation 2010; World Health Organisation 2016; Dyro 2004).

One of the barriers to the optimal use of imported/donated MDs is the 'mismatch' between the design of the device and the context in which it is used (World Health Organisation 2010). The global market is dominated by high-income countries (HICs) (World Health Organisation 2012), with up to 80% of MDs in low-to-middle income countries (LMICs) donated or imported (World Health Organisation 2011). In many cases, donations bypass local procurement systems of the recipient country hence local requirements, capabilities, and available levels of technical expertise for maintenance are not considered (World Health Organisation 2011, 8). As a result, approximately 40% of MDs in LMICs are out of service, 70–90% of all donations never function as intended (Chan 2010) and up to 98% of donated medical equipment in developing countries is broken within five years (Prestero 2010). The World Health Organisation (WHO) identified local production and decentralised manufacture as a way to increase access to appropriate MDs in LMICs (2016, 1).

When designed appropriately, hospital environments can reduce stress and promote healing (McAndrews 2005, 7; Kopec 2012). Furthermore, design in healthcare can enhance operational efficiency while reducing the chance of human error, improving the work experience for staff (Kopec 2012). Devices that fail to meet user needs or misunderstand the context, potentially contribute to use error and harmful incidents (Martin, et al. 2012). However, the complexities of involving users throughout the MDD process, coupled with business constraints and fast turnaround demands, often leads to manufacturers making the mistake of prioritising the perspectives of medical experts and those making purchasing decisions, rather than the perspectives of end-users (Money, et al. 2011). The lack of appropriate, sustainable MDs, particularly in LMICs suggests the need for a shift towards a more human-centred, design-orientated MD industry, which promotes local manufacture.

Approximately 90-95% of MDs in South African hospitals are imported or donated (SAMED n.d.; Mitchell 2017). The limited amount of local medical device design in South Africa may be attributed to the lack of formal MDD training at any South African design institution, and until 2017, no local regulatory framework. Although underdeveloped (SAMED n.d.), in a 2014 study, South Africa showed great capacity to support strong local production of MDs (World Health Organisation 2016). Coupled with the introduction of the new regulatory framework, there is an opportunity for increased local development of MDs specifically geared towards local needs.

This paper provides an overview of a study (Bullock 2019) that aimed to define a design process model for paediatric medical device design (MDDes) to better prepare local industrial designers for sustainable MD outcomes for the South African context. The paper begins by identifying the key

findings from the literature review and multiple case study, and thereafter, introduces and describes the MDDes process model.

Methodology

The study consisted of three phases, *identify*, *analyse* and *model* (Figure 1), inspired by Yin's (2003) multiple case study model. **Phase 1** involved an in-depth literature review, problem identification, case selection and case study planning. **Phase 2** aimed to investigate, analyse and report on three MDD processes using the *multiple case study* method. Our study added a phase to Yin's model in that **Phase 3** went beyond a cross-case comparison and used abductive thinking (Flick, von Kardorff and Stienke 2004) to synthesise the case study data and the existing MDD literature into the design of a final MDDes process model. This section briefly describes the activities and tools used in each phase

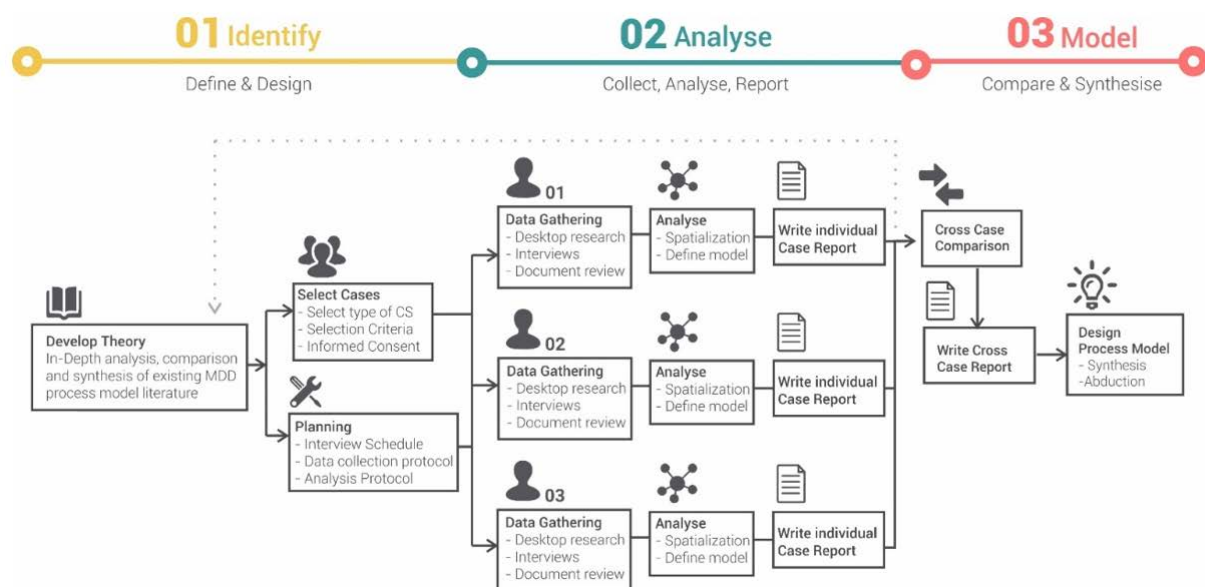


Figure 1: Research design (Bullock 2019)

Phase 1 - Identify

An in-depth literature review on existing MDD process models was conducted. Upon reviewing the literature, three key themes were identified. First, although numerous explanations of the MDD process exist, none identify or discuss South African specific data regarding regulatory bodies, authorities or procedures, with almost all literature focused on the EU and USA regulatory systems. Secondly, almost all of the models reviewed were written by authors in the fields of engineering and published in engineering or biomedical journals. Finally, it was found that no existing models or literary sources take into account or specifically discuss *paediatric* MDs. These three observations highlighted an opportunity and directly informed the research aim of this study to: 'define a design process model for paediatric medical device design in the South African context' (Bullock 2019).

To fully understand the influence and complexities of *context* on the MDD process, a multiple case study (Yin 1981) was conducted. Cases were purposively sampled (Etikan, Abubakar Musa and Sunusi Alkassim 2016) using predetermined criteria (Gray 2004). The absence of design-related insights in existing MDD literature informed the decision to document MDD processes from

designers' perspectives, therefore, each case represented an industrial design-led project. To ensure the entirety of the design process could be documented within the given timeframe, each case had to have been an already completed project, resulting in a retrospective multiple case study (Starman 2013). Each case had to have already been publicly documented to some extent to allow for fact-checking and data triangulation (Flick 2004). According to Yin (2014), each case should be carefully selected so that it either predicts similar results (literal replication) or produces contrasting results for predictable reasons (theoretical replication). The last three criteria, therefore, stipulated that each case had to represent a different context, age group (of the patient) and device complexity/classification. In doing so, contrasting results were predicted and when found, could be attributed to these three factors. Based on the above selection criteria, the following three cases were selected:

1. PearsonLloyd's *DBO Commode* designed in a HIC for HICs.
2. Design that Matters' *Firefly*, a newborn phototherapy device designed in a HIC for LMICs.
3. Praestet's *Symba*, a hospital cot designed in South Africa for HICs and LMICs.

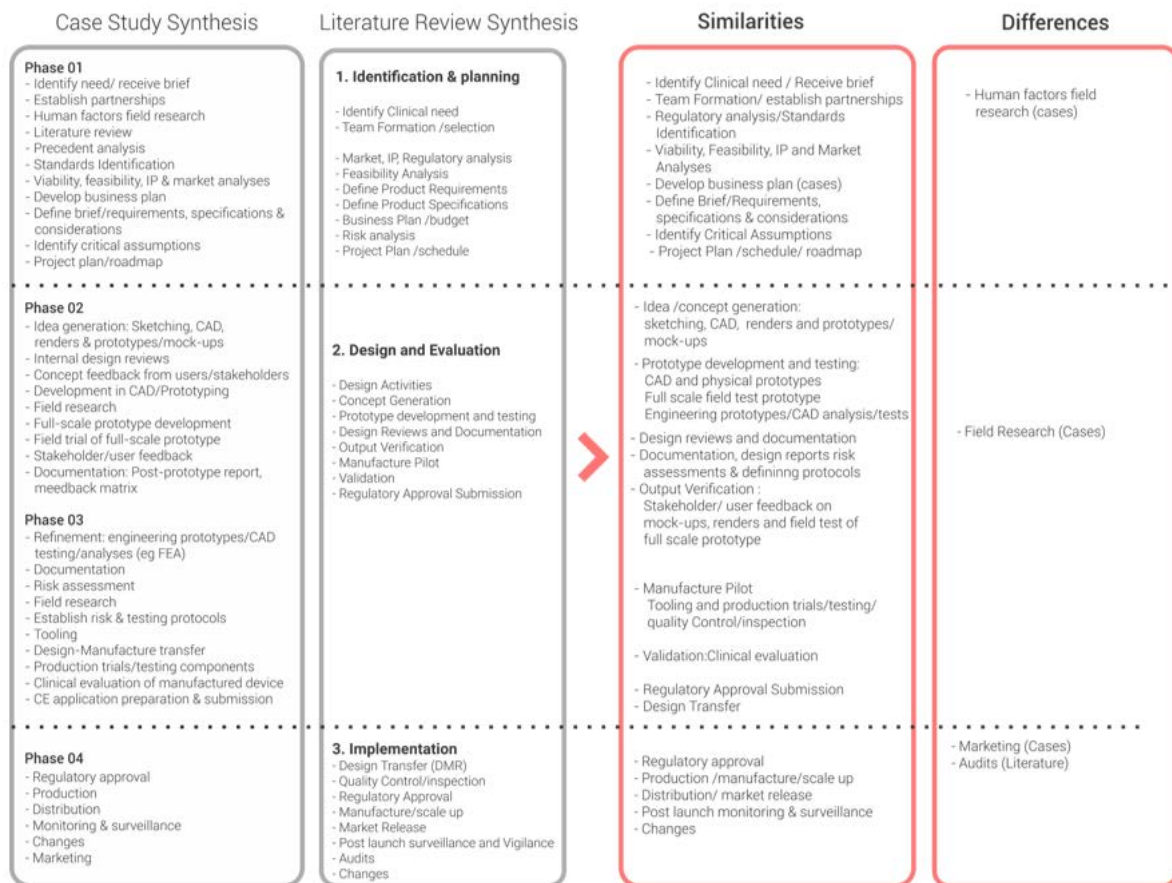
Beyond the selection criteria, each of these cases had been recognised as particularly noteworthy design outcomes.

Phase 2 - Analyse

This phase investigated, analysed and reported on the three design process models. Each process was documented in a comprehensive case report and visualised in three visual formats a summary table, project timeline and process model.

Phase 3 - Model

In this phase, the cases were compared, analysed and synthesised. Synthesised case study data was then compared to synthesised MDD literature, highlighting similarities and key differences (Figure 2) unpacked below. Finally, abductive thinking (Flick, von Kardorff and Stienke 2004) was used to further synthesise the case study data and the existing MDD literature into a final MDDes process model, with particular focus on the South African context.



Findings

Figure 2: Case study and literature synthesis comparison (Bullock 2019)

and business requirements and meeting clinical needs. As a result, most existing models define the ‘design process’ as only a small component of the overall process. We argue, however, that this is not a suitable delimitation and that the entire process is design. The multiple case study highlighted the important role and value of *design* in the MDD process to appropriately address *user* needs rather than just clinical needs. This finding motivated and supported our decision to use the term *medical device design* (MDDes), rather than *medical device development* (MDD). This differentiated our model from existing MDD literature and highlighted the focus on the role of *design* in the development of MDs. Furthermore, case study findings and analysis highlighted the integral role of users and human factors in the process. This supported the notion that HCD is not only *useful* but *essential* in successfully meeting the user and clinical needs of a MD. The key finding from the comparative analysis of case study data was that although one would expect the design process to differ in different contexts, the reality was that the process itself was universally consistent. The main differences between each case were attributed to the country-specific regulatory requirements and processes. This suggested that two separate resources were required: firstly, a generic process model illustrating the overarching MDDes process; secondly, a country-specific ‘regulatory document road-map’¹ that guides/directs designers to the essential resources and documentation needed for the process. Although this study initially aimed to define a *paediatric* MDDes process

¹ An explanation of this regulatory framework has not been included in this paper, however, for more information read Bullock (2019).

model, it was found that there is no considerable difference in the process when designing for paediatrics.

Process Model Description

This section illustrates and describes our MDDes process model. The purpose of the model is to serve as a resource/tool for designers to enable their increased participation in the field. Many of the existing process models illustrate the process as a linear series of steps linked by lines to suggest a chronological order/progression (Figures 3 and 4). This flowchart diagramming method does not accurately describe the organic nature of the design process.

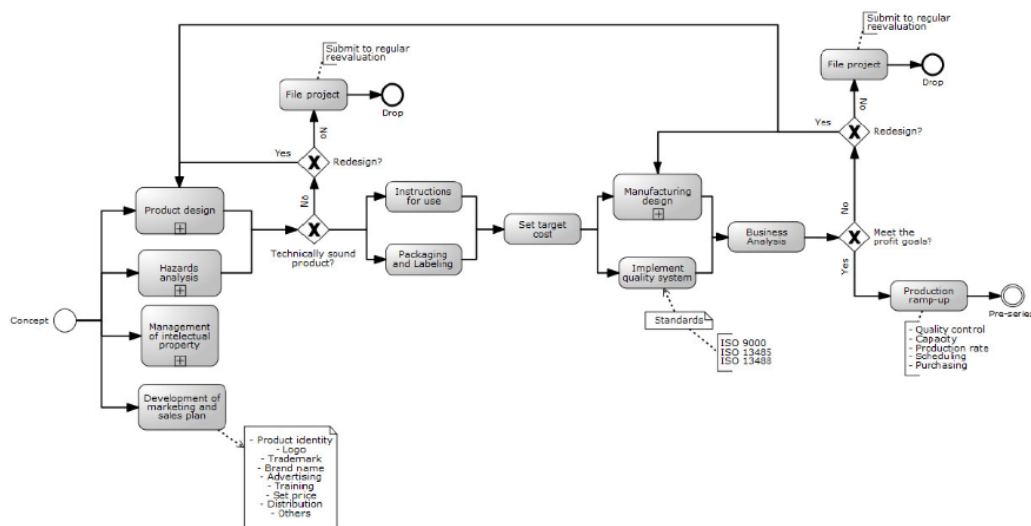


Figure 3: Medical Device Design Process (Santos, et al., 2012)

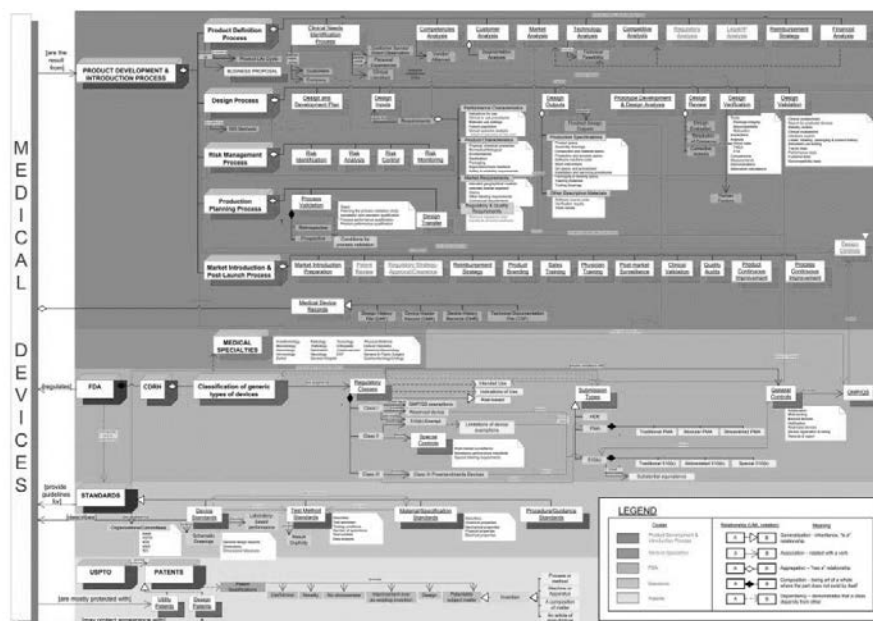


Figure 4: Product Design Process Model for Medical Devices (Medina, Okudan Kremer and Wysk 2013)

Although most of the information included in our model (Figure 5) is similar to that of the existing MDD literature, informed by the design process models described in each case study, our model attempts to encapsulate the *nature* of the process more accurately. The entire cyclical design process is situated within a *cloud* that represents all the factors that influence and inform the design process and outcomes during each phase of the MDDes process. The centre of the diagram represents the users, informants and project stakeholders whose needs and expectations also directly inform and influence the design process and outcome. Placing *users* centrally in the model highlights their pivotal participatory role in the design process. The doughnut-shaped ring represents the *project*, situated within a context of influencing factors (the cloud) and guided by the needs of users and stakeholders. Each *phase* is represented with a ‘cycle’ icon rather than a block, this describes the iterative cyclical nature of each phase rather than a linear step-by-step flow chart as seen in existing MDD models. The dual-direction arrows between each phase in the design process, the cloud and the centre, illustrate the designer’s interaction with and consideration for the users and stakeholders, and contextual factors during each phase of the project/process. Each cycle aims to achieve a particular *milestone* and various activities are conducted and repeated until the relevant critical deliverables of that phase are achieved. Only once a milestone has been achieved can the designer move to the next phase/cycle. To improve the readability of the final MDDes model, textual information was provided in a separate table (Figure 6) so as not to over-populate the visual. Unfortunately, the scope of this paper does not allow us to delve into the specifics regarding the activities involved in the 4 phases, but for more detail on this please refer to Bullock (2019), Chapter 8.

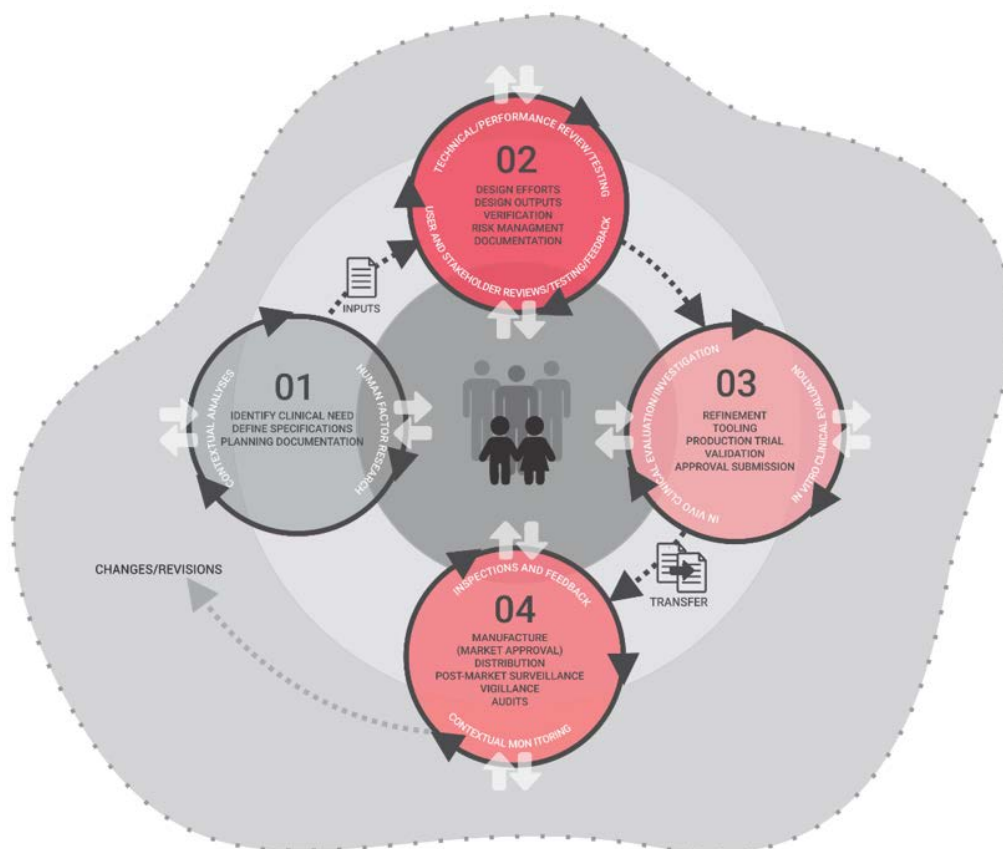


Figure 5: Medical Device Design (MDDes) Process Model (Bullock 2019)



Figure 6: Medical Device Design (MDDes) Process Phases SummaryTable (Bullock 2019)

Conclusion

For MDs to be sustainable they need to meet the emotional and operational needs of the people using them and be suited to the context in which they are used. Current MDD is driven mostly by clinical, engineering and business concerns that focus on regulatory requirements and reliance on best practice insights from medical experts. This risks neglecting users' needs and local requirements. Our research suggests a shift towards a HCD approach that promotes and supports local manufacture as essential in the success of medical device design and implementation, particularly in LMICs.

Our study found that *design* cannot be confined to a small step in the MDD process, as in the existing MDD literature, but rather *design* (particularly HCD) is the entirety of the process. Our study aimed to raise awareness of the need/value of design in healthcare and the participation of designers in the MDDes process. Three best practice design-led cases served as examples of successful, sustainable MDDes solutions in different contexts. The resulting design-informed, and human-centric MDDes process model and regulatory road map aimed to demystify the MDDes process to encourage and enable more designers to enter this field both locally and internationally.

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Co-design of an app used to monitor symptoms of depression in young adults

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ABSTRACT *The paper describes the development of an app able to monitor symptoms of depression in young adults using sensing technologies integrated in smartphones. As stated in a study conducted by the Faculty of Education of the University of Ljubljana, Slovene youth often find mental health services inaccessible and struggle to find professional help, which usually leads to symptoms aggravation. According to WHO, the use of digital technologies for preventing depression has promising results. The exploration of possibilities in which said technologies could be applicable became the focus of my research. I used the bottom-up approach and organized multiple co-design workshops to discover the user needs of young people and to design a beneficial solution. The participants were college students, some of them with diagnosed mental health issues, and were included as equal design partners in the overall process. The workshops were carried out in four phases (empathize, define, ideate and prototype), using various design thinking methods (user journey mapping, five whys, wireframing, etc.). Engaging young people in rethinking the existing ways of dealing with mental health issues and help-seeking provided us with new insights and directions for researching and generating new ideas. The result of the workshops is the prototype of an app that can help young people with depression affected by the inaccessibility of mental health services to efficiently monitor and control symptoms and offer them support while they continue the search for professional help.*

Keywords: co-design, mental health, sensing technologies, depression symptoms, young adults

Introduction

Childhood and adolescence are important stages of life in regard to the well-being of all individuals, as the capabilities formed in this period directly influence their mental health for the rest of their lives (WHO 2018). In Europe, over 10% of adolescents suffer from mental health issues (WHO 2014). Depression is among the main causes of the overall disease burden, and suicide is the leading cause of death among adolescents in many European countries (WHO 2018). Only about 20% of cases are recognized, which implies that the majority of youth do not receive appropriate care (WHO 2005). As the absence of appropriate support can cause symptoms to aggravate, early identification of mental health issues is crucial (WHO 2018).

I decided to conduct this research on the case of Slovenia, where the inaccessibility of professional help for young people facing mental health issues was repeatedly discussed in the media over the past years (Dekleva et al. 2018). The question I asked myself was if I could aid in the improvement of mental health services by developing a digital solution using methods of participatory design.

Youth mental health in Slovenia

Slovenia is among the top European countries in the number of youth (8.2%) reporting having chronic depression in the European Health Interview Survey, as stated on the Eurostat webpage in November 2019.

According to the Slovenian National Institute of Public Health, through the years 2008 and 2015, the number of first visits due to mental health issues increased by 26% on the primary and by 71% on the secondary level of care. The hypothetical reasons for such an increase are an actual increase in mental health issues, decreased stigma and higher awareness regarding mental health. Adolescents aged 15 to 19 were most often seeking help for eating disorders, anxiety, depressive episodes, stress and adjustment disorders (Jeriček Klanšček et al. 2018). People above twenty most often search for help due to anxiety, depression, adjustment disorders, stress, eating disorders and disorders caused by the use of psychoactive substances. Self-harm is one of the main reasons for hospitalization among children aged 7 – 14 and adolescents aged 15 – 19. Among people aged 20 to 29, self-harm is also still present (Bajt et al. 2009).

Accessibility of youth mental health services

In 2018, the Faculty of Education from the University of Ljubljana carried out a study exploring the accessibility of organized types of support for young people having mental health issues; accessibility not meaning just physical accessibility, but also young people's views on offered help. The average age of interviewees was 20.74 years (Dekleva et al. 2018). The barriers they mentioned when seeking help are:

- not being aware of their issues;
- not knowing how to search for help;
- perceiving school counsellors as unapproachable;
- fear of stigmatization;

- not wanting to burden their parents;
- fear of measures of psychiatric treatment and social work services (Dekleva et al. 2018).

The barriers when using mental health services are:

- crowded formal help system;
- payable treatment;
- geographical distance;
- exclusion out of service;
- incoherent process of help;
- parents obstructing the use of help;
- unresponsive services;
- dissatisfaction with previously received help (Dekleva et al. 2018).

If the barriers when searching for help highlight the presence of misunderstanding regarding mental health issues and treatment, which seems is due to the lack of correct information, the obstacles when using mental health services are contrary, as most need to be solved on the systemic level.

Digital technologies in mental health services

The Slovenian Resolution on the National Mental Health Programme 2018–2028 was published in 2018. Several goals regarding youth's mental health are included. Some of them mention digital technologies, thus showing that their potentials are being recognized (*Resolucija o nacionalnem programu* 2018). They can offer people with mental health issues the possibility to access health information online and contact their peers, while healthcare providers can offer their services, making them accessible and less stigmatising (HM Government Department of Health 2011).

Another aspect of e-mental health to explore are smartphones as devices with sensing capabilities and potential to provide insights into human behaviour. As symptoms manifest as changes in one's behaviour, analysis could lead to a better understanding of these types of issues (Osmani 2015). The data could also be beneficial for patients directly, to motivate them toward improving their well-being (Patel, Asch, and Volpp 2015). When developing e-mental health solutions which utilize sensing technologies the aspect of user engagement should not be overlooked, as it is essential to ensure data quality (Abdullah and Choudhury 2018).

Design process

Methodology

Based on the conducted research I combined the two aspects: the issues with accessibility of mental health services and the potential digital technologies have to tackle those issues. The goal was to use the participatory design approach to create a digital platform, offering young people support when seeking help or undertaking the treatments.

Applications are often designed using a top-down approach, trying to get people to do what we think will help them, instead of helping them do something they are motivated to do (Mohr, Zhang, and Schueller 2017). This prompted me to organize co-design workshops, where young people, as end-users, could participate in the design process. Using the design thinking methodology, the workshops were carried out in four phases (empathize, define, ideate and prototype). I chose widely used design methods that are verified and therefore give reliable results. Another criterion for choosing the methods was simplicity in terms of ease of explanation and execution. The results of the workshops are evaluated in the discussion chapter, including the potential for further development.

Participants

Thirteen students aged 21 to 26 participated in the workshops. Four of them had been diagnosed with mental health issues in their adolescence and had experiences with mental health services. They were recruited via Facebook posts on my personal page and on the page of the project 'Kako si?' ['How are you?'] carried out by psychology students from the Faculty of Arts, University of Ljubljana, to inform the public about the importance of mental wellbeing. The criteria were that they are aged from 18 to 25, have diagnosed mental health issues and have previous experiences with mental health services. Others had no mental health issues - I included them to represent the youth who are seeking help for the first time. They were recruited at the Academy of Fine Arts and Design, University of Ljubljana. Not all participants took part in every workshop, as I tried to keep an even ratio between the participants with experiences and those without.

Workshops

Workshop 1

The first workshop was conducted in two parts: the first part was executed with students without and the second one with students with mental health issues. Both included an icebreaker activity to prepare the participants for collaboration. The activities used were creating the mood board of what makes them feel happy and connecting various emotions with colours. The results inspired the design of the user interface.

The main activity in both parts was discussion. In the first part, it was about whom the participants would first turn to if they realized they had mental health issues. For minor issues they would turn to their closest friends or relatives. However, if the issues were serious, they would turn to their general practitioner. Regarding the usage of the internet for checking your symptoms, they agreed there are good and bad sides. In the second part, the discussion was about participants' experiences

with help-seeking and undertaking treatments. We used the user journey mapping method to map the crucial steps and evaluate their experiences.

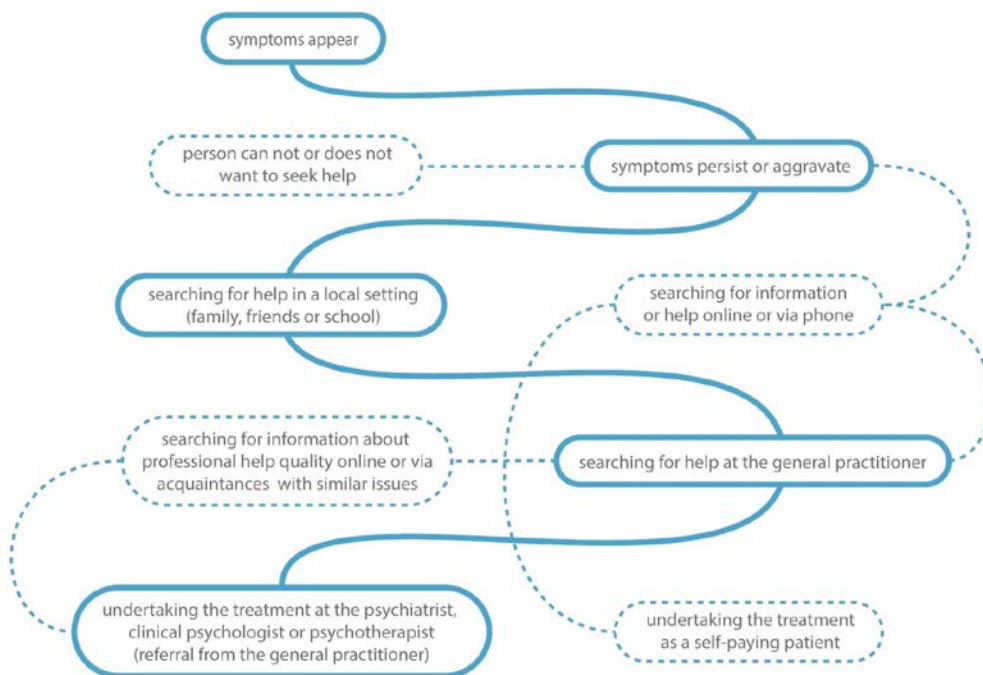


Figure 1: A simplified version of the user journey map representing the way young people usually take when help-seeking (dashed lines represent additional or alternative steps).

Workshop 2

The workshop started with the five whys method to explore different sides of problems discovered in the previous workshop. The participants chose the ones they felt were important to tackle and used them to create 'how might we' questions (HMW).

HMW ...

- ... provide people with knowledge to recognize mental health issues and offer appropriate advice?
- ... make sure that the information about mental health targeting young people is easily available?
- ... use smart devices to support mental health treatment?

Workshop 3

The third workshop began with the method Crazy6s, where the participants had to sketch quickly their ideas in the form of answers to previously created HMW questions. The goal of the method was to create several ideas and choose the ones with the potential for further development.

- App that monitors the connection between mental health and premenstrual syndrome (PMS) symptoms.
- Online platform with information about ongoing mental health treatment.
- Smartwatch that detects panic attacks and offers advice on preventing them.

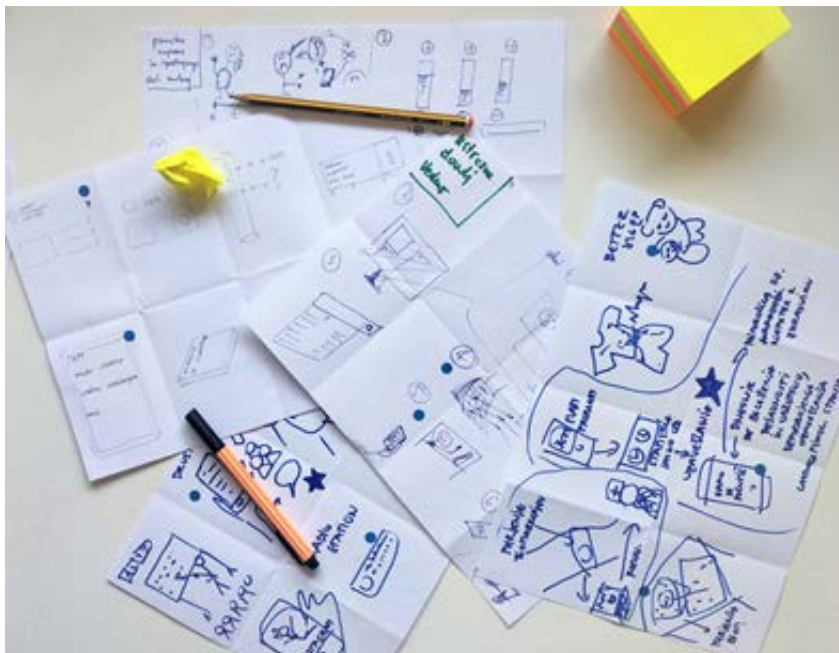


Figure 2: Sketches created during the workshop.

Next, I presented the participants with the personas representing end-users, based on the findings from the previous workshops.

Last was the storyboard method, where the participants were asked to build upon previous ideas, with at least one persona as the main character. The goal was to develop ideas into user-centred solutions. The chosen solution was a mood and symptoms monitoring app for young people with depression, stuck in long waiting lists while receiving no support. The participants voiced their concerns about not receiving timely professional help, aggravation of symptoms and the feeling of helplessness while waiting. This is consistent with findings by Dekleva et al. (2018), which state that long waiting lists are among the reasons for youth to stop help-seeking. Some interviewees said that if they were not searching for help in multiple places, they would probably commit suicide before they received any.

Workshop 4

The participants were asked to choose some apps they use and discuss why they think the apps are good. The goal of the activity was to gain an understanding of what the users perceive as indicators of a “good” app. The most often valued apps were simple to use, had a pleasant user interface and offered personalization. The participants were asked to create simple wireframes for typical screens based on the final concept of the app. I used the descriptions and the wireframes as a guide to create the prototype.

Results

As stated, the final solution was a mood and symptoms monitoring app intended for young people with depression stuck in long waiting lists. It could also help someone who just realized they might have mental health issues or someone who is already undertaking treatment. The features the app would offer are:

- daily mood tracking;
- sleep, physical activity and other behavioural changes tracking (using sensing technologies);
- goal-setting;
- PMS tracking;
- exportable reports on well-being;
- warnings in case of aggravation;
- advice on self-help;
- information about treatment, a list of nearby mental health services and emergency contacts.

As the list of functions is long and not everyone experiences mental health issues in the same way, personalization is important. For someone who suffers from lack of motivation, the goal-setting function might be the primary feature, while for someone who is having trouble sleeping the focus would be sleep tracking. When creating the prototype, the idea of a modular daily dashboard evolved to prevent the overload of irrelevant information. The user could choose the information presented in the main section; hidden information would still be tracked and accessed if needed.



Figure 3: Example of the daily dashboard.

The daily dashboard would also allow easy access to goal-setting, self-help advice and emergency contacts. The screens are presented in Figure 4.

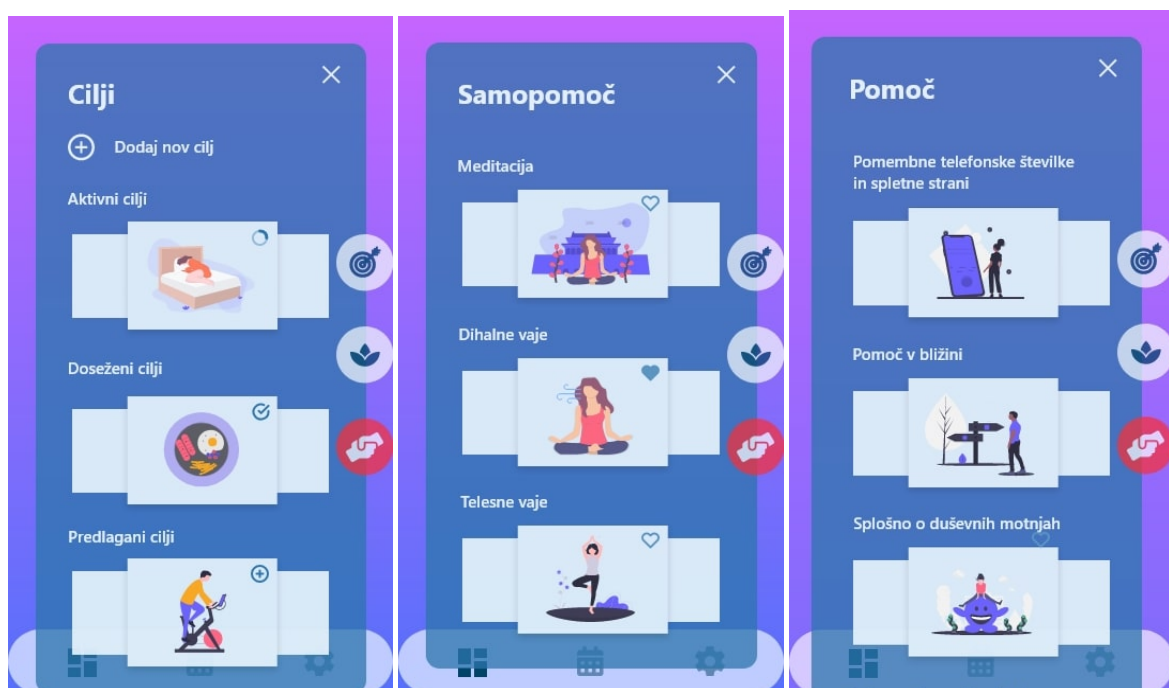


Figure 4: Examples of pop-up screens for goal setting, self-help and emergency contacts.

Mood monitoring is another key feature. While we strove to make the data input as simple as possible, we agreed that collecting daily mood might not be enough, so we added the possibility to write short notes and answer daily questions about well-being. They were made optional to avoid overwhelming.

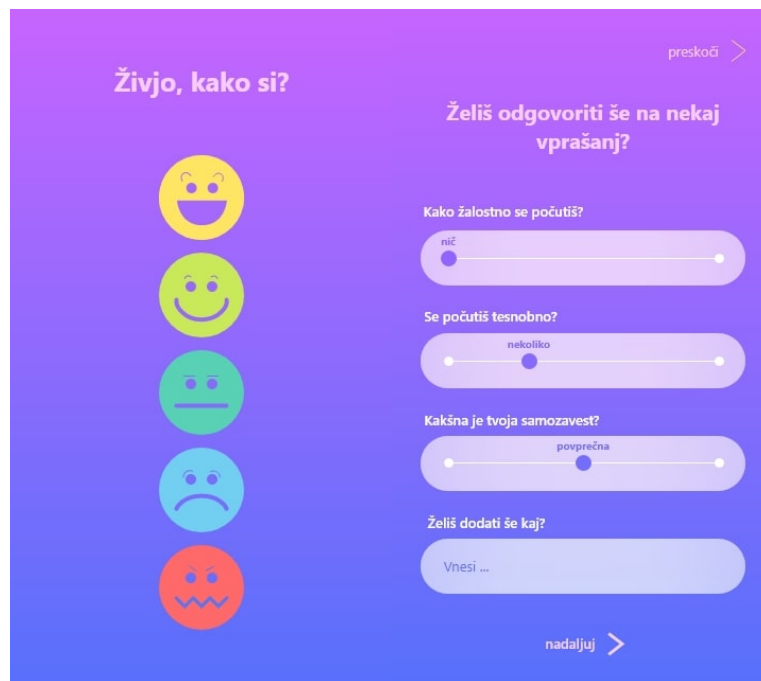


Figure 5: Examples of daily mood input.

When deciding which type of device to use for automatic sensing, we weighed the pros and cons of smartphones and smartwatches. While smartwatches might have better sensing capabilities, smartphones were chosen, as the young persons most affected by long waiting lists are coming from low socio-economic backgrounds and are dependent on most cost-efficient types of help (Dekleva et al. 2018).

The first version of the prototype was simplified, and the user interface did not yet include all of the functions. While the prototype was relatively unpolished, it allowed us to determine if the solution is suitable or if anything is missing. The upgraded version will be used in later user testing.

Discussion

Findings

This paper demonstrates how the engagement of young people experiencing mental health issues in design processes can contribute to the creation of beneficial solutions. While the execution of co-design workshops required a lot of flexibility due to differences in students' availability (both in terms of their busy schedules and mental health condition), it highlighted the importance of cooperation by providing us with results that reflect various participants' perspectives yet remain objective. Inclusion of end-users offered us the possibility to deepen our understanding regarding the inaccessibility of youth mental health services and allowed them to voice their concerns, generate unpredictable ideas and develop them into meaningful solutions.

In terms of the app, the participants highly contributed to the overall solution. The features the participants determined as most important are mood and symptoms monitoring (consistent with findings by Hetrick et al. (2018)), goal setting, warnings and a selection of emergency contacts. The participants stated that the user interface should be clear and easy to use. There was a lot of

emphasis on data presentation, which should be presented in a way that is meaningful to the user. This is consistent with findings by Patel, Asch, and Volpp (2015), who stated that the collected information should be presented to the user in a way that speaks to their goals and motivates action. Finally, yet importantly, the participants agreed that while the app should encourage user engagement, the user should not feel overwhelmed.

Limitations and future directions

I am aware there are several limitations to be considered. This is why a plan for further development is crucial. First iterations of the prototype were already carried out according to the feedback of the workshops' participants. For further upgrades, the number of young people involved in testing should be increased to ensure more accurate results. There should also be greater variability in terms of age and social background among the participants.

While mental health practitioners were not involved in the workshops directly, they were involved in the project's research phase via interviews. I am also planning to include them in prototype testing, as it will help to evaluate the efficacy of the app and allow me to avoid the hidden risks related to the well-being of the users. The concept will also be upgraded according to additional research regarding sensing technologies and data safety, with the inclusion of app developers in the further design processes.

The presented concept is the first step and a guideline towards a wholesome solution that will answer to the needs of youth with mental health issues.

Acknowledgements

I would like to acknowledge all of the students who participated in this project.

This paper is the result of ongoing research for a master thesis at the University of Ljubljana, Academy of Fine Arts and Design, Department for Industrial Design and Applied Arts, Service Design II, mentor Assistant Professor Barbara Predan, 2020.

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Constructing a framework to design with and for excluded factors in mental disorders: a proposal for Eating Disorders attunement to recovery and the Other Self

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ABSTRACT *This paper is an extract from my Ph.D. candidacy proposal, which aims to develop a framework to explore and design for the multidimensionality of the experiences of people who struggle with mental disorders in their context, including their relational and material everyday life surroundings.*

Considering that the aim of design research is 'to provide alternatives to deeply ingrained habits of thinking' (Koskinen et al. 2011, 47), this framework should aim at providing insights in the disorder's experience as it unfolds in context, inspiring the generation of newly distributed and material systems of care that seek to shift our perception of everyday lives practices which would shed new light on how mental disorders emerge. The research focuses on the field of Eating Disorders (EDs).

The paper starts with a review of the mental disorders discourse and EDs research. It describes the model used to analyse mental disorders and identifies the factors have been excluded from such analysis, which may prevent new understanding of disorders. Moreover, it provides a brief overview of design research, its affordances and the state of the arts on the topic of mental disorders, pointing out that a cohesive and critical standpoint of design in mental health is missing. The paper ends by describing the framework and how it applies in the context of EDs: by including factors excluded by the biomedical model and proposing new ways of looking at EDs, a networked and participatory systems of care for recovery attunement from EDs can be proposed.

Keywords: *design in mental disorders, eating disorders, excluded factors, biopsychosocial model, actor-network theory, framework, recovery attunement, participatory approach*

Mental Disorders and Eating Disorders: a brief review on models and exclusions

WHO defines mental disorders as a broad range of problems comprehending different symptoms which can be generalized in abnormal thoughts, emotions, behaviours or relationship with others (Saxena et al. 2014). Although the causes of mental disorders are still unknown (Graham 2013), they lie between a combination of individual, socio-cultural, environmental, and economic factors (Saxena et al. 2014). The main disciplines who historically took care of mental disorders are medicine, psychiatry, and psychology, which identify the mental disorder inside the individual or address it through therapeutic practices applied to the individual experiencing the disorders, and when possible, to close relationships.

The model used to conceptualize mental disorders is the biomedical one. The rationale behind that choice is that psychiatry still questions whether it is possible to apply the same model for the medicine of the tissue to the mind (Bracken et al. 2012). Specifically, the biomedical model affords researchers in the field of mental disorders to operate by reducing factors to observe and by excluding all the factors that resist measurements (Garrett 1997) and that do not allow for high comparability amongst different experiences of mental disorders (Valentine et al. 2017). This reductionist approach provides incremental and detailed information on the efficacy of treatments but leaves behind a richer understanding of the multidimensionality of the patient's experience of the disorder, which fails to provide new points of views on the understanding of mental disorders. The biomedical model has been subsequently amended into the Biopsychosocial Model (BPSM) in order to include the social sphere of individuals and to allow a holistic understanding of mental disorders (George and Engel 1980).

However, how are the factors outside the individuals addressed in practice? By providing a brief review of EDs research advancements, the aim is to highlight that the understanding of mental disorders and the relative care approach depends on the epistemologies used to look at the disorders, which provide frameworks for including or excluding certain factors from the analysis. EDs are considered coping or existential problems *displaced* in a complicated relationship with food (Bruch 1974). Such disorders are multifactorial: heterogeneous factors merge uniquely in different individuals so that it is impractical to generalize to others (Polivy and Herman 2002). However, general standardized treatments exist for EDs: some of these treatments exclude factors, some exclude bodies and experiences, and others exclude context. EDs treatments have a relative efficacy (Federici and Kaplan 2008) and for these reasons, Fassino and Abate-Daga (2013) describe them as disorders that signal a crisis in the reductive approach of the biomedical model in understanding mental disorders. What can we learn and, consequently, do about EDs if we embrace the various dimensionality and complexity of such disorders as it unfolds in context, by allowing design research to be part of the discourse, in ways of looking at the disorder and by proposing new ways of caring for the disorder?

Design research in the context of mental disorders: affordances, state of the art and gaps

Design research affords idiosyncratic interpretations, values subjectivity, and includes participation and context in the process of designing (Groeneveld et al. 2018). It embraces and makes sense of complexities and ambiguities, flirts with uncertainties, and aims to provoke change. Design research develops propositional theories (Zimmerman et al. 2010) and describes alternatives to how reality is by challenging habits of thinking (Koskinen et al. 2011). Design intrinsic, imaginative skills can

provoke superficial change or challenge the underlying assumptions of the issues tackled while making reality more malleable (Dunne and Raby 2013).

Although design research approaches are opposite to health research ones, design interventions embrace a wide range of health-related topics, such as improving the experiences of everyday life by product design or tackling experience, emotions, and mood (Hassenzhal et al. 2013; Desmet and Pohlmeier 2015). Design focuses to purposefully steer behaviours by means of design function in topics related to wellbeing, e.g., improving eating habits (Niedderer et al. 2017). Design improves health care experience, too (Tseklevs and Cooper 2013).

In order to individuate the role that design takes in the context of mental disorders, it is useful to distinguish between design interventions for ‘cognitively impairing’ and ‘functionally challenging’ issues (Shepley and Pasha 2017). Dementia is an example of the former category. In that case, design interventions take the form of products that enhance personhood, developed by using codesign processes (Niedderer et al. 2020). My research, however, refers to the latter category, to which EDs belong. In this category, design interventions focus on improving the experience of therapy for people affected by psychosis (Nakarada-Kordich et al. 2017), bipolar disorder (Matthews et al. 2015), recovery from addictions (Champ 2018), and burnout (Visch et al. 2011).

This review shows the existence of scattered design frameworks that tackle singular mental disorders; however, a wholesome and cohesive design framework and standpoint for mental disorders are missing. The use of participatory design approach is one commonality among the design interventions mentioned above. The use of this approach shows an orientation towards the inclusion of patients’ voices in the design of their healthcare experiences. Considering design research affordances, the current design interventions for mental disorders limit themselves in provoking change by materially translating current paradigms of mental health. Such interventions miss the chance to learn more about the conditions that produced the disorder and its experience and miss the opportunity to provide alternatives to ways of caring, preventing us to learn more about the way we conduct our everyday life.

One design intervention, mentioned in the field of Design for Behaviour Change (Niedderer et al. 2017), seeks to remind people in workplaces to take breaks in order to avoid burnouts. This intervention, however, does not allow us to know more about the phenomenon of burnout nor critically consider the context that produced the burnout or how people work. As Nöel (2017) states, there is a lack of understanding of what design can do for healthcare: design interventions for health should focus on rethinking how healthcare is implemented rather than aiming at superficial solutions.

A proposition: describing an unwieldy framework to design for EDs

The heterogeneous factors that play a role in the insurgence of EDs and their recovery are complex, networked, and embedded in everyday life. Polivy and Herman (2002) mention that a model that holds together such factors can become unwieldy, but Fassino and Abate-Daga (2013) invite complex models to look through this disorder. The critical psychologist Dreier (2008) claims that therapy gives clients agency to change and that happens in their everyday life settings rather than in ‘a privileged nowhere of mental change’ (Dreier 2008, 5). Dreier, thus, emphasizes the importance of contextualizing therapy. ‘Extra-therapeutic factors’ are a combination of individual, relational and situational factors that contribute to a therapy’s 40% success rate (Dreier 2008).

A ‘sociological imagination’ (as the capacity to see how social forces interact with individuals) (Mills 1959) is needed in mental health discourse, together with medical humanities, in order to provide

new conceptual and systematic understandings of the disorder experience and its meaning (Kleinman 1988). In the same way, the design's imaginative skills might afford us to include the subjects' voices and their presence in the design process of a possible distributed and material system of care. The imaginative skills include elements as they assume importance through people's narration of their experiences while embracing their complexity and heterogeneity. Additionally, these imaginative skills afford us to look at the disorder as it unfolds in its context and, thereby, design for that social fabric, to make idiosyncratic and unexpected interpretations, and to tweak materiality in order to propose new practices of care. Finally, they afford us to show reality under a new light and to propose different ways of living, communicating, encountering and being together. By redistributing the responsibility and care of mental disorders in the design of our everyday lives, we might find out about ways to 'design away' (Tonkinwise 2013) the conditions by which the mental disorders appeared in the first place.

Actor-Network Theory (ANT) (Latour 2008) is a theoretical framework that can hold together such complexity and heterogeneity. ANT allows us to see the social fabric as a heterogeneous assemblage of actants, made of humans and non-humans (e.g., artefacts). Such networks have agencies. We can create new assemblages and their agencies by adding or removing elements in the networks. ANT allows to describe ED as an assemblage with a disordered agency: it is a network of elements (individual, relational, social, and contextual elements) in tension, which allows the ED's agency to emerge as a coping mechanism to mediate the everyday life. The ED, therefore, is not enclosed in a subject, since the subject is already a network of heterogeneous elements. By mapping how the agency is distributed (Storni 2015), we might dissolve the condition by which the ED is needed (the ED network): by designing new artefacts with a specific program of action and adding them to the network, we might be able to modulate the behaviour of the assemblage.

Tweaking the Eating Disorder network by design: a participatory, networked, contextual approach

A framework to design with and for people who experience EDs is missing. Design interventions that address eating habits are relatively relevant in this case since the disordered eating in EDs is the symptom of an existential, relational, and networked issue. Mental disorders are a response to an unsustainable system (Watzlawick et al. 1971). The ED assemblage is co-created: the heterogeneous factors, which constitute the assemblage, are in tension and have a different starting point from where they emerge, which is usually in a disordered eating actor. To allow other modalities of being to emerge (e.g., from disordered eating selves to recovered selves), we can rearticulate the agency of ED assemblages.

The design framework to look at and design for and with EDs new agency should incorporate the physical context in which the disorder unfolds (e.g., the home). With this framework, we can develop a system of care that acts on the outside of the individual too, as a temporary material aid that suggests new everyday life practices toward healing, including the relationships, the communication and the beliefs system that take place in the context observed, in the network analysis, and design interventions.

The design framework should furthermore include recovery as a process (Lester 2019). Qualitative studies show the necessity of tackling the underlying issues of an ED in the process of treatments rather than focusing only on symptoms reduction (Bardone-Cone et al. 2018). The authors describe how the interviewees cannot imagine themselves as recovered. It is of extreme importance to infuse a strong attitude to change and to inspire to develop an identity- the other self - outside EDs (Lester 2019). Furthermore, incorporating patients' needs and recovery stories from former patients in the framework can improve the understanding of the disorder. (Garrett 1997)

Cedar Grove, a Centre specialized on treatments of EDs (Lester 2019), has implemented best practices in which every action is 'imbued with therapeutic potential' (Lester 2019, 139). Those practices suggest various non-linear approaches: developing new forms of eating control, which would outgrow the disordered control, and shows its fallacies to the patients; developing a holding environment (Winnicott 2009) and techniques to hold and process emotions; addressing boundaries and communication.

Scattered frameworks of various design disciplines target issues such as managing control, enhancing moods, regulating emotions, and supporting therapeutic communication. Such approaches can construct the framework to design for EDs.

In my prospective research design, I plan to adopt a participatory design approach, guided autoethnography, and probes. This methodology will respect the sensitivity of working with patients who currently experience and have experienced EDs while mapping how the EDs network articulates in context. Additionally, I will organize workshops with former EDs patients in which we will co-design tools that enable new practices aiming at eliminating the required conditions of EDs.

Acknowledgments

This research has been initially made possible by funding from the U.S. – Italy Fulbright Commission and the Institute of International Education (IIE); The Design School (TDS) at Arizona State University; Arts, Media and Engineering (AME) at Arizona State University, and the Center for Philosophical Technologies (CPT) at Arizona State University. I want to thank my Ph.D. supervisors (Prof. Adam Nocek, Prof. Kristina Niedderer, Prof. Rebecca Lester, Prof. William Heywood), their guidance, critique, and feedback lead to the reflections at the base of this paper. Also, I want to thank Prof. Alvise Mattozzi for reviewing and discussing the article with me, the Anonymous Reviewers for the insightful comments and critiques, and Amelia Miholca for English proofreading.

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Open-ended data probing to inform the future of home health care

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[ABSTRACT only] Chronic heart failure (CHF) is a complex disease with a high mortality rate, affecting millions of patients worldwide (Savarese and Lund, 2017). In many countries, healthcare systems are already under stress and with the ageing population the number of CHF patients is expected to increase even further. Remote patient monitoring has already been shown to decrease length and frequency of hospitalization in patients with heart failure, as well as mortality (Hindricks et al. 2014). Thus far, the monitored data has been primarily clinical, while heart failure patients also struggle with personal and emotional challenges and with changing relevant aspects of their lifestyle. As each CHF patient copes in their own way and context, effective data collection requires high degrees of personalisation and versatility.

In this research, we focus on collecting and curating non-clinical data that qualitatively describe patient lifestyle changes and psychological condition. We investigate forms of complementary use with clinical data sets and outline the benefits of personalised care through remote monitoring techniques in the home environment. To gain a nuanced understanding of how individuals track personal health data in an everyday context, we are developing a methodology for open-ended data tracking. Through iteratively designing probes, we are creating a system that will allow patients to assign which data they want to monitor and share with their health care professionals, based on best practices in data tracking. Results of our preliminary field deployment show that the data collection activities provoke the reflection of participants and further encourage them to envision the better cases, as they were more aware of their needs. The positive findings warrant our next phases of expedition with more participants.

Keywords: human centred design, participatory research, design approaches, rehabilitation

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Implementation and Involvement of a Dynamic Instrument as a Practice Support in Rehabilitation Processes of Chronic Diseases

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ABSTRACT In the rehabilitation of chronic and severe illnesses, it is common to use paper-based questionnaires to capture experiences of symptoms associated with illness or treatment. Managing such instruments consumes time, and offers care professionals a narrow space of possible actions toward the patients. The purpose of this paper was to report the initial concerns we encountered in the early phases involving a dynamic instrument in nursing practice. This project is based on the Self Management Assessment Scale (SMASc) with the purpose to provide digital support that enables personalized work methods with the patient. With SMASc, patients answer questions on a mobile phone, tablet or computer. The compiled result is provided instantly before the patient-nurse consultation. SMASc is here understood as an interactive artefact with dynamic affordances. A dynamic instrument manifests a theoretical foundation aligning to the use situation, is programmable and digitally distributed, and offers individually compiled datafied views that connect the person's situation and the theoretical apparatus - in this case, a person's need for self-management support. The data this report builds on was produced during two project meetings and throughout the design and development of the instrument prototype. Data analysis approach applied was an analysis focusing on emerging concerns surfacing from discussions that followed the introduction of the prototype. We found that the nurses cared for the development of their practice and strived to advance and steer it in a more nursing-oriented direction. They did not fully comply with the instrument's item formulations and how these should or could be used. Further work has to be done to involve more stakeholders in the future work so that everyone feels engaged and can put their views on the design of the instrument, and on the implementation work itself.

Keywords: caring, co-design, dynamic instruments, implementation, nursing, ownership, rehabilitation, trust.

Introduction

This paper focus on the initial concerns encountered during the early phases of the design and implementation of a dynamic instrument. In the rehabilitation of severe and chronic illnesses - such as diabetes, heart failure and cancer - it is common to ask patients about their symptoms associated with the illness or treatment via paper-based questionnaires. However, managing such instruments is known to be time consuming, and offers care professionals a narrow space of possible actions toward the patients.

Rozendo et al. (2017) define nursing as a transformative practice; nurses care for other people's situation and intervene in the world caring for people's needs with an aim to improve their health. Nurses manage and cultivate transformation in their workaday, thus dealing with patients whose health situation demands reflexive stance and approach. Nursing is also subject to transformation and change. Healthcare practice is already technologically intensive from decades of computerization (Aanestad et al. 2017). Digitalization transforms healthcare practice and adds dimensions of complexity that challenge the organization and the workaday (Greenhalgh et al. 2017; Fitzpatrick and Ellingsen 2013). No technology is however introduced in a vacuum. Within the current ongoing wave of digitalisation in healthcare, nurses are given new opportunities following the introduction of new digital platforms following a person-centered logic (Grisot et al. 2020). These platforms offer new ways in which healthcare professionals and patients can interact digitally and physically. During the Covid-19 pandemic, digitally mediated interactions have offered safer options for interaction. Besides being a resource during extreme times, digiphysical practices also have a potential to pave paths towards person-centered care practices (Ekman 2018).

This project is based on the Self Management Assessment Scale (SMASc) (Öberg et al. 2019) with the purpose to provide digital support that enables the development of personalized work methods. It takes a person-centered perspective (Håkansson Eklund et al. 2019) and puts the patient's self-care ability in focus. The instrument captures five knowledge dimensions combining domains from self-management; the person's knowledge of the illness, perceived social support, everyday routines, future plans and well-being. With SMASc, patients answer questions on a mobile phone, tablet or computer and the compiled result is provided instantly before the patient-nurse consultation.



Figure 1. Digital prototype 1.0, Self-Management Assessment Scale (SMASc).

SMASc is here understood as an interactive artefact (cf. Janlert and Stolterman, 2017) that have dynamic affordances. A dynamic instrument manifests a theoretical foundation aligning to the situation. It is programmable and digitally distributed, and offers individually compiled datafied

views that connect the person's situation and the theoretical apparatus, which in this case is a person's need for self-management support. These affordances together provide means for both the nurse and the patient to facilitate interaction in both physical and digital contexts. We aim to explore the design and implementation of this instrument through the research question: *How to involve and implement the affordances of digital instruments as a part of the rehabilitation process of chronic diseases?* The purpose of this paper is to report initial concerns we encountered in early phases involving a dynamic instrument in nursing practice that will guide the coming design of the new work routine.

Method

The point of departure of this study was an invitation to present a digital prototype of the SMASc instrument. The instrument served as a probe (Sanders & Stappers 2014) intending to facilitate a discussion about the current state affairs at the health care clinic, and from the nurses' first encounter with the digital instrument understand what they see as matters of concern (Latour 2004) to guide the design process forward.

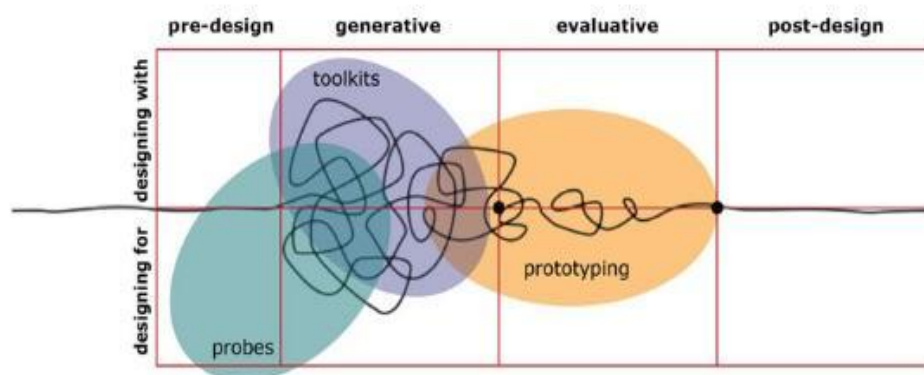


Figure 2. Sanders and Stappers (2014) revised CO-design framework

The introduction of the prototype initiated a co-design process (Sanders & Stappers 2014), which is expressed through the structure found in the Quality Implementation Framework (QIF) (Meyers et al. 2012). We use this process model to support and guide the implementation process, but also to provide a bridge between the disciplinary fields combined in the study translating research into practice (Nilsen 2015). The QIF provides practical guidance in both planning and execution of implementation and provides strategies to facilitate the implementation with a structure to address barriers and enablers for translating research-based interventions into clinical practice. QIF consists of four phases and fourteen critical steps. In this paper, the focus is primarily on phases 1 and 2. For an overview, see Figure 3.

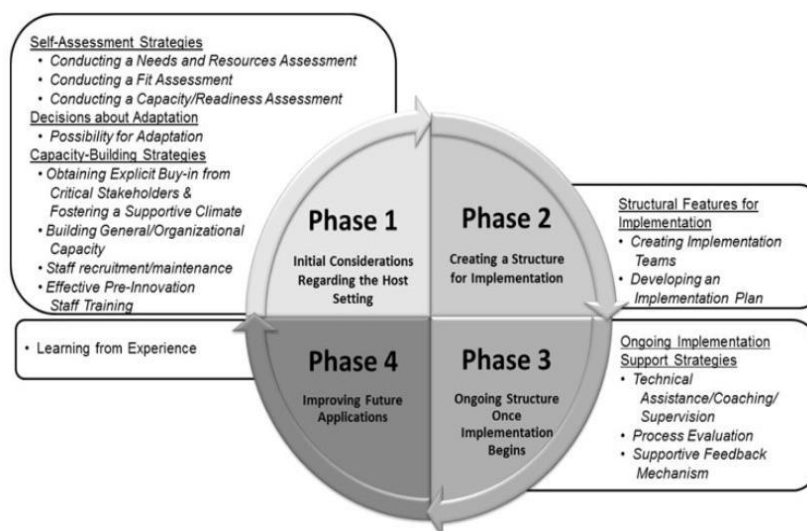


Figure 3. Overview of the application of QIF (Meyers et al. 2012).

The data this report builds on was produced during two project meetings and throughout the design and development of the instrument prototype. Persons participating in these meetings were the head manager and three nurses. The nurses worked at three different wards (diabetes, cardiovascular disease and rheumatology) within the same health care clinic. The first author was on site for both meetings. In the second meeting, the second author participated via a Kubi Robot setup. The data analysis approach applied was an analysis focusing on emerging concerns surfacing from the discussion that followed the introduction of the prototype. Design choices taken until this point were decided by the researchers. The participating nurses gave informed consent regarding audio-recording the meetings and using the material in this paper.

Involving dynamic instruments in nursing practice

Phase 1: initial considerations regarding the host setting

During the first phase, the setting was considered regarding assessment, possibilities for adaptation and capacity building strategies (cf. Meyers et al. 2012). The initial meeting between the collaborating partners resulted in identifying and considering concerns (Latour 2004; Andersen et al. 2014) that need attention in the implementation of SMASc.

The first meeting

The first meeting was initiated by the head manager at the health care clinic against the background that the nurses at the health care clinic had been using other questionnaires in their work that they were not totally satisfied with. Additionally, the questionnaires was experienced having a medical focus instead of nursing focus, experienced as hindering their intention to work with a nursing perspective.

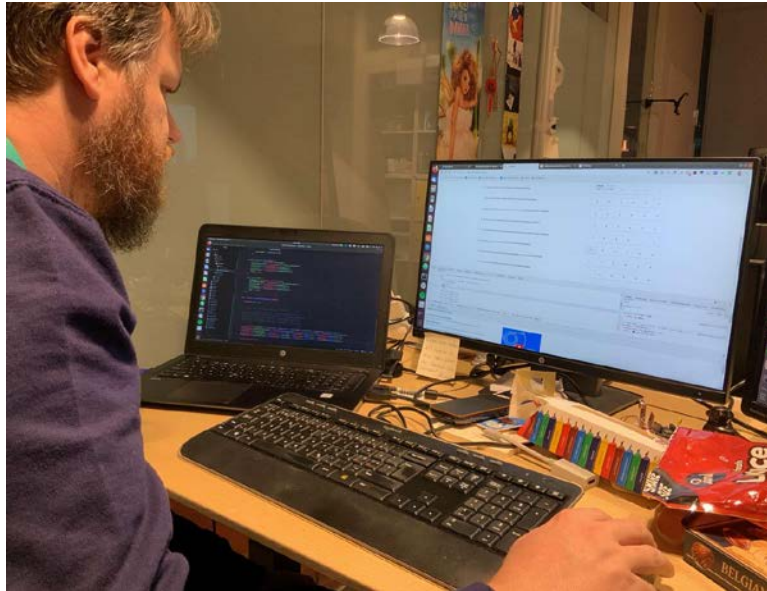


Figure 4. Design and coding of prototype

A prototype was developed before the first meeting based on ten questions in SMASc (Öberg et al. 2019). During this first meeting, the first author, the head manager and three nurses at the health care clinic participated. The instrument was introduced, which initiated discussions and reflections about how the dynamic instrument could support the change activity the nurses at the health care clinic had already initiated. When studying the items, one nurse expressed:

‘If we were to use this instrument in our work with our patients, it would mean a paradigm shift for us...’.

The presentation of the prototype opened up a discussion regarding the nurses’ way of working and the possibilities of changing this towards a more person-centred work. In addition, the nurses also raised curious and critical reflections on the design of the instrument and how it could be introduced in the workday with patients. One concern that surfaced came out of their experience with other instruments the nurses used or had used before. They could see that the rationale of the SMASc differed since it provided them with other possibilities to act and use in the meeting with the patient. It was clear that the instrument could complement those instruments already used, but with a possibility to advance their work practice. Another concern was directed towards how to deal with the results that the SMASc provided. The spectrum of the knowledge domains making up the instrument raised concerns regarding which profession would be most suitable to care for the patient depending on the results of the instrument.

‘...If the answer is red all over- what does that really mean? Is it me the patient supposed to meet, it might be better if the patient is taken care of by either the doctor or someone more fit to meet the needs of the patient...’

It became visible that the nurses aimed to bridge an existing gap in their practice. The nurses expressed that in everyday work their role primarily focused on the medical concerns of their patients’ needs, forcing them to downplay their nursing role to provide self-management support and health promotion for their patients.

The second meeting

Before the second meeting, the activity got project approval by the management. The prototype was redesigned; ten questions were added. Five of these were added to enhance validity, and the other five questions were aimed to give the patient a possibility to emphasise a certain domain of importance. The second meeting focused primarily on the instruments design, content, and appropriateness of the included questions.



Figure 5. Meeting going through the questions asked in the instrument

This meeting took the character of fit assessment, where questions like to what extent the dynamic instrument is to consider the feasibility and accord with needs, values and priorities in the health care clinic. In this step, it was clear that cultural beliefs and preferences played a central role. This can be viewed as both possible facilitating as well as a possible constraining factor for implementing the instrument. When discussing the instrument, some questions were raised about the design and content of the questions, as well as suggestions for further additions to the questionnaire.

‘...is this question, one I would understand myself? Are there any possibilities that I can add questions on my own?’

Concerns surfaced that the instrument needed to be contextualised as they wanted to have examples or personalise the items. There was an evident concern in making these questions their own. More importantly, the nurses' concern was: will the patients understand these items? We are currently working on this in two directions, partly by planning for further discussions about the content of the instrument and the meaning of the questions together with developers of the instrument, and by looking at possibilities for adaptation and revision of the instrument based on nurses' perceptions. One more practical note is that the distribution of the instrument to the patient is a bit problematic in terms of making it easy for the patients to access and answer the instrument. At the meeting, a possible solution raised was to give the patient the possibility to answer the instrument when in the waiting room on an iPad. In the light of the current pandemic, the routine for distributing the SMASc to patients is an option in need of development and re-evaluation.

Phase 2: creating a structure for implementation

In phase two, the structure is planned, which includes the outline of the implementation team and developing an implementation plan (cf. Meyers et al. 2012). One concern focused on the possible cultural differences between professions (i.e. nurses and physicians) in the workplace. The nurses expressed a fear that the physicians might not have the same positive attitude to involve SMASc in the interaction with the patients, which could influence the implementation in a negative direction.

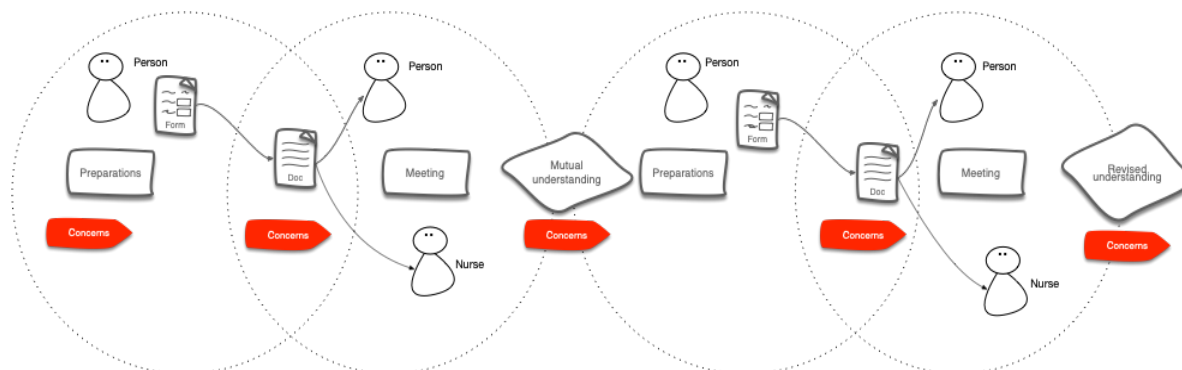


Figure 6. The discussed process model illustrated.

It here becomes apparent that a facilitating concern for the implementation lies in the fact that the nurses initiated the activity of using SMASc as a tool to redirect their practice. These two concerns, and the dynamics involved, will require a certain amount of sensitivity from all parties involved in the following steps in the development of the activity (see figure 6).

Concluding remarks

In this study, we identified concerns raised by the nurses in the early phases when implementing and involving a dynamic instrument as a practices support for nursing practice. Some concerns were raised by the nurses throughout the discussion over the digital prototype, concerns belonging to the nurses' knowledge and experience of caring, trust and ownership.

On the note on caring - in the nurses' care for the development of their practice and strive to advance and steer it in a more nursing-oriented direction, the use of SMASc could harmonise towards that goal.

On the note on trust - the nurses did not fully comply with the instrument's item formulations and how these should or could be used. Thus, we aim to create activities and opportunities to support the nurses' confidence and trust in the instrument, both regarding the instrument itself (i.e. structure and items) as well as in the use of the instrument with their patients.

On the note on ownership- it was clear that the nurses were actively working to maintain their ownership of the change activity. Onwards, more stakeholders need to be involved, i.e. patients, other professions and leaders. It is important that the nurses are given support to maintain their ownership; at the same time as, other stakeholders feel shared ownership. Their engagement and their views on the design of the instrument, and on the implementation process itself will be crucial.

The coming steps of this work will continue to explore the design and role of the dynamic instrument in the rehabilitation processes as a support for care professionals and their work giving patients person-centred care. Furthermore, it is of importance to investigate, not only the instrument's effect on self-management but also the outcome of the implementation process.

Acknowledgements

The authors wish to acknowledge the nurses and the head manager at the healthcare setting for sharing their concerns, thoughts and perspectives in the work with this activity implementing the SMASc instrument. We are also thankful to Johan Holmberg for coding prototype 2.

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Exploring the service system perspective on designing intelligent health ecosystems: the co-responsibility study

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ABSTRACT *Data-enabled design is an approach used when designing for intelligent ecosystems. It makes use of open-ended design probes situated in participants' everyday life. These probes are employed both to gain contextual, behavioural and experiential insights and to remotely conceptualize and deploy new design interventions. While the user-experience oriented perspective and the experimental, prototype-centric perspective on designing for intelligent ecosystems through a data-enabled design approach have been extensively described in previous literature, an examination of a service-system perspective is missing to date. In the present contribution, the latter perspective is explored through the lenses of a first-of-a-kind case study. The study was directed towards the development of an intelligent ecosystem for post-operative bariatric care, fuelled by clinical, behavioural, experiential and contextual data, able to provide tailored and personalized care and connecting patients, partners, and health professionals. Practical challenges and opportunities related to the adoption of a service-system perspective within the study were identified and connected to a reflection on the role of service design in contemporary eHealth innovation.*

Keywords: service design, data-enabled design, intelligent health ecosystem

Introduction

Data-enabled design (DED) is an explorative and situated design approach in which both objective and subjective data, remotely collected from the users' everyday context, is used to design for intelligent ecosystems of products, services and people. Previous case studies showcase applications of this design approach in the health domain (van Kollenburg et al. 2018, Bogers et al. 2018).

DED is an inherently multidisciplinary design approach, in which the main relevant competences (design research, data design, software development, data science, domain experience) are represented by team members from different backgrounds. In previous literature (van Kollenburg and Bogers 2019), two specific design roles have been presented as essential to the DED approach;

- The role of the design researcher, adopting a user-experience oriented perspective rooted in qualitative and ethnographic research techniques;
- The role of the data designer, adopting an experimental, prototype-centric perspective rooted in digital prototyping, software development, data analytics, and visualisation techniques.

In this contribution, we introduce service design capabilities as a third design skillset that can be relevant to a DED process. First, we provide brief theoretical considerations on these capabilities. Following, we present the results of the introduction of a service system perspective in DED through the co-responsibility case study, review the encountered challenges, and propose relevant opportunities for further research. By doing so, we intend to enrich the DED approach with a novel and relevant perspective, and to stimulate a more general reflection on the role of service design in novel paradigms of value creation in digital health.

Service design for intelligent ecosystems

Service design is a branch of design knowledge and practice which is 'concerned with systematically applying design methods and principles to the design of services' (Holmlid and Evenson 2008). Secomandi and Snelders (2011) indicate service design to be concerned both with the service interface and with the service infrastructure, identified, respectively, as the sociotechnical resources involved on the 'front-end' and 'back-end' of the exchange relations between service providers and clients. They place emphasis on the service interface as the locus in which service-related exchange relations are materialized, to the point of suggesting that the design of the service interface constitutes the design of the service itself.

Such considerations can support us in identifying a role for service design capabilities within a DED process. In fact, DED processes aim at developing propositions that reach users through specific kinds of service interfaces: those of an intelligent ecosystem.

Van Kollenburg and Bogers (2019, p. XIII) characterize the intelligent ecosystem as:

'a collection of products and services, that can together gain a detailed and nuanced understanding of the user and context. This understanding allows the intelligent ecosystem to adapt, to deliver experiences at the moment and place where they matter most.'

If we adopt Gadrey's (2000) definition of a service as the provision of a 'temporary right to use' a technical system, we see that, within intelligent ecosystems, service interfaces themselves need to be adaptive in order to ensure the timeliness of the service provision. Focusing on designing services that explicitly embed such timeliness and personalization at the level of the interface is deemed to constitute a relevant concern within DED, and one that we recognize to pertain to the disciplinary domain of service design. Because this aspect of service provision is intimately linked to the functioning of the intelligent ecosystem, we will refer to this as the *service-system* perspective.

Like the other roles within DED, the service designer cannot work in isolation. To design services that possess the aforementioned qualities, the service designer needs to obtain an understanding of the flow of information and knowledge through the ecosystem, and of its use in different touchpoints (in a certain context, at a certain moment). This understanding connects to both experiential and technical aspects of the ecosystem. In this sense, the role of the service designer in a DED process could be preliminarily identified as that of an integrator of:

- Experience-related insights, provided by the design researcher from a user-experience oriented perspective; and
- Infrastructure-related insights, provided by the data designer from an experimental, prototype-centric perspective at the level of the service interface.

Furthermore, the characteristics of services in intelligent ecosystems can be connected to a perspective that is specifically explored in traditional service design literature; the one of the *facilitator* of co-production. A central tenet of service design lies in fact in the difference between products and services, identified in the need for services to rely on a certain degree of participation from their users to become visible and tangible. Edvardsson and Olsson (1996) link service design to the responsibility of facilitating the engagement of customers in co-producing the outcome.

In intelligent ecosystems, the element of co-production is materialized not only in the user interacting with the services as intended, but also in the passive and active production of the contextual data fuelling the ecosystem. From a service system perspective, the user of the intelligent ecosystem is a continuous 'co-producer', whose actions and interactions, materialized in the form of data, sustain the ecosystem intelligence. An additional potential role for service design in a DED process is therefore recognized in the capacity to safeguard, prioritize and facilitate digitally mediated co-production in the intelligent ecosystem.

Case study

The Co-responsibility study

The 'Co-responsibility' study was a clinical trial following an explorative data-enabled approach. The study focused on the time following a bariatric or weight-loss surgery, in which keeping up with suggested lifestyle changes (e.g. regarding nutrition and physical activity) can prove challenging for patients.

Long-term success in maintaining optimal lifestyle appears to be significantly affected by the support provided by the healthcare professionals and the social circle surrounding the patient. Therefore, it

was decided to investigate the potential value of an intelligent ecosystem designed for *co-responsibility* between patients, partners, and healthcare professionals. In line with Neutelings et al. (2017), we defined co-responsibility as the ‘responsibilities of people being intertwined, not in the sense that people share the same responsibilities, but in the sense that peoples’ responsibilities are interdependent’.

An intelligent ecosystem consisting of a communication platform (chatbot and mobile application), a Fitbit activity tracker, open-ended data trackers (flic button, rotary buttons) and event trackers (smart power sockets, motion sensors) was designed and deployed at the homes of six participating families. Using this system, we were able to explore the context and to develop and test design interventions involving the patient, partner and a team of healthcare professionals. Each family was recruited via the Obesitas Clinic of the Catharina hospital residing in the Eindhoven region of the Netherlands. The study was classified as a clinical trial and its setup was approved by the Philips internal ethical committee (ICBE), the medial ethical review board of Santeon Hospital group (MEC-U), and the local feasibility committee of Catharina Hospital.

The project was initiated by a team of design researchers and a data designer. By decision of the team, a service designer adopting a service-system perspective was then involved to support the project. This introduction surfaced both practical challenges and opportunities, which will be described in the next section.

Challenges and opportunities

Service designer as the integrator of the other data-enabled design perspectives

By the time the service designer had joined the team, extensive data-enabled explorations had already been performed. This had resulted in the accumulation of rich insights both into experiential factors related to the post-surgical context, and into the technicalities related to the explorative ecosystem built for the study. Several ideas and intuitions related to possible (smart) functionalities and features of services in a future ecosystem had emerged.

Among these, we can mention

- Ideas on how to provide the intelligent ecosystem with adaptive capacities (e.g. based on a user profile including medical history, baseline questionnaires, etc.);
- Ideas on how to surface and foster co-responsibility within the intelligent ecosystem;
- Ideas on how to provide health information previously delivered through non-digital media;
- Ideas on how to use specific probing devices (e.g. Fitbits, smart sockets, open data trackers) within the intelligent ecosystem.

From a service system perspective, each of these sets of ideas could provide valuable insights into desirable characteristics of service *interfaces*, and as such could be used as service design input.

Yet, early efforts to sketch the map of an integrated digital infrastructure that would permit the development of these ideas within and ecosystem framework proved challenging. This is

because each of the indicated interface-level features required the conceptualization of an automatized sub-process at the level of the infrastructure. For instance, the interface-level feature of 'adaptivity of service based on user profile' required, at the level of the service infrastructure, the conceptualization of a sub-system that would automatically manage options for personalization in a structured way, and would influence ecosystem interactions accordingly.

To this end, it is important to note that the conceptual complexity of the infrastructure behind an intelligent ecosystem tends to increase exponentially, rather than incrementally, with the addition of each element of 'smartness' perceivable at the level of the interface. This is because each newly added subsystem needs to interrelate to all other subsystems in a planned and rigorous way to ensure system coherency. Consequently, even simplified conceptual maps of an intelligent ecosystems' underlying infrastructure appeared overcomplicated and lacked capacity to show all of the relevant logical interdependencies (see Figure 1.) From a service-system perspective, this challenge surfaced opportunities for future efforts to improve the *integration* of rich experiential and technical data-enabled insights through:

- A strict prioritization of the features considered for service design, at least in early conceptualizations of the ecosystem;
- A strong alignment between the service designer and the data designer in order to manage technical trade-offs;
- A clear value proposition to guide interdisciplinary design choices.

Service designer as the facilitator of data-enabled co-production

Some of the most interesting service feature ideas emerging from the study relied on active user participation. For instance, the idea of embedding a way to track 'co-responsibility' trends between a patient and partner relied on both participants periodical filling of a fixed questionnaire, thus on their disciplined co-production of ecosystem-relevant data. From a service system perspective, this raised questions on the possibility and opportunity to impart designerly control over the behaviour of the users in the ecosystem setting. In these terms, a challenge was identified in reaching an appropriate balance between the designerly control necessary to guarantee the intended functioning of the ecosystem, and the flexibility necessary to embrace and accommodate users' possible non-compliance or deviation from expected behaviour.

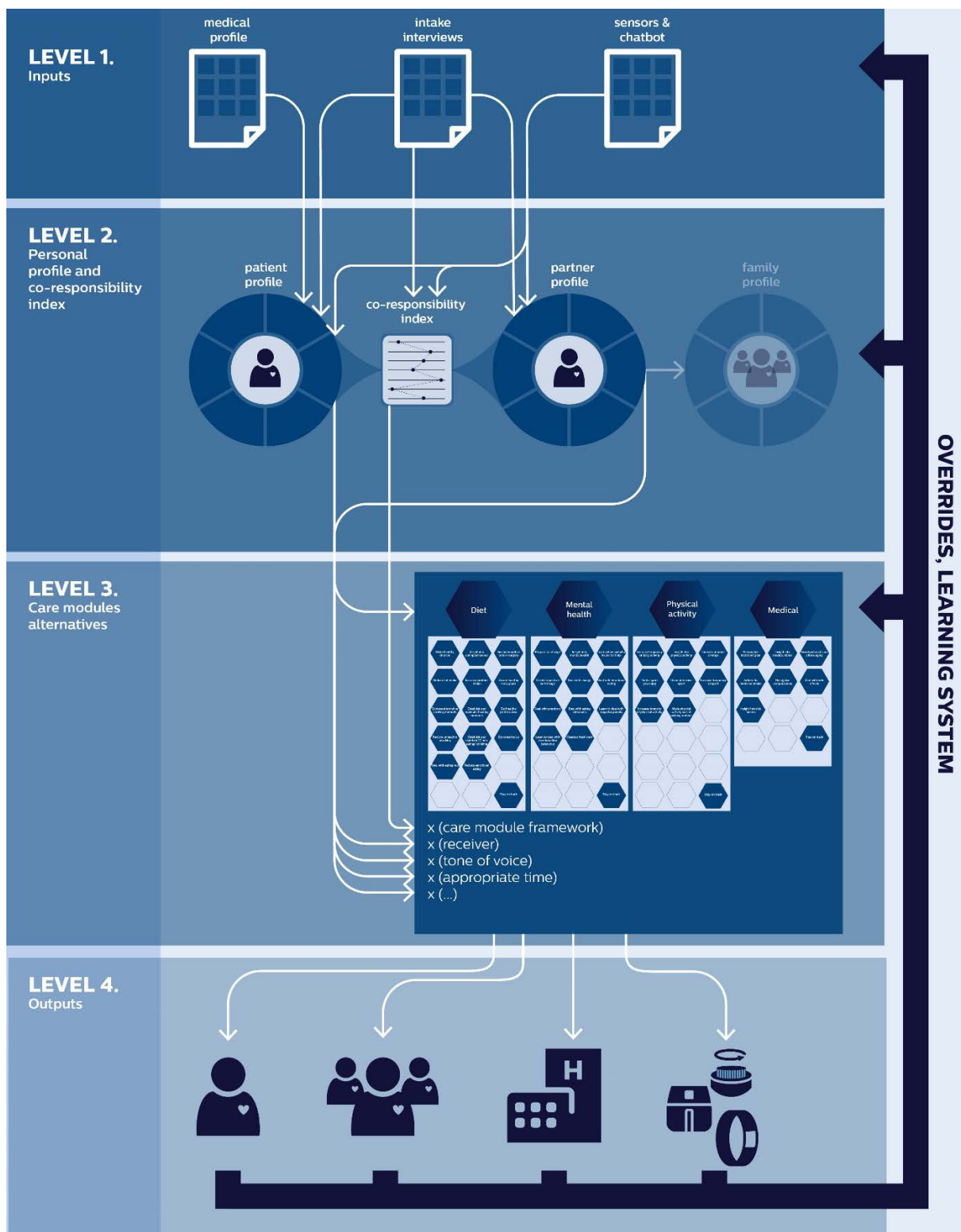


Figure 1. Early system map

An opportunity to overcome this challenge could be found in Snelders et al. (2014), who can be credited with the notion of an appropriate balance of designerly control in service design, and who posit that 'the degree of control that designers possess should be contingent on the degree in which people in a service setting can accept the intervention of external parties to improve their social well-being'.

Their contribution suggests a connection between the levels of user tolerance for designerly control and the perceived utility of the service for the 'greater good' of improving social wellbeing. Similarly, in the Co-responsibility case, we can imagine that acceptance for designerly control would be conditional to the perceived utility of the service in supporting users' successful post-operative recovery. Future research could investigate the accuracy of this expectation, and further inform service design best practices when balancing between control and flexibility in digital health.

Discussion

Relationships between service designer and data designer

As previously specified, service designer capabilities can only be integrated within in a DED project through close collaboration with the other capabilities involved in the project, mainly design research and data design. However, we would like to reserve special attention to the relation between service designer and data designer. In fact, we experienced the establishment of mutual understanding between these two roles to be possibly hard, but indispensable for successful collaboration. This is because the sketching of even just early service ideas within an intelligent ecosystem does require an iterative back-and-forth between a service-system and an experimental, prototype-centric perspective. During our project, we sometimes struggled to reconcile the two perspectives due to important differences in approach, knowledge, experience, and even vocabulary. However, we have found such struggles to be not only fruitful for the project, but also, ultimately, mutually enriching.

Implications for service design in eHealth

The considerations contained in this contribution can lead us to a more general reflection on the role of service design within the contemporary discourse in eHealth innovation. eHealth is in fact a domain in which both the *integration* of different disciplinary perspectives and the *facilitation* of digitally mediated service co-production appear to be recognized as largely unanswered needs.

Regarding the former aspect, Pagliari (2007) offers a compelling overview of the need for improved interdisciplinary integration in eHealth design and evaluation, while Romm and Vink (2019) reflect on the capacities of service designers in healthcare to act as 'catalysts' of the multiple relevant points of view.

Regarding the latter, Tummer et al. (2016) points out the opportunity to improve care co-production through enhanced use of Information and Communication Technologies (ICTs), and Boye (2012) provides an early theoretical framework for digitally mediated health co-production. In this sense, we believe our contribution's relevance to extend beyond the borders of DED, and to connect to the broader discourse at the intersection of service design and digital health.

Limitations

An important limitation of our work consists the uniqueness of the presented case study, a first-of-a-kind project under several points of view. Furthermore, we acknowledge that the dynamics we

observed in the project might have very well been drastically influenced by independent circumstances, such as the team members' backgrounds, skills, and personalities. Accordingly, we see our preliminary considerations on the service-system perspective in DED to be project- and team-dependent. Finally, we believe our conclusions should not be interpreted in a way that constrains design professionals into too rigid roles and definitions. To this note, we point out that tasks that could be considered to be afferent to service design have been successfully executed in previous DED projects without the involvement of a formally trained service designer.

Conclusions

In this contribution we introduced the role of the service designer within the data-enabled design process. After touching on some theoretical considerations, we reviewed the challenges and opportunities related to such role as observed in a single case study. Finally, we briefly reflected on the relationship between the role of the service and the data designer and situated our contribution within the larger context of digital health innovation.

Acknowledgements

We would like to gratefully acknowledge Dirk Snelders and Jeroen Raijmakers for the helpful feedback and advice.

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Beyond Speculation: Using imperfect experts for designing the collective futures of healthcare for space

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ABSTRACT From healthcare products and services to hospital environments, designers have been involved in shaping tangible transformations and improvements for the future of health(care). Lesser developed are design practices for shaping care models, strategies, sustainability, policies and other less tangible and longer-term health(care) futures. Critical speculative design, scenario planning and road-mapping have been practiced by designers to address such futures. However, there are problems with using these methods to envision new futures in action: critical speculative design has poor feedback loops and dissemination issues, confining it to special interests, and scenario planning has the top-down issues of ‘impartial’ observation, making it unsuited to wicked problems. The further we look into the horizon the more unknown-unknowns we encounter, the harder it is to rely on existing knowledge, trends and extrapolation for envisioning new health(care) futures. Inspired by these issues, we explored a new method to generate alternative futures - encouraging wider participation and in the context of complex technology-driven healthcare for space. Through abductive thinking and participant observation, a new concept of the ‘imperfect experts’ was developed to address the issues of design futures, scenario planning and participation in complex futures.

Keywords: imperfect experts, collective imagination, healthcare futures, healthcare design

Introduction

Design is embedded in healthcare systems to support the delivery of tangible transformations through solving well-scoped problems - typically as product, service or innovation design in medical devices or in a hospital management. As the world's population increases, urbanises and ages, the demand for sophisticated and complex healthcare intensifies. Meanwhile, connectedness and mobility add further complexity and reduced predictability. Beyond reduced predictability, known-unknown healthcare issues such as rare diseases and antimicrobial resistance persisted in the background. On top of that, flash surges of unknown-unknowns for healthcare induced by black swan events are not that rare: Ebola, Zika, Covid-19 outbreaks, violent political protests in Hong Kong, Chile, Iran, and Brazil and extreme weather events are in recent memories. Finally, new brittleness and capabilities are added by digital technologies, which take effort and time to be proven and integrated, then, disproven or reintegrated with updates. The problem space in healthcare is increasingly wicked as a result. The increasing wickedness calls for new approaches for designers to contribute to future healthcare issues.

How might we design future resilience for healthcare products, services, systems and policies, given the wicked and chaotic nature of the problems?

Healthcare Futures

There are many methods available to designers to tackle future issues e.g. anticipatory design science (Fuller 1992), prospective design (Galdon and Hall 2019), speculative and critical design (Dunne 1999), scenario planning (Kahn and Wiener 1967) and design roadmapping (Simonse 2018). We have identified specific examples of speculative and critical design (SCD), scenario planning and design roadmapping in healthcare settings to illustrate the disciplinary diversity of and the common limitations when addressing unknown-unknowns in futures design methods.

SCD emerged from industrial design and was largely established by Anthony Dunne and Fiona Raby at the Royal College of Art in the 1990s. The idea is to shift from designing manufacturable technology products to designing speculative objects that provoke critiques on the social implications of technologies in the future (Dunne 1999). For example, Chamberlain and Craig (2017) created speculative objects by merging furniture with medical objects, e.g. infusion lamps, to critique the invasion of healthcare into domestic home spaces. Whilst the objective of speculative design is 'not to be didactic' (Dunne 1999, 13-14), such speculative design requires the viewer to be imaginative, reflective and be able to enlarge the conversation into wider cultural, social and political concerns. Design fictions, a recent evolution on SCD, appears to address this issue by providing a hypothetical context for the speculative objects.

'A design fiction is (1) something that creates a story world, (2) has something being prototyped within that story world, (3) does so in order to create a discursive space.' (Lindley and Coulton 2015)

For example, *Uninvited Guests* (Jain et al. 2015) is a short film that explores the implication of speculative smart objects for healthcare. In which, the organised disharmony created by the technological objects was illustrated in a spelt-out context - at the home of an elderly man whose children cannot be present to care for him. In the United Micro Kingdoms (Dunne and Raby 2013), Dunne and Raby have further structured the alternative future contexts. Instead of one context, four

alternative contexts are created: Digitalitarians, Bioliberalists, Anarcho-evolutionists and Communo-nuclearist. Within each context, a corresponding speculative object (transportation) is situated.

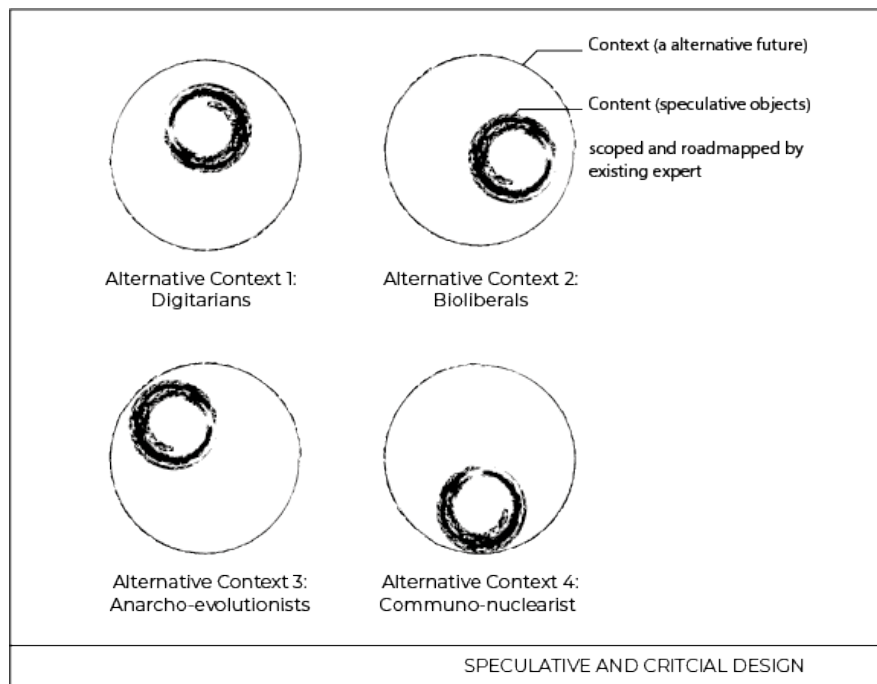


Figure 1: Structure of design fiction (SCD)

By placing the alternative futures into the same temporal world, interactions between alternative futures are afforded in thought-experiments. The limitations are that thought experiments are, however, not automatically a discursive space and certainly not part of a systematic feedback loop to design a resilient healthcare system and policies.

Scenario planning stems from military-political practices in the 1950s, the formalisation of the field is attributed to Herman Kahn. A scenario is defined as 'a set of hypothetical events set in the future constructed to clarify a possible chain of causal events as well as their decision points' (Kahn and Wiener 1967, 6). It is only one aspect in 'a framework for speculation', situated within a systematic context. The context is known as an alternative future - a 'canonical variation' from the 'standard world'. The standard world is constructed based on extrapolation on trends and the canonical variations are based on the main expectations of the policymakers and other cases of interests. Kahn and Wiener (1967) defined three alternative futures: a 'more integrated world', a 'more inward-looking world' and 'a greater disarray world'. This structure of using four contexts has been adopted by many other scenario planners (Amer et al. 2013).

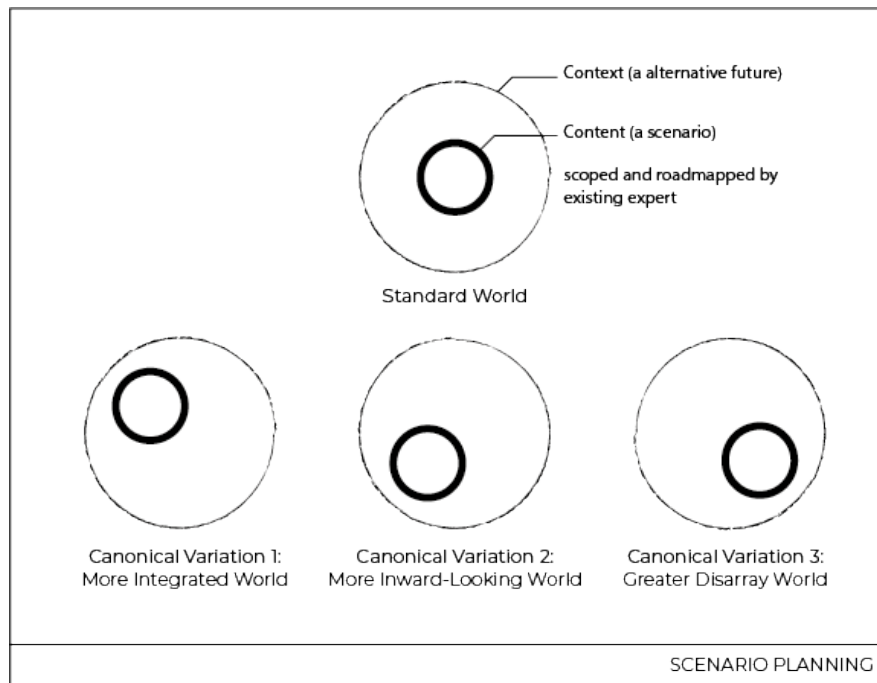


Figure 2: Structure of scenario planning

In a way, the structure of scenario planning and design fiction is not dissimilar: an alternative future (context) and one or more tangible content (scenarios or speculative objects) within it. Where a 'design-for', expert-led approach is taken to construct the contexts and contents. The speculative designer or an invited group of experts in scenario planning design for the public.

Finally, the alternative futures do not exist independently from the present. Design roadmapping is a visualisation tool, used by designers, to map out products and services, forming tangible links between the present and future.

The issue, in all three methods, remains that the further we look into the horizon, the more unknown-unknowns we encounter and the harder it is to rely on existing knowledge, trends and expertise. The ability to design for unknown-unknowns is a critical weakness in all of these methods - in that they are invariably limited by current expertise that is largely based on the historical knowledge of what is known. A number of key questions emerge: Who can we design with for healthcare futures characterised by unknown-unknowns? What is the designer's role? How can we link future experts with current experts?

Imperfect Experts

The problematic nature of wicked healthcare futures is exemplified in the extreme context of healthcare in space - the context of our 18-month research project. Firstly, experts are rare and hard to access: only 600 spacefarers have been to space to date. Secondly, known knowledge is limited: health hazards, system and knowledge are developed from and for a population of narrowly selected and highly trained spacefarers. Finally, the trends in human spaceflight are at odds with the existing healthcare knowledge and system, as commercial spaceflight will change the demographics of spacefarers. Although less visible, such wicked healthcare problems also exist in everyday healthcare problems: in designing for rare diseases or responding to black-swan events. Views on

alternative futures are extremely vital to address the unknowns in these cases as the projected future (business-as-usual extrapolated) is a vision of false-safety. The concept of 'imperfect experts' emerged from exploratory research to design for such context.

Methods and Approach

The overarching research method used was research-through-practice, driven by abductive thinking.

One imperfection probe (online), three design games (over seven workshops), one co-speculative design workshop and one design improv was created to facilitate an effective process for the collaborative design of the contexts and contents of wicked healthcare futures. Many issues are addressed beyond the issue of expertise in the project. In this paper, we are only discussing aspects of the project of significance to addressing this one issue: expert for unknowns, which can be broken down into smaller objectives: (1) who are the future-experts and (2) how to form a feedback loop with the experts. The two most relevant methods and associated tools created are described below:

The Imperfection Probe and Future-Zines

Taking inspiration from the cultural probe (Gaver et al. 1999), the imperfection probe was developed in order to probe the distance of imperfection in speculation. An implementation takes the form of an online participatory design fiction activity, technically using a tool that is widely used for online surveys. A short fiction (a job advert: New Opportunities for Adventurers to join Mars Occupational Adventure) and the ground rules for participation are embedded at the start of the 'survey'. Participants were invited to read the short fiction and perform participative storytelling using the navigation mechanisms of a survey, i.e. survey 'questions' were part of an extended storyline that guided narrative contribution. To facilitate abstract and visual thinking, a tool called future-zines is created. Future-zines are a set of front-covers of reading materials from the world of fiction. For this study, they are related to health and wellbeing on Mars, these specialised future-zines are called Marzines.

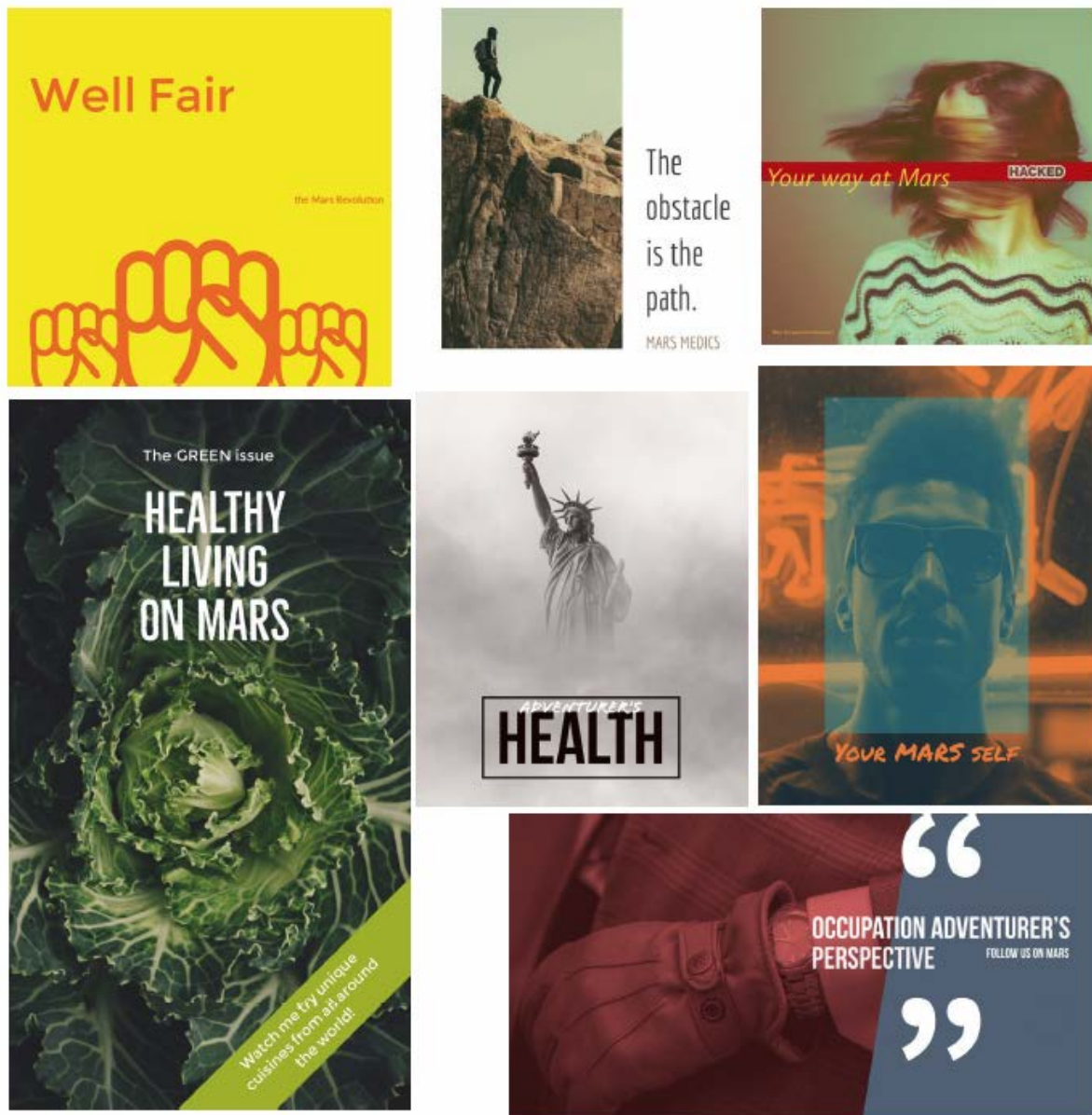


Figure 3: Marzines

Design Improv: 'Design Fiction: Mars Adventure'

The design improv takes inspiration from improvisation theatre to evolve a collective narrative, but without the focus on character work. The warm-up and planning stage is facilitated by visual thinking via Mars Landscape Cards (images of real Mars landscape with simple descriptive text), pre-created props and materials for props creation by participants. The session is three hours long, with mostly warm-up and prop creation activities, leading up to the performance of a sketch of the alternative futures (which is then iterated once more).

Both methods are designed to create a permission to voice alternative views and articulate tacit knowledge. Alternative views and tacit knowledge are ways to uncover future unknowns, to 'know' beyond the standard world and expert knowledge.

Discussion

We started with the experts before arriving at the imperfect experts. The experts, in this context, are the extreme/space medicine researchers and astronauts. These (perfect) experts provided views that are cutting edge but firmly grounded. As de Bono puts it: 'It is not possible to look at the different direction by looking harder in the same direction.' (De Bono 1974, 26) The 'perfect experts' are perfectly disadvantaged by their expertise, as it imposes a self-limit on the permission to imagine with unknown-unknowns.

Who can contribute context and content of the alternative futures? We propose that they are the imperfect experts. But who are the imperfect experts?

In June 2018, a workshop was conducted with a community of practice to co-speculate the future of healthcare in space. A community of practice is a group of the public with a shared concern - the participants to co-speculation as proposed by Julia Lohmann (Lohmann 2017, p.90). Such a group naturally diversifies the point of views when envisioning the potential and possible futures (Lohmann 2017, p.74). The twelve participants are invited by a living lab (Living off the Earth II). Divided into two groups, the community of practice created two design fiction (included speculative objects): (1) space nomads that can manipulate and collide stars for entertainment to relieve wellbeing issues and (2) the design of a 'hoppercraft' and other facilities for mountain rescue in terraformed Mars. Whilst the co-speculative process was very much enjoyed by the participants, it was not immediately clear how this set of results would work as a feedback to the experts. The contexts appeared to be not expansive enough, such that the content reached dead-ends: with the space nomads, dead-end of not being able to further imagine was encountered at one point; with the terraformed Martians, dead-end takes the form of all problems solved.

In parallel, the imperfection probe was being designed. The imperfection probe was sent to people who work and/or study in design, space, healthcare or related industry. The self-limitation observed from the perfect experts was also observed to a lesser extent from terrestrial healthcare professionals who participated in the imperfection probe. People who worked in terrestrial healthcare or related industries have consistently juxtaposed a present-day medical issue with a well-known space environment effect in a rather objective way; in one case, a participant remarked that 'it's too hard for someone who doesn't know much about space'. Whereas the designers and some outliers have taken their content further and alluded to contexts of alternative futures in their narratives. The outliers are attendees to a technology-culture festival in the UK and are additional participants to the original list. In the technology-culture festival, a three-hour workshop entitled 'Design Fiction: Mars Adventure' was attended by eleven participants. The two groups of participants were facilitated to create props and perform an improvisation act of three to five minutes each. Team Deuterium Scouts performed a design fiction in the early days of terraforming Mars, where humans are enveloped in life-supporting technologies; complicated, action-fuelled, power dynamics unfolded between the medical professionals and the explorers within the team - all for the sake of the new energy source. Team Plant Fodder performed a design fiction where humans come into contact with unknown lifeforms on Mars; a series of everyday issues were raised and a drama of profiteering by pharmaceutical organisations has twisted and turned towards a comical end of total galactic infection.



Figure 4: [top] Participants posing after the improv with props constructed by themselves (except helmet)
[bottom] Props generated in the workshop

This group of culture-sensitive-technologists created deep contents (props as speculative objects/diegetic prototypes) and rich contexts about alternative futures of healthcare in space. Without turning into the extremes of utopia or dystopia, hopes and fears, facets of wicked problems of the futures are explored. The expression is succinct and articulated. Overall, the output can easily be imagined as feedback for perfect experts. This, as it emerged, are the views created by the imperfect experts.

During this process, a new requirement emerged. Given the qualities of the alternative futures created by native imperfect experts is identified and our role is to facilitate: Can we facilitate people into acquired imperfect experts who would produce results of the defined quality? Can we scale up the approach?

Such is the question XHealth Lab is trying to answer. XHealth Lab is founded on the tools and techniques that have succeeded in facilitating imperfect experts to imagine alternative futures. The objective is to shift from the construction of the context of the alternative futures from a design-for to a design-with approach, addressing the 'impartial' construction of the structure in which experts speculate. In this way, perfect and imperfect experts collaborate in a way that combines their strengths and alternative future perspectives.

Conclusions

Imperfect experts are defined as people whose expertise is not an obvious match with the problem and futures that are being researched and might not even share the concern of the topic. The imperfect experts (1) do not have to have a recognised profession, their expertise can be in their tacit knowledge, for example, for being a cyborg and (2) do have the permissions to imagine. The outputs from the imperfect experts are the deep contents (props as speculative objects/diegetic prototypes) and, more importantly, rich contexts about alternative futures.

Participatory speculation with imperfect experts leads to results that are the inverse of speculative design. It does not explore the unknown implication of the latest technology but explores the well-known hopes and fears for the futures from the imperfect experts. The gap of unknown knowledge is addressed by answering a different question: what is desirable, as opposed to what is preferable given the state of technology or forecasts. Unlike utopia or dystopia, hopes and fears are not dead ends and can be expanded and explored. It is by setting the context of alternative futures using different hopes and fears that we would be able to account for and deeply engage in wider stakeholder perspectives. Ultimately this has allowed us to reposition the issue of expertise of the future.

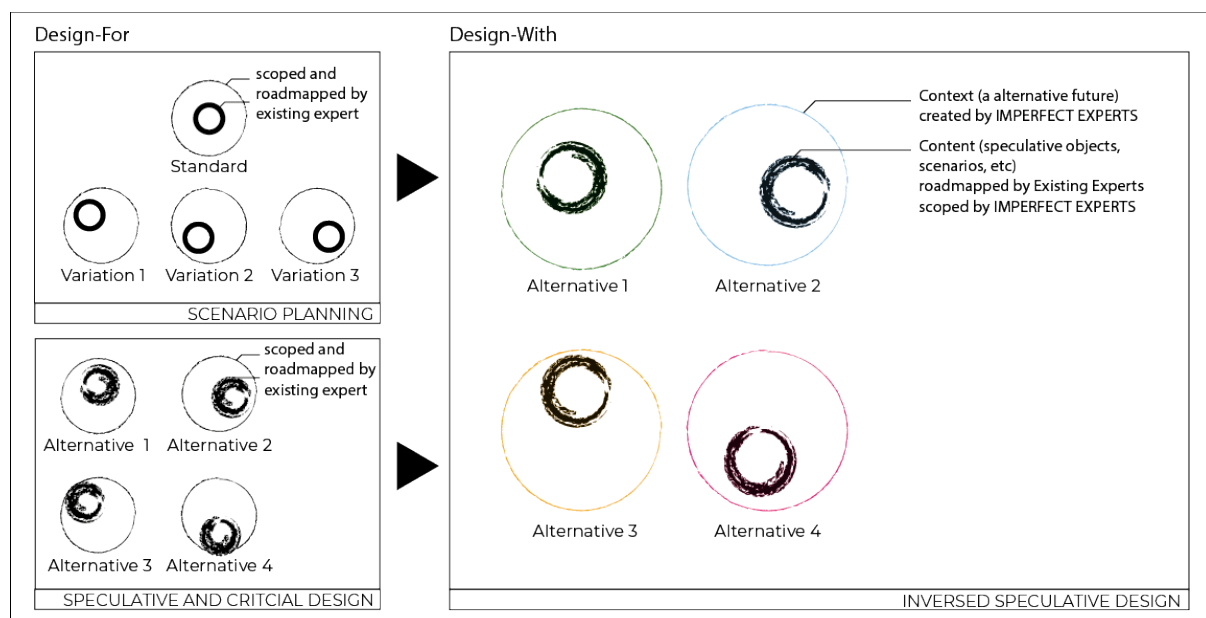


Figure 5: Structure of inverse speculative design with imperfect experts and experts

By bringing together the experts and imperfect experts we have a new opportunity to avoid further polarisation or disconnection in the design of resilient future healthcare products, services, systems and policies.

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Healthy and happy ageing in rural areas: The contribution of architectural interventions

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ABSTRACT *In Belgium, the share of persons aged 60 years and older is projected to reach 32.4% by 2050. Moreover, the older population itself is ageing, and is continuously becoming more diverse. At the same time, it is clear that people entering old age have different housing experiences, expectations and needs. As home and the home environment gain importance when growing older, it should be considered as a significant type of place providing the link between one's dwelling and one's wellbeing and identity.*

In Belgium, the housing landscape is scattered over urban and more remote, rural areas. Although most people are aware of the paradoxes that rural living brings along (e.g., tranquillity of living vs. lack of services and poor infrastructure), an over-representation of Belgian older people live in non-urban areas.

In a Masters class, we explored how older people living in a particular selection of two small-scale villages in rural areas, try to perform 'healthy and happy ageing' in place today. Via the application of an intergenerational approach, Masters students in Interior Architecture performed research with the help of local inhabitants. They first documented how people living in these villages, organize their daily life and living practices. Various research methods were applied: students performed interviews, used walking as a research method as well as observations throughout the villages. Evidently, also sketching was applied. As a next step, students developed spatial scenarios of inspiring (living) practices for the villages involved in the project, all enabling healthy and happy ageing. The designerly 'solutions' to stimulate healthy and happy ageing in place demonstrate students' efforts to design and reassure sustainable rural community living, contributing to people's subjective well-being.

Keywords: design for wellbeing, ageing in place, spatial scenarios, lifelong living, interior architecture

Introduction

Living in general, and living for older people in particular, faces many challenges today and tomorrow: there is the double wave of the greying of older people, the changing zeitgeist and a shift in mentality regarding ways in which older people want to be able to live when getting older. In addition, there are changing family structures. Also, like many other population groups, older people are very heterogeneous and diverse, and ideally this diversity should be reflected in the residential landscape (Petermans et al., 2019). To date, however, this is not self-evident; this is also the case in the region of Flanders, the Dutch-speaking northern part of Belgium.

Many Flemish municipalities pursue a policy of lifelong living, and are increasingly trying to take account of the influence of the ageing of the population which also affects the so-called 'Leader' area (see Figure 1), which concerns a region in the South of Limburg (one of the Flemish provinces).



Figure 1. Leader area in the province of Limburg, Flanders, Belgium

Source: Provincie Limburg, 2020

We know from research that the countryside in particular colours 'grey' if one looks at the composition of the population (De Decker et al., 2018). In 2020, at least 25% of the inhabitants of every Leader municipality will be 60 years of age or older; in 2030 this percentage will already increase to +/- 33% (Steunpunt Sociale Planning, 2013). Many older people will be in need of care. But does the Flemish countryside lend itself to this? In what follows, we concisely summarize noteworthy findings regarding housing in the Flemish countryside:

- (i) Flanders is characterized by a spread of housing, whereby houses often are concentrated along main roads that form a kind of line or 'ribbon' of development.
- (ii) On the countryside, the presence of services is an issue. There are many small villages, many of which lack facilities (e.g., a bakery, a small-size supermarket). Due to this, people become more dependent on surrounding cities. This has an impact on many aspects, for instance mobility.
- (iii) There is a high percentage of house ownership in Belgium, thus also on the Flemish countryside, certainly among older people. The fact that many people in Belgium are

owner of the house where they live, is inextricably linked to the desire/necessity/feeling to adapt (or not) something in one's house. Moreover, we know that today, a relatively large proportion of older people in Belgium live in relatively old houses, which are generally not (well) adapted to ageing and possible difficulties that older people might experience in this phase of life (PETERMANS et al., 2019).

- (iv) Although we know that the housing situation of older people in Flanders is far from good (i.e., 40% of older people live in dwellings that are highly inadequate for old age) and moreover, it appears that 37% of Flemish houses have insufficient housing quality (measured by objectifiable parameters), Flemish people appear to be very attached to their own house.

Over the past few years, research projects have been launched in which consideration has been given to housing modifications and/or innovations in housing for older people, but this usually involves a great deal of attention to objectifiable parameters and ways in which these can help improve or stimulate the quality of living and, ultimately, people's well-being. Internationally, however, attention to people's well-being and happiness has also been growing in recent years, calling for more attention to be paid to subjective aspects (Desmet & Pohlmeier, 2013) and the importance of 'activity' in these (Lyubomirsky, 2007).

This paper elaborates about the set-up and results of a Masters class, focusing on healthy and happy ageing in rural areas via an exploration of the contribution of architectural interventions.

Master Class

Set-up

In a Masters class that was set-up as a two-week full-time workshop, students were offered a mix of theory and practice. In this intense class of 2 weeks, all Masters students of the Interior Architecture training program were involved and in different teams, focused on two small villages: Montenaken and Binderveld. This Masters class was part of a Leader project on 'lifelong living' in which the aim is to learn from people how they already try to 'live lifelong' in a number of small villages in Haspengouw. We have consciously chosen to do this research in dialogue with residents: older people, but also the young generation, i.e. the children who live in the selected villages and / or go to school there. In this way we hope to indirectly strengthen the social dialogue in the village.

Successful ageing has to do with activities, and with the ability to be or become older in an active way. This depends partly on older persons themselves, of course, but is also related to a present local offer (regarding various aspects) & the 'desire' of older people to participate in these offerings. For instance, are there (enough) local opportunities and possibilities for older residents to meet others, to do things they like (physically, cognitively, emotionally, ...)? In the Masters class, such considerations were taken into account.

Locations

In the Masters class, we focused on 2 municipalities in South Limburg: Gingelom and Nieuwerkerken. In Gingelom, students focused in particular on the village of Montenaken. In Nieuwerkerken, the students focused on the village of Binderveld.

Montenaken is a village in Gingelom that has 1442 inhabitants. Today, Montenaken already has more than 30% of inhabitants who are 60 years of age or older. Montenaken is well equipped in terms of facilities: there is a residential care centre, a primary school, and there are several basic facilities: bakery, butcher, etc. There is also a sports hall and a culture house. The board of the residential care centre that is present in Montenaken is currently considering expanding and creating a larger department for people with dementia. In addition, consideration is also being given to the start of a 'village house' in Montenaken, as this could be a real meeting place for the inhabitants. In this Masters class, both avenues (i.e., an extension for the residential care centre and new village house) were presented as inspiration for the students: can a kind of hybrid concept be developed around this that facilitates lifelong living and healthy and happy ageing in place in Montenaken?

Binderveld is a village in Nieuwerkerken that has 663 inhabitants, where the number of people over 60 currently fluctuates around 25%. The village is 'cut off' from neighbouring villages or municipalities. In Binderveld there is a kindergarten; above the spaces that accommodate the kindergarten, there is a meeting place present. No other facilities are present. In the class, we want to find out how this village currently works, and how the residents organise their daily lives. How do they work? How do they shop? How do they live? In other words, how do they organize themselves in terms of many facilities, care, mobility, ... So the key question in the Masters class for the teams focusing on this village, is what the future prospects are for this village, and for the houses in this village. Is it possible to live here 'lifelong'? This is already happening today (see the number of older people currently living in the village), but can this also be realised in the future? Is that possible; is that desirable?

Methodological approach

The group of students as a whole was split into 5 teams who focused on Binderveld and 5 teams who focused on Montenaken. Every team consisted of 4 students.

After being offered an introduction and a variety of inspiring lectures, the students were triggered to 'break out' of the faculty building and go explore the small villages concerned. Here, they documented their experiences and observations via a diversity of research methods, ranging from (i) walking through the villages in order to get to know and grasp the context (ii) making photographs of various kinds of inspiring things, aspects and people they discovered (iii) studying maps of the village (iv) doing interviews with inhabitants of various ages (v) performing observations in the village to learn 'how things are being done'. This diversity of methods was employed in an effort to learn how the concerned villages 'work', how people organise their daily lives, and what kind of movement patterns they develop in order to structure their lives. The students also collected stories and experiences of residents regarding 'lifelong living' by exploring how inhabitants of these small villages 'live' in their houses, gardens and neighbourhood. Starting from these accumulating insights,

the student teams pitched their design concepts at the end of the first week of the Masters class. In the second week, they further developed their ideas in detail. At the end of the second week of the class, their final results were shared in a jury, consisting of design studio teachers, involved researchers and a policy maker of the involved municipalities.

In what follows, we describe one project per village, that was very positively welcomed by the final jury.

Results

Montenaken project: “Buurtkast”

After their exploration of the small village, this team soon decided that inhabitants could easily have contact with each other, but they also noted a feeling of solitude; people do talk to each other, but often these talks are not very profound. They also look forward to getting to know new people. Inspired by this finding, the team proposed to work on an intervention in public space where people could share something, or where they also could leave a note about who they are and what they're good at. In that way, people could 'offer' something that could be of use or meaning to somebody else. This resulted in the 'Buurtkast' (see Figure 2).



Figure 2. Concept sketch of the 'Buurtkast'

The 'buurtkast' concerns an old cupboard that one of the inhabitants of Montenaken donates to the neighbourhood. A small group of volunteers transforms the cupboard into a mobile cupboard that is easy to use and transport. The cupboard is an important gathering point for cards that in first instance are spread all over the village via a postal mailing. Evidently, inhabitants also will be enabled to print the cards at home, or they can find them in the facilities that are present in the village. On the cards, they can mention who they are, where they can be contacted, what they like or want to share, or with what kinds of activities they would like to help or assist others. For instance, a

person who is living alone, loves to bake cakes, and is looking for people to want to share a piece of cake with her. Or a girl for instance likes pets but doesn't have one of her own, but would love to help others in taking care of a pet. Such messages can be shared on cards they bring to the 'buurtkast' to share their qualities or capabilities with others and broaden their networks.



Figure 3. Spread over cupboards over Montenaken

In the design, this student team foresaw various cupboards to be spread over Montenaken (see Figure 3). As these cupboards can be considered as 'strange objects' in the environment, which 'travel' over the village, they have the ability to quickly become a kind of 'landmark' that triggers curiosity from various inhabitants. By coming up with this intervention, this team contributed to community building and a feeling of connectedness among the inhabitants of this village, instigating their subjective wellbeing.

Binderveld project: "Opening (up) the landscape – a park in Binderveld"

Overall, this team of students noticed that people enjoy living in this peaceful, quiet village and would prefer, if possible, to be able to live here for life. The interviewed people discussed how they mostly have a good contact with direct neighbours, but contacts of less quality with new neighbours or people living a bit further away from their house. They are aware their house probably would need some kinds of adaptation in order to perform 'lifelong living', but they demonstrated a willingness to do so if that would make 'lifelong living' possible. In their view however, taking initiatives or setting up architectural interventions that could help boost social contact among inhabitants is more important than providing co-housing or kangaroo houses, for instance.

This team took up this challenge, and decided to open up the landscape in Binderveld to create a place where people from various generations, from in- and outside the village, could meet up. By walking around in the village in the first week of the Masters class, they discovered a park-like environment that is currently informally closed-off from the village (see Figure 4).



Figure 4. Location of park-like environment in relation to the village of Binderveld

By proposing to 'clean up' this environment and designing installations that would be created with natural materials, they re-designed the space and came up with a beautiful park environment where people could meet up. The different symbols, present in Figure 5, demonstrate how this team foresaw places for being physically active, exploring nature, having a coffee, playing or just relax and enjoy nature. These different interventions appeal to a diversity of people of different generations and allow them to take part in activities that contribute to their subjective wellbeing and health.

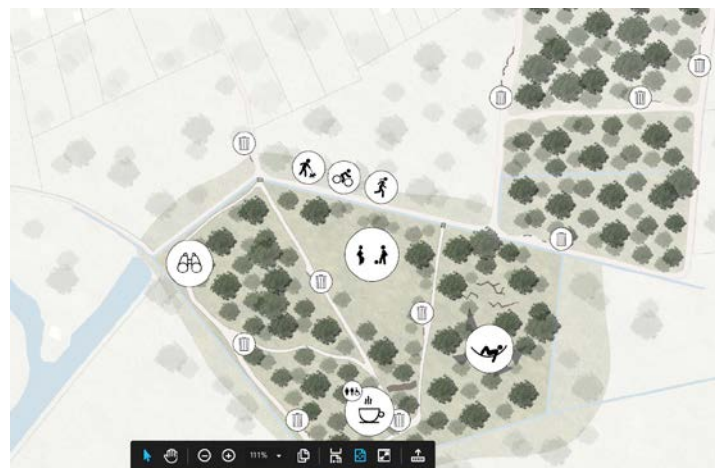


Figure 5. Concept overview of activities in Binderveld park

Discussion of results

Overall, the design results mainly came down to a focus on space for meeting other people, as well as the importance of the social fabric of the village as a healthy space that is safe, accessible and attractive. Students' concepts that were presented in this paper can be synthesized as (temporary) interventions in the public space (street or inner area), or as a 'hub' where people could meet up. Within the framework of life-long living, students thus looked at how a space could be arranged carefully, functionally, experiential and meaningful, contributing to the subjective wellbeing of the people living in the concerned small villages.

Conclusion

This paper discussed the results of a Masters class studying how older people living in two small-scale rural villages in Belgium, try to perform 'healthy and happy ageing' in place today. We hope that the set-up and results of this pedagogical project inspire, certainly because the selection of results illustrates the importance that inhabitants attach to social contact and being enabled to meeting others. As the project was limited to a specific rural area of Belgium, future research might open up this particular focus to other areas so as to broaden perspectives.

The results show that designing in collaboration with local stakeholders has a lot of potential. Formulating answers to this project's focus didn't have to do solely with performing studies 'about' older people, but about discussing 'with' older people, as well as with other citizens of various generations so as to explore 'their' lifelong living practices to date. In future research, the intergenerational approach that was applied will be more actively explored. In addition, various avenues for sharing the accumulated knowledge on healthy and happy ageing in rural areas with a wide audience, among which evidently the inhabitants of the concerned villages as well as local and regional policy makers, will also be explored in more detail.

Acknowledgements

I want to thank all partners and municipalities involved in this research project, as well as all teachers, colleagues and students who were involved in the realisation of this Mastersclass.

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Hand rehabilitation for children with Cerebral Palsy: from clinical settings to home environment

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ABSTRACT For children with unilateral spasticity, therapy plays a crucial role in the improvement of their motor skills. Of particular interest are Constraint-Induced Movement Therapy and Bimanual Training (BiT) for children between 4 and 18 years old. These therapies are intense programmes that focus on training unimanual and bimanual skills. Moreover, these skills help children perform everyday activities that promote their sense of independence, such as preparing food or dressing themselves. However, after these short training sessions are finished, the lack of adherence to follow up programmes at home increases the risk of losing the gained skills. Technology supported home-based therapies offer opportunities to provide personalized training that will maintain and improve the developed fine motor skills. A question is how to design these home-based therapies in a way that they are complementary to regular therapy and extend their benefits. In this study, we observed two successful and commonly used interventions for the treatment of children with Cerebral Palsy in The Netherlands: The Pirate and the Handig2Handig groups. We analyzed current literature of these programmes and observed assessment and therapy sessions, which provided further information about the process, the structure and the tools used. Then, we identified which elements that characterize these therapies could also be used at home, and what are the challenges for their implementation. Finally, this study resulted in a list of elements that can be implemented in the development of future home-therapies; the identified elements are: BiT, goal setting, feedback, opportunity of repetition, the role of the caregiver and the role of play. We discuss these findings while considering the opportunities that smart personalized technologies in the home environment bring to a future vision of technology supported at home-therapy for this group.

Keywords: hand therapy, home-therapy, children, cerebral palsy, motor skills

Introduction

Cerebral Palsy (CP) is a disorder caused by damage in the brain with consequences for movement and posture impairments. According to CP Nederlands, the Dutch organization of people with CP, cerebral palsy is the most common cause of impairment in children and spasticity is its most common form. This creates obstacles in development, confidence and overall quality of life. Physical and occupational hand therapies intend to help children increase manual performance to overcome these obstacles. Constraint-Induced Movement Therapy (and its modified version) (CIMT) and Bimanual Training (BiT) are such therapies. They are commonly used to treat hand spasticity and have shown to be successful (Chamudot et al. 2018). Specialized rehabilitation centres are able to successfully provide these therapies; however, specialists recommend additional daily home-therapy to maintain the skills learned. In the case of children, there is a lack of continuity of progress in the home environment. Some of the reasons mentioned for this are low motivation in children to perform repetitive activities, tiredness after school activities and the disruption of the family routine. Then the question arises: what are the elements of the therapies at rehabilitation centres that could be taken into the home environment to motivate children to exercise? Therefore, we studied two groups based on CIMT and BiT that are widely used in The Netherlands (Pirate group and Handig2Handig group). A better understanding of these programmes can lead to design tools for home-therapies to improve the wellbeing of children with CP and their families.

Hand Therapy

Hand therapy for children with CP aims to increase the range of motion, coordination and strength of the affected upper extremity and thus gain autonomy. A lack of treatment can lead to fixed contractures of the muscles and joints, which in turn contributes to physical and emotional pain.

Constraint-Induced Movement Therapy (CIMT)

In CIMT the unaffected (non-spastic) hand is restrained with a sling or similar device that limits the movement of the arm. The core elements are *repetitive practice* and *shaping* used through activities selected to elicit movements in the joints with most deficit and with potential for improvement, and considering age and preferences of the children (Gordon, Charles, and Wolf 2005). In the modified version for children (mCIMT) the therapy is done during 3 to 6 hours per day instead of 24 hours as in the original version for adults. Daily play activities are broken into repetitive tasks with increasing complexity. Feedback is given to explain the appropriate movement and to give encouragement. Two example activities are puzzles to elicit precision grasp, release accuracy and in-hand manipulation and board games to elicit supination, wrist extension and precision grasp. According to Novak et al. (2013) CIMT is effective in providing improvement of motor activities (speed and dexterity) while being aligned to the families' goals.

Bimanual Training (BiT)

BiT focuses on the use of both hands to provide functional independence during daily activities. According to Charles and Gordon (2006) bimanual interventions are needed to increase the coordination of both hands, something that children with CP struggle with. The objective of BiT is to learn to use the affected hand as an assisting hand in predefined goals (e.g.: dressing, eating, cutting

with scissors). Children learn movements via bimanual activities in a child friendly setting. The activities involve repetitions of the movements that have deficit. This is accompanied by strategies to increase the difficulty of the task to match the increasing ability of the child and the desired goals. Activities include card games, video games and arts and crafts. Furthermore, BiT also has a family centred approach. Studies (Novak et al. 2013) have shown BiT to be effective in improving motor activities.

Pirate group and the Handig2Handig groups

The Pirate group is an intervention protocol designed for children with CP aged 3 – 8 (Aarts et al. 2012). It is based on four components: (1) combination of mCIMT with BiT, (2) motor learning theory and strategies, (3) play in a group therapy context and (4) involvement of parents in a homework programme. The Pirate group is an 8 weeks programme where children attend the rehabilitation centre 3 times a week, 3 hours a day. During the first 6 weeks the focus is on mCIMT activities followed by 2 weeks of BiT aimed at extending play and self-care activities. The intervention has a 'pirate' theme as a way to motivate the children to use only the affected hand.

Handig2Handig is an intervention based on the Pirate group but aimed at older children, 8-18 years old (van der Burg, Aarts, and Steenbergen 2013). It is an intense one-week programme where mCIMT and BiT activities are practiced working towards predetermined goals. In Handig2Handig the exercises are also done via playful activities with opportunity of repetition. During the programme children work on mCIMT and on BiT activities in an equal amount of time. In the last two days of the intervention, extra attention is given to the initially set goals.

Method

Observations of the Pirate and Handig2Handig groups were conducted at Roessingh Rehabilitation Centre in Enschede, The Netherlands. Due to the availability of the therapy programmes the observations were divided into two stages. In the first stage, two assessment sessions of participants of the Pirate group and one assessment session of a future participant of the Handig2Handig group were observed in June 2019. There were 3 female participants in this session (aged 4-17). The second stage was an observation of the Handig2Handig rehabilitation group in August 2019, with 6 participants (3 female, aged 9-17). Qualitative data was gathered via field notes where the following themes were recorded: setting, exercises, material used, role of the therapists and behaviour of the children. Interviews with the therapists were done to understand better the process, the limitations and the possible role of new technologies in the therapies. With the compiled information we made a list of possible elements that characterize the therapies, this was later verified with the existing literature and finally an expert reviewed the items and provided feedback. Photos of the materials (toys, drawings and equipment) were taken with the authorization from the organizers of the sessions.

Results

Pirate Group and Handig2Handig assessment session

The assessment sessions for both groups have similar structure and they mainly differ by the use of age-appropriate toys.

Setting: Table 3 shows the description of the setting.

Table 1 Setting of the assessment sessions

Objective	To establish comparable metrics at the beginning and at the end of the programme to determine improvement.
Participants	Child Occupational therapist Physiotherapist Parent (to accompany)
Structure	1 hour of bimanual exercises directed by an occupational therapist and 30 minutes of Unilateral exercises directed by a physiotherapist.
Protocols used	Assisting Hand Assessment (AHA) Melbourne Assessment Video Observation Aarts Aarts (VOAA)
Observed hand movements	Pinch, hold and release, grasp, reaching with elbow extension, supination and dorsiflexion.
Physical space	Room with a table, one chair for the child and one chair for the therapist. The parent is present in a place close to the child to give reassurance but at a distance to not interfere. The session is video recorded. All the tools used are at a close proximity from the therapist.

Exercises and materials: The session consist of a series of exercises (Table 4) that allow the therapists to observe the child's quality of hand movements. The exercises are playfully done in repetitions in an allocated amount of time. A variety of materials are used to maintain the motivation and as a reward (the child can later eat the cake and chocolate).

Table 2 Exercises and materials of the assessment session

<i>Bimanual exercises: These activities help identify how the children do movements with both hands, and if/when there were compensatory movements.</i>	
A chocolate in a cake	Take a cake from an oven, make a whole in the cake and place a chocolate in it
Store the cookies	Pass a rope through a wooden ring and store them in a container
AHA	Handle different toys: music box, crown, marbles in a bottle, etc.
Cubes storing	Move cubes, from one side of a box to the other, first with the non-affected hand then with the affected hand
<i>Unimanual exercises: Following the Melbourne Assessment, the child is asked to only use the "pirate" (affected) hand.</i>	
Activity	Observed movement
Button	Reach forward
Crayons	Grasp and release
Chocolates	Pincer grasp and release
Block	Manipulation
Image	Pointing
Caress the head and neck and reach out and touch shoulder	Supination, pronation and reach

Role of therapists: The therapists provide instructions of the actions to be performed. Because the exercises are a sequence of steps, sometimes the children need reminders of the following step. Encouraging feedback was often heard like "Goed zo!" [Well done!].

Behaviour of the children: Most participants were willing to take part in the activities. However, frustration and embarrassment were observed in challenging activities, while defiance was noted in easy exercises.

Handig2Handig rehabilitation sessions

After an initial assessment, the children together with their parents define their goals (Figure 14), which are displayed in the common room as a reminder.

Setting: Table 5 shows the description of the setting.

Table 3 Setting of the rehabilitation sessions

Objective	Reach predefined motor goals by improving the fine motor skills of children.
Participants	6 Children 6 Therapists
Structure	Group activity: a shared moment between all the children and therapists, parents are also present. 4 hours of mCIMT 4 hours of BiT
Observed hand movements	Pinch, hold and release, grasp, reaching with elbow extension, supination and dorsiflexion.
Physical space	Several rooms in the children's rehabilitation department, including the swimming pool, carpentry workshop and music classroom.

Exercises and materials: Exercises (Table 6) were done with the aid of toys (Figure 15) to promote hand movement related to the goals. For example, to learn to zip a jacket, a pincer grasp is exercised by moving the pegs of the smart pegboard (Figure 15). These activities are designed and proposed by the therapists, but the children can also choose.

Table 4 Exercises and materials of the rehabilitation session

<i>Unimanual exercises: Wearing a sling to practice mCIMT activities</i>	
Therapy putty	To exercise grasp and release
Wooden tic tac toe, clothespins and Smart pegboard NEOFECT	To exercise pincer grasp and rotation
Cosmo Training	To exercise upper limbs extension and to run
<i>Bimanual exercises: Children do more practical daily activities without the sling.</i>	
Lunch	Half of the children and therapists are in charge of preparing lunch
Carpentry workshop	The other half work on a wooden box, they exercise by assembling, nailing and painting the box
Music class	With a percussion class different rhythms and combinations are practiced
Swimming pool	Different team games like tossing the ball and racing
Goal training	Allocated time to specifically practice the selected goals

Role of therapists: During this process the therapists play close attention to the improvement of the children, provide feedback and adjust the complexity of the exercises accordingly.

Behaviour of the participants: All the participants were enthusiastic to participate, showing improvements and camaraderie through the activities. Furthermore, the trust in the therapist was noticeable.

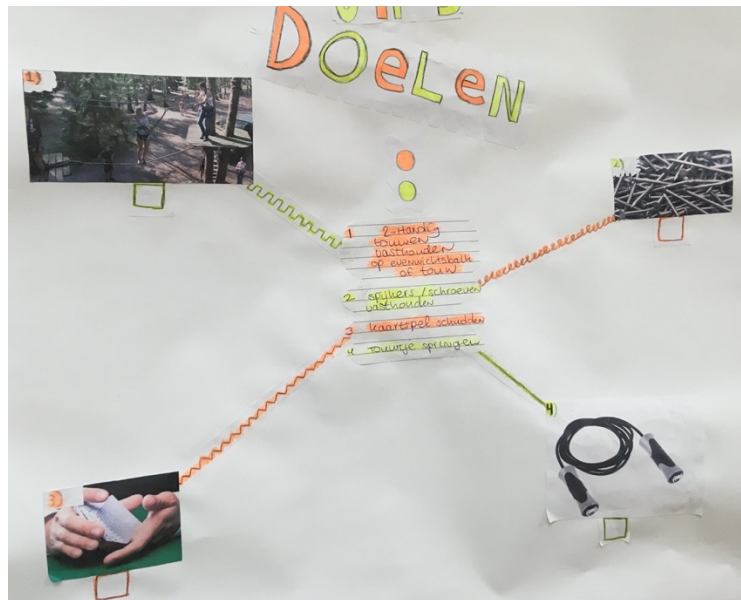


Figure 2 Goals of one of the participants [climbing, tightening screws, shuffling cards, jumping rope,]

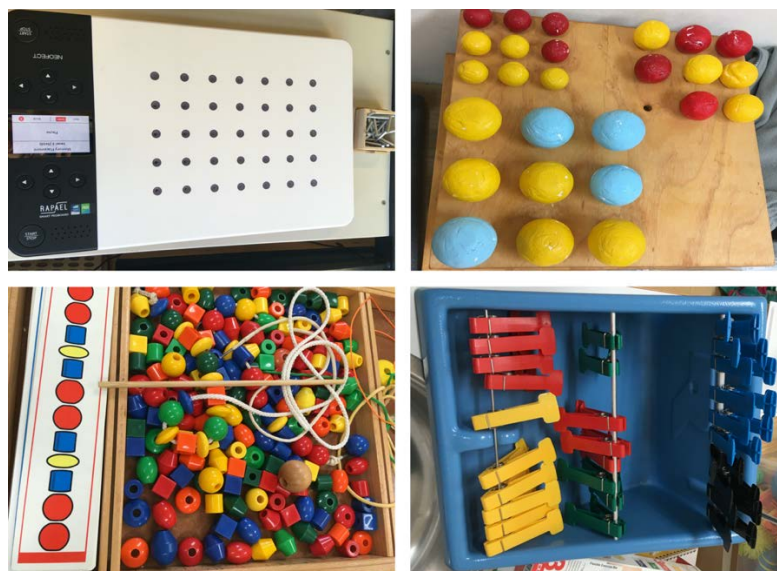


Figure 3 Example of toys used: Smart pegboard NEOFEET, beads and string, balls, clothespins.

Interviews: At the end of both sessions we asked the therapists a series of questions to clarify what was observed, the protocols used, the overall structure of the sessions and what they consider the motivating factors to participate: shown improvement, playfulness, fun, nice games, little presents

like stickers, verbal encouragement and commitment of the family. As well as the demotivating factors: exercises too difficult, lack of variation in activities, tiredness and pressure on parents. We also interviewed Dr. Pauline Aarts, creator of the studied programmes, we discussed the programmes, the role of new technologies in home-therapies and reviewed the list of characteristic elements which is outlined in Table 7.

Table 5 Characteristic elements of the therapies that can be used in home-therapy

<i>BiT</i>	The importance of using both hands in activities at home gives confidence and independence. Although mCIMT is highly effective in hand therapy, it is preferred to do it only at the rehabilitation centres where there is a constant attention of the therapists and falls or accidents can be prevented
<i>Play</i>	Children find playing an appealing activity and they are naturally drawn to engage in them, keeping them motivated
<i>Role of the parents or caregivers</i>	Similar to what the therapists do at the rehabilitation centre, parents could have a role of providing feedback, proposing variety of exercises and adjusting the complexity
<i>Goal setting</i>	Aligned with the practices of BiT and mCIMT, the setting of goals gives direction towards a certain achievement which will increase motivation
<i>Implicit and explicit feedback</i>	Provide instructions of the relevant tasks, how to perform it, number of repetitions, outcome and performance.
<i>Opportunity of repetition</i>	Motor learning strategy that allow children to achieve relatively permanent changes in motor skills.

Discussion

This study set out with the aim of identifying the elements of successful hand therapies that could be applied in home-therapy. These findings may be somewhat limited by the number of sessions observed and the sole perspective of the therapists interviewed. Further research should be undertaken to investigate the perspective of the children and their parents and to obtain a deeper understanding of the home situation. Nonetheless, this first list of elements highlights opportunities in home-therapy that can be supported by new technologies. For example, smart personalized technologies provide customization of exercises to match the movement disorder of the child and the established goals. They monitor the actions performed and their quality. they detect and adapts to fit improvements in hand motion and they promote playfulness and feedback to maintain motivation. During the observations a high interest from the children to use the ‘smart’ tools (Cosmo, Neofect, etc.) was noted, which is understandable as computer games and new technologies are popular among children. And because they can give the opportunity to repeat often in a motivating way, other researchers are starting to use them. For example, at Saint Maartenskliniek (in Nijmegen, The Netherlands) there are already initiatives to use VR and Leap Motion. Next steps are to further analyse existing home programmes and compare them with our

list of elements, expand the scope of this research and involve more participants, because in times of social isolation (due to Covid-19 at the time of writing), the urgency of successful home-therapies is emphasized when access to rehabilitation centres is limited.

Acknowledgements

We thank the therapists at the Roessingh Rehabilitation Centre and Dr. Pauline Aarts from the Sint Maartenskliniek for sharing their knowledge, experience and feedback.

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Social Wellbeing in Service Design: How does Co-creation contribute to the social wellbeing between patients and physiotherapists in order to facilitate recovery pathways?

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ABSTRACT *Rehabilitation services are changing towards a Person-Centred Care approach in which physical, psychological and social wellbeing are involved in the relationship between patients and physiotherapists. However, current research has predominantly focused on the provision of solutions for physical wellbeing.*

Research question: How does Co-creation contribute to the social wellbeing between patients and physiotherapists in order to facilitate recovery pathways? By using a service design methodology and co-creation approach, this research investigated the relationships between patients and physiotherapists with a focus on social wellbeing. Data was collected through developing a co-creative interview toolkit that combined semi-structured interviews and co-creative design tools. The relationship was investigated from a total of eight co-creative interviews: four patients with rehabilitation experience lasting more than a year and four physiotherapists. The researchers compared and synthesized the two perspectives.

Results: Concerning the relationship between physiotherapist and patient, we revealed four critical factors evidenced with the insight tree: (1) Lack of communication between patient and physiotherapist when sharing information about the recovery process, (2) Building respect and honesty/meaningful relationship over time, (3) Sharing emotional wellbeing, (4) Setting and reaching goals, were the commonly shared categories in both groups of participants. The four factors allowed the researchers to design the recovery pathway. This was designed to guide the implementation of a new rehabilitation process, in which social wellbeing practices are integrated in new touchpoints interactions among the two actors.

Keywords: service design, healthcare system, design thinking, co-creation, social wellbeing, second line of care, physiotherapist

Introduction

The role of the patient in the healthcare system is changing. Increasingly the patient is seen as an active actor in the centre of the care network that takes part in shared decision-making (Ekman et al., 2011). Decisions that impact and concern a patients' quality of life, on which it is of vital importance to take into account the patient's personal views: his own health and wellbeing in the areas of physical, psychological and social functioning (Polonsky, 2000).

This research paper focuses on the social wellbeing dimension, defined as the individual's perceptions, influenced and supported by other social relationships. It showcases the relevance of Service Design and co-creation as a methodology to improve healthcare services by focusing on the patient experience and by including users as a resource and part of the design process. The objective of this research is to unravel the social wellbeing in the relationships between recovery patients and physiotherapists. Service design and design thinking tools can generate insights to develop future services that improve the social wellbeing between them. We aim to contribute to a better understanding of the social interaction and the emotional connection between patients and physiotherapists that might over time prove to be a success factor for overcoming diseases.

Theoretical Framing

Service Design and Co-Creation in Healthcare

Service design is considered as the activity of design thinking, planning and implementing change in order to improve a service's quality (Josefsson et al., 2017). Design thinking is a systematic innovation process that prioritizes deep empathy for end-users' desires, needs and challenges to understand a problem and develop more comprehensive and effective solutions (Roberts et al., 2016) while introducing co-creative tools to facilitate analysis. By including interdisciplinary knowledge, service design could add value to the healthcare system, by recognizing stakeholders' needs, desires, different perspectives and voices from the various actors, while testing ideas and solutions to address real problems.

Social Wellbeing in the Second Line of Care

Healthcare has been defined as a complex service system that interacts with other service systems to co-create value (Spohrer et al., 2008). In the context of such a complex system where different stakeholders are interacting, this research is focused on the 'second line of care'. Caregivers, family, community, nutritionists, psychologists, physiotherapists, dieticians and social assistants are involved in the patient ecosystem and are influencing and extending the meaning of wellbeing. Overall, the healthcare system provides solutions strategically oriented around physical wellbeing, mostly considering physical condition and symptoms. Based on the definition of Quality of Life (Polonsky, 2000), we can extend the overview of the patient's perception introducing social wellbeing, where an individual's perception and support from others are considered.

Recovery process and Care Pathway Design

In this context, service design must work on the social perspective and social environment of the

patient, developing a person-centred care pathway that provides a better understanding of the social and psychological problems that people with specific diseases may confront. Healthcare systems are changing towards a Person-Centred Care approach in order to explore new pathways and develop solutions for the actors in the complex healthcare network (Geerse et al., 2019). The analysis of interactions between different stakeholders is the key to discover new opportunities (Seys et al., 2017).

Research question

Current research is showing a lack of depth in the study of the 'second line of care', as it is showing interest and the provision of solutions just for physical wellbeing in the 'first line of care'. By using a service design methodology and a co-creation approach, this research investigates the relationships between patients and physiotherapists by focusing on social wellbeing, guided by the research question: How does Co-creation contribute to the social wellbeing between patients and physiotherapists in order to facilitate recovery pathways?

Starting from the impact of the rehabilitation recovery process, to better understand that the emotional connection between patients and physiotherapists might over time prove to be a success factor for overcoming recovery processes.

Method

Study Design

Qualitative methods are considered appropriate to gain an in-depth understanding of the phenomenon of interest (Corbin et al., 2008) since they have the advantage of producing a wealth of detailed data on a small number of individuals (Patton, 1990), along with the capacity to analyse complex systems as healthcare services. This study employs qualitative research based on service design. For this research, we developed a social experience toolkit by a blending and co-production of methods including the TU Delft set of design thinking tools that can be used to analyse social dimensions by exploring emotions, feelings, relationships, interactions, and latent connections (Desmet, 2019). With the social experience toolkit, designers can explore the strength and weaknesses of services through the patient's healthcare experience.

Observation

An observation template was designed in order to collect specific information about 'the who, where, when and what' factors, always focusing on the interactions between patients and physiotherapists inside the Basalt centre. The observations allowed the researchers to map the recovery process from an external point of view and structure the boundaries of the context where the participants were interacting with each other.

Sampling

This research was developed in collaboration with Basalt (Netherlands), a rehabilitation centre with a large network of professionals specialized in chronic diseases. To increase the validity of the research the topic was investigated from a total of eight co-creative interviews in which different participants were involved: four patients recovering from different situations with their rehabilitation experience lasting more than a year and four physiotherapists.

PARTICIPANTS	GENDER	AGE	NATIONALITY	YEARS OF DISEASE / EXPERIENCE
PATIENTS				
Patient 1	Male	25	Dutch	2
Patient 2	Female	38	Dutch	23
Patient 3	Female	35	Dutch	6
Patient 4	Male	65	Dutch	2
PHYSIOTHERAPISTS				
Physiotherapist 1	Female	29	Dutch	8
Physiotherapist 2	Male	44	Dutch	21
Physiotherapist 3	Male	39	Dutch	15
Physiotherapist 4	Female	35	Dutch	12

Figure 1. Sampling table

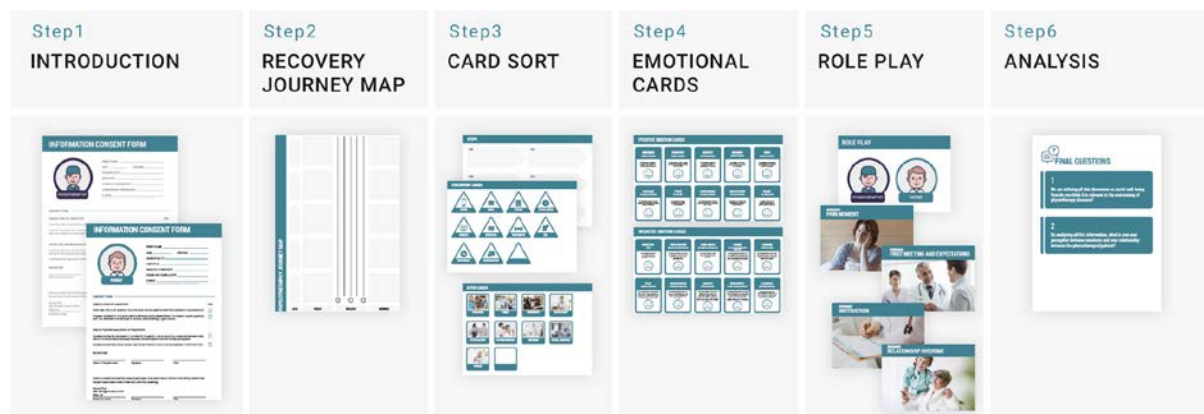


Figure 2. Co-creative interviews: social experience toolkit

Co-Creative Interview

Based on the research question, the interview guide was structured to explore the same topic with different participants in order to provide comparable data following six main steps while still maintaining the freedom to investigate specific directions (Patton, 2002). By matching co-design

tools and a semi-structured interview, it became possible to define a research tool, such as the ‘co-creative interview’, that allows researchers to understand the emotional and psychological dimension of the participants and translate the insights perceived in visual mapping outcomes, contributing to the improvement of the level of reliability of the research. The structure of the session was divided into four sub-topics, in which the use of follow-ups/probes was implemented in addition to the design thinking tools developed by the research team. By developing an interactive and dynamic discussion, the researchers explored in detail the social and emotional participants’ situation with the following tools (Figure 2). Secondly, a specific guide for each category of participants, patients and physiotherapists was defined to provide relevant answers and references for each sub-topic. All the methods were designed to explore the topic with the participants and to co-create an overview of opportunities that the researchers can define to develop new services (Scan QRCode).

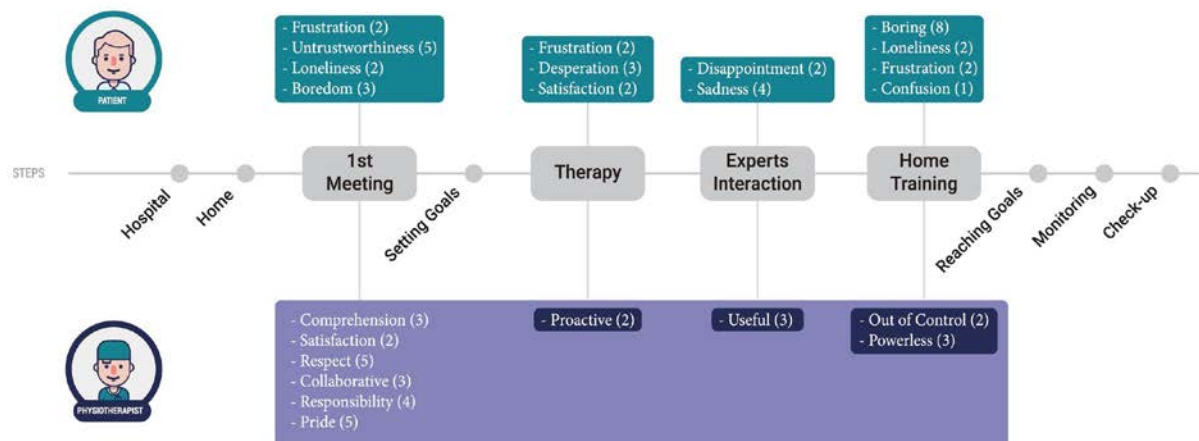


Ethics

This research is performed according to the guidelines provided by TU Delft (HREC) Human Research Ethics Committees based on the Helsinki Declaration and Nuremberg principles (Human Research Ethics TU Delft, 2018-2024).

Data Analysis

The data analysis followed an inductive approach where triangulation is used to increase the level of validity. First, the field observations inside the clinic were analysed to identify the connections between the actors. Secondly, the design of the tools allowed the researchers to analyse the social wellbeing issues and topics. By clustering insights from the one-to-one co-design session, a visual map was developed to clearly represent the latent expectations that influenced the social wellbeing experience in the physiotherapist-patient relationship. Insights for each step and tool were identified to facilitate the comparison between the participants’ experience and to analyse differences and similarities. The induction process of making categories and building the insight tree outcomes allowed the researchers to design a new recovery pathway, where social wellbeing enhances the interaction between patients and physiotherapists.



Results

Experienced Recovery Journey: social interaction issues

The first result (see figure 5) is the co-designed journey map of the current recovery process from the perspective of the physiotherapist and the perspective of the patient. By co-designing both journeys it became possible to generate a two-sided journey map to identify the social interaction issues by comparing the different perceptions (physiotherapist vs. patient) in relation to the main steps, emotions, actors, touchpoints, positive and negative factors involved. The findings show that in the current situation, both physiotherapist and patient have positive and negative feelings during the recovery journey. There is a clear fluctuation in the emotions expressed by the patients. Physiotherapists' perceptions are less affected by the personal interaction and the touchpoints involved.

Figure 3. Social interaction between Patient and Physiotherapist Journey Map

For the main steps of the recovery journey patterns of differences and similarities were identified. Comparing the journeys, pain points from both the perspectives identified issues for new opportunities of service design.

The data analysis results identified four relevant issues during the recovery journey: (1) there is an evident lack of communication between the patient and the physiotherapist when sharing information about the recovery process; (2) building trust over time is a difficult task because of individual interests and unexpected changes; (3) the sense of belonging from the patient's perspective is influenced by different touchpoints and actors; and (4) the establishment of the recovery goals should be clear for patient and physiotherapist, and take into consideration the different actors involved. All these insights illustrated in the map, were used to design the new recovery pathway.

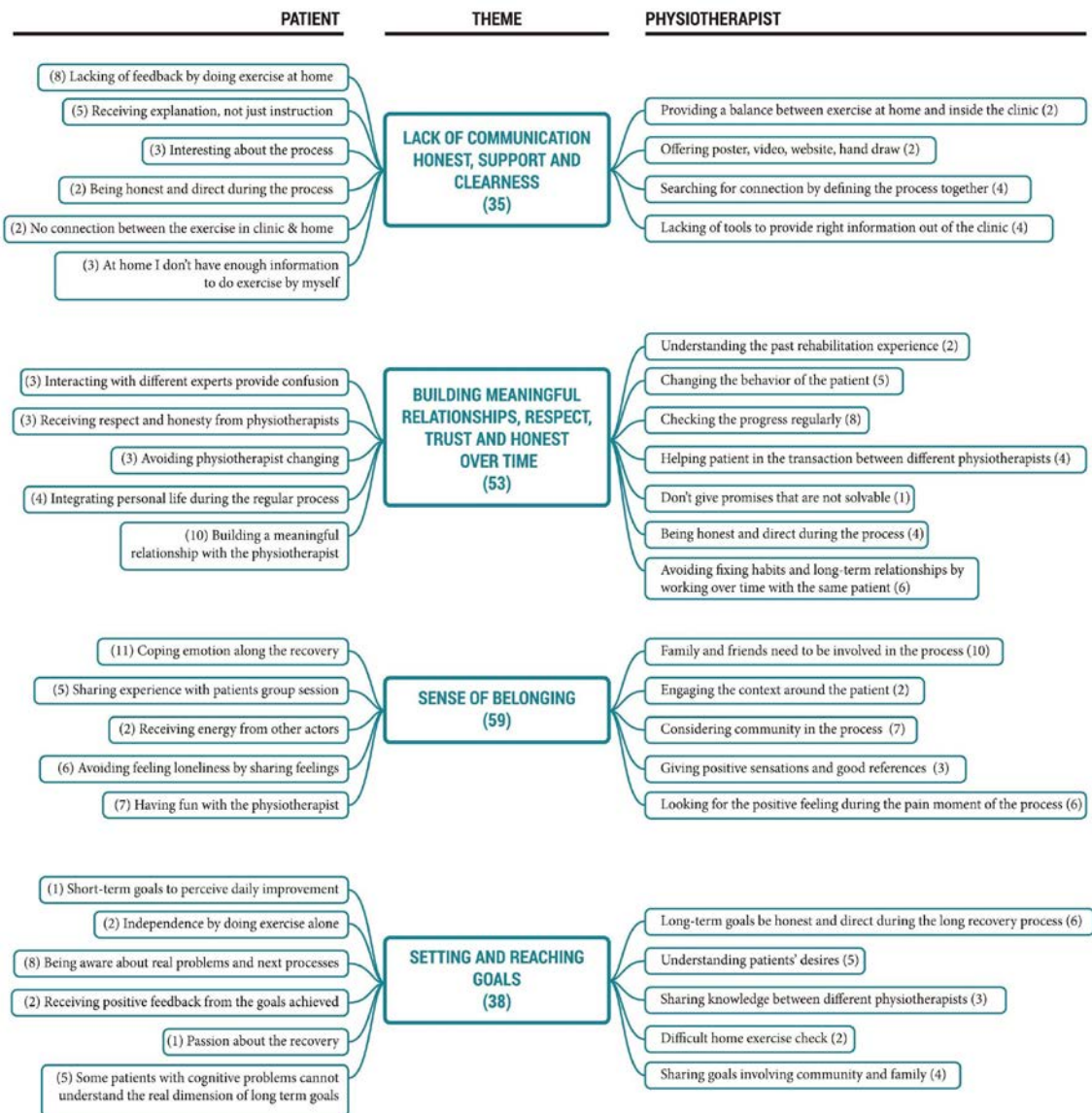


Figure 4. Insights tree

Care Pathway Design

Figure 5 presents the design of the new Care Pathway for patients and physiotherapists involved in a recovery process / service. In the new service situation, the hospital, families, and friends (actors from the second line of care) have a crucial role in supporting patients. Besides that, before starting the recovery process in the rehabilitation centre, the

communication between doctors, physiotherapists and other experts should be done in order to understand the previous diagnosis and particular boundaries (data reporting). When setting goals, families are also important actors that support decisions and give relevant feedback. The community ensures that patients are sharing experiences and feelings.

Communication with other experts (including the changing between physiotherapists) during the process also ensures that professionals and decisions are the most suitable to patients' situations.

Furthermore, to ensure that the patient is sufficiently supported at home by the experts, digital communication platforms are designed to keep patients and physiotherapists up to date.

When finishing the process, it's crucial for patients to keep in touch with physiotherapists by using social media and digital platforms. The new Care Pathway ensures that the social wellbeing of the patient is in the centre of every decision and step.

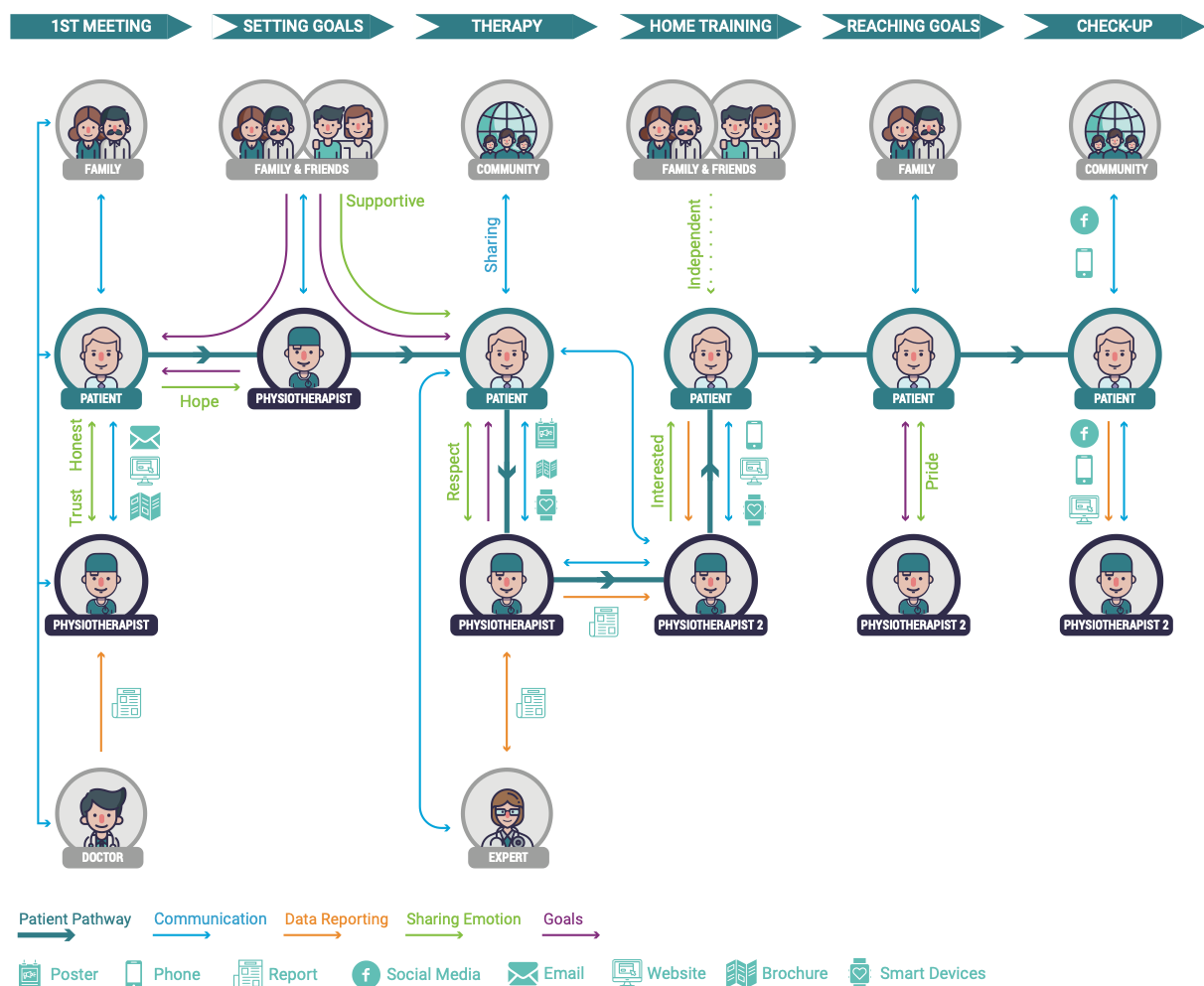


Figure 5. New care pathway design for the recovery service

Discussion

Principal Results

With this co-design study, it became possible to analyse and design the social experience and link the active roles of the patient and the physiotherapist on the different factors of the social wellbeing and ensuring the inclusion of the social dimension in the recovery process. By adopting co-creative methods, the patient recovery pathway unveiled two different aspects: (1) the emotional involvement and (2) the interactions between the actors. The research showed that in the current situation, the role of the physiotherapist in the rehabilitation process is crucial in the overcoming of diseases when the patient is fully involved in the relationship. The new care pathway design suggests improvements on the recovery journeys, in which new touchpoints are introduced and involvement of the various actors is considered. The data analysis allowed to compare the social feelings of the two groups of participants and define opportunities for re-design and implementation. Furthermore, the social experience toolkit allowed to co-create the pathway by crossing the information from both perspectives. First, building trust over time determines the starting point of the relationship in which the physiotherapist expresses his empathy in his effort to link patients' past experiences to the new recovery process. Second, the engagement of the 'second line of care' that should be practically integrated into the new recovery journey, considers the significant role of family, friends and community as external factors affecting the patients' progress and emotional stability. Third, the participants showed a lack of daily communication between them. The new care pathway implements the role of the physiotherapist outside of the physical meeting, considering as crucial the autonomous activity to be performed by the patient at home. Fourth, patients and physiotherapists are sharing experiences and activities and they must also share goals and expectations to ensure short and long term progress. The new pathway design incorporates a new procedure that defines specific steps taking into consideration the social wellbeing dimension during the recovery process; this may ensure empathy creation and development of a better experience for all the actors involved. The new touchpoints can help to solve the lack of communication and build trust.

Limitations and Future Research

Several limitations relate to the chosen method of qualitative research. For the purpose of creating in-depth understanding the study is based on one case setting. To verify the consistency across other centres and countries, more studies are required in specific diseases by adding new variables. In the area of second line care, the present research could be further extended by analysing other actors, such as family and communities, who are also involved in the recovery process.

Comparison with Prior Work

Most of the existing body of knowledge on service design in health focuses on the ‘first line of care’ by considering the role of doctors, nurses and pharmacists during the recovery process in which the physical wellbeing is analysed as the main consideration. Reasons to consider the relationship with a physiotherapist as a crucial factor in the overcoming of the disease have been researched in other studies (Lundvik Gyllensten Gard et al., 1999). This research adds how the social involvement of the patient meets the commitment of the physiotherapist during the recovery process.

Conclusion

This is the first study that presents a care pathway for the recovery process in which co-creation methods are used to explore the social wellbeing dimension by comparing the different perspectives of patients and physiotherapists. This study showed that service design methodologies can add value to existing qualitative research methodologies, by investigating and exploring emotions, and providing different directions for new product/service developments. By creating the social experience toolkit, this research paper encourages future patient-centric studies to use this design toolkit for the development of new services. The care pathway displays new touchpoints to successfully implement the recovery process of the patient in the rehabilitation centre and at home.

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The co-design of a psychoeducational tool for children and young people with ADHD

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ABSTRACT Attention Deficit Hyperactivity Disorder (ADHD) is a neurodevelopmental disorder characterized by inattention, hyperactivity and impulsivity. The effects of ADHD can impact on the individual, their family and community.

Evidence supports a multimodal approach to ADHD management. This involves pharmacological and non-pharmacological interventions that incorporate psychoeducation specifically aimed for children and young people (CAYP). Although this approach is recommended in various clinical guidelines internationally, it is yet to be incorporated into UK ADHD clinical guidelines.

There is a paucity of psychoeducational material available for CAYP. In addition, non-pharmacological interventions for CAYP with ADHD are often not suitable or designed appropriately. Therefore, this is a promising opportunity for co-designing materials with CAYP, as co-designed interventions are reported to be more likely to be accepted by end users, resulting in better suitability, engagement and subsequent effectiveness.

This project adopted innovative methodologies to co-design a psychoeducational tool (a magazine) for primary aged CAYP with ADHD. To establish the clinical need for the tool and what it should contain we conducted focus groups, interviews and co-design workshops with specialist ADHD clinicians, parents/carers and CAYP with ADHD. Thematic analyses found the content for the magazine should include information such as what ADHD is, how it affects CAYP, how to explain ADHD to friends and family and how it affects CAYP in adulthood.

Age appropriate, short and varied tasks engaged CAYP with ADHD during the workshops. This, coupled with parent/carer and clinical involvement through the co-design process, provided a valuable insight into the requirements for a complex intervention for a complex condition, which may result in better acceptance and future impact.

Keywords: ADHD, psychoeducation, co-design, complex intervention

Introduction

ADHD is a comorbid neurodevelopmental disorder characterized by inattention, impulsivity and hyperactivity (NICE 2018) which can impact the individual, their family, their educational attainment and is associated with premature death (Harpin 2005). Children and young people (CAYP) with ADHD often experience a number of ADHD related difficulties including poor social skills, learning difficulties, disruptive behaviour, low self-esteem, unsettled relationships and lower academic attainment (Harpin 2005; Powell et al. 2018). The mean cost for the NHS, social care and education systems is around £670 million for CAYP, amounting to £5493 annually (Telford et al. 2013). This means that ADHD management creates a large economic burden on healthcare services and society.

Currently, in the UK, when a young person is diagnosed with ADHD, the parent or guardian is provided with information sources about ADHD, how it can be treated with both medication behavioural interventions such as attending an ADHD parent course (NICE 2018). CAYP are often not provided with any information for themselves and therefore rely on clinicians and parents for information about their condition. However, educating CAYP and the parent should be a first step to treatment as this can lead to more positive life choices that could help CAYP avoid falling into future crises and more expensive longer-term interventions (NHS England 2016, Ferrin and Taylor 2011).

There is some reliable and unreliable information available online, however few websites are aimed at CAYP with ADHD and are therefore unsuitable. In addition, these sources of information are often not designed in partnership with end users and or stakeholders and do not account for the variable contexts they are delivered in. Therefore, it is important for future complex interventions to be designed using methodologies (e.g. co-design) to increase the likelihood of long-term acceptance and impact (Greenhalgh et al. 2016).

Co-design involves end user(s) and stakeholders in intervention development. Co-design is defined as 'the creativity of designers and people not trained in design working together in the design development process' (Sanders and Stappers 2008, 6). Fekete and Lucero (2019) found that co-design with CAYP with ADHD was feasible if individual needs and preferences are considered, adapting the Diversity for Design Framework (Benton et al. 2014) accordingly (Figure 1).

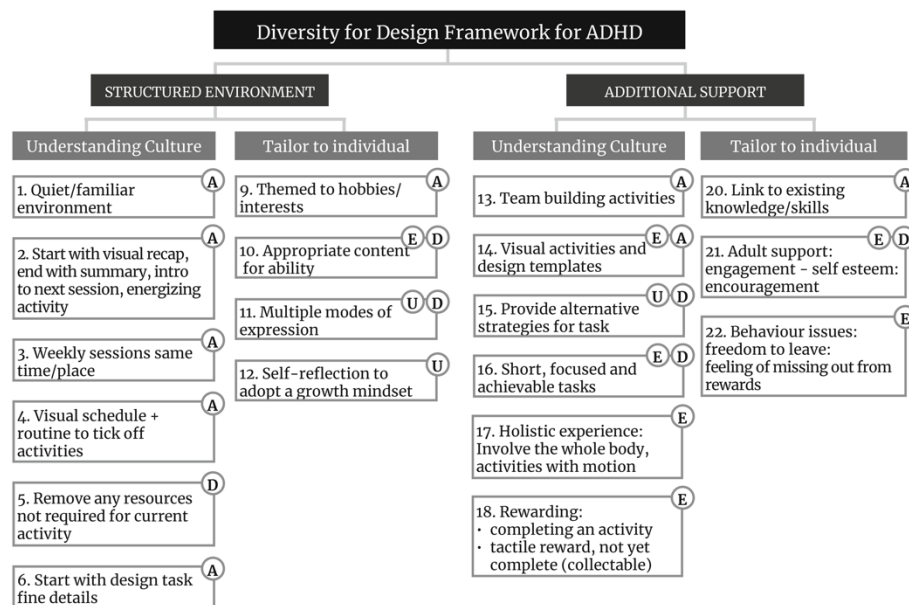


Figure 1: Adapted D4D Framework (Fekete and Lucero 2019).

Fekete and Lucero's study did not involve intervention development, and authors are not aware of other studies in this context. Whilst Fekete and Lucero's work was published after the co-design activities described in this paper, the latter followed many of the key principles outlined in the D4D framework. Therefore, this paper will focus on the specific tools and methods used to engage this population, and key insights generated.

Aims and questions

Prior work by the authors, including a first-of-its-kind workshop involving Lego® Serious Play (Powell, Parker, and Harpin 2017), suggested scope for an intervention targeting primary school aged CAYP with ADHD, to educate them about their ADHD in a fun, engaging age appropriate way, to help them self-manage it effectively, alongside usual care. This paper outlines two subsequent co-design workshops, conducted with CAYP with ADHD and their parents, to explore and develop this idea together, guided by the following questions:

1. What do you find difficult as a result of your ADHD?
2. In which contexts do you experience ADHD related difficulties?
3. What would you like to learn most about your ADHD?
4. What types of paper-based tasks do you like and why?
5. Which of these paper-based tasks would you like to help teach you about your ADHD?

Methods

The workshops

The workshops took place at a quiet, familiar location to participants in May 2019. The goal was to encourage creative thinking through designer-led activities.

Activity 1: An introductory task that involved CAYP colouring in a template of a superhero and annotating it with their 'super-powers', which referred to things they like about themselves that result from their ADHD e.g. lots of energy.

Activity 2: Participants watched a short (2 minute) cartoon portraying the message that everybody with ADHD is different and experiences their ADHD differently. This was followed by group discussion around ADHD related difficulties in different contexts e.g. home, school.

Activity 3: CAYP were given a packet of paper slips outlining ADHD related topics they could learn about. E.g.: 'how to manage my emotions', 'being more organized', 'what causes ADHD?', 'how to tell my friends about ADHD.' They were asked to put the slips they were not interested in; in the bin and stick the ones they did like onto a sheet of paper. They then identified topics they were most interested in learning about.

Break: Important due to limited attention spans of the population. CAYP could redeem 'golden tickets' to reward their efforts for a packet of Lego to take home.

Activity 4: The final activity looked at a number of ADHD themed activities e.g. word search, maze, true or false questionnaire and an origami fortune-teller (see Figure 2). CAYP were introduced to these tasks on a one-to-one basis. This gave them an opportunity to speak with the facilitator individually. CAYP then completed the activities, stated what they did and did not like about them and identified which tasks they would prefer to undertake in the future to learn about their ADHD.



Figure 2: Dr Wheeler introducing paper-based activities to some of the CAYP.

Results

Participants

Pseudonym/ Workshop (W)	Age (yrs ¹)	Gender	Diagnosis	When ADHD diagnosed	ADHD medication during workshop?	SDI ⁴
Ryan (W1)	9	M ²	ADHD	2017	Yes, Elvanse 20mg	14300
Billy (W1)	12	M	ADHD	2014	Yes, Concerta 54mg	4913
Jack (W1)	9	M	ADHD	2016	Yes, Lisdexamphetamine 40mg	32596
Laura (W1)	9	F ³	ADHD, ASD	2016	Yes, Equasym 30mg	17403
Ross (W1)	7	M	ADHD	2017	No	17539
Ben (W1)	10	M	ADHD	2015	No	17290
Megan (W2)	12	F	ADHD, ASD	2013	Yes, concerta, 54mg	820
Dennis (W2)	9	M	ADHD, ASD	2017	Yes, equasym 20mg	30041

Table 1. Participant demographics

SDI⁴: Social Deprivation Index. 1 = indicative of most deprived area in United Kingdom. 32844 = most affluent area in UK.

The superhero warm up activity identified characteristics the CAYP liked about their ADHD:

- Lots of energy to play;
- Enjoys playing computer games;
- Having a 'super brain';
- Being 'good at maths';
- Being neat and tidy.

What do you find difficult as a result of your ADHD and which contexts do you experience ADHD related difficulties?

Group discussion identified difficulties in different contexts (Table 2).

Context	ADHD related difficulties identified
School	Difficulty concentrating during lessons Difficulty making friends

	Difficulty keeping old friends when moving to secondary school Hard to tell others about ADHD Daydreaming during lessons Keeping up with lesson pace Forgetting PE kits/other equipment Missing out on parties/playing games during break/lunchtimes Lots of noise/hard to concentrate
Playing with friends	Trying to save energy for tasks the following day when it is too tempting to play with friends the day before (makes him tired the following day) Hard to make new friends and keep old friends
Home	Waking up in the morning Wants to play with friends outside at unsociable hours (not allowed!) Telling the truth Managing emotions
Family	[Participants preferred to focus on other contexts]
Hobbies	
Other	Disliking loud environments

Table 2. ADHD difficulties in different contexts

What would you like to learn most about your ADHD?

This was addressed in activity 3 (described above). The CAYP had specific comments around the topics listed. For example, Dennis stated he wanted his friends to understand ADHD because his teacher ‘doesn’t help’, he wanted to understand why he has ‘frustrated feelings’. He felt these things got in the way of learning at school. Megan wanted her friends and family to understand her ‘special needs’ and how to ‘cope’ with her emotions. Billy wanted to know how to manage ‘anger better’ and similarly, Ryan wanted to learn how he could ‘keep calm’ but did understand his ADHD medication helps him concentrate and stops his head from ‘banging’. Jack wanted to understand what ADHD stands for. He suggested using YouTube to find out. Laura wanted to understand why she had ADHD and how to ‘keep calm... in a crisis’. Lastly, Ben was interested in ADHD medication. He wanted to eat during the daytime rather than have his hunger suppressed by the medication and wanted to understand why ‘normal Calpol® (painkillers) won’t work’.

What types of paper-based tasks do you like and why and which of these paper-based tasks would you like to help teach you about your ADHD?

Answering these questions involved CAYP completing a number of ADHD themed paper-based tasks (see Figure 3).

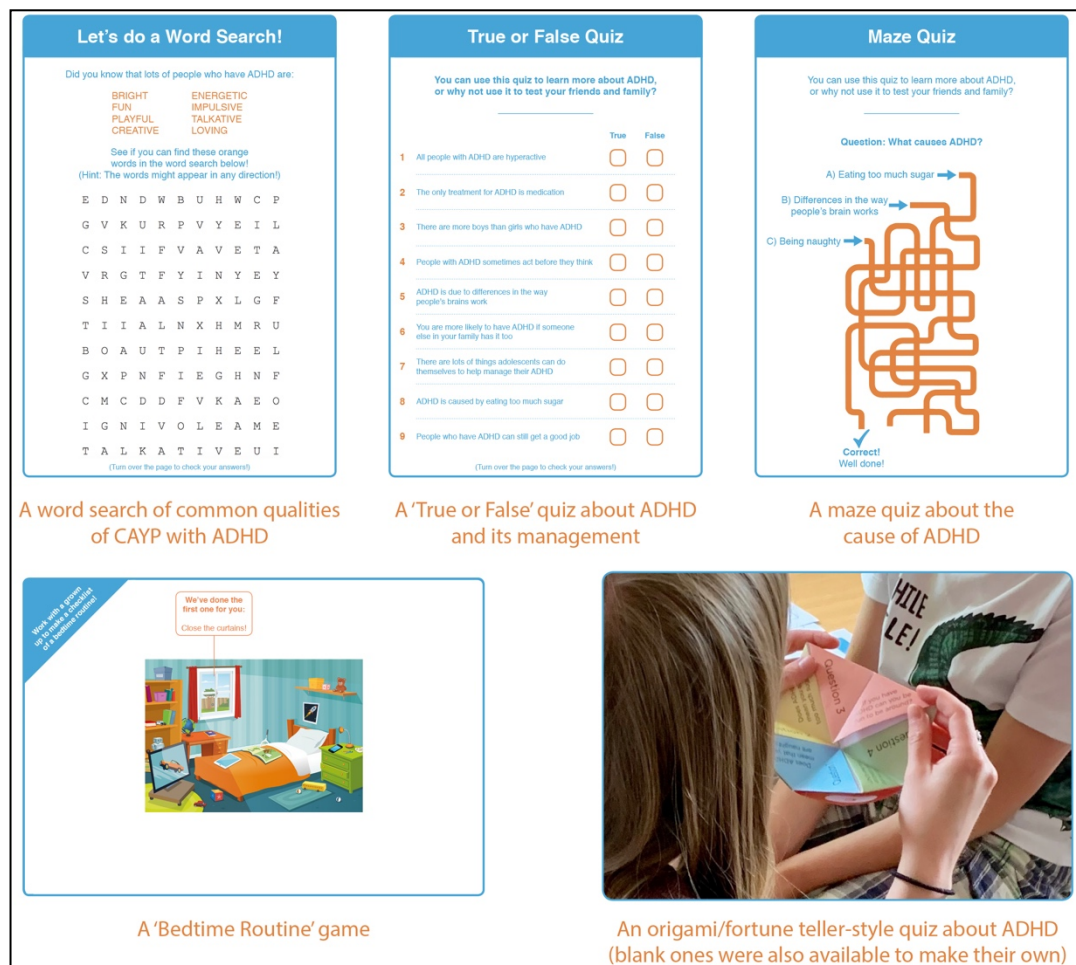


Figure 3: Example of the gamified learning activities

Participant engagement with the tools above was positive, with CAYP completing each of the activities. Ross stated he enjoyed the true or false questionnaire and marked it 10/10. Megan enjoyed the tasks but felt they were too easy for her, with the exception of the true or false questionnaire (she also expressed an interest for more unicorn themed tasks). Dennis said he enjoyed the tasks and would like to complete them at school. He found the word search challenging but worked with his parents to complete it. It is clear, then, that a key challenge of creating this resource will be striking a balance between making the activities achievable, engaging, and educational.

How workshop findings could feed into intervention development

A number of key learning priorities were raised, which will influence the development of the proposed magazine (Table 3). The suggestions of how these priorities could be addressed are

tentative; decisions around this will be made following further co-design work with CAYP with ADHD, families and clinicians.

Key learning points	How it could be addressed in the intervention
Find out what ADHD stands for, what it means, what causes it and how it affects behaviour	Paper-based activity could cement this learning (e.g. true/false questionnaire)
How to teach friends and family about ADHD	Suggestions and key phrases could be introduced in the magazine
How ADHD medication works and what ADHD medications are available	Use of analogies. E.g. a postman working alone and losing messages/letters versus a many postmen working together and not losing letters. This is an analogy for the improvement of working memory when taking ADHD medication.
Techniques to help with routines at home and how to manage difficult emotions	Cartoon strips and scenarios could be presented within the magazine. This could be followed by a quiz.
How to set future goals	The magazine may not set goals for the young person as everybody is different and the goals should be achievable. Advice could be provided about how to think about goal setting and think about what is important to the individual and why.

Table 3. Potential next steps of the intervention

Discussion

Whilst some of the activities aimed to address 5 questions, some aimed to create a positive, creative environment. For example, the first ‘superhero’ task (Figure 4) drew from previous experience (Wheeler et al. 2018), whereby activities that encouraged self-expression, had no ‘right’ answers and took an asset-based approach were found to be effective when co-designing with children. This is particularly important in this context, as it is documented that the negative aspects of ADHD are focused on too much (Powell et al. 2019), with further reports demonstrating low self-esteem in CAYP with ADHD (Harpin 2005; Powell et al. 2019).

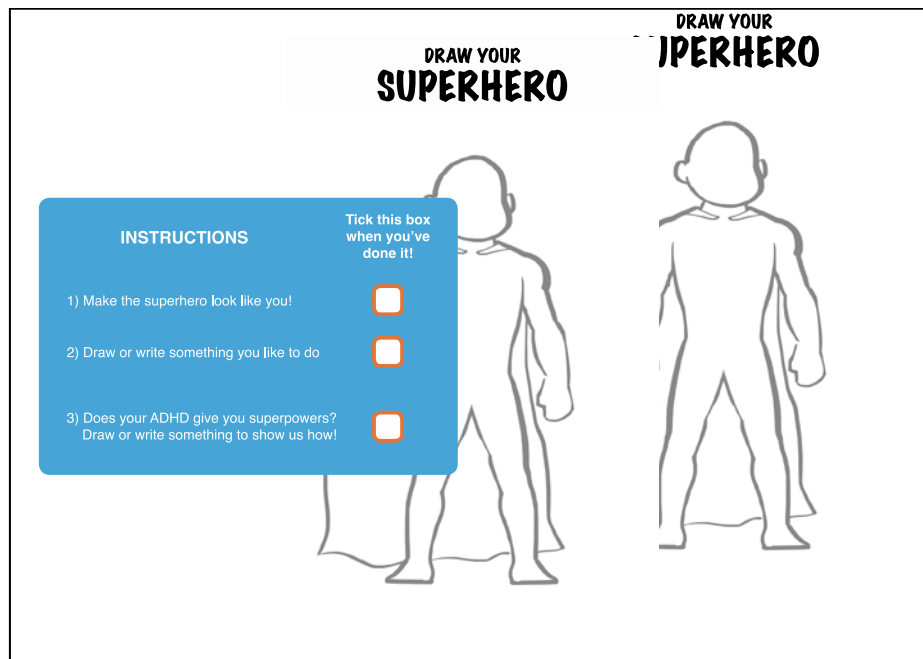


Figure 4: 'Superhero' activity

Working one-to-one with CAYP with ADHD and encouraging 'making' and 'doing' was beneficial. For example, paper-based activities were individually introduced and optional. All CAYP chose to engage with them, also demonstrating feasibility for the 'psychoeducational magazine' concept. The learning benefit of physically doing a task is also supported by John Dewey's Theory of Experiential Learning (Dewey 1997). This is because physical tasks can provide individuals with an experience, and the physical action(s) involved in the task can supplement learning.

It is also important to highlight that CAYP are able to articulate the challenges they face, and therefore *should* be engaged in co-design processes. For example, CAYP identified difficulties particularly in relation to school, including making and maintaining friendships, managing frustration and feeling of anger. This is important as educational attainment is reported to suffer in CAYP with ADHD (Harpin 2005; Powell et al. 2019). It is encouraging that CAYP could identify their ADHD related difficulties, as one could argue that identification of challenges is necessary to optimally self-manage a condition.

Strengths and Limitations

Given the small sample size, workshop findings should not be generalized to the broader population. However, there is a broader literature base that supports many findings of these workshops (Bussing et al. 2012).

The adapted D4D framework for ADHD (Fekete & Lucero 2019) will be used moving forward to provide a more theoretical basis. However, a number of the recommendations made by this framework have already been implemented during the present workshops e.g. quiet familiar environment, ticking off activities, ability-appropriate content and rewards.

The workshop sample was limited to a male majority. This is arguably not surprising as gender differences in ADHD have been identified with a ratio of 3:1 (male-to-female). The M:F ratio is from clinic populations only. Therefore, it could be concluded that the limited number of female recipients may not make this sample any less representative of the wider paediatric ADHD population.

Conclusion

The aim of these workshops was to begin the iterative co-design process of a psychoeducational magazine for primary aged CAYP with ADHD. The use of this approach is novel with this population as there are few published instances of co-designing with CAYP with ADHD.

Next steps are to design a prototype of the psychoeducational magazine and iteratively co-design is with end users and key stakeholders, with expert clinical input. This intervention will aim to educate primary aged CAYP about their ADHD alongside usual care e.g. ADHD medication, strategies to manage their ADHD at school, parent groups and ADHD clinics.

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Goal Setting for Physical Activity for Older Adults: An Exploratory Context Research

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ABSTRACT When individuals set the right goal it will improve their performance and motivation. Setting a goal isn't easy as it is personal and needs to be derived from the motivation of the person. Setting goals is already applied in many fitness apps, but there is still a lack of knowledge of how to apply this to specific target groups, like older adults. It is important for them to practise regular exercises as it contributes to healthy aging (Schutzer and Graves 2004; Peel, McClure, and Bartlett 2005). Motivating older adults to exercise more can potentially reduce costs in health care for older adults (Aoyagi and Shephard 2011) and could subsequently reduce work pressure for caregivers. However, some older adults still refrain from exercising because they do not see the benefits, are led by barriers and are insecure about their abilities.

This exploratory research aimed at finding insights in applying goal setting in a motivational tool to help older adults engage in an active lifestyle. It consisted out of two phases: Phase 1 aimed at identifying the relevant characteristics of older adults who might likely benefit from goal setting; Phase 2 examined to what extent goal setting could improve physical activities of these older adults. A group of 7 older adults participated in the study, they filled in questionnaires about their barriers, attitude and motivation regarding physical activity. They also participated in a goal setting workshop where they worked with a goal setting tool that was specifically designed for this research and target group. Additionally, they were interviewed about goal setting and their vision towards physical activity. This data combined gives insights in ways to motivate older adults and their characteristics relevant to goal setting.

Keywords: older adults, goal setting, motivation, physical activity

Introduction

Increasing the quality and years of healthy life is a big societal challenge with the populating ageing trend. Healthy aging includes the process of optimizing opportunities for preserving physical, social and mental health, as well as independence, the quality of life and enhancing successful life-course transitions (Peel, McClure, and Bartlett 2005). Being physically active is important to promote healthy ageing and prevent chronic diseases (Peel, McClure, and Bartlett 2005)(Schutzer and Graves 2004). Unfortunately, activity levels progressively decline while age increases. Knowledge about factors of exercise adherence will help the providers of healthcare solutions to develop interventions to stimulate physical activity (PA) of sedentary elderly (Schutzer and Graves 2004). How to motivate elderly people to remain physically active is the focus of this paper.

Goal setting is one of the commonly applied motivational strategies for behavior change. This research looked at how to apply it to motivate older adults to be physically active. The nature of this research will be exploratory: the context will be assessed together with the barriers and benefits related to goal setting. The results could gain knowledge of applying goal setting to specific target groups for behavior change.

Related Work

The Goal-Setting Theory of Motivation (Locke and Latham 2002) states that there is an important relationship between setting goals and performance on a specific task. The goals are used to evaluate the performance and are linked to feedback on the results and they create commitment and acceptance. However, individuals must have sufficient ability, accept the goals and receive feedback related to performance (Lunenborg 2011). Self-efficacy is, next to someone's ability, important for setting successful goals. Within setting goals there is also a distinction between intrinsic goals and extrinsic goals. The intrinsic goals focus on community contribution, self-acceptance, self-development, affiliation and physical needs: they satisfy basic individual needs. Extrinsic goals focus on social recognition, image, attractiveness, financial success and power (Wilson and Brookfield 2009). The Self-Determination Theory predicts that events that enhance self-determination and competence will facilitate intrinsic motivation (Wilson and Brookfield 2009). Setting a goal could enhance this self-determination and autonomy within the context of PA for older adults.

Goal-setting has been widely used in physical therapy and disease management with older adults where the professional medical staff often defines the goal themselves while the participation of older adults in goal-setting are desired (Brown, Bartholomew, and Naik 2007)(Baker et al. 2001). It has been found effective in encouraging PA among older adults in combination with behavioral self-monitoring and feedback (Gardiner et al. 2011). It has, however, not been widely used by commercial exercise apps in the Netherlands to stimulate physical activities of older adults. These apps (the Beweegapp (Senioren Sport en Bewegen 2019), the FysioFit app (FysioFitApp 2019) and the Fitavie application ('Bloeien Door Bewegen' 2019)) use push messages as reminders for exercising and give visual rewards, but no goal-setting strategy is integrated. This paper focuses to what extent older adults can apply goal setting themselves to become more physically active.

Method

This research adopted an exploratory approach. It was expected that setting the goals would influence the way participants saw and performed physical activities. The approach consisted of the following studies: 1) a qualitative study based on interviews and workshops with a specifically designed tool and 2) a quantitative study with questionnaires about attitude and barriers. The research was conducted together with Stichting Ontmoet and Groet. This foundation hosts a community centre that provides activities for older adults. For this research the participants of the sports club were targeted. During the sports activities the participants conducted indoor exercises with a sports coach. Targeting the participants at the sports club made sure that people already had a fixed schedule of exercising. 7 people of the sports club participated in this study (2 male, 5 female) with an average age of 83.14 years old.

Probe

A probe specifically for this target group to practice goal setting themselves (see Figure 1) was developed together with an expert at Stichting Ontmoet and Groet. The participants confessed that they were afraid of the mental and physical deficiencies of aging, which made it difficult for them to think about their future, therefore a step by step approach was chosen to slowly work towards a future goal. The goal setting tool is bundled in a small booklet which they worked with during a workshop setting. In a few steps they were asked to look at the past, present and future regarding PA.

SETTING GOALS
This tool supports and researches setting goals to stay physically active.
Name: _____

What do you do now?
What are your activities now? What do you like to do? Does it serve what your physical activities are like. Think about hobbies, sports activities, things you do in the neighborhood, etc.

What are your motivations?
Venn diagram: What do I want? (left circle), Goal! (intersection), What am I able to do? (right circle).

Then.
Physical Activities: What physical activities did you used to do? For example: cycling, hiking, swimming.
Why & which goal? Why did you participate in these activities? Which goals did you set?
why? goal?

Now.
Physical Activities: Which physical activities do you do now?
Why & which goal? Why do you participate in these activities? Which goals did you set?
why? goal?

Future.
GOALS: Write down your main goal. Think about the things you write down in previous pages.
Sub-goal: Working on a big goal is hard, therefore we split it in smaller ones.
why?

Figure 1: The goal setting tool.

Deployment and assessment of the Goal Setting Tool

The research took place over a period of 5 weeks with 3 sessions. To assess their attitude the Attitude towards physical activity (ATPA) (Nelson, Benson, and Jensen 2010) was used. This questionnaire assesses the positive and negative attitudes towards physical activity (Nelson, Benson, and Jensen 2010). To gain more insight in the barriers participants might face the Barriers to being

active quiz (BBAQ) was used. The BBAQ gives insight in what refrains someone from being active (What are your barriers to exercise?, 2012). The data gathered in the sessions using the goal setting tool were thematically analysed. An overview of the sessions held with participants can be found in Figure 2.

Session 1	Session 2	Session 3
Participants were asked to fill in the questionnaires, where after a workshop about setting goals with the goal setting tool was held.	Feedback was given on the goals and participants were asked to reflect on their goals to give them the opportunity to work on their goals.	Participants filled in the questionnaires again, after that an in depth group interview was held.

Figure 2: Overview of the sessions with participants.

Results

The qualitative and quantitative information generated an overview of the context and future focus points for designers and researchers within this context. Not all participants were able to finish the study due to illness during the test period, 3 of the 7 participants were unable to be there during Session 3.

Goal Setting

The goals set by the goal setting tool were thematically analyzed and coded by a deductive, latent approach. Many *intrinsic goals* (focused on self-development and physical needs) were set, derived from both intrinsic and extrinsic motivation. At the same time these goals had an extrinsic reward: staying active and fit results in a better physique, which is a physical reward. During session 1, it was observed that when they talked about PA in the past they talked about *'I liked participating in sports'* and *'I loved to walk around in nature'*. When they talked about sports in current time or the future participants say things like: *'I have to do it to stay active'* and *'I do it because I have to'* (see Figure 3). There seems to show a shift from being more intrinsically motivated to more influenced by extrinsic factors regarding their goals. During the interviews one older adult kept coming back: the community feeling and the atmosphere of the sports club. They motivated each other by coming together, drinking coffee and eating together. This was the main goal for them to come to the community centre, not the sports itself. They did consciously make the decision for participating in the sports club to stay healthy and fit (intrinsic motivation) but they kept coming back to the club because of the strong social aspects next to the sports (extrinsic motivation).

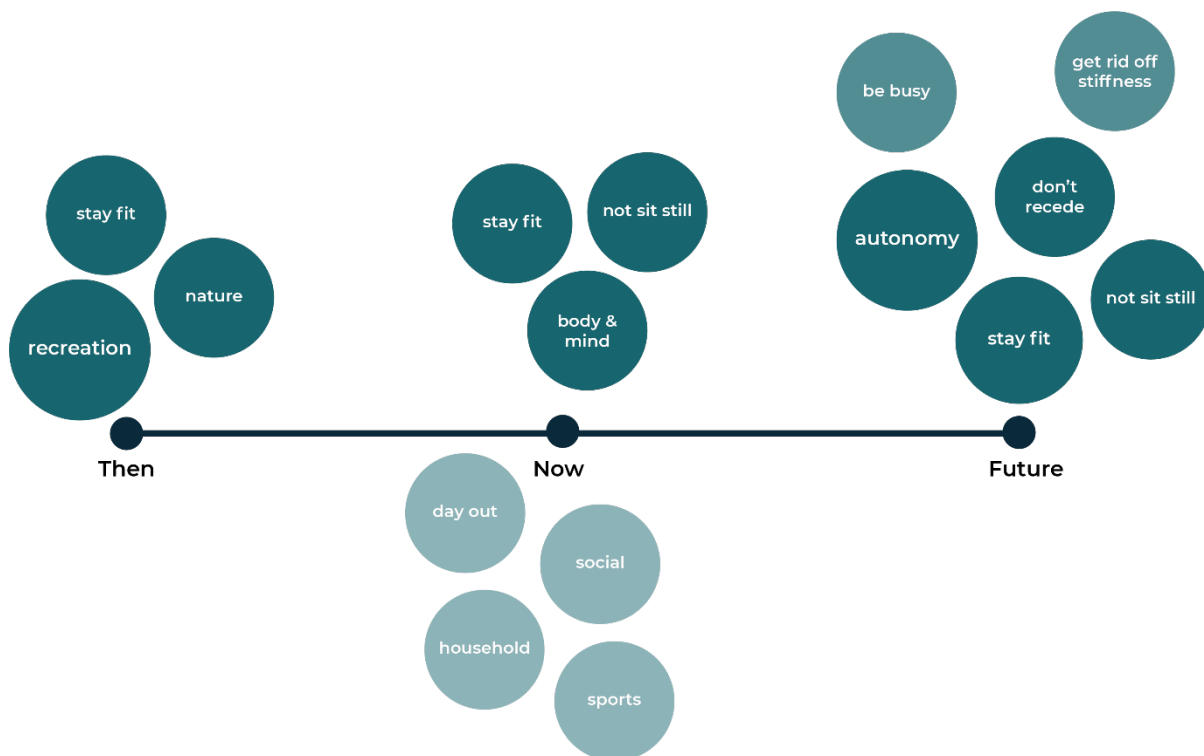


Figure 3: Thematical overview of the goals and motivations in the goal setting tool.

During the second session they reset their goals based on feedback of the researcher. This was hard for them as they did not want to change from their current patterns. Some participants did add and changed their goals slightly based on their social motivations, because they influenced them positively. Therefore, they added this to their goal: to work on the social as well as the physical side of the sports club. They saw it as a social commitment and nice social gathering where they looked forward to. Further feedback was not taken into account by the participants.

Barriers

Analysis of the results of the BBAQ in general (Figure 4) showed that the main barriers were a lack of willpower and lack of energy. The questions about the willpower were about commitment of the participants: *'I want to get more exercise, but I just can't seem to make myself stick to anything'*. Even though the participants were very committed to the sports club, they experienced a barrier to do more. The overview in figure 5 also shows that some participants experienced more barriers than others. Participant 4 and 5 both perceived multiple barriers during the first measurement, both participants had according to the questionnaire fewer barriers at the second measuring point. Barriers that the participants currently experience related to their declining physical ability. They were constantly measuring their current self with their previous self: *'I am can now do half of what I used to do'*. They also had struggles with talking about the future and about future steps. There is hesitance towards PA and talking about the future: *'My body has declined, I cannot do it anymore, so I won't do it anymore'*.

	N	Minimum	Maximum	Mean	Std. Deviation
Lack of time	7	0	5	2.29	1.890
Social Influence	7	0	5	3.00	1.732
Lack of energy	7	0	8	2.71	3.147
Lack of willpower	7	0	8	4.29	2.628
Fear of injury	7	0	7	2.29	2.430
Lack of skill	7	0	5	2.43	1.718
Lack of resources	7	0	4	1.00	1.528

Figure 4: Results of the BBAQ at session 1.

Participant	Lack of time		Social Influence		Lack of energy		Lack of willpower		Fear of injury		Lack of skill		Lack of resources	
Session	1	3	1	3	1	3	1	3	1	3	1	3	1	3
1	2	-	4	-	1	-	8	-	3	-	4	-	0	-
2	0	-	4	-	0	-	6	-	1	-	2	-	0	-
3	0	-	0	-	0	-	0	-	0	-	0	-	0	-
4	4	4	5	4	8	4	5	4	7	4	5	3	2	2
5	5	7	2	4	6	2	5	4	2	0	1	2	4	6
6	2	1	4	6	3	1	2	1	3	3	2	4	1	0
7	3	0	2	1	1	0	4	2	0	1	3	3	0	2

Figure 5: Overview BBAQ, score >5 means a barrier on that topic (marked blue).

The barriers identified in the questionnaire were not similar to those from the interviews. The barriers from the interviews were about ability (physical and mental), while the barriers out of the questionnaires were focused time, social influence, energy, willpower, skills, resources and the fear of injury.

In Figure 6 is an overview of the mean of the ATPA showed, where Question 8 relating to the influence of time had the highest mean: 3.33. In the barriers to being active quiz they also assessed the influence of time, however, Figure 4 and 5 did not identify lack of time as one of the biggest barriers. Question 5 on Figure 6 relating to lack of energy had a mean of 3.20. Figure 4 and 5 shows that energy levels are a barrier for the participants, but not as much as the social influence and the willpower.

If I were to be physically active on most days...	N	Mean	Std. Deviation
...it would be painful	6	2.33	1.506
...it would be difficult	6	3.00	1.414
...it would be embarrassing	6	2.00	1.265
...it would make me feel uncomfortable	6	2.83	1.329
...it would make me tired	5	3.20	0.837
...it would make me sore	6	2.67	1.033
...it would be a hassle	6	3.00	1.095
...it would take too much time	6	3.33	1.211
...it would help me cope with stress	6	2.67	1.633
...it would help me make new friends	6	3.67	1.033
...it would get or keep me in shape	6	3.83	0.408
...it would make me more attractive	6	3.83	1.472
...it would give me more energy	6	4.00	0.632
...it would make me better in sports, dance and other activities	6	3.50	1.643

Figure 6: Overview Positive and Negative Attitude towards Physical Activity (Nelson, Benson, and Jensen 2010).

Benefits

The goals that participants set were intrinsic, with both intrinsic and extrinsic motivational factors. Overall, they perceived the sports activity as positive as it was tailored to the physical abilities of each person. The goals the participants created were derived from knowledge of the positive aspects that PA has on their body and their personal motivations to take action upon them. Further social aspects were recognized as the main benefit of participation in the sport group.

Discussion and Conclusion

As an actual change in behavior was not observed during this research it is hard to make claims on what intervention functions will certainly help for active aging. The influence of the environment of the community centre had a positive influence on the participants of the study. They continued coming back to the community centre because of the positive social environment. While designing and researching this context and target group it is impossible to rule out the influences of the aging process and the declining abilities of the bodies. It should be considered that the older adults are inevitably going to face physical and mental struggles while maintaining a healthy lifestyle. The tool developed in the research did contribute as a means to find motivations and thinking processes of the participants, but it did not influence the way people viewed and participated in PA. It did not show significant differences in the behaviour pattern of the participants. The goals they set about their PA were too broad to be actionable. This observation is in line with earlier research where a collaborative goal-setting with professional medical/care staff was done (Brown, Bartholomew, and Naik 2007)(Baker et al. 2001). The participants were not really receptive for the feedback and changes they had to make during the second session. The goals they wrote down were mainly goals they already worked on for multiple years. The tool might work better for a group who is starting with a physical activity instead of using this tool with a group that is already familiar with sports. The goals that were set and their explanations gave more insight in their motivation and barriers instead of facilitating behavior change.

The group motivated each other and created a positive atmosphere around the sport activities through social support and peer pressure. Declined mental and physical ability are barriers for people that are already participating in sports activities, as well as for people that want to start with exercising at a later age. Further barriers that were found during the research lie in the lack of willpower, which could also be a result of declined ability. The social aspect is also a benefit according to the participants as they described multiple times how the community feeling motivated them in participating. Another barrier that was identified during the tests is their hesitance to look towards the future, future plans and goal setting. Making plans and setting goals assumes most of the time that they work towards a better physical state, but due to their age they struggle with this because it is inevitable that their physical state will decrease.

In previous work related to goal setting, self-efficacy is found to be one of the factors that influences goal setting, motivation and performance. In this research self-efficacy is not actively taken into account.

This study is conducted with a group of 7 participants; to gain more insights in goal setting for physical activity for older adults a larger group with different levels in physical activity could be researched.

Conclusion

Applying the Goal Setting Theory of Motivation to a small group of older adults to see whether their performance will improve does not work the way it was envisioned with the goal setting tool. The tool did provide knowledge and insights about the target group and their current view on PA; however, it did not motivate people to work more on the goals they had regarding PA. The atmosphere in the group and the community feeling influenced the participants in a positive way and worked as a big motivator for the target group. The inevitable declining physical state did influence the participants in a negative way. The further measured barriers could also be led back to this as well as the hesitance towards looking at their future. Future research and design could use these findings as a starting point in their process.

Acknowledgements

We want to thank Ontmoet and Groet and the participants for making this research possible.

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The miners' banner as a conduit for wellbeing in the post-industrial mining villages of North East England

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[ABSTRACT only] Although the last colliery in North East England closed in 1993, the ceremonial miners' banners remain vital central artefacts in the pit villages stripped of their identity and purpose. These economically disadvantaged communities are using the emblematic power of their miners' banners to represent their resilience. The traditional parade of communities and their banners at the annual Durham Miners' Gala (DMG) becomes a focus for the pit villages' emotional regeneration.

During their working lives, miners' banners were taken to rallies and picket lines and were generally involved in action that left them damaged, or in some cases, completely destroyed. As a result, communities either retired their banners to museums, or were galvanized into action to restore, or make a new banner to re-engage their community around a central artefact. When Norman Emery calls the banners "Graphic messages of hope" (Tallentire 2014), he is referring to their powerful imagery, in which mining communities historically called for social justice and working-class rights. Now, it could be argued, the banners are being used as a 'message of hope' for the wellbeing of the communities themselves.

This paper will report on the creation, pilot use and evaluation of Relic; a tangential object; a design provocation created to distil the elements and essences of what a miners' banner is to its community in order to isolate and then interrogate the individual parts. Relic provides an uncommon lens for post-industrial mining villages in North-East England to draw on their own experiences of their banners; to find a new voice and give new insights into how a banner can promote citizenship, define a collective identity and function as a conduit for emotional wellbeing.

Keywords: banner; community; identity; emotional wellbeing; citizenship; co-creation

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Critical analysis of the new Indian currency design from the perspective of visually impaired

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ABSTRACT *India is a cash-rich economy where 90% of day-to-day transactions are conducted in cash (Chowdhury and Hosain 2018). In 2016, following a demonetization drive, the Government of India launched a set of 7 new banknotes, eliminating INR 500 and 1000 from the system to introduce two new denominations of INR 200 and INR 2000. This resulted in a mix of new and old banknotes in circulation for the same denominations.*

At present, India has approximately 4.8 million people with visual impairments (PVI). This paper presents the study done in two phases. In part one, the design of the new currency was critically analysed and compared with the recommendations of DNB. The second part of the study reveals the findings of the investigation done on the various difficulties faced by the PVI in identifying and transacting with the new banknotes. The situation became complex when the mix of new and old banknotes started coexisting.

Phase-2 presents the learning from the tasks of identifying the banknotes by PVI participants. Findings were drawn from the observations and semi-structured interviews with participants.

Surprisingly no participant could identify the new currency denominations even after two years of being in circulation. All the denominations below INR 100 have no tactile marks. Therefore, the variation in the size remains the only identifying feature for the PVI. The size differences of the banknotes were found insufficient to make them distinguishable.

The findings indicate that the design of new currency introduces evident visual changes with vibrant colours, facilitating quick identification for people with vision. However, the unrecognizable change in dimensions and unimproved tactile cues raises issues about the concerns towards inclusiveness in the design of currency for the PVI population.

Keywords: currency design, inclusive design, design for visually impaired

Introduction

November 2016, Indian government banned INR1000 and INR500 banknotes. Following this, the Reserve Bank of India (RBI) launched Mahatma Gandhi (MG) new series of banknotes in seven denominations of Indian Rupee (INR) 10, 20, 50, 100, 200, 500, and 2000, gradually over 2 years. However, the old banknotes in five denominations of INR 5, 10, 20, 50, 100 continued to exist in circulation. This created a unique mix of 12 types of banknotes in circulation (Figure 1).

Defining PVI and scope of the study

After India changed its four-decade-old definition of blindness in 2017 from 6/60 to WHO criteria of 3/60 in the better eye, the blind population in country reduced to 4.8 million (2019) from 12 million (2006-07) (N. C. Sharma 2019). De Heij (2009) categorised the PVI into three sub-groups, colour blind, partially sighted and the blind. Our study was limited to identifying the denomination of new and old banknotes with partially sighted and blind. The design of the coins is not covered in this study.

New banknotes and the PVI population

The design of new banknotes was well received by people with normal vision but was found unsatisfactory by the PVI population. Multiple articles in media voiced this issue. In response, National Association of Blind (NAB) filed a petition in Bombay high court stating that the new currency is difficult to identify and distinguish for the PVI (The Wire 2019).

Structure of enquiry

The concern regarding dissatisfaction among the PVI populations led this study into two parts. The first part focuses on the critical analysis of the design of new MG banknotes by comparing it to the recommendations by De Heij (2009) for 'Banknote design for the PVI'. The second section of the paper describes study conducted with the PVI participants regarding the accessibility features of the new and the old banknotes through semi-structured interviews and observations drawn during the identification task.



Figure-1: Left- 7 denominations of the MG banknotes; Right- old banknotes in circulation

Critical analysis of the design of new MG notes

This section analyses the design of new MG notes with respect to available international guidelines.

Accessibility features for the partially sighted and the blind

Sight plays a significant role in transacting money. Well-designed accessibility features in a currency can ease the identification of denomination for the PVI population. However, the PVI is not a homogenous population. It includes people who are born blind, have lost sight due to various reasons at a later age or turned blind in childhood, have limited visual acuity or acquired visual problems with growing age. In India, untreated cataract is a significant cause for blindness in the aging population. Moreover, most people cannot read braille. Therefore, designing the currency for a country is a challenging task and requires a universal design approach (De Heij 2016).

The designing of any currency is striking a delicate balance of art, science, and economics (Williams and Anderson 2007). Accessibility features must compensate the absence of sight or poor vision. The recommendations to facilitate blinds in identifying denominations include; variation in note length as per denomination, tactile patterns of dots or lines on the short or long edges, and symbols with intaglio printing. For the partially sighted, a considerable numeral denomination height at the same location across denominations, numerals on the front and reverse with clear contrasts are recommended (De Heij 2009). BEP 1983 and NRC 1995 reports that change in size with denomination is the most valuable feature for the PVI (De Heij 2009).

Design of new MG series banknotes

RBI promotes the new currency through its interactive posters (RBI n.d.) on its website. The essential features incorporated in the MG banknotes include variation in colour and note size across denominations, tactile patterns on both the short edges and symbols with intaglio printing for all notes of denominations above INR 100 (Figure 2).



Figure-2: The new MG banknote INR 500 with features for PVI (RBI n.d.)
1. MG Portrait in intaglio printing. 2. Ashoka pillar emblem-intaglio printing.
3. Tactile pattern on both short edges and tactile identification symbol.

Analysis of currency design for the partially sighted

The denomination on MG banknotes is mentioned in words and numerals. Numerals are mentioned in English (oriented horizontally) and in Devanagari script (oriented vertically) on the obverse and the reverse of the banknote. All numerals are placed at the same location for all denominations (Figure 1). They are repeated thrice or more on each side. The height of the largest denomination numeral (LDN) on the MG banknote is 8.34 mm (Figure 3). However, it is much smaller in comparison to the recommended height of minimum 15mm or preferred height of 22mm for the partially sighted (De Heij 2009).



Figure-3: Scaling the LDN for INR 2000 (8.34mm height) to the recommended size of 22mm without rupee symbol

Use of Rupee symbol as prefix with the LDN

MG banknotes use the rupee symbol as prefix with all DN. Other countries studied (USA, European Union, Japan, Australia, Sweden, Singapore, Hong Kong, Switzerland) do not use currency symbols as prefixes, especially with the LDN except for the British pound. Authors suggest that MG notes should drop the use of rupee symbol prefixing the LDN across all banknotes and increase the height of the LDN to more than 15mm. This will ease the identification of the LDN for the partially blind. The smaller size numerals repeated on other locations could continue using rupee symbol.

Position and colour contrast of LDN

The numeral location is consistent in its position across all denominations. The plain background behind LDN results in acceptable contrast (Figure 1). The position and colour contrast for the LDN meet the recommendations in the MG banknotes.

Analysis of currency design for blind

Variation in banknote length

In the absence of visual clues, the variation in the banknote length is the most valuable feature for the blind. De Heij (2009) recommends incremental increase in the length of the banknote with the increasing denomination keeping height constant. The MG banknotes are not consistent with this recommendation. INR 10 and 20 of MG banknotes differ in height as compared to other denominations. INR 50, 100, 200, 500, and 2000 have the same height, but the difference in length is not incremental. The marginal difference of 4mm in the denominations of INR 100 (142mm), 200

(146mm), and 500 (150mm), is insufficient for identification. The mixture of the new MG notes sizes with the old note sizes adds to confusion. 1mm difference in length of MG INR 200 and old INR 20 note and 2 mm difference in old 10 with MG 50 is almost impossible for a blind to differentiate (Figure 4). The old series INR 100 is significantly larger than the MG INR 500 note. (Figure 5).



Figure-4: Above: New 200 1mm shorter in length and 3mm taller as compared to old 20
Below: New 50 2mm shorter and 3mm taller as compared to old 10



Figure-5: Old 100 157mm long and 73mm tall is larger than new 500 of 150mm x 66mm

The National Research Council (NRC 1995) has prescribed the minimum value of Weber fraction for banknotes as 0.03. However, De Heij's (2009) study finds it to be ineffective and recommends 0.06 value. In an ideal scenario, the Weber fraction throughout the banknote series across consecutive denominations should remain constant (De Heij 2009).

In the MG banknotes, with rounding-off, the Weber fraction is 0.05 for the denominations up to 100 (Table 1). However, the fraction suddenly drops to 0.03 for INR 200 and 500, making it difficult to distinguish between INR 100, 200 and 500 banknotes.

Table-1: Weber fraction for new MG and old banknotes

Value	New MG banknotes					Old banknotes in circulation				
	Length	Height	ΔL	Weber Fraction	Remark	Length	Height	ΔL	Weber Fraction	Remark
5					Replaced by coin	117	63			
10	123	63				137	63	20	0.17	
20	129	63	6	0.05		147	63	10	0.07	
50	135	66	6	0.05		147	73	0	0.00	Change in Height
100	142	66	7	0.05	3 mm height difference	157	73	10	0.07	
200	146	66	4	0.03	Fraction reduced to 0.03.					Didn't exist
500	150	66	4	0.03						Discontinued
2000	166	66	16	0.11						Didn't exist

Use of tactile patterns and high raised intaglio printing

In MG Banknotes the tactile patterns and intaglio printed symbols on the front of the banknotes on short edges. However, denominations below INR100 do not have tactile patterns or embossments. De Heij (2009) suggests midpoint on the edge as the most active area for tactile pattern. In the older banknotes, the tactile marks are placed slightly below the midline and for MG, slightly above the midline.

The tactile patterns and codification

The tactile patterns are a combination of angular bleed lines. For INR200, it is a combination of lines and circles (Figure 6). A simpler and visually consistent logic for codification could have been devised, as seen in Canadian banknotes. They use raised dots as a tactile feature with simple codification (Figure-6) (Bank of Canada 2012). Interestingly this is not in braille as their research with the blind or partially sighted people in Canada indicated that all users cannot read braille (Bank of Canada 2012).



Figure-6: Tactile markers on the new MG Banknotes along the short edges with intaglio printed symbols of various shapes (top). Raised dots as tactile markers on the Canadian polymer banknotes (bottom-left). A simple codification method (bottom-right)

Limitations of the analysis

We could not analyze certain features of the banknotes, such as the reason for the choice of font, frequency of denomination numerals, space between the tactile patterns, height of the tactile pattern, choice and shape of symbols for intaglio printing. RBI has not published any document stating the rationale for the design decisions of the new MG notes.

Study with the PVI users to identify banknotes

The second phase of the study explores how PVI manage transactions with a mix of old and new banknotes and identify the challenges faced. Participants were presented with banknotes and asked to identify the denomination. The task was followed by the interview to understand the various methods they use and the scope for errors.

Methodology

Semi-structured interviews and observations were used to collect data. Participation was voluntary with prior consent and no monetary compensation was offered. The interview responses were voice-recorded and transcribed. Participants were provided with new and old banknotes and requested to identify its denominations. Some tasks were video recorded with prior approval to facilitate re-looking.

Participants

Eleven participants, 3 female and 8 male in the age-group of 35 - 60 years were interviewed for the study. Two of them (one male and one female) were partially blind with 5% vision and nine were completely blind. Four participants work in banks, 2 in government offices, 2 street vendors, one runs an NGO for blinds, one is a music teacher, and 1 is a housewife. 8 participants out of the 9 were blind from birth, and one of them turned blind at the age of 25.

Identifications task

Participants were handed over the banknotes one after the other and later in a bunch and asked to identify the denominations.

Various ways to identify the denomination of a banknote

The accessibility features in the MG banknotes for the partially blind and the blind include tactile patterns, intaglio printed embossments, and variation in the colour and length of the banknotes (Table 2). However, their implementation is inadequate in two columns, the size and tactile markers, which are crucial for the blind.

Table-2: Currency design features for visually impaired (Williams and Anderson 2007)

Issuing Authority	Primary colours that differ by denomination	Size that differs by denomination	Tactile recognition symbols	Certain oversize numerals	Machine readable features for banknote readers
India	Y	Y*	Y*	N*	Y

Y* They are present but with problems in implementation.

N* Largest numeral height is 8.34mm against recommendation of 15-22mm

Methods the participants use when the tactile feature fails

Estimation using length for single banknote identification

Since the tactile features are not adequately perceived, the difference in length of the banknote is the only reliable feature for the blind. When a single banknote was presented for identification, the participants tried to estimate the length by measuring it with their hands by aligning it with the base of palm or fingertips (Figure- top) or by measuring from the center and travel to edges (Figure 7 bottom). This estimation is verified against their stored memory of the prior experience.

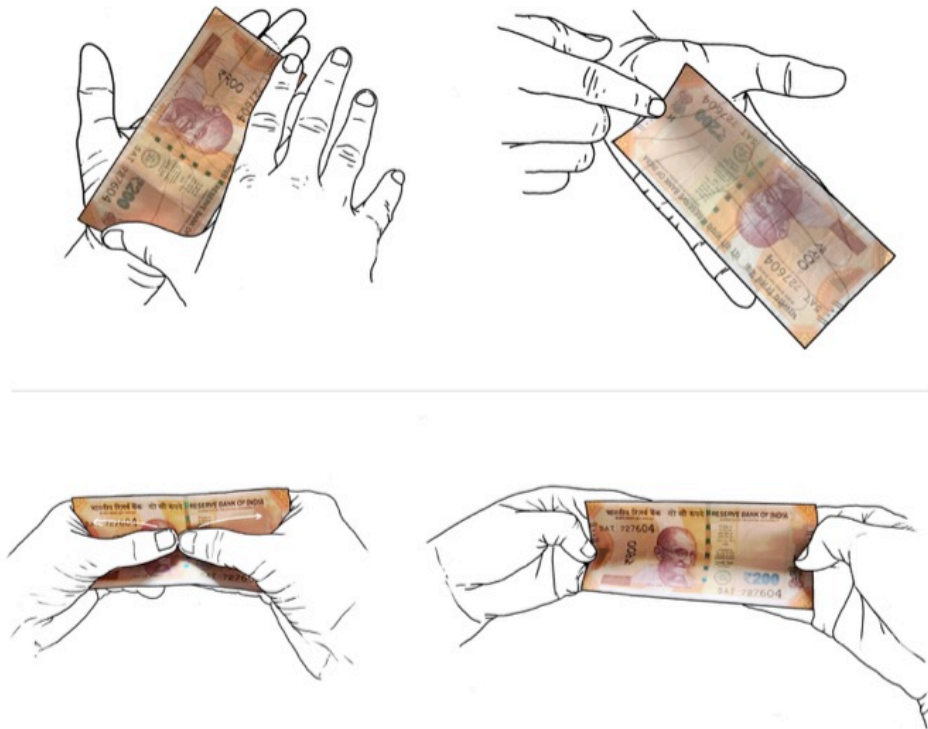


Figure7: Estimation technique to identify single note denomination

The folding technique to identify single banknote denomination

The participant folds the banknote into half and aligns it from the base of the fingers and measures with respect to the fingers (Figure 8).



Figure-8: Estimation technique with folded note

Comparison technique to identify denomination

When the participants were handed two banknotes they try to compare the difference in length by touch (Figure 9). If the difference is not discernable, then it is difficult to identify the denomination. In MG banknotes, the lengths difference of 4mm for INR 100, 200 and 500, is too subtle for identification by the sense of touch. Whereas, the difference of 10mm across all denominations in old notes makes them easier to identify.



Figure 9: Comparison technique to identify denomination

Problems in identification due to mix of old and new

When participants were given a mix of the new MG and old notes, they were unable to identify the denominations using the length of the long edge. One group of banknotes given for identification included old INR 100 (157mm length), new MG banknotes of 100 (142 mm) and 500 (150mm). Participants were familiar with old INR 100, but since the new INR 500 was smaller in size, it confused. The participants also failed to differentiate the MG note of INR 200 (146 mm) and old INR 20 (147 mm); MG note of INR 50 (135mm) and old INR 10 (137mm) as the differences were subtle.

Other ways to identify banknotes

All participants knew about signature guides, which help the blind to identify denominations. A signature guide Notex made by the National Association of Blind (NAB) was used by 60% of the participants. It is a small plastic strip with indentations, where they fold the banknote and match the indentation to identify its denomination. The new notes cannot be identified with the device because of changes in lengths. To compensate for the failure of tactile markers, RBI launched MANI (Mobile Aided Note Identifier), a free mobile app for android and apple in January 2020. It works without an active Internet connection. It announces the denomination when the note is held in front of the camera, in Hindi and English.

Digital payments and hassles of transactions with new and old currency

All participants had a mobile phone and made digital payments using the talkback feature within apps. However, at certain occasions digital payments were not possible and one has to transact with cash. The common scenarios they quoted were shopping for vegetables from a street vendor, hiring an auto-rickshaw, or receiving money from an ATM. Participants reported that they have got accustomed to the old currency, but the mix of old and new makes transacting difficult. Participants reported being short-changed while paying off for a taxi ride as there is less time to check the returned money. The overall feedback summarized that the new currency is difficult to decipher with touch and the feeling of being dependent on others to identify a denomination is frustrating. The use of a mobile app is possible, but it is time-consuming.

Conclusion

In summary, the new MG banknotes incorporate the recommendations mentioned by DNB (De Heij 2009) for the PVI population but inadequately. The tactile markers and embossments appear on higher denominations and not on the frequently used lower denominations. The next reliable feature of identifying a banknote was to compare the length of the banknote within denominations. It was hampered by a mix of various lengths of the old and new banknotes in circulation. As a result, the day-to-day transactions became stressful for the PVI.

Blinds have resorted to their ways of guessing the denominations by measuring the banknotes against their palm and fingers. Very few manage to guess it correctly and often fail. This method is time-consuming. Signature guides and mobile apps launched by RBI are other ways of identification and were used by participants. Nevertheless, all participants desired accessibility features, as they are more convenient and accessible than to be device-dependent.

The change in the length and colour of the banknotes with the increasing denomination is a valuable feature, as it benefits everyone, the normal sighted as well as the PVI. The MG banknotes can be improved if the difference in length is increased and made more apparent to the blind by touch. For the PVI, sense of touch is their way of seeing the world. Treating PVI as a special group and providing alternative ways for them to access currency, does not pronounce equitable access and well-being. The ease with which a sighted person performs his daily transactions, the PVI should also be able to transact with such ease using touch and feel. Currency is to be understood by designers as a product of frequent and mass use; errors in decision-making are long-lasting and difficult to repair. Therefore, the design of currency must exercise a rationale and an inclusive approach.

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The Wall of Change: Inclusive Futures Designed by People with Learning Disabilities and Autistic People

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ABSTRACT This paper discusses a speculative design research project called *Inclusive Futures*. The project aims to imagine alternative versions of the future based on what people with learning disabilities and autistic people would most like to change about the world. *Inclusive Futures* is part of an interdisciplinary research project called 'Heart n Soul at the Hub', funded by the Wellcome Trust. The paper provides an overview of two key phases of the *Inclusive Futures* project: a public exhibition and two 'futuring' workshops. An analysis of the data generated during these phases was undertaken in order to better understand what disabled and non-disabled participants believe are the most important things to change within the development of a more inclusive future. In sharing our approach, we aim to advance the established practice of speculative design and position people with learning disabilities and autistic people at the centre of the expanding understanding of speculative design as a catalyst for social change.

Keywords: human-centred design, speculative design, learning disability, autism.

Introduction to the Authors

The Inclusive Futures project is led by a team of eight people. Two are researchers from the Helen Hamlyn Centre for Design (Will and Chris) and six are co-designers with learning disabilities and/or autistic people (Aysen, Bobby, Castro, Rajah, Robyn and Thomas). The authors' names are used throughout this paper to highlight passages written directly by a specific member of the team.

Introduction

'Inclusive Futures is an example of when people really listen to you. Camaraderie - we all work together . . . it's really important that disabled people are empowered to do things and know that they can change things.'

(Robyn)

Inclusive Futures is a speculative design research project that aims to create alternative versions of the future based on what people with learning disabilities and autistic people would like to change about the world. Inclusive Futures is part of Heart n Soul at the Hub – an interdisciplinary research project that brings together disabled and non-disabled artists, scientists, researchers and clinicians. The project is led by Heart n Soul, a creative arts company and charity that believes in the power and talents of people with learning disabilities and autistic people. At its core, Heart n Soul at the Hub understands that research processes that relate to disabled people are inherently political with the potential to either exploit or empower those involved. The project builds on emancipatory and participatory approaches within the field of Disability Studies that have '(re)positioned disabled people as social actors with rights, and research as a potentially democratizing activity aligned to disability politics' (Liddiard et al. 2018). Pino Frumiento, co-founder of Heart n Soul, notes:

'All our lives people ask us questions, from benefits interviews to doctors' appointments – we are under the microscope. Now with this research project we are in charge, and we are the ones asking you questions.'

(Frumiento and Collins 2019)

Inclusive Futures addresses the concern raised by Gieben-Gamal and Matos (2017) that although the field of Disability Studies has created a significant increase in theoretical and practical understandings of disabled people's lives, there has been little crossover between this and the field of design.

Imagining Futures

Speculative design is the use of design to imagine how things could be different. Speculative design 'can give form to the multiverse of worlds our world could be. Whereas it is accepted that the present is caused by the past it is also possible to think of it being shaped by the future, by our hopes and dreams for tomorrow' (Dunne and Raby 2013, 160). However, the perspectives of people with learning disabilities and autistic people are notably absent in existing literature and practice concerning speculative design (see Tharp and Tharp 2018; Dunne and Raby 2013). This lack of representation is discussed more broadly within the fields of Critical Disability Studies (Goodley

2017) and Inclusive Design (Hamraie 2017). In response, Inclusive Futures aims to position people with learning disabilities and autistic people at the centre of imagining new possibilities and possible futures. 'The most important thing about Inclusive Futures is getting to say what we want to do. Coming up with our own ideas on what we want to change' (Thomas).

There are a number of speculative design approaches that have informed the project. These include the Royal College of Art's *Gateway* project (Harrow et al. 2018) which visualizes future cities where driverless vehicles have changed how people live, and *Madlove* - a collaborative project led by artist and activist the vacuum cleaner which reimagines the asylum as 'a safe place to go mad'.



Figure 1: The Vacuum Cleaner and Hannah Hull's Madlove - Wellcome Images

The following sections detail two key phases undertaken during the Inclusive Futures project: an exhibition titled 'The Wall of Change' and two 'futuring' workshops.

The Wall of Change

The initial stage of the Inclusive Futures project was the design of a participatory exhibition titled The Wall of Change (figure 2), open to the public at the Wellcome Collection in London between June and August 2019. The exhibition presented a series of speculative ideas illustrating what people with learning disabilities and autistic people would like to change about the world. The intention was to encourage the public to imagine and respond to a more inclusive version of the future. Four people with learning disabilities were recruited through the existing networks of Heart n Soul to join the exhibition team as co-designers. The co-designers were introduced to the *Gateway* and *Madlove* projects detailed above to familiarize them the speculative design process. Through a co-creation workshop (Marlow 2013; Liddiard et al. 2018), working with artist Ben Connors, the group visualized objects, environments and services that they would like to change. Each co-designer selected one idea to present to the public. These included a multifunctional electric can opener that works at the push of a button, an accessible tube station that better supports the needs of people with sight loss,

a universal freedom pass that enables disabled people to travel where and when they want, and a proposition for a hospital that makes people with learning disabilities feel comfortable and welcome. Audio description was made available via a QR code next to each image, increasing the accessibility of the exhibition for people with sight loss. The descriptions were written and read by the co-designers - placing their voices at the heart of the exhibition.



Figure 2: The Wall of Change Exhibition - Wellcome Images

The public were invited to consider the artworks and respond by describing or illustrating what they would like to change. 'Ideas templates' (figure 3) were provided, encouraging people to write or draw their ideas and add them to the exhibition. In total, 245 contributions were added by members of the public of which 71 (29%) self-identified as disabled, 57 (24%) as non-disabled and 117 (47%) did not specify.

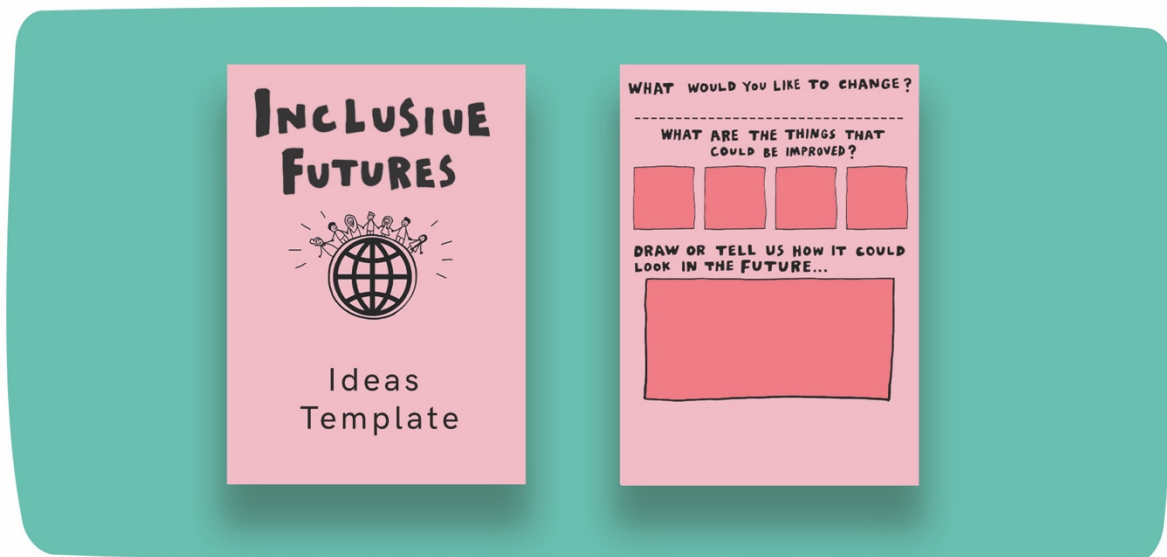


Figure 3: Ideas Template

Futuring Workshops

‘We are making something not just sitting around talking about it . . . it’s not non-disabled people making something for you, it’s disabled people making things for other disabled people.’

(Robyn)

In August 2019, two futuring workshops were hosted at the Wellcome Collection to develop the previous speculative design process with a larger group. 33 participants with learning disabilities and/or autistic people were recruited through the networks of Heart n Soul, charity Artbox and Westminster Learning Disability Partnership. A visual story (figure 4) was created for each event, providing a clear understanding of what to expect. This included information such as:

- The location, date and time of the workshop as text and easy-read symbols
- Sensory information about the workshop environment including lighting, acoustics and available furniture
- The anticipated number of attendees
- Photographs of the workshop team
- A list of accessibility provisions that were and were not available, such as accessible toilets and a chill-out space



Figure 4: Workshop Visual Story

The visual stories were an important component in making sure participants felt comfortable during the design process. ‘Working inclusively isn’t just about what happens in the room (although that’s important too), it’s thinking about how people will get to the room or if they need to know about stuff like lighting before they come in’ (Robyn). During the futuring workshops participants used ideas templates (figure 3) to share what they would like to change, what elements of that choice could be improved and how their idea might look in the future.

Participants worked individually and in small groups to complete their templates and attach them to a large cork wall. Participants could complete multiple templates for multiple ideas and mark connections between them on the wall using coloured string. With a map of ideas in place, three artist-led spaces were created focusing on 2D, 3D and sonic materials. Each space was designed to support the participants to discuss their ideas in more detail from different sensory perspectives. Participants could remain in one space or move between all three. The 2D area focused on materials such as paper, card, pens, pencils and crayons. Participants created drawings, illustrations and newspapers that were displayed on the cork wall. The 3D area used tactile materials such as cardboard boxes, plasticine, pipe cleaners and stickers. Participants created speculative models of objects, vehicles and buildings (figure 5). The sound area was located within the Wellcome Collection radio studio. In this space informal conversations were recorded during which participants discussed their ideas for change with other members of the group. An edited video of these conversations is available online (<https://vimeo.com/399873009>).



Figure 5: 'The Perfect Job Centre' (Thomas)

Having presented two key phases of the Inclusive Futures project, the following section will provide a brief analysis of the data collected.

Analysis

The following analysis focuses on 304 responses to the question 'what would you like to change'. 245 were submitted by members of the public via the Wall of Change (public) and 59 were submitted by people with learning disabilities and autistic people during the futuring workshops (workshop). The analysis uses a topic modelling tool *Text2Speech* (<https://github.com/ual-cci/Text2Analysis>) developed at the Creative Computing Institute at University Arts London. *Text2Speech* uses the Machine Learning capabilities of a variety of sources including the Python Genism package (Rehurek and Sojka 2010) and the LDAviz visualization system (Sievert and Shirley 2014), based on Latent Dirichlet Allocation modelling (Blei et al. 2003). The tool applies heuristics to make these sources more accessible via a web application framework.

Initially the most common terms were extracted from the data along with the percentage of the overall corpus that each of these terms represents, listed below.

Top five terms (workshop):

1. People (3.62%)
2. Disabled (2.71%)
3. Accessible (2.1%)
4. Change (1.44%)
5. Jobs (1.08%)

Top five terms (public):

1. People (2.84%)
2. Mental health (1%)
3. Better (0.82%)
4. World (0.73%)
5. Access (0.64%)

Significantly, the most common term in both data sets is 'people', suggesting that disabled and non-disabled participants in both settings were primarily concerned with change related to people. Both lists include a specific theme and word for transformation: 'jobs/change' for the workshop data and 'mental health/better' for the public.

Building on the above, a 10-part topic model analysis was undertaken for each data set to identify;

- a) prominent topics within the participant responses
- b) key terms associated with each topic
- c) how the topics relate

The topics were assigned a title based on a topic ranking system proposed by Bischof and Airolidi (2012) which looks at the *frequency* of the terms within each topic and their *exclusivity* (i.e. the extent to which each term exists in one or multiple topics). Figures 6 and 7 present two visualizations based on the analysis. Topics are represented by coloured circles, the size of which represents the prevalence of topic and the percentage of the corpus it uses. The distance between circles highlights the inter-topic similarity – the closer the circles are to each other, the greater the similarity.

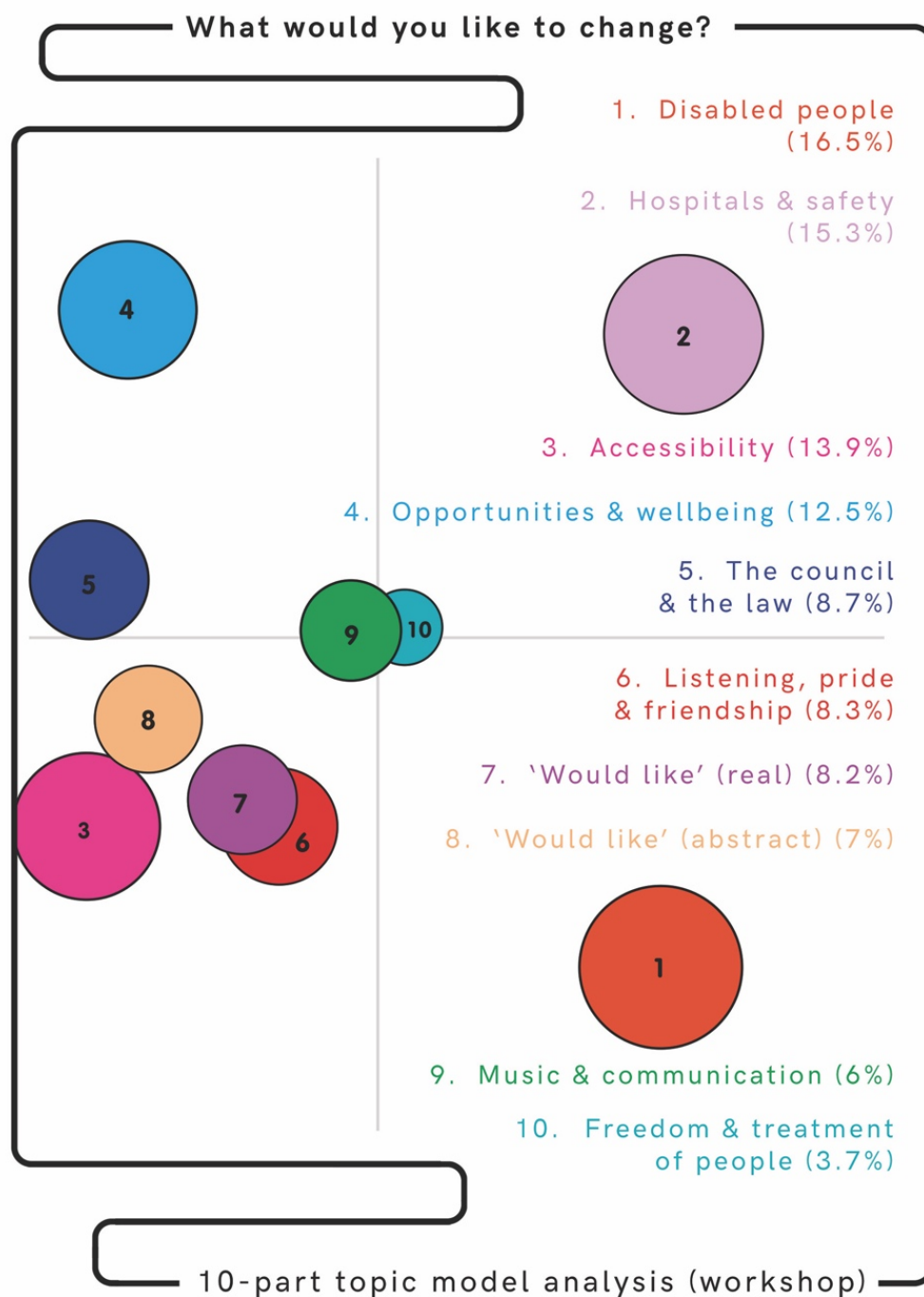


Figure 6: topic model analysis of workshop data using *Text2Speech* tool

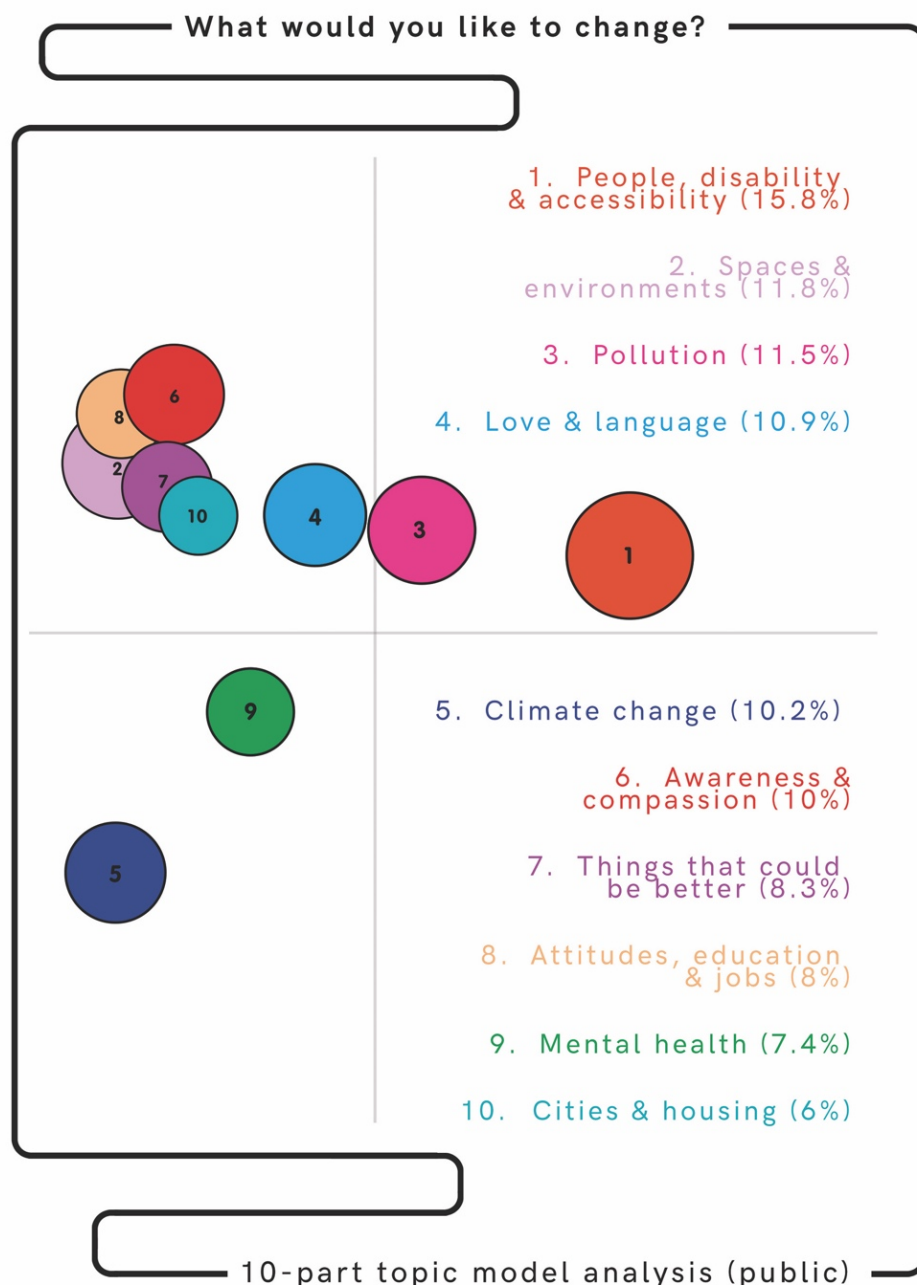


Figure 7: topic model analysis of public data using *Text2Speech* tool

Within the workshop data there are 3 distinct topics: 1. 'disabled people', 2. 'hospitals & safety' and 4. 'opportunities & wellbeing'. Collectively, these use 44.3% of the overall text corpus. The remaining 7 topics use 55.7% of the corpus and are much closer together. This suggests that just under 50% of the responses from workshop participants related to three distinct topics, with the other half addressing similar themes and/or using similar words. Each topic contains a number of associated key words used frequently by participants in relation to each theme. Topic 1 - disabled people - contains key words including positive, access, toilet and story. Topic 2 - hospitals and safety -

includes words such as bullying and stress. Topic 4 - opportunity and wellbeing - includes key words such as artist, salary and single.

Within the public data there are also 3 distinct topics: 1. 'people, disability and accessibility', 5. 'climate change' and 9. 'mental health' which collectively use 35% of the corpus. These are more closely related to the other topics than in the workshop data. The close proximity of the remaining 7 topics suggests that 65% of the public responses used similar words and/or related to similar themes, particularly topics 2, 6, 7, 8 and 10 which are tightly connected within the visualization. Topic 1 - people, disability and accessibility - includes key words such as selfish, other and norms. Topic 5 - climate change - includes words such as government, environment and world. Topic 9 - mental health - includes key words such as public and support. The proximity of topics 5 and 9 highlights the similarities between responses relating to mental health and climate change.

This analysis considers the similarities between the two data sets – they both foreground people, use comparable terms for transformation and, fundamentally, address issues relating to disabled people and accessibility. The analysis reveals several key themes from each data set. The public responses are particularly concerned with pollution, climate change and mental health, whilst the workshop data considers hospitals, safety, opportunities and the law.

Conclusion

The Inclusive Futures project goes beyond simply creating designed outputs. It strives to demystify the design process and focuses on how the imaginations of people with learning disabilities and autistic people might raise critical questions about everyday life. 'Use the information (Aysen) . . . it's a good project (Bobby) . . . helping to make things better for everyone' (Thomas). As Dunne and Raby (2013, 189) suggest, speculative design can act as a catalyst for social change 'adding to what life could be, challenging what it is, and providing alternatives that loosen the ties reality has on our ability to dream'. 'We need to give people ideas and tell them what's important for people with disabilities' (Rajah). During the project, a strong sense of collective agency emerged, with the co-designers sharing their lived experiences of in/exclusion openly and having the confidence and support to propose positive alternatives. The designed outputs to date represent a core set of values about a world designed with disabled people in mind, and the data highlights clear connections between people and a shared desire for change. 'Inclusive Futures is about disabled people designing things that work for them and hopefully for other people so that we can all be included in the world' (Robyn). 'Check it out and see the work that we have done. It gives me the idea that we can change things for the better' (Castro). In a world that is increasingly designed around specific ways of being and doing that gives priority to particular bodies and minds, it feels more important than ever to imagine genuine alternatives that consider divergent experiences. We believe that by using design as a way to consider a diversity of hopes and fears about the world, the proposition of a more inclusive future can begin to evolve from a speculation into a reality.

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Birds of a Feather Sew Together: A mixed methods approach to measuring the impact of textile and e-textile crafting upon wellbeing using Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS)

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ABSTRACT *In this paper two textile-based craft workshops focused on constructing and personalising 3D fabric birds are presented; one using traditional textile materials and another also incorporating electronic components. Working with the public, we employed a mixed methods approach measuring social and mental wellbeing factors using the Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS) and conducted semi-structured ‘conversations’ throughout the crafting sessions. Our findings showed a statistically significant increase in wellbeing following both sessions, with no significant difference between the traditional or e-textile workshops. We contribute findings relating to the quantitative evidence of an increase in wellbeing during crafting sessions and the learning associated with e-textiles crafting in comparison to traditional textile crafting. Although previous textile craft studies have shown benefits to wellbeing, the approach has been qualitative and e-textile crafting is underexplored for its impact upon wellbeing.*

Keywords: craft; textiles; e-textiles, wellbeing scales; WEMWBS

Introduction

Increasingly textile making is employed to improve and support good health and wellbeing (Riley, Corkhill, and Morris 2013), by alleviating symptoms of physical and mental health conditions (Bedding and Sadlo 2008). Yair (2011) reported that crafting can support individuals in building relationships as it encourages collaboration and shared experiences. Additionally, makers described the immersive effects of making as:

‘the feeling of being lost in the “flow” of things’ (Yair 2011)

Csikszentmihalyi (2002) describes flow as where both body and mind work in sync.

As a material, textiles are sensory objects that

“help us communicate and learn, add beauty and stimulation to our days, and make our lives richer’ (Gordon 2011).

The naturally tactile qualities of textiles have been extended further as traditional textiles are combined with electronic components like power, light, sound and small computers to create smart or e-textiles (Posch 2017).

Several qualitative studies in both traditional and e-textiles (e.g.; Burt and Atkinson 2011; Kettley, Sadkowska, and Lucas 2016; Yair 2011) suggest that crafting in general has a positive impact on wellbeing. In the context of this research, wellbeing, which is broadly defined as

‘feeling good and functioning well’ (Huppert 2009)

is measured quantitatively through the Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS; Tennant et al., 2007). An evidence-based or scientific approach allows inspection of design activities and associated wellbeing claims and provides another way for designers to evaluate their own practice.

In this paper we discuss related work, our methodology, and findings which demonstrate a statistically significant increase in wellbeing following both the traditional and e-textile crafting sessions, with no significant differences between the workshops. Qualitative data revealed several themes providing a better understanding of participants’ relationship between crafting and wellbeing.

The Gap

Previous studies have explored the benefits of traditional textile craft for health and wellbeing (Corkhill et al. 2014; Green 2017; Katz-Friberg 2010; Kenning 2015; Nevay et al. 2019; Reynolds 2000). Predominantly these have employed qualitative methods including surveys, interviews and written exchange. Until recently, when a pilot study was conducted and reported by the authors of this paper in 2019, the use of both qualitative and quantitative methods to capture the effect making with e-textiles has on wellbeing had not been explored (Nevay et al. 2019). Additionally, while previous studies have focused on specific groups including people living with dementia (e.g.

Treadway et al. 2019, Robertson et al. 2019) this study employed a self-recruitment method inviting the general public to participate in textile workshops for a research project.

The research reported in this paper builds on previous studies by examining both traditional and electronic textile crafting. Data on participants’ wellbeing states were gathered in conversation and by employing WEMWBS scales pre and post crafting. The research questions explored were:

- 1. Is there any quantitative difference in wellbeing between traditional and e-textile crafting?
- 2. What are the wellbeing experiences of traditional and e-textile crafting?

Methodology

A mixed-methods approach was used to gather qualitative and quantitative data during textile and e-textile workshops. Conversations were recorded, transcribed and thematically analysed, whilst quantitative wellbeing data was gathered using the Warwick-Edinburgh Mental Wellbeing scale (WEMWBS) before and after crafting activities. This data was used to establish relationships between both textile and e-textile crafting and wellbeing.

Process

Both workshops followed the procedure outlined in Figure.1 and Table 1. In response to the different stages throughout the workshop the researchers took on a range of roles; observer, facilitator and instructor.

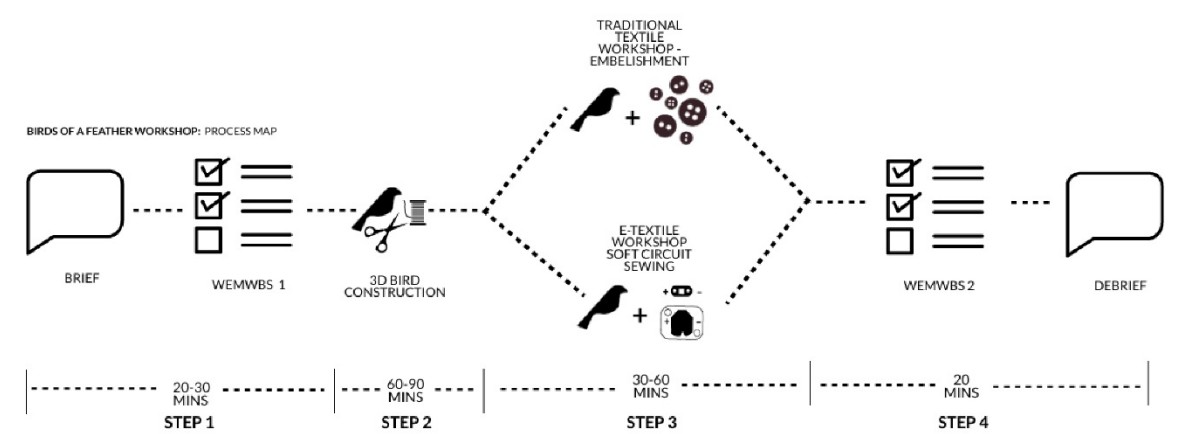


Figure 1: Workshop Process.



Figure 2: Left to right; Storyboard e-textile guide; Sewing patterns; E-textile sewing kits.

Table 1. Workshop Process Step by Step.

Step	Task	Detail
1	Briefing, Consent and WEMWBS	Briefing about the workshop and research, consent forms and WEMWBS completed.
2	3D Bird Making	Create a 3d textile bird with the provided template (Figure 2). This activity included picking their fabric cutting the pattern shapes, sewing them together and stuffing the bird to make it 3D.
3 Traditional Textile workshop only	Embellishment	The traditional textile participants were given the rest of their time (30-60 minutes) to embellish their bird using buttons, feathers, ribbons, sequins, other fabrics and bells.
3 E-Textile workshop only	Soft Circuit Sewing	The E-textile participants used the storyboards to sew their soft circuit and create their light up bird. (Figure 2)
4	Debrief, Feedback and WEMWBS 2	Participants were invited to complete a second WEMWBS survey and provide any feedback about the workshop itself.

Data Collation

Cronbach's alpha was calculated for the WEMWBS responses across both workshops before ($\alpha = .87$) and after ($\alpha = .90$) the activity and was found to be good. Sum scores were generated for each participant based on their responses to the WEBWMS scale pre- and post- participation in the workshop. In addition, a wellbeing change score was generated. Based on simple non-differentiation analysis, one participant showed evidence of giving the same response to all questions and so their data was removed from the analysis. There were two participants in the pre- responses and one in the post- responses who missed a question on the scale, and so a mean value was calculated based on their other responses to replace the missing value. Further to this, extreme outliers for each of the measures were removed from the analysis (wellbeing score pre-, $N = 4$; wellbeing score post-, $N = 2$; wellbeing change score, $N = 2$).

Participants

Participants were recruited via University, craft and community networks. 65 participants were recruited overall (Table 2). Whilst we acknowledge that the gender balance within our sample is unequal, we followed the same recruitment approach as previous related studies (e.g. Corkhill et al. 2014; Kenning 2015) who similarly found that self-selection resulted in more female participants. Across both workshops there was a range of sewing abilities, but no experience of e-textiles.

Caption Table 2. Workshop Participant demographics.

	Female	Male	Gender not disclosed	Total
E-Textile Workshop	27	4	2	33
Traditional Textile Workshop	27	4	1	32
				65

Ethics

This research was conducted with the ethical approval of Duncan of Jordanstone College of Art and Design, University of Dundee Research Ethics Committee.

Findings, Results and Analysis

Quantitative Findings

An independent t-test demonstrated that there was no significant difference in wellbeing change scores between the traditional and e-textile workshops, $t(60) = 0.70$, $p = .49$. Based on this, the two workshop types were analysed collectively to explore the difference in wellbeing scores pre- and post- participating in the workshops. A paired-samples t-test demonstrated an overall significant change in wellbeing, with mean values shown in Table 3 suggesting an increase following participation, $t(59) = -6.72$, $p < .001$, $d = .87$.

Caption Table 3. Means (and SD) for measures of wellbeing change following participation in both workshops.

	WEBWMS Pre-	WEMWBS Post-	Difference score
E-Textile Workshop	50.42 (4.75)	54.91 (6.27)	23.61 (3.93)
Traditional Textile Workshop	51.61 (6.60)	54.65 (6.68)	2.94 (3.60)
Total	51.02 (5.73)	54.78 (6.42)	3.26 (3.75)

Qualitative Findings

Thematic analysis identified five themes: Textile Relationships; Textiles and Wellbeing; Identity and Self Expression; Sharing Life Experience; and Learning and Skill Sharing. Participants are identified by number and workshop with 'E' for e-textiles and 'T' for traditional e.g. P1E is Participant 1 from the e-textile workshop.

Textile Relationships

Similar to Kenning (2015), participants explored sharing and the passing down of skills through generations, describing family members who had influenced their interest and knowledge of textile processes i.e. sewing and knitting. Birds were personalized in representation of significant relationships, for example, P6E:

‘I’ve chosen this lovely map fabric...showing France as my sister lives there and I want my bird to symbolise my connection with her’.

In identifying the people or places that they associate with textile crafting participants were able to reflect upon their relationship with making textiles.

Textile and Wellbeing

Participants with previous textile experience expressed awareness of existing cognitive and emotional benefits: P5T:

‘I am very aware that doing crafting is something I just enjoy, it is like escapism – I suppose a lot of the time I am quite stressed at work so [craft is] a good thing to do for your health...because it makes me focus not on work’.

and P1E expressed that textile crafting makes them:

‘feel happy ... I want to say it ignites something, it gives you a little bit of excitement...you are taking flat things and making something 3D’.

Further, P2E highlighted:

‘I think it’s good for your brain to be really focused on something and wanting to make a good job of it – it’s good for your emotional wellbeing’.

Identity and Self Expression

Participants used their creations as vehicles for expressing themselves (e.g. elements of their own identity, histories and personality) by using resonant fabrics and material: P7E:

‘I’ve chosen these materials as the clash reminds me of my favourite jumper.’

Thus participants were able to quickly communicate aspects of their character and their lives. This prompted further conversation and bonding as they established parallels between each other’s’ lives. Possibly reflecting their new connections, participants were influenced by and echoed peer design choices including embellishments with feathers, bells and buttons (Figure. 3).



Figure 3: Left to right; Storyboard e-textile guide; Sewing patterns; E-textile sewing kits.

Whilst identity is also highlighted in previous works, (e.g. as crafter/maker in Kenning (2015)) in this study, participants' various personal identities were expressed through the fabric and embellishments they used to construct their birds.

Sharing Life Experiences

While reflecting upon their individual motivations for engaging in textile crafts during the workshops, participants broached some highly personal and potentially sensitive or difficult subjects. The researchers observed an exchange between two participants concerning retirement and ill-health, P4T chatted to P7T:

'I had to retire for medical reasons earlier than anticipated – I went with a bit of a grudge.'

Despite not being previously known to one another, their shared participation and interests (i.e. textile crafting) enabled conversations about wider issues within their lives. This suggests that the workshop activities facilitated both social activity and connections with like-minded people, fostering mutual understanding and confidence between participants as they worked.

Learning and Skill Sharing

Both workshops presented challenges around bird construction (e.g. manipulating fabrics of different weights and textures and using the sewing pattern) but the e-textile workshop, combining familiar hand-sewing skills with less familiar rules of electronic circuitry presented difficulties for several participants. Other participants who did not encounter difficulties offered practical advice and encouragement to their peers evidencing group cohesion, inspecting birds for circuitry problems and giving verbal support.

Across both workshops, participants supported each other by sharing skills and knowledge such as pinning and button-sewing techniques and demonstrating the use of a pen to smooth and define seams once turned inside out.



Figure 4: Participants show their birds to the group as they successfully complete their soft circuits.

This process of learning - applying new knowledge and techniques and rectifying any mistakes made - instilled a sense of personal fulfilment and provided opportunity for social interaction. Across both workshops participants expressed satisfaction with their creations but e-textile participants expressed particular joy at successfully completing their circuits, showing their lit-LEDs to the group and sharing that they were 'proud' and 'pleased' with their accomplishments (Fig 4) and some planning to further their new skills by undertaking future e-textile projects.

Discussion

This study explored two research questions:

1. Are there any quantitative wellbeing differences between traditional and e-textile crafting?
2. What are the wellbeing experiences of traditional and e-textile crafting?

Both qualitative and quantitative data revealed a significant increase in wellbeing following both traditional and e-textile crafting. The WEMWBS result is perhaps unsurprising as parallels exist in both crafting experiences - both are hands-on activities, grounded in textile construction techniques and act as drivers for social activity and interaction. However, comparison of the qualitative data of the workshops reveals that the experiences of traditional and e-textile crafting can be very different, and therefore could impact differently upon wellbeing: the traditional textile crafting workshop is an exercise in personalisation whereas the e-textile crafting is focused on learning a new skill. Our results reflect Hendry & Kloep's (2002) notion that wellbeing is also dependent on undertaking new challenges and experiences, and that improved perceptions of one's capabilities and self-esteem help towards stabilising or improving wellbeing. Our findings also link with the Five Ways to Wellbeing (Aked et al. 2008) model which purports that it is important to 'Keep learning and engage in challenging and rewarding activity' (one of its' five evidence-based actions for improved wellbeing). Participants' descriptions of 'relaxation' and 'flow' are similar to those reported in previous work (Corkhill et al. 2014, Yair 2011) where crafters have achieved experiences akin to meditation and mindfulness, both of which are beneficial to wellbeing.

Like our study, previous works have established commonalities between both traditional and digital crafting (e.g., Buechley and Perner-Wilson 2012). Consistent with our study, their findings established that both crafts can produce enjoyment, fulfilment and frustration, this was also demonstrated within research undertaken by the Crafts Council (e.g. Yair 2011).

Limitations and Future Work

We acknowledge limitations within this study including gender imbalance and participants' own inherent interest in textile crafting activity. This might produce possible bias in assessing the impact of textile-based crafting upon wellbeing. Additionally, the sampling for this study was self-selected and therefore participants who had previous positive experiences of this type of crafting could be naturally drawn to textile making as a pastime or personal coping strategy for everyday life stresses.

Future work might include: replication with specific sample groups (e.g. by gender); carrying out a series of textile crafting workshops over a longer time span to measure wellbeing longitudinally; and applying the workshop process to different crafts such as pottery, to examine and gain deeper insight into the wellbeing impacts of e-textile and traditional textile crafting.

Conclusion

This paper details the use of the WEMWBS scale to explore the impact of both traditional and e-textile crafting upon wellbeing. Statistical analysis demonstrated a significant increase in wellbeing across both the traditional and e-textile workshops and thematic analysis of conversation revealed experiences consistent with positive wellbeing. However, whilst our findings suggest that both types of textile crafting are beneficial for wellbeing, differing wellbeing effects were observed as a result of the respective workshops. In the traditional textile workshop participant experience was characterised as 'relaxing', whereas in the e-textile workshop, participant experiences were focused on learning and applying a new skill (i.e. soft circuitry).

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A Health Life with Type 2 Diabetes: personas of patients with a low socioeconomic status

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ABSTRACT *The prevalence of type 2 diabetes (T2D) is relatively high among people with a low socioeconomic status (SES). As lifestyle is crucial in T2D management, patients are advised to live healthily, but incorporating lifestyle changes in daily life is not easy. It may be even more difficult for people with a low SES, as they often struggle with more urgent issues in daily life that supersede healthy lifestyle. How to promote a healthy lifestyle such that the needs of low SES patients are met? A boundary condition is a thorough understanding of the target group, and of the differences between individuals in this group. Too often, people with a low SES receive either general advice, or advice targeted to literacy level or ethnic background, whereas the diversity within the low SES population is much wider than that.*

We developed personas to identify archetypes of the target group, each reflecting a distinct pattern in goals, attitudes and behaviours, to help grasp the diversity of the target group. Ten interviews with low SES T2D-patients revealed their perceptions and experiences related to what is important in life, a healthy lifestyle, living with diabetes, and lifestyle advice. Following Goodwin's persona development methodology (2011), three groups were qualitatively extracted from the data. In short, the personas are: 1) the worrisome caregiver: wants to live healthier, but is incapable of incorporating advices into one's life; caring for others is first priority; 2) the conscious self-confident: willing and able to follow up advice in order to reduce medication use; 3) the self-willed survivor: dealing with multiple (health) issues, and dedicated to solve things one's own way. Each persona likely responds differently to health promoting strategies. Additional research is needed to enrich the set of personas, for example by verifying them with the target group's family or health professionals.

Keywords: personas, lifestyle, type 2 diabetes, low socioeconomic status

Introduction

Health differences between social groups are prevalent worldwide. Socio-economic status (SES) – often measured by educational level, income, occupation and/or neighbourhood deprivation – often plays an important role in these health differences. Life expectancy of people with a low-level education is as much as 5 years shorter than life expectancy of people with a high-level education. Focusing on life expectancy in ‘perceived good health’, the difference between these two groups is 14 yearsⁱ. The differences in health and life expectancy are partly due to differences in lifestyle. People with a low SES usually have unhealthier eating habits, smoke more often, and are less often physically active in their leisure time (Geurts and van Rossum 2015; Kunst 2017; Beenackers et al. 2012). They also have a higher risk of lifestyle-related diseases, such as type 2 diabetes (T2D).

Being diagnosed with T2D can impact a person’s daily life significantly. Whereas patients may want to continue to live their lives as usual after the diagnosis, they are urged to change their lifestyles drastically (Johansson, Ekebergh and Dahlberg 2009). They receive information about a healthy lifestyle (nutrition, exercise, smoking) from their General Practitioner or his/her assistant (Rutten et al. 2013). Although this healthy lifestyle could yield large health gains (Witkamp et al. 2017), changing a lifestyle is not easy. Diabetic patients indicate that they find it difficult to consider their lifestyle continuously, and to fit the advice in with their daily lives (Ahlin and Billhult 2012). If health professionals want to aid people to live more healthy lives, they need to incorporate the patients’ daily reality into their health advice. To find solutions that truly assist people in maintaining a healthy lifestyle, these solutions need to be developed with and for the target group.

This paper describes a first step towards that final goal. We qualitatively investigated what it means for T2D patients with a low SES to try to live healthily. We aimed to gain insight into their daily lives, their experiences, and beliefs related to living healthy, and differences that may exist between people in this target group. For that purpose, we developed personas: fictitious archetypes that represent a specific part of the target group, each reflecting a distinct pattern in goals, attitudes and behaviours.

Interviews with the target group

Methods

The interview guide was developed with input from eight external professionals, each experienced in working with the low SES target group from different disciplines including healthcare, research, and design. Besides suggesting specific health questions to ask, they advised us to not only talk about health but also about respondents’ daily lives in general, to prepare an assignment for respondents prior to the interview, and to recruit a diverse sample (e.g. in terms of cultural background).

Between March and September 2018, we held 10 semi-structured interviews with T2D patients with a low SES. SES was determined either by neighbourhood or by educational level. Respondents were recruited through local key figures (e.g. the general practice nurse), and local activities (e.g. organized group walks).

Respondents were asked to make three photographs prior to the interview of ‘something related to health’. The photographs were meant to have respondents think about health already, and as a

means to break the ice; respondents were invited to talk about the photos early in the interview. The interview guide (available on request) included the following themes:

- Background (open and general)
- Daily life in general (what/who is important)
- Healthy living (meaning and importance)
- Life with diabetes (practical implications and meaning)
- Lifestyle advice (provided by whom, content, adherence)
- Conclusion (expectations for the future)

Interviews lasted one hour and were mostly held at the respondent's home in the Netherlands. They received a €10 gift token as a sign of appreciation after completion of the interview. Respondents gave written informed consent before the start of the interview. All interviews were audio-recorded and transcribed verbatim.

Results

We interviewed seven women and three men. Respondents were 64 years old on average (age range 50-87). Three respondents were born in the Netherlands, three in Surinam, two in Morocco, one in Turkey, and one in Aruba. Participants were diagnosed with T2D 14 years ago on average; two of them received the diagnosis less than a year ago, five more than ten years ago. Four respondents lived alone, four together with a partner, and two together with partner and children. Five participants were retired, three had paid jobs, one was in search for a job, and one was on social security. Two respondents had completed a high education (bachelor's degree), three a middle education (intermediate vocational), and five a low education (primary or lower secondary). Eight respondents (including those with high and middle educational levels) lived in a neighbourhood with a relatively low status score.

Five respondents described their health status as 'mediocre', three as 'good', one as 'very good', and one as 'very bad'. Some respondents indicated to have trouble understanding letters or brochures. Most respondents indicated to have accepted their disease. Although all respondents had been asked to make photographs prior to the interview, less than half of them (four out of ten) had actually done this. The other respondents had not, for various reasons, e.g. because they were unable to make photos with their phones, or because they had forgotten.



Figure 1: Photograph A taken by respondent prior to interview

Respondent about photograph A (Figure 1): *“On my fridge, I have a couple of lists with all sorts of things. [...] These are lists of how many fats, how much salt, how much sugar there is in all these different things. So what you’d best avoid or are allowed to eat.”*



Figure 2: Photograph B taken by respondent prior to interview

Interviewer about photograph B (Figure 2): *“What is that at the bottom?”* Respondent: *“Those are bacteria, some sort of probiotics. And it lives on sugars. And that’s supposed to be very healthy. I know that from a friend of mine, a fellow believer.”*

The interviews provided insights in perceptions, worries, and experiences of people with T2D, and the diversity among them. The transcribed interviews formed the basis for persona development.

Persona development

For the development of personas based on the interview data, we followed the relevant steps described by Goodwin (2011):

1. Identify variables on which respondents differ from each other
2. Map respondents on variables
3. Identify patterns
4. Define goals
5. Clarify distinctions and add detail
6. Develop the narrative

Step 1. In a working session with the project team (consisting of both designers and academic researchers), the variables on which respondents differ from each other were identified. In preparation for this session, three project team members read all interview transcripts. During the session, the team reached consensus on the following variables (anchors between brackets):

- Perceived support from social environment (related to diabetes) (much-little)
- Familiarity with diabetes (e.g. what they can expect) (much-little)
- Importance, priority of diabetes (high-low)
- Focus of attention (self-others)
- Worries about consequences of diabetes (e.g. hypo, co-morbidity) (many-few)
- Self-reflection (high-low)
- Self-control (high-low)
- Confidence in (following) advices of health care providers (much-little)
- Confidence in own ability to control diabetes (much-little)
- In search of solutions themselves (yes-no)
- Disease burden (high-low)
- Worries about other issues than diabetes (many-few)

Step 2. All respondents were mapped on the variables from step 1 (see Figure 3).

Step 3. In a second working session with the project team, we identified patterns in the answers.



Figure 3: Overview of respondents mapped on variables. Each colour represents one respondent.

Figure 3 shows all respondents mapped on the identified variables. Looking for patterns, we noticed, for example, that the pink and the purple paper strips were often positioned in close proximity. Checking the corresponding interview transcripts confirmed their similarity in terms of the variables. The transcripts were essential to verify whether respondents with similar patterns indeed belonged to one group. This necessity was exemplified by two respondents who showed similar patterns for some variables, but only for those variables where their position was not very pronounced (positioned near the middle). The transcripts revealed that the respondents did not fit in one group.

Step 4. After multiple iterations of searching for patterns and checking transcripts, we identified three main groups with distinctive goals. Nine out of ten respondents could be placed in these three groups. One respondent (the dark red paper strip (Figure 3)) showed deviant answers. The transcript showed that this was a respondent who was diagnosed with T2D only recently, who did not physically notice having the disease, and who had not shared the news with anyone. Compared to the other respondents, this person was an exception; and we did not have enough data to add this person as a fourth group. It could be that this person will eventually fit in one of the other groups, e.g. when the disease becomes more manifest.

Step 5. Based on the identified variables, the background information of the respondents, and quotes from the interview transcripts, we further refined the three groups.

Step 6. The narratives for the three personas were developed, but are not reported in this paper, as explained in the discussion section. They are available on request.

Results

The three distinct subgroups or personas we identified and refined are:

1) The 'worrisome caregivers' ...

"My hobby is to take care of others. And very little time for yourself."

- ... worry much about the consequences of diabetes, and have little confidence in their own ability to control the disease.
- ... have difficulties following health advice; they want to but can't manage.
- ... are easily tempted to behave unhealthily. They keep on trying to change that though.
- ... have confidence in health care providers.
- ... try to gather much information, but don't manage to structure and apply it themselves.
- ... primarily take care of others, and take little time for themselves.

2) The 'conscious self-confidents' ...

"Well, I just accepted it [diabetes]. My greatest goal is to once live without tablets."

- ... are aware of the consequences of diabetes but have confidence in their own ability to control the disease.
- ... aim to live healthily (and they often succeed) in order to need as little medication as possible.
- ... have confidence in health care providers.
- ... find their way relatively easily through the information they receive.
- ... like to have a check-up once in a while (e.g. of their blood values), for confirmation.
- ... want to be a diabetic as discreetly as possible

3) The 'self-willed survivors' ...

"And then I know I'm not supposed to, but you also have to enjoy a bit, right?"

- ... have relatively little confidence in health care providers. Like to do things their own way; take care of things themselves.
- ... are aware that some things are not healthy but want to enjoy life too.
- ... worry much about other things, such as their own health.

- ... feel that health problems hold them back.
- ... perceive considerable support from their social environment. Search for like-minded to exchange experiences.

Discussion

This study provided insights into how T2D patients with a low SES view a healthy life. The diversity within this patient group was captured in three personas. The personas can help others to put themselves in the position of the target group, for example when designing healthcare solutions for this group.

The results of this study, including the personas, were discussed in a peer review session with about 20 experts from various disciplines (e.g. health care, design, research). Overall, the personas were recognizable to participants, although they missed a persona with less motivation to be healthy than the three personas we developed. They felt that the personas make people think, and will likely be helpful for professionals who develop policy or services *for* the target group, but do not actually work *with* people in this group. The personas trigger empathy and creativity. Participants especially valued the identified variables (step 1-5); they indicated that these variables clearly reflect underlying needs of the target group. There was less consensus about the narratives; the details made the personas livelier, but made it, for example, difficult to extrapolate the persona to individuals with other characteristics. Therefore, we decided to focus on the personas' position on the identified variables in this paper.

Some caution is needed in using the personas. First, the personas are based on ten interviews. Additional research among the target group is needed to verify whether the current set of three is sufficient, or whether the set needs to be extended or adjusted. Besides research among the target group, it may be worthwhile to verify the personas among their social environment (e.g. professionals who work with them, friends or family). Second, this study focused explicitly on perceptions and experiences of people in the target group. Therefore, only those people were interviewed. It might well be that their views deviate from the experiences of professionals. Third, although personas help to differentiate among T2D patients with a low SES, it is still necessary to acknowledge that every single person is unique; attention for individual differences remains essential, also within one persona.

In sum, this study showed that the target group of T2D patients with a low SES is indeed heterogeneous. Patients differ from each other in how they cope with their disease and regard a healthy life, and thus likely respond differently to health promoting strategies. The personas give insight in the factors underneath the differences, and as such provide hints how to target efforts to promote a healthy lifestyle. The personas are not end-products, they need further development and validation in follow-up studies, in which researchers, designers, health professionals, and people from the target group join forces to design proper solutions that support a healthy lifestyle.

Acknowledgements

This research project was partly funded by the Taskforce for Applied Research (part of NWO), for which we are grateful. We thank U-CREATE for the opportunity to organize a peer review session.

We are also thankful to all professionals participating in the sessions, and to our respondents for their frankness during the interviews.

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Creative Wellbeing Futures: Friendly hacking, lo-fi living labs and improvised co-creation

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ABSTRACT Evidence about the benefits of using the arts for health and wellbeing promotion has prompted the World Health Organisation to recommend the incorporation of art programs as part of future health policies. However, implementing art programs as part of care services is not easy, and designers, artists and health workers find several operative and technical barriers as part of the process. Literature reporting on successful art programs makes emphasis on outcomes and impact, but do not tell much about the ‘behind scenes’ process that made the programs possible. This paper aims to fill this gap and contribute to the discussion about the arts in health by sharing experiences of a participatory design project where designers, allied health professionals and psychiatric inpatients collaborated to co-create the Creative Wellbeing Program. The design process that led to this program built on ‘friendly hacking’ principles to constitute a ‘lo-fi living-lab’ focused on conducting non-intrusive design interventions based on the delivery of art activities. These interventions made possible to ‘live-prototype’ the activities the program would have and informed the design of toolkits and guidelines for its implementation. The Creative Wellbeing Program encourages participants to use visual arts as a mechanism for positive self-reflection and personal expression through the production of symbolic meaning. The paper discusses how this project gives an idea of how the future of mental healthcare could look like and concludes by encouraging health organizations to facilitate collaborative work between designers, artists, staff and users to incorporate creative practices as part of their care services.

Keywords: arts in health, participatory design, hacking, lo-fi living labs

Introduction

A recent report of the World Health Organisation reviewing hundreds of studies documenting benefits of the arts for health and wellbeing suggests that creative practices should play a significant role in the future of health services and policies (Fancourt and Finn 2019). The use of creative activities as part of healthcare services has a long history. This practice is usually classified in two different categories: *art therapy*, run by art therapists to achieve clinical goals, and *arts in health*, run by artists, designers and healthcare professionals to promote general wellbeing (Sapouna and Pamer 2016). The benefits of both approaches, and their different variations, have been demonstrated in an extensive body of literature preceding the WHO's report. Nevertheless, the report is important because its influence in future policies will open opportunities for the design of creative practice programs in the healthcare sector.

Despite the benefits of the arts for health and wellbeing, the design and implementation of creative programs in health facilities can be challenging. In the specific context of mental health, which is the case discussed in this paper, bureaucracy and an unimaginative system are some of the limitations that workers find when they attempt to implement creativity (Gillam 2013). In addition, there are time constraints and lack of frameworks, guidelines and tools for running art-based activities in meaningful ways and beyond recreation and leisure. Anecdotal evidence shows that sometimes art activities are seen as a mechanism of distraction for keeping patients 'busy' while psychiatric medicines take effect.

Many health organizations and art centres have been able to overcome these difficulties and develop creative programs. Most reports of these initiatives discuss their outcomes, evaluation and impact, but not the collaborative processes that creative practitioners and healthcare workers deploy as part of their conception, design and implementation. In other words, there are very few accounts of the 'fuzzy-front end' (Sanders and Stappers 2008) of the design of these projects, which is a discussion that can inspire and provide insights for future programs and inform policies.

This paper contributes to fill this gap in the context of the arts in health by presenting the design process that led to the Creative Wellbeing Program (CWP), an ongoing initiative to incorporate art activities in the care services of Bendigo Hospital's Psychiatric Services. This initiative is part of an ongoing partnership between RMIT University and Bendigo Hospital, and builds on previous research where Sumartojo (2020) looked at practices of 'care on the move' in this psychiatric unit. The design process of the CWP was informed by hacking mindset and improvisational techniques that made possible to introduce meaningful creative practices in mental healthcare using a participatory bottom-up approach, without requiring expensive interventions or bureaucratic processes.

Although the project started before the WHO's publication, we consider their report important as it will open up future opportunities for collaborations between creative and health disciplines. In this context, the CWP can work as an example of how designers and healthcare professionals can collaborate to shape together a future health system where creative practices play an important role in preventing illness, promoting health, and managing treatment.

The following sections present the design process behind the CWP and its outcomes. Following calls from the field Participatory Design to engage with politics of self-representation (Light 2018), the

discussion is written in first person and plural. The first person (I) is used to introduce and recognize my own position and agency as designer working in a healthcare setting, and the plural (we) to acknowledge the role of participants as active agents in the project. I have chosen this style as an attempt to capture elusive aspects of the design process usually overlooked when reporting research and to acknowledge that as author, I am presenting a personal perspective of collective and collaborative experiences.

Friendly hacking and the lo-fi living Lab

The CWP is part of a research project that built on the concept of friendly hacking to constitute a lo-fi living lab within a psychiatric unit. Friendly hacking is a framework based on Participatory Action Research, where multidisciplinary teams are embedded in organizations to challenge the robustness of public policy and instruments, identify weakness and implement improvements (Jégou et al. 2013). Inspired by this framework, I embedded myself in this psychiatric unit and initiated an unstructured collaboration with members of the allied health team to explore opportunities for conducting design interventions. My initial aim, following previous participatory design projects where friendly hacking has been used, was to set a living lab (Nilsson, Topgaard and Ehn 2014). However, as I adjusted myself to this context and realised that staff were everyday designing (Duque 2018) and using visual and material slang (Ventura, Keinan-Guy and Adani 2018) to improvise their own solutions, I reframed my intentions and configured what I call a 'lo-fi living lab' (LFLB): a space for unsophisticated and improvised co-creation of using tacit knowledge, low-tech and DIY processes.

Building on previous research about the role of food and cleaning trolleys in the delivery of care services in this psychiatric unit (Sumartojo et al. 2020), one of the design interventions planned as part of the LFLB was to create trolleys for assisting the delivery of occupational therapies. As the project evolved, I found that one staff member was running improvised art sessions as part of these therapies. Instead of using a room allocated for allied health activities, which implied to take inpatients out of their everyday environment, she decided to bring the sessions into the wards and embed them into their everyday life. For doing this, she adapted a clinical trolley (Figure 1) to transport art tools and materials that were put on a table around which patients gathered around. Based on this experience and her expertise, we both proposed a project for designing a trolley for enhancing the art sessions and transforming them into a cohesive art program.

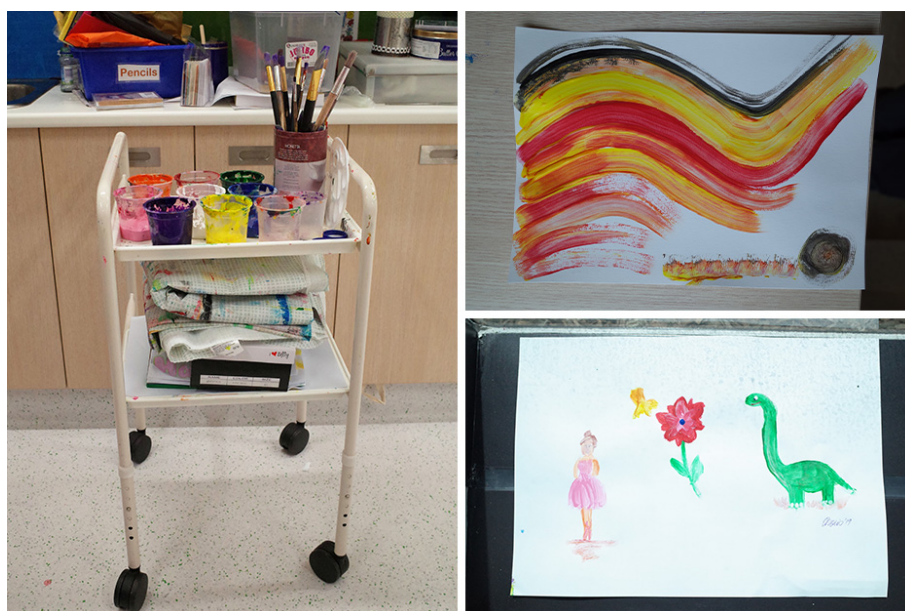


Figure 1: Clinical trolley utilised in the improvised art activities and patients' work

Inspired by hacking and lo-fi techniques, I decided that instead of organizing codesign workshops with staff and patients, the best way of imagining how the trolley would work and look like was live prototyping with them the activities that would be part of the program (Figure 2). Building on creativity and arts in health frameworks (Gillam 2018) I prepared non-disruptive design interventions (Calderón Salazar, Zuljevic and Huybrechts 2018) based on art sessions that would help me to discuss the future trolley with future users of the arts program. I transformed a second-hand hospitality trolley into a vehicle for storing and bringing tools and materials into the wards, and for displaying visual guidelines with examples of things that could be made with them. Using second-hand picture frames, I organized pop-up exhibitions to showcase the works made during the sessions in the wards and invited patients to comment on their works.

The non-disruptive interventions allowed us, not just to discuss, but to co-create different aspects of the future art program (e.g. trolley, art sessions, exhibitions) with a variety of stakeholders (e.g. participants, other patients, clinicians, allied health staff, managers, cleaners, security guards). Through this process we found that the trolley should incorporate an external storage system to keep tools and materials that staff could put in the trolley depending of the activities they wanted to run, and that the design should be open for appropriation in use (Björgvinsson, Ehn and Hillgren 2012) to integrate new techniques and functions as they emerge.



Figure 2: Live prototyping sessions

Although the live-prototyping sessions revolved around creative skills, we decided to focus the program not just on technical aspects of art, but on creative expression. More than learning a technique or reproducing a style, the art sessions would allow participants to explore their own feelings, reflect on their emotions and express themselves producing symbolic representations. We also found that running art exhibitions was a rewarding experience for participants and allowed other patients to engage with art contents.

Subsequently, based on insights from these interventions, the first functional prototype of the toolkit system was manufactured, and using this prototype we initiated a pilot implementation. The final design was inspired by IKEA hacking (<https://www.ikeahackers.net/> 2019), and included the arts and crafts trolley, a storage system, and exhibition displays. In the live prototyping sessions, we utilized several IKEA products that were easily adapted to different functions, and for the final design we decided to incorporate these products. The use of IKEA hacking makes possible the future appropriation and reproduction of the trolley by other health facilities and enables staff to adapt the system to new functions once the project has concluded and there are no designers around.

Discussion of results

Insights and experiences from the collaborative design process shaped the CWP. Although this initiative is based on the delivery of visual art activities, it goes beyond the use of arts and crafts as recreation or distraction and aims to engage inpatients of the psychiatric unit in creative practices that contribute to their wellbeing. The activities, including art sessions and art exhibitions, provide a safe space for self-reflection, personal expression and production of symbolic meaning. The program includes two elements: the toolkit system for delivering visual art activities, and guidelines explaining how to facilitate those activities in ways that contribute to the wellbeing of participants.

The creative wellbeing toolkit system responds to requirements identified in the design process and characteristics of this context (Figure 3). It includes a trolley that operates as a movable storage and display system, and whose contents can be easily changed depending on the that will be delivered. Rather than having predefined art activities based on techniques or styles, staff can configure the trolley for mixed visual arts by choosing from a series of IKEA's Trofast boxes containing specific tools and materials and sliding them into the trolley. By changing the contents and accessories, the trolley can be used for delivering activities based on specific techniques (e.g. pottery, painting, photography) or topics (e.g. vision-boards, zine making), depending on the physical and cognitive abilities of different patients and the purpose of the sessions. The toolkit also includes movable displays for exhibiting the works made by participants.



Figure 3: Final toolkit for implementing the Creative Wellbeing Program

The use of a trolley and movable displays makes it possible to run program activities across different places and for diverse publics. When the project started, one of the issues raised by staff in charge of occupational therapies was that having to take patients out of the wards and taken to a different room out of their living environment could be intimidating and coercive and put limits to the number of participants. Our moveable approach overcomes this problem and presents the arts as part of the everyday life of a psychiatric ward, rather than something exclusive to art spaces or art studios. The exhibitions allow other patients to engage in creative activities as 'art audiences'.

The creative wellbeing guidelines explain how to use the toolkit system for wellbeing promotion. The guidelines used in the first live-prototyping sessions introduced participants to art styles and techniques and explained how to use specific tools and materials to reproduce them. Most of the time, however, participants did not follow these guidelines and decided to mix-up styles and techniques to represented personal themes in their works. This 'bottom-up co-creation' process made me aware that for contributing to people's wellbeing, the CWP should go beyond technical skills or reproduction of art styles and use visual arts as mechanisms for creative expression. Following this insight, the final guidelines invite participants to self-reflect in positive ways about their lives, better understand their feelings and emotions and express themselves by producing symbolic meanings. Although these elements (self-reflection, emotions, expression and symbolic

meaning) are at the centre of art therapy, the CWP is different because it is not run by art therapists but allied health staff and does not link creative expression to clinical outcomes. We do not see this as a limitation, but as a specific approach to the use of the arts in health for creating de-clinicalised art spaces within a clinic. The CWP pilot implementation demonstrates that this perspective can contribute to the wellbeing of participants through self-esteem, sense of achievement, and emotional expression.



Figure 5: Creative Wellbeing Program pilot implementation

Conclusion

This short paper presented the design process that led to the CWP. It attempts to fill a gap in the field of arts in health, where current discussions make emphasis on outcomes and evaluation of art initiatives, but overlook the tactical procedures involved in their conception and development. The design process discussed here has a collaborative nature, but a different approach to traditional participatory design processes. Instead of disrupting into a context to run co-design workshops to collect information and going back to the design studio to complete the project, I built on friendly hacking to embed myself in the hospital through the installation of a lo-fi living lab, from where I conducted non-disruptive design interventions to live-prototype an arts in health program with staff and patients.

This approach enabled improvised co-creation processes, where several stakeholders had a direct input shaping the project process and its outcomes. The resulting program responds to specific characteristics of this psychiatric unit (e.g. architecture, patient distribution, social and cultural conditions), and it might not fit or work well if it is taken as it is to other facilities. For this reason, the paper makes more emphasis on the process and less on the outcomes, and the invitation to health organizations is to establish meaningful partnerships with creative disciplines to make possible long-

term collaborations between artists, designers and healthcare workers. These partnerships are crucial for creating art programs able to build on existing capabilities and respond to requirements of specific contexts.

Creative practice programs at the intersection of design and health, where the arts are used, not just as distraction or recreation, but as means for creative expression, can contribute to shape a future where the idea of 'the patient' understood as someone who is just 'waiting' to get healthy while receiving treatment, can be transformed into a new one, where users of health systems are creative agents that participate in the management of their health and wellbeing.

Acknowledgements

I would like to acknowledge the role of Shanti Sumartojo, Lisa Spong and Carly Mc Rae shaping this project, and express my gratitude to all staff and patients who have participated in this project.

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Radically self-organized care: what can designers learn from the evolutionary dynamics of cooperation

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ABSTRACT For many years, top-down performance management systems have strongly influenced organizing structures in the health sector (De Blok, 2010). Recently, new organizational forms based on self-governance have begun to emerge where authority is more widely distributed amongst healthcare staff and work is conducted by decentralized, self-managing teams or networks. In this paper we aim to develop a better understanding of the distinctive design properties of these highly collaborative organizational structures and to reflect on the designer's role in this context. We are interested, firstly, in exploring how service and system designers can best support health organizations to advance in such a changing environment, and, secondly, how design practice might help to address the inevitable tension between (a) formal bureaucratic controls and mechanisms for accountability and (b) continual adjustments and distributed authority. Elinor Ostrom's Core Design Principles, founded on her Nobel-prize winning work in the management of Common Pool Resources, have advanced to describe the evolutionary dynamics of cooperation more generally. We propose that combined with insights into humanization these principles may provide a sustainable approach for the future design and delivery of care provision. Investigating a healthcare case study characterized by self-organization, we aim to facilitate a collective reflection and inspire further experimentation in the field.

Keywords: service design, evolutionary science, cooperation, self-organization, humanization

Introduction

Over recent decades, there has been a growing interest globally in the development of programmes to support healthcare professionals and managers in improving the quality of healthcare services and associated health outcomes. Although today many advocate the early involvement of patients, carers, healthcare professionals and members of the public in the healthcare design process, for many years top-down performance management approaches from the industrial sector have been used as key management strategies in healthcare systems, underpinning the vertical design of many healthcare organizations (De Blok, 2010). Such approaches have resulted in some efficiency gains, arguably a key measurable benefit for any healthcare system. However, what has come to be viewed as a reductionist industrial manufacturing perspective is increasingly judged as insufficient (Kings Fund, 2020). Transactional healthcare models have lost sight of the whole person and the interconnectedness of medical needs and conditions (for example, we see ‘the diabetic’ as opposed to a ‘person who also happens to have diabetes’) despite healthcare, at its core, being deeply human and relational, delivered by and for people (Haque, 2015). As the healthcare system struggles with the context of rising demands and limited resources, the need for creativity has also come into focus alongside a recognition by long standing leaders of the Quality Improvement (QI) movement of the limitations of the industrial management practices which have largely shaped mainstream healthcare improvement work (Batalden, 2018). In response, this paper explores what designers can learn from evolutionary dynamics of group collaboration and (re)humanising care practices.

Dehumanization in healthcare

Michel Foucault used the term ‘clinical gaze’ to describe not only the way doctors have come to view patients today but as representing an entire worldview that defines roles and relationships in the healthcare system, which type of knowledge is taken seriously, how power is being exercised and how care is organised (Foucault, 1973). From this has arisen the notion of the ‘production-line healthcare worker’ who aims to manage care through care pathways akin to mechanical production lines - by reducing inefficiencies and accumulating marginal gains of time - but to the detriment of the relational and human aspects of health (Hannah, 2014). Although a production-line metaphor can acknowledge the dynamic nature of healthcare by allowing space for energy, creativity and improvement it also indicates a lack of meaning, evolution, purpose, connection and soul (Laloux, 2013). Treatment of people as mechanical systems often results in a particular form of dehumanization — objectification — in which others are viewed as being incapable of emotional responsiveness or interpersonal warmth (Haslam, 2006). Through the prism of Haslam’s framework, the positivist turn in organizational studies appears like a form of mechanistic dehumanization which results in leaving little humanity at the core of a modern organization (Petriglieri, 2020). For healthcare, this is deeply problematic given that positive health is based on the fundamental principles of common humanity, interconnection and our relationships, not merely the absence of disease (WHO, 1948).

Haque and Waytz define dehumanization as the denial or removal of distinctively human qualities of a mind, independent thought or feeling for other people (Haque, Waytz, 2012). They identify six key causes of dehumanization in our healthcare systems and propose a series of strategies for

(re)humanising care through incorporating improved clinical practices and organizational measures (see Figure 1).



Figure 1 Six strategies for (re)humanization (adapted from Haque and Waytz, 2012)

Evolutionary Science For Self-organised, Cooperative Behaviour

As causes of dehumanization began to be explored, a growing recognition has emerged that evolutionary processes can be harnessed as a way to humanise organizations and create new environments that support cooperation and balance individual self-interest with group purpose (Atkins et al, 2019). Evolutionary science offers a novel perspective for design practice. One key insight relates to small group formations that shape the basis of the social environment of most of our evolutionary history (Atkins et al. 2019). Similar to the cells of a multicellular organism, Atkins and Wilson (2019) argue that small groups need to remain the key building blocks of modern large-scale organizational structures and that we can learn from evolution when seeking to understand the way they are established. Evolutionary science not only tells us where we come from but also provides ideas about what we need to do, in order to consciously shape our behaviour to be more cooperative and human with each other.

Multi-level selection theory (MLST) as defined by David Sloan Wilson, could provide a suitable lens for designers to better understand some of the evolutionary drivers underlying healthcare including the behaviours of a healthcare organization and its workers. It examines two concurrent and often conflicting forces, such as the purpose of an organization as a whole and the interest of individuals within it. Understanding the interaction between the levels is critical because knowledge of how humans tend to behave individually and within groups, shaped by, for example, status seeking, leadership preferences, a sense of fairness and gender differences, allows us to generate novel predictions for when we should expect to see more individual (self-interested) or more collective (altruist) behaviours. Such understanding may in turn allow us to design more mindfully for an appropriate balance between the two.

Although organizational leadership has historically adopted a top down hierarchical approach to management, recent research suggests a new paradigm is surfacing, one that demonstrates striking similarities with insights offered by MLST. This new organizational paradigm advocates rehumanization and is characterised by three key pillars of ‘self-management, evolutionary purpose and wholeness’ (Laloux, 2015). The latter suggests the arrival of a new *homo economicus*² who relies on their entire authentic and human self in the workplace, as opposed to a narrowly confined professional persona. This radical departure from our existing view on human nature³ not only changes what we do individually but it determines the forms of governance we design and implement and enabled fundamental breakthroughs in organizational human collaboration (Laloux 2014).

Laloux identifies a set of organizational paradigms that are operating concurrently today and that move along an evolutionary spectrum of organizational consciousness. Today, we see some real-world examples of pioneering, humanised organizations which operate with novel structures and management practices based on high levels of cooperation and a strong sense of individual autonomy. They tend to be self-managed and purposeful, produce significant cost savings in corporate functions, are able to re-engage staff through autonomy and improve the quality of the services provided. At their core, these new practices demonstrate how we may be able to deal with the complexity of our times in completely new ways and how work can become a place of personal fulfilment and growth.

The Buurtzorg model of care

One inspiring example rapidly spreading across the sector is the Buurtzorg model of care. Originating in the Netherlands in 2006, Buurtzorg is a model of community nursing. Each neighbourhood is looked after by a team of nurses who take time to connect and get to know the residents. It is widely cited as an evidence-based approach to improving the delivery of integrated nursing and social care in community settings. Buurtzorg’s organizational structure is simple and flat with no middle management layers, no departmentalization and minimal back-office functions. Home care employees are organised in independent and self-managing teams with no team leaders, avoiding line-managerial direction. The model is characterised by high levels of patient and staff satisfaction, professional autonomy exercised through self-organised nursing teams, client empowerment and holistic, patient-centred care. Buurtzorg is remarkable in that it is built on a shared mission of helping residents to manage their own lives as much as possible and giving its care team an extraordinary amount of freedom and agency to do just that. It provides an excellent example of the cultural evolution that can take place when groups are provided with local autonomy and an ability to self-organise by adopting a complex form of polycentric governance combined with semi-autonomous decision-making capabilities.

Buurtzorg is just one examples of organizations being set up with the intention of placing humanity at its core and using self-organization to achieve that. We propose that there is value for designers

² Classically, the *homo economicus* is solely focused on satisfying their own self-interest at the lowest possible cost irrespective

³ See ‘Tragedy of the Commons’ by Hardin, 1968. It provides a vivid parable of a social dilemma: In an imaginary village, farmers are free to graze their cows in a commonly owned pasture. The pasture can only support so many cows but each farmer can gain by adding more of their cows to the herd, resulting in the tragedy of overuse.

working in healthcare to better understand the evolutionary dynamics of cooperation in order to improve health services. Our interest is to understand the ways that a healthcare organization that exists within largely traditional management and hierarchical structures can reinvent itself and how designers can effectively support self-organization using the principles of evolutionary science for healthcare. If succeeding at group level is a key driver for evolutionary transitioning, and thereby limiting the opportunities for individuals to benefit at the expense of others, we suggest that one way of framing the conversation is by investigating the relevance of Ostrom's Core Design Principles in designing better healthcare solutions. Ostrom's work around polycentric systems is said to have particular relevance in healthcare and has recently been explored in the context of health and social care provision for formerly incarcerated prisoners in the United States (Robert et al. 2020).

Theory & Methods

We conducted a review of literature relating to Buurtzorg implementations. Based on Yin's definition of a case study⁴, we also aimed to understand the context in which Buurtzorg was implemented and its impact on creating more humanised and humane service interactions. We have analysed and reviewed reports on Buurtzorg by means of desk research (including published articles on Buurtzorg, internal documentations, in-depth evaluation reports, news articles, internet sources, filmed staff meetings) to map and identify to which extent Buurtzorg follows the evolutionary dynamics of cooperation inherent in all species, and thus foundational evolutionary principles. We looked at Buurtzorg through the perspective of evolutionary transitions studies (Wilson 2008; Smith & Szathmari, 1995, Van Vugt, 2006) and specifically Ostrom's conceptualization of the conditions of self-organization and cooperation which provides a framework to understand the evolution of group level adaptations.

Ostrom observed that self-organization happens in structured environments, under specific conditions and within specific domains in collective action processes. She found that while individual actors have self-organizational capabilities, there are also conditions that determine whether or not they will organise themselves. She codified the conditions of self-organization in collective action processes using a set of Core Design Principles (CSPs), which resulted from her investigation into groups who manage publicly accessible and finite resources and avoid top-down regulation in favour of balancing individual and collective interests. In order to practically adopt the principles to improve group collaborations, Wilson (who co-authored the original CDP paper together with Ostrom) amongst others recently created an iteration of the CDPs entitled 'Prosocial or 2.0 Version' (see Figure 2) which we adopt in this paper (Atkins et al. 2019). As a generalised version of Ostrom's original principles, 'Prosocial' uses the essence of Ostrom's work but broadens it in scope with the aim to develop a more practical and therefore improved way for applying the principles to all kinds of groups and at various organizational levels. Good action-led principles, according to Atkins et al., should have scope, precision and depth, in that they should be general enough to be applicable to a variety of circumstances and contexts but specific enough to provide practical and useful guidance.

⁴ As "an empirical inquiry that investigates a contemporary phenomenon within its real-life context" (Yin, 2003)

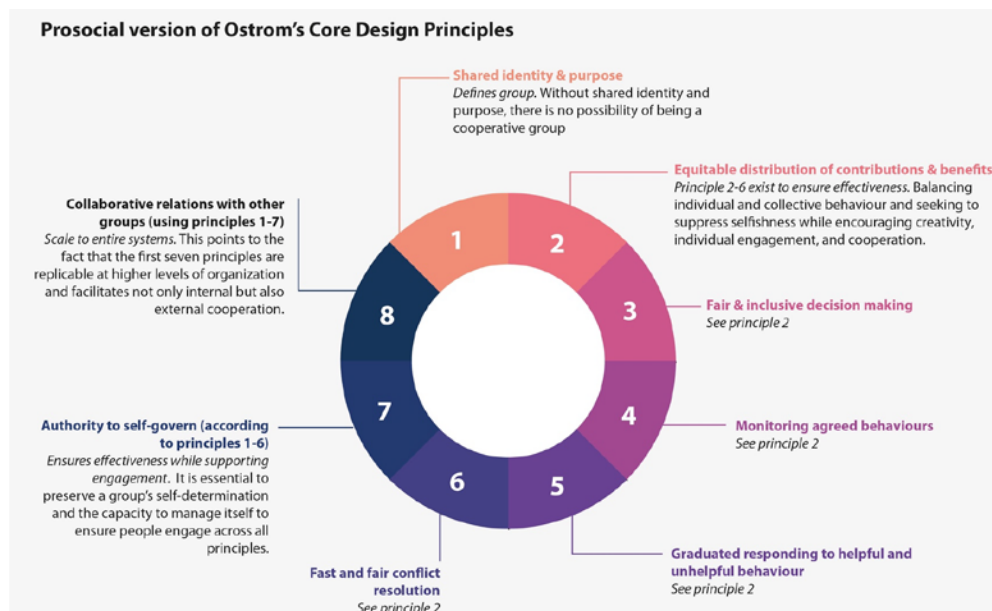


Figure 2 Prosocial Core Design Principles building on Ostrom's original CDPs (adapted from Atkins, Sloan Wilson & Hayes, 2019)

By mapping the Buurtzorg case against the prosocial version of Ostrom's Core Design Principles, we analysed to which extent it utilises the core design principles and is therefore inherently, perhaps unintentionally, built on aspects of multi-level evolutionary science. Cross-referencing this with Haque & Waytz' work in humanization in medicine, we then aimed to better understand if this may offer a set of guiding heuristics and a way to design for self-organization and evolutionary purpose in autonomous groups.

Using Evolutionary Dynamics of Cooperation to Design for Radically Self-organized Care

We found striking resemblances between the way Buurtzorg constituted itself based on an initial experiment and the scientific research found in evolutionary science, notably MLST and the concept of major evolutionary transitions as exemplified in Atkin et al.'s updated prosocial set of design principles. Buurtzorg appears to organise itself according to many of the reformulated principles by Atkins et al. By doing so, it achieved the highest client ('patient') satisfaction in the country, 40% lower costs than their peers, used far less medicine, won 'best employer' prize 5 years in a row, employed 850 self-managed teams freed from bureaucratic tasks, and proved to be very profitable (Olesen, 2016). We also found that applying Atkin et al.'s design principles may positively complement Haque & Waytz's prospective strategies for rehumanising medicine.

PROSOCIAL VERSION CORE DESIGN PRINCIPLES (OSTROM & ATKINS ET AL.)	BUURTZORG NEIGHBOURHOOD CARE CASE STUDY (BUURTZORG NL)		HUMANISATION STRATEGIES (HAQUE & WAYTZ)
1. Shared identity & purpose	/ A key element of Buurtzorg is having a clear purpose and a shared mission that ties the whole organisation together: helping patients lead better lives	/ Each team signs up to the mission of taking the best possible care of their 'clients' but figures out autonomously how this is best done for each individual person	/ Agency. Helping patients lead better lives translates into supporting 'clients' to recover their ability to take care of themselves & reorientate agency towards co-production of health / Individuation. By focusing on empowering 'clients' to lead better lives as opposed to fixing an ailment, 'clients' experience a strong level of trust and connection
2. Equitable distribution of contributions & benefits	/ Under a union agreement nurses are paid according to their educational level with a standard annual increase and bonuses spent on years working for Buurtzorg	/ Nurses earn the highest salaries of any home care nurses in the Netherlands. Nurses are paid more than other organisations but are not paid extra for specialisation	/ Similarity. Balancing individual and collective interest (including sense of compensation fairness) encourages the nurses to 'go the extra mile', emphasising aspects of common humanity and fairly distributed systems / Agency. Decision-making based on a set of shared principles, encourages nurses' overall engagement in providing care and collaboration between client and nurse in order to find the most suitable treatment option for the client / Empathetic balance. In reorienting agency towards the client, it allows nurses to combine part empathic and part cognitive skills when deciding on diagnosis, prognosis, treatment and care logistics in collaboration with their clients / Moral engagement. Mutually agreeing on a shared set of working principles refrains individuals from behaving in ways that violate set standards to the detriment of client care / Personification. Referring to their patients as 'clients' creates a sense of seeing the whole person instead of reducing a person a mechanical system made of separate parts / Individuation. With nurses deciding how many and which 'clients' to serve, they are able to forge less anonymous and more caring relationships with their clients / Personification. By liaising with the client's family and friends and other involved health and social care professionals as part of routine procedures, nurses are able to offer more integrated, personalised care
3. Fair & inclusive decision making	/ Decision-making is collective, based on an 'advice process' which means shared consensus must not be reached as long as there is no objection to a proposed idea. There are no line managers, or team leaders or people of positional authority to make decisions on behalf of the teams.	/ Team members can request changes which are evaluated by 'Ecare' in terms of a set of agreed criteria: a) does the proposed change serve the client and/or the professional?, b) does it create additional complexity?, c) in what ways is this change beneficial to clients or professionals?	
4. Monitoring agreed behaviours	/ Individual team members mutually agree to be available 24/7 and to meet a productivity target of 60%	/ Teams use Buurtzorg's quality system which involves monitoring patient satisfaction & recording outcomes. The adoption of this system was discussed and tested extensively in practice by the teams themselves.	
5. Graduated responding to helpful & unhelpful behaviour	/ Team members appraise each other on the basis of a competence appraisal system agreed by the team.	/ The organisational structure has evolved and continues to evolve on the basis of the teams experimenting, retaining their best practices and transmitting their best practices to other teams for their consideration	
6. Fast & fair conflict resolution	/ New teams have access to training on decision-making, conducting meetings, active listening, non-violent communication, conflict-resolution and problem solving	/ Independent regional coaches assist with problem-solving. They help with coping with difficulties, crises and emergencies, allocating roles & responsibilities, meeting productivity targets & raising a flag to the team	
7. Authority to self-govern	/ Teams do not operate under the supervision, instruction or direction of the directors, the regional coaches or anybody else. They are operationally autonomous and self-governing.		
8. Collaborative relations with other groups	/ By embarking on a multi-level approach to care delivery, Buurtzorg enables more integrated, community-based care	/ Coaches support the notion of establishing a learning culture, by interconnecting different teams. They have no job description, no performance targets, no responsibility for team performance and have no decision-making or other authority.	

Figure 3 Applying Ostrom inspired Prosocial Core Design principles to the Buurtzorg model of care to understand how they can contribute to humanization in healthcare (authors' own)

However, despite Buurtzorg building on principles of cooperation, we noticed an absence of practices that explore early citizen involvement in relation to creating changes to the prevailing care system and conclude that there is an opportunity to further the active participation of citizens as co-producers of health. Reflecting on our retrospective case study (Figure 3), we propose that the generality of the Ostrom inspired core design principles - guiding *what to do* functionally to ensure cooperation within groups - could be combined with Haque & Waytz' insights into (re)humanization - guiding *how to do* it relationally in the most human-centred and humane way. This could enable healthcare designers to apply them as a set of emerging premises in organizational healthcare contexts - from improving internal functioning of a healthcare team to improving or innovating the ways that healthcare organizations deliver care.

Reflections on the designer's role

We view design practice and its methods as one means of enabling self-organised cooperative ways of working which actively contribute to humanising healthcare. By building on Ostrom's original design principles and merging these with deeper insights on how to rehumanise aspects of medicine, we hope to inspire designers and healthcare practitioners in finding ways to self-organise and humanise health services. As a combined set of premises, they could help us understand what constitutes the distinctive design properties of deeply human and highly collaborative organizational structures, and most importantly, design for them.

The emerging premises we explore in this paper remain untested in practical design terms. As a next step, we recommend using them in the context of improving relationships between healthcare organizations and between individuals in the healthcare ecosystem. Our hope is that through continued evaluation of the premises, design practice can help to establish the conditions that nurture new conversations amongst groups, create a shared identity with a clear purpose, addressing equity, inclusiveness in decision making and above all, humanity, in a different, prosocial way.

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The Art of Handing Over: Improving the Patient Handovers at the Intensive Care Unit by a Human-Centred Design Approach

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ABSTRACT *This study aimed to enhance the patient handovers within the Intensive Care Unit (ICU) by design, based on experienced qualities and pain points by the ICU team, existing of doctors and nurses. At the ICU, care is delivered by multidisciplinary healthcare teams who strongly rely on teamwork and communication. Patient handovers are scheduled moments of communication where information between different healthcare professionals is exchanged. However, patient handovers involve failures as well, which can be the result of educational, psychological, and organizational factors. To discover how design can overcome these failures in information sharing, first observations and interviews within the ICU were done. The aim of the observations was to reveal everyday practices of the ICU team. The purpose of the interviews was to get a deeper understanding of their personal experience with the different patient handover moments. The observations provided insights in the interactions between doctors, nurses, and both groups. The interviews revealed the experiences ICU doctors and nurses have with patient handovers. The obtained insights were captured in two work models showing the handover activities, touchpoints, and experienced qualities and pain points over time. Based on that, a design was iteratively created in co-creation with the ICU team and evaluated within an ICU. All in all, it was discovered that a design should facilitate more structure, overview, and reflection. The human-centred design approach in combination with Research through Design (RtD) turned out to be key during the study.*

Keywords: *intensive care, patient handovers, human-centred design, research through design*

Introduction

The Intensive Care Unit

An Intensive Care Unit (ICU) is a complex adoptive system for the provision of care for critically ill patients. At the ICU, they can be provided with intensive and specialized medical and nursing care, an enhanced capacity for monitoring, and multiple modalities of physiologic organ support to sustain life during a period of life-threatening organ system insufficiency. Admitted patients need 24 hours a day specialized medical care and the admission time can vary from hours to weeks, or even to months (Marshall et al. 2017). The ICU team exists of highly trained doctors (intensivists, fellow intensivists, and residents) and nurses who are specialized in caring for critically ill patients. Other healthcare professionals, such as cardiologists and surgeons, are often closely involved in patient care as well.

Patient Handovers

A patient handover is a process that involves the passing of responsibility for some or all aspects of care for a patient or group of patients, and the sharing of relevant patient information. Information shared includes clinical information, functional status, changes in clinical status, and plan of care as well as psychological and social issues (Wilson et al. 2009). To enhance communication about patient data, both the ICU doctors and nurses document their findings in the Patient Data Management System (PDMS). This is a software package supporting the data documentation of patients specifically designed for critical care departments.

As patient care responsibility is transferred or shared among different healthcare professionals continuously, the communication between them is fundamental for the quality and continuity of patient care (Cohen et al. 2012). However, patient handovers at the ICU currently involve failures in information sharing. These failures can be a consequence of educational, psychological, and organizational factors (Weller et al. 2014) (Figure 1).

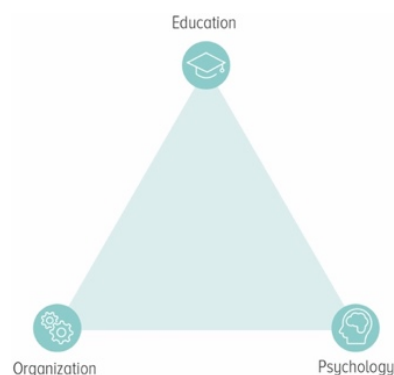


Figure 1: Failures in information sharing can arise from education, psychology and organization.

Aim and scope of the project

This project was initiated by doctors working at an ICU within an academic hospital who identified a need for enhanced patient handovers at their department. Besides qualities of the handovers, such as the good relationship between the team of doctors and team of nurses, they discovered that the handovers are often ineffective and inefficient. Furthermore, the handovers did not always facilitate a shared understanding of the patients, although this is crucial. Therefore, the main question to be answered during this project was: How can design support that the patient handovers within the ICU are experienced as more effective and efficient, and simultaneously realize a better shared understanding of patients' needs among the ICU team?

Methods

This study was executed in a period of five months by one Industrial Design student as a graduation project. Since it aimed for a design solution as outcome, design-related methods were applied. The study started by diving into the context through fieldwork existing of observations and interviews. To translate the obtained insights into design, a research through Design (RtD) approach was leading. RtD covers a range of approaches in which design and research activities inform each other with the aims of generating new insight and new solutions (Stappers and Giaccardi 2017). Since the project was done in collaboration with an ICU, doctors and nurses as participants for interviews, co-creation sessions, and evaluations could be recruited via the unit's team leaders.

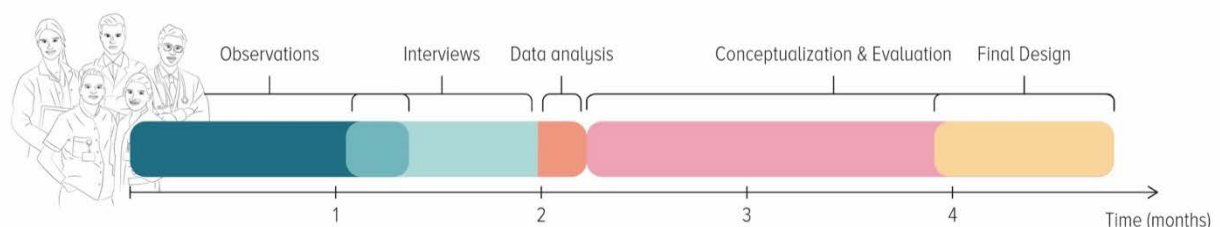


Figure 2: Study process

Observations

The aim of the observations was to understand and interpret the behaviour of ICU doctors and nurses throughout their day. Mainly semi-structured observations were done: The behaviours of interest were not defined prior to the study. Simply field notes were made. This allowed for being open to every kind of behaviour, suiting the explorative nature of this study. The observations took place several times a week over a period of four weeks. Three different observational roles were taken on. The observer-participant role was taken on when observing the different handover moments, the participant-observer role was taken on when shadowing doctors and nurses, and the complete-observer role was taken on when observing the hallways and rooms by walking around at the unit (Mulhall 2003) (Figure 3).

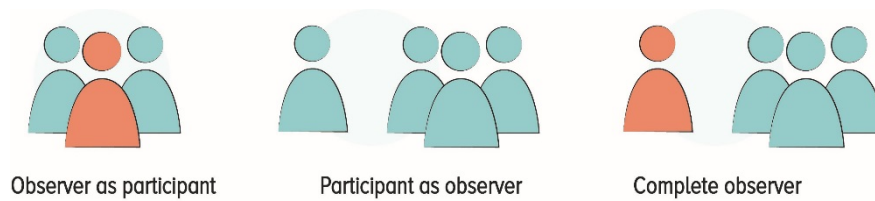


Figure 3: Observational roles

Interviews

Interviews followed to obtain a deeper understanding of the ICU team's experience with and needs regarding the different handover moments. In total, twelve interviews were executed.

Participants

To get a proper view on the experiences and needs of the ICU team, it was decided to involve doctors as well as nurses into the interviews. Eventually, six doctors and six nurses were recruited. The participants varied in age (29-64 years old) and gender (half male/half female).

Sensitizing

Collecting the desired insights required that the participants be had been involved in the research topic for some time, which required some preparation. Therefore, the interviews were based on sensitizing materials (Sleeswijk Visser et al. 2005) (Figure 4).

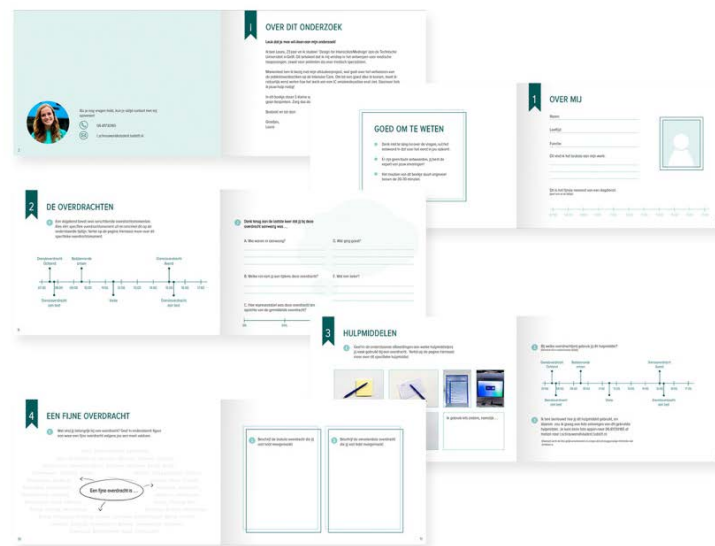


Figure 4: Sensitizing booklet.

Procedure

One week prior to the interviews, the participants received a sensitizing booklet, which they had to complete and bring to the interview, where these booklets were discussed. The interviews were semi-structured, as this offered to have a clear focus, but simultaneously ensured some flexibility. Every interview lasted 30-55 minutes and was recorded and transcribed afterwards.

Data analysis

The field notes, interview transcripts and sensitizing booklets were analysed. Thereby, Grounded Theory was leading (Corbin and Strauss 1990). This means that the data was leading, resulting into emerging, non-pre-defined themes rather than being hypothesized beforehand. First, the observation notes, transcripts, and sensitizing booklets were re-read and relevant passages in were highlighted. Then, interesting passages were stated on post-its, whereupon these were clustered into categories. Eventually, two work models were created (Beyer and Holtzblatt 1998).

Conceptualization and Evaluation

Based on the fieldwork analysis it was possible to brainstorm about different concepts. The concepts responding to the identified needs during fieldwork were quickly sketched and discussed with the ICU team. Furthermore, a co-creation session was organized which invited the ICU team to think collaboratively about how products, systems, or services could enhance handovers (Boeijen et al. 2017).

Data and Design Development

Insights from the observations and interviews

The observations provided insights in the interactions between doctors, nurses, and both groups. The interviews revealed experiences and ICU team regarding patient handovers. The created work models included the handover activities, touchpoints, and experienced qualities and pain points over time (Figure 5).



Figure 5: The created work models presented in a handover room.

It was discovered that there is a lack of common purpose: Every handover moment has a specific goal, but everyone attending has a (slightly) different interest or expectation of being there.

‘You have intensivists who are going to give very comprehensive education. That can be fun, but often you lack time for that. It is just the wrong moment’ – Nurse

Moreover, discussing many complex patients in a short amount of time makes it difficult to keep the overview and understand the core message. The PDMS should support this but turned out to result in an information overload during handovers.

‘We have screens in the handover rooms, but you have to flip through pages a lot. Lots of information is presented simultaneously, which makes it difficult to have an overview.’ - Doctor

Furthermore, though teamwork is one of the most important elements within an ICU, there exists still poor collaboration and communication. This directly hinders handovers as well.

‘Sometimes it is more an internal discussion of the doctors. Then I am just sitting there without being involved.’ – Nurse

Insights from Conceptualization and Evaluation



Figure 6: Co-creation session and concept proposals.

By discussing potential concepts and a co-creation session with ICU team (Figure 6), it was discovered that a common handover structure is necessary, but yet difficult to realize because of different priorities.

‘It is important that a common perspective of the handovers is formed among the ICU team’ – Doctor

Also, many different ideas for improvement of the PDMS arose, which included a presentation mode, an overview screen, and more integration of the doctors’ and nurses’ interface.

‘I think it is very useful to make a presentation mode for the PDMS, especially when the patients have to be divided over the nurses.’ – Nurse

Furthermore, a need for reflection became clear, which was especially recognized by the team leaders and the department head.

‘Making sure the nurses feel heard is actually a task we have to fulfil as doctors, but this is not always observed by us’ – Doctor

Creating and evaluating the final design

Eventually, the obtained insights were translated into a final design: ICoon, partly paper based and partly digital, consisting of three components: *overdragen*, *overzien*, and *over hebben* (Figure 7). *Overdragen* is a guideline for the handovers. It aims to align the expectations of the ICU team regarding each handover moment by providing structure. *Overzien* is a dashboard implemented in the PDMS especially designed for the handovers. It provides a clear overview of the patient population and only shows relevant information. *Over hebben* is a tool to facilitating critical reflection within the ICU team on scheduled moments. The tool includes different reflective questions presented stepwise.

ICoon is an example of a design for enhanced patient handovers, based on the insights obtained in this study. It was not intended for further development or implementation, but the aim was to obtain additional insights through evaluation of the design. Therefore, ICoon was evaluated through semi-structured interviews with the ICU team, in which prototypes of the different components were presented (Figure 7). Moreover, ICoon was tested during two actual handover moments of the doctors and one handover moment of the nurses (Figure 8).



Figure 7: From left to right, ‘overdragen’, ‘overzien’, and ‘over hebben’.

The doctors and nurses agreed that *overdragen* summarized their common perspectives regarding the handovers and provided them with a clear structure.

‘It makes the patient handovers more effective in the sense that people are now better able to distinguish main issues from side issues.’ - Nurse

The dashboard overzien improved the patient overview and assisted in focusing on the most important aspects of patient care.

‘You use the human senses effectively to facilitate absorption of the necessary patient information’ - Doctor

Over hebben, the tool for reflection, was valued a lot among all the doctors and nurses as they expected it might improve their teamwork, but the future use and implementation was questioned.

‘This lowers the threshold to start a discussion and change things, which is very important’ – Doctor



Figure 8: Evaluation

Results

Based on the findings, it can be concluded that a design aiming to enhance patient handovers within an ICU should facilitate more structure, overview, and reflection.

Structure

Structure turned out to be an important element within handovers, however the highly varied patient population within the ICU makes it difficult to come up with a detailed and consistent communication structure. Nonetheless, structure can be created in a sense that agreements about important elements for each handover moment have to be made explicit so that the team will comply with them. Aiming for a common structure will result in more efficient handovers. Moreover, it will ensure that expectations are aligned, thereby making the handovers feel effective for everyone.

Overview

Overview mainly relates to seeing the overall picture, the ability to distinguish details from main issues and communicating that well. The PDMS can have a central role in this, as this system includes all patient data, which currently can cause an overload of data during handovers. It would be recommended that this system assists in forming an overview, by showing a patient overview, distinguishing patients based on criticality, and only showing the relevant information for each specific handover moment.

Reflection

Intensive teamwork requires reflection, which is often lacking at critical care departments because it does not seem to be priority. However, there exists a need for reflection within the ICU to improve teamwork. Reflection will allow the ICU team to speak out and ensures that the handover procedure will keep on corresponding to the necessities of doctors and nurses continuously. Moreover, reflection can reduce the gap that is still present between doctors and nurses.

Discussion

Strengths and limitations

This study investigated how the patient handovers within the ICU could be enhanced by design. Convincingly, the adopted human-centred design approach in combination with RtD greatly supported the development of the design and the obtained insights. ICoon is only one example of how these principles can be applied to a design. It will be interesting to evaluate how these principles will apply to other ICUs as well. However, more research is needed to investigate that.

Therefore, a limitation of this study is the local impact, as only one academic ICU was included. In the future it would be interesting include a more heterogeneous population, with as a first step involving medical professionals of ICUs from different hospitals including peripheral hospitals as well.

The power of RtD

The RtD approach in combination with an open and enthusiastic attitude as a designer opened up the possibility to extensively collaborate with the ICU team. Continuously aiming for their involvement in the process allowed for multiple iterations in which the input from the ICU team was leading. This involvement resulted in a fruitful design: It seamlessly suited their current workflow and did not require extra protocols or work, which is often the case with innovations.

Aiming for ongoing change

Elaborating on that, the adopted human-centred approach turned out to be a key element in this study, because this leads to ongoing change (Mezirow 1997). Thorough involvement of the ICU team was entailed by investing in the relationship with them by being physically present, talking to them in the corridors, and leaving artefacts made physically behind. This study showed that this approach, including relatively small investments in a relatively short amount of time, supports the implementation and continuation of new tools and services within an ICU.

Conclusion

The research question to be answered was: How can design support that the patient handovers within the ICU are experienced as more effective and efficient, and simultaneously realize a better shared understanding of patients' needs among the ICU team? Through fieldwork and conceptualization activities ICoon was designed and evaluated with the ICU team. Combining all the insights, it can be concluded that to enhance the patient handovers at the ICU, more structure, overview, and reflection should be provided. A common structure will make the handovers more efficient and entails that expectations are aligned, making the handovers feel effective for everyone. Overview will assist the ICU team in forming a shared understanding of each patient's needs. Reflection will ensure that the handover process keeps on corresponding to the necessities of the ICU team continuously. Adopting a human-centred design approach in combination with RtD turned out to be key during the study and would be interesting to repeat in other hospitals as well.

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Supporting people's independence through Voice User Interface (VUI) devices

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ABSTRACT *The use of well-designed assistive devices may improve the quality of life of individuals living with severe and permanent impairments and reduce the burden on their caregivers.*

Interactive Smart Agents (ISA)s use the latest smart home technology to control devices around the house through voice interfaces. This study aims to investigate whether ISAs may be effective to support individuals who are affected by multiple sclerosis, stroke and spinal cord injury (SCI). The study's approach is user-centred to ensure inclusion. The study has achieved NHS Research Ethics Committee (REC) and Health Regulatory Authority (HRA) approval (Project ID: 255096) and includes two main parts: 1. the initial development of an adoption model informed by secondary research and exploratory primary data, 2. a second in-depth investigation of the initially identified constructs and relationships through a multi-points qualitative study including prototype evaluation.

The research is in collaboration with the North Thames Regional Environmental Control Services (NTRECES), an NHS organisation that provides Environmental Control (EC) devices to manage the patients' electrical and computing appliances. Clinical staff have indicated an increasing patients' demand of ISAs instead of traditional EC devices and have suggested that their clients are keen to experiment with more intuitive interfaces.

This paper presents the findings from the first part of the study and it is structured as follows: in the first and second sections literatures on ISA and technology adoption are reviewed respectively. In the third section findings from the preliminary study are presented. In the fourth section a proposed model of adoption of ISAs among severely disabled patients is discussed.

Keywords: voice user interface, sustainable health and well-being, interactive smart agents, technology adoption.

Interactive Smart Agents (ISA) and Sustainable Healthcare

The use of emerging technology in healthcare is one of the fundamental markers of a sustainable healthcare system. A sustainable healthcare system should be economical, adaptable and acceptable (Fineberg 2012). In order to move towards a sustainable system, the healthcare services may have to invest more significantly in the latest technological equipment and inventions to be utilised at home (Pencheon 2014). This also aligns with the NHS's goal (Smith 2019).

ISA devices like Amazon's Alexa, can support the care of older adults with multiple and chronic conditions (Halim 2019). ISA devices, or smart speakers, operate through VUI. Through ISAs users can control other smart devices around the house, including lights, door locks, TV and thermostats. ISA devices can also be used for streaming music, accessing online information and setting reminders. Investment in technology to deliver patient-centred care has been the focus of much debate (Klecun 2016). Albeit not designed specifically to support healthcare services, ISA devices can aid the care of older adults with chronic conditions. Voice might be a preferred mode of interaction amongst older adults, given its natural attributes not requiring demanding and technical learning. Although ISAs adoption among this segment of the population is still ambiguous (Spinelli, Micocci, Martin, and Wang 2019), their benefits in primary care settings have already been discussed (Halim, 2019).

Technology Adoption

According to previous research, on average one third of all assistive technology devices get abandoned (Goodman, Tienne, and Luft 2002). Factors responsible for this are: lack of motivation, changes in medical condition, difficulty in device configuration, appearance, performance, lack of training for the users (Goodman, Tienne and Luft 2002; Carmien 2010). Low appeal and basic functionalities contribute to increase the stigma associated with assistive technology (Ringland, Wolf, Boyd, Baldwin, and Hayes 2016).

The Matching Person and Technology (MPT) model (Goodman, Tienne, and Luft 2002), suggests that designers should focus on three factors: i) psychosocial environment ii) personal traits iii) technology. Factors like age, gender, social status, financial situation, have been recognised as having significant impact on access to information, digital literacy and availability of resources (Greenhalgh, et al. 2013).

The Technology Acceptance Model (TAM) (Davis, 1989), Unified Theory of Acceptance and Use of Technology (UTAUT) (Venkatesh, Morris, Davis, and Davis 2003) are well-known theoretical contributions in this field. Along with these theories the Theory of Reasoned Action (TRA) and the Theory of Planned Behaviour (TPB) (Ajzen 1991) have been used to understand the adoption of technology, and through some adaptations, scholars have been able to cater for specific emerging technologies (Kowalczyk 2018; Yang, Lee and Zo 2017).

Given the ability of TPB to be used across different settings (Matheison 1991; Heath and Gifford 2002) TPB is the blueprint for the adoption model presented later on. TPB states that an individual's behaviour is determined by the individual's intention to perform that behaviour. This behavioural intention is in turn affected by an individual's attitude, subjective norms and Perceived Behavioural Controls (PBCs) (Ajzen 1991; Heath and Gifford 2002).

Technology adoption literature has little contribution to make towards the understanding of technology adoption behaviour by users with disabilities (Djamasbi, et al. 2006) and the application of any adoption theoretical framework without modifications may not be specific enough to capture the factors playing a role in the adoption of ISA devices by the specific user group considered in this research. This is the intellectual gap underpinning this research.

Findings from Primary Data: Patient's Observations

NTRECES is an NHS based organisation in north-west London. To gather an initial understanding of the patients' abilities and requirements some preliminary observations were carried out. Ethnographic-inspired observations occurred by shadowing NTRECES staff during patients' home visits and hospital outpatients' rehabilitation sessions. All the patients were either existing patients or new referrals. The observations were followed by interviews with clinical staff, patients, EC designers and providers. These initial explorations were carried out from August 2017 to October 2018.

Initial inquiries from the NTRECES clinical staff revealed that the target user group for this research has the following characteristics:

- They have minimal exposure to technologies available on the market due to their mobility impairments. Most of their exposure to market and innovations is through, friends, family, caregivers and the media.
- Their adoption or acceptance decision about a technology differs from the norm as their assistive technology devices are funded by the NHS.

NTRECES's patients are issued with EC equipment to control the electrical and computing devices around their homes. Most of the EC equipment is controlled by a switch, a single click button, which scans through a menu of options, until the required one is highlighted (Wellings and Unsworth 2011). As more devices are added to the EC system, the selection and control of each individual device becomes a lengthier and slower task (Verdonck, Steggles, Nolan, and Chard 2014). Moreover, for patients with severe or deteriorating mobility impairments, clicking the switch can be cumbersome (Craig, Tran, McIsaac, and Boord 2004).

Patients demonstrated great interest in ISA devices and often enquired whether NTRECES would issue ISA devices. For patients who are paralysed from the neck down, the use of their voice to control facilities around the house would provide them with meaningful degree of independence. As humans communicate through verbal dialogue, ISA may prove to be the most intuitive device for them (Cohen and Oviatt 2015).

A comparison between technology has highlighted that ISA devices can support all the functionalities that are enabled by EC devices, bar a few (Shamim, Spinelli, Woodcock, and Nair 2019) (see figure 1). Hence, a network of EC devices controlled by a central ISA is possible and would enable patients with mobility impairments to have a better quality of life. ISA devices are however designed as mainstream consumer technology and not as an assistive technology.

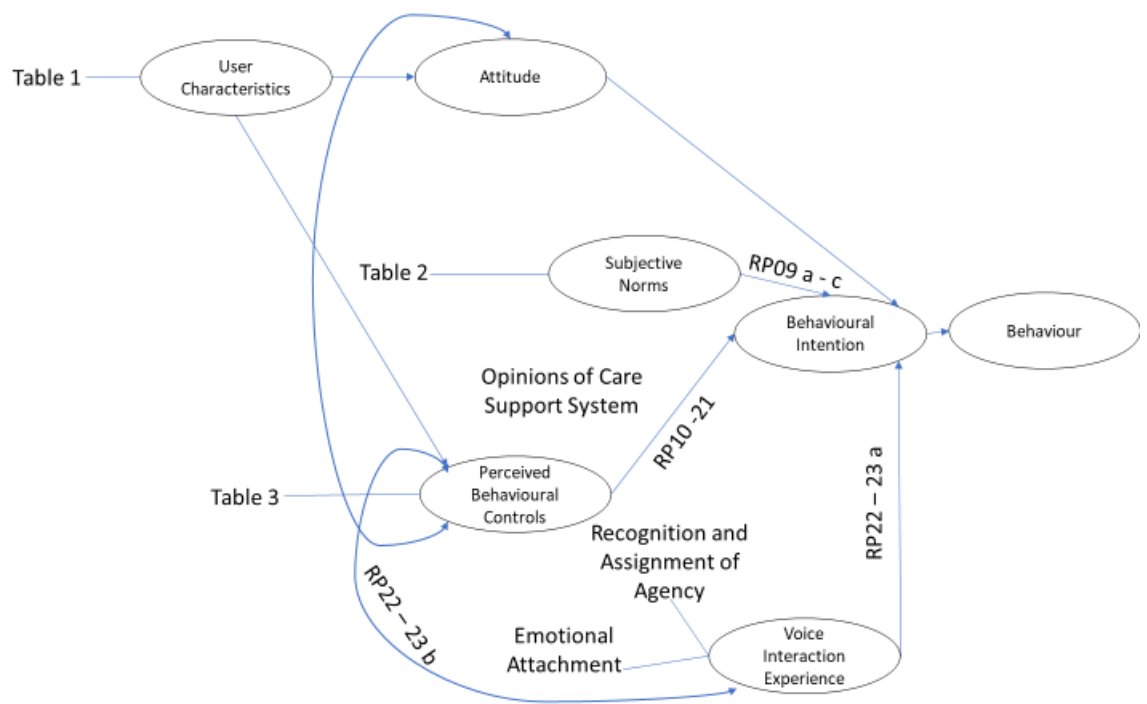


Figure 2: Proposed model of acceptance of ISA devices among NTRECES patients

Attitude

If a user has a positive attitude towards adoption of a technology, then the user develops a positive intention towards said behaviour (Ajzen 1991; Davis 1989). Scholars demonstrated that a positive user attitude leads to the adoption of smart speakers (Chu, Galetzka, and Van Deursen 2019). Hence:

(RP) 01: Positive attitude towards ISA devices is associated with the intention to adopt them.

User Characteristics

Users' personal characteristics play a significant part in the uptake or abandonment of technology (Goodman, Tiene and Luft 2002; Samaradiwakara 2014). The relevant user characteristics are presented in table 1. In the proposed model the user characteristics affect both Attitude and PBCs (see fig. 2).

User characteristics	Literature in support	Research propositions
<i>Age</i>	(Conci, Pianesi, & Zancanaro, 2009)	RP02a: Old age has a negative effect on PBCs. RP02b: Old age has a negative effect on the attitude towards intention to adopt ISA device.
<i>Gender</i>	(Li, Glass, & Records, 2008)	RP03a: Females have a negative attitude towards intention to adopt ISA device. RP03b: Females have a negative effect on PBCs.
<i>Desire for Independence</i>	(Kintsch & Depaula, 2002)	RP04a: Desire for independence can positively influence attitude towards intention to adopt ISA device. RP04b: Desire for independence can have a positive effect on PBCs.
<i>Voluntariness</i>	(Agarwal & Prasad, 1997)	RP05a: Voluntariness to try a new technology have a positive attitude intention to adopt ISA device. RP05b: Voluntariness to try a new technology have a positive effect on PBCs.
<i>Openness to Innovation</i>	(Laukkanen & Pasanen, 2008)	RP06a: Openness to innovation leads to a positive attitude towards intention to adopt ISA device. RP06b: Openness to innovation has a positive effect on PBCs.
<i>External Engagement</i>	Primary research	RP07a: Users with higher external engagement have positive attitude towards intention to adopt ISA device. RP07b: a higher level of external engagement has positive effect on PBCs.
<i>Income</i>	(Feder, Just, & Zilberman, 1985)	RP08a: Users with higher income have a positive attitude towards intention to adopt ISA device. RP08b A higher income has a positive effect on PBCs.

Table 1: User Characteristics affecting Attitude and PBCs

Subjective Norms

According to the TPB, the opinion of the people who are important to the user, is vital in forming one's intention. Yang, Lee and Zo (2017) established in their study that if the people who are important to the users think they should use smart home services then it will result in the intention to use smart home services. This model suggests that:

RP09: There is a positive relationship between Subjective Norms and the Intention to adopt ISA devices

There are three items included in Subjective Norms, as per table 2.

Subjective Norms	Literature in support	Research proposition
<i>Peer Pressure</i>	(Ajzen, 1991), Primary research	RP09a: Social peer pressure positively affects the intention to adopt ISA device.
<i>Trust in NTRECES Advice</i>	(Ajzen, 1991), Primary research	RP09b: Trust in NTRECES advice is positively associated with intention to adopt ISA device.
<i>Care Support System</i>	(Ajzen, 1991), Primary research	RP09c: There is a positive relationship between the opinions of those who provide care and support and the intention to adopt ISA devices, specifically if caregivers are enthusiastic towards ISA devices, the users will form a positive intention to adopt.

Table 2: Subjective Norms affecting behavioural intention

Perceived Behavioural Controls

PBCs are the users' perception of how difficult or easy it is to perform a certain behaviour, in this case to use ISA devices. This perception is based on previous experience and anticipated obstacles (Ajzen, 1991). PBCs have been demonstrated to have a positive effect on behavioural intention (Yang, Lee, and Zo 2017). The model here proposes that:

RP10: PBC is positively associated with the intention to adopt ISA devices.

Extending and applying the definition of PBCs by Ajzen (1991) to the context of this study, several factors that constitute PBS has been identified and listed in table 3.

PBC	Literature in support	Research proposition
<i>Familiarity with technology</i>	Primary research	RP11: There is a positive relationship between familiarity with technology and intention to adopt ISA device.
<i>Technical support system</i>	(Goodman, Tienne, & Luft, 2002)	RP12: Users with a good technical support network have a positive intention to adopt ISA device.
<i>Residence type</i>	Primary research	RP13: Users' residence owned by a housing association negatively effects the attitude towards the intention to adopt ISA devices.
<i>Trust in NTRECES advice</i>	Primary research	RP14: Trust in NTRECES advice leads to a positive attitude towards the intention to adopt ISA devices
<i>Lack of access to open market</i>	Primary research	RP15: The lack of access to the open market has a negative effect on the intention to adopt ISA devices.
<i>Perceived ease of interaction</i>	(Davis, 1989)	RP16: PEoI leads to positive attitude towards intention to adopt ISA device.
<i>Perceived reliability</i>	(Goodman, Tienne, & Luft, 2002)	RP17: Higher perceived reliability leads to positive intention to adopt ISA device.
<i>Perceived confidentiality</i>	(Yang, Lee, & Zo, 2017)	RP18: Higher perceived confidentiality results in a positive intention to adopt ISA device.
<i>Perceived security</i>	(Jutai & Day, 2002), (Kowalczyk, 2018)	RP19: Higher perceived security has a positive impact on intention to adopt.
<i>Perceived usefulness</i>	(Davis, 1989), (Kintsch & Depaula, 2002)	RP20: Higher perceived usefulness leads to a positive intention towards adoption of ISA device.
<i>Perceived trust in service provider</i>	(Chung, Iorga, Voas, & Lee, 2017)	RP21: Perceived trust in service provider leads to a positive intention towards adoption of ISA device.

Table 3: Items included in PBCs

Voice Interaction Experience

This study proposes a construct, Voice Interaction Experience, that acknowledges the unique characteristics that VUI enables (Lopatovska and Williams 2018). These are described in table 4.

Voice Interaction Experience	Literature in support	Research proposition
<i>Identification and Assignment of Agency</i>	(Klein, 2016), (Wagner, Nimmermann, & Schramm-Klein, 2019)	RP22a: Identification and assignment of agency to ISA devices will positively affect the intention to adopt the ISA device. RP22b: Identification and assignment of agency to ISA devices has a positive effect on PBCs.
<i>Emotional Attachment</i>	(Knijnenburg, Willemsen, Gantner, Soncu, & Newell, 2012)	RP23a: The Greater the emotional attachment to the ISA devices, the stronger the intention to adopt the ISA device. RP23b: Emotional attachment has a positive effect on PBCs.

Table 4 Items included in Voice Interaction Experience

The model proposed is an initial elaboration of secondary and primary research. Future work, consisting of primary qualitative data collection and analysis will clarify and qualify the postulated research propositions and the existence of new ones.

To investigate the proposed research propositions, data will be collected from a sample of 15 patients. The protocol will include three visits to each participant at their place of residence. The repeated visits over a course of 5 months have been designed to enable the collection of deep insights in the characteristics, socio-technical environment and user requirements. Data generated from visit 1 will lead to a prototype of an ISA based EC hub able to demonstrate the control of few functions around the home. Visit 2 will be centred on the prototype and capture details on PBCs and Voice Interaction Experience. Visit 3 will focus on user-prototype interaction and service provision that may enable adoption. The final outcomes of this study will consist of a refined model for the adoption of ISA devices among patients with severe mobility impairments and a set of design and service improvements that would enable the adoption of ISA technologies as assistive devices.

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