



**Proceedings of the 5th International  
Conference on Design4Health  
Sheffield 4th – 6th September 2018**

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Editors: Kirsty Christer, Claire Craig & Dan Wolstenholme

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**Volume 1**

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## Foreword

Welcome to the official proceedings of the fifth international Design4Health conference, Sheffield Hallam University. This year's conference saw a full programme which stimulated discussion and debate, and saw participants share best practice and explore new territory in this developing academic field.

Since its inception in 2011 the conference has grown in scale and reach. Our scientific committee were excited to see submissions from over 19 countries with a far broader representation of contexts where design research in the field of health is occurring. Papers reflected a growing emphasis on the role of design in promoting wellbeing, in managing and preventing illness; an increased confidence in the application of methods, which cross design and health and a more critical discourse in relation to the challenges and opportunities that bringing together such disparate disciplines, can bring.

Last year the conference was hosted by Swinburne University and situated in the iconic Melbourne Cricket Ground. Whilst this year's venue could not promise the grandeur of the cricket ground or the Australian weather, we invited delegates to an interesting conference space as for the first time we hosted in the Faculty of Health and Wellbeing, a campus dedicated to healthcare teaching and research.

Despite the change in venue the original aims of the conference remain largely unchanged: to bring together researchers, industrial partners, users of products and services from across a myriad of design and health contexts to share experiences and to learn from each other so that the potential of design in health can be realised.

On behalf of the conference organising committee and the wider university, welcome.



Dr Claire Craig

Co-director, Lab4Living, Art & Design Research Centre,  
Sheffield Hallam University

September 2018



## Supporters and Partners

This year's conference was generously supported by the **Creating Knowledge Fund** and the **Art and Design Research Centre** at Sheffield Hallam University.

We gratefully acknowledge the support of our sponsors:

**National Institute for Health Research (NIHR)**  
**Collaboration for Leadership in Applied Health Research and Care (CLAHRC) Yorkshire and Humber**

CLAHRCs are collaborative partnerships between the National Health Service, public services and Higher Education Institutions, focused on improving patient outcomes through the conduct and application of applied health research and evidence-based implementation.

The CLAHRCs were set up to improve patient outcomes across the geographical area covered by the Collaboration through three key interlinked functions:

- conducting high quality applied health research,
- implementing the findings from research into clinical practice,
- increasing the capacity of NHS organisations to engage with and undertake applied health services research.

Our principles are Engagement, Co-production, Capacity Building and Addressing Health Inequalities.

Find out more <http://clahrc-yh.nihr.ac.uk/>

## Devices for Dignity

Devices for Dignity is one of 11 UK MedTech and In vitro diagnostic Co-operatives (MICs). We are funded by the National Institute for Health Research (NIHR) to act as a catalyst within the UK NHS for the development of new medical devices, healthcare technologies and technology-dependent interventions. We focus on developing technology solutions to meet clinical needs and for chronic health conditions that are often overlooked, and that are typically associated with loss of dignity and independence, and poor patient outcomes.



CLAHRC  
Yorkshire and  
Humber



## Review Panel and Policy

All abstracts included in these proceedings were double-blind refereed by the review panel, and expanded to full papers or visual essays taking into account the referees' recommendations. Full papers, visual essays and Posters were refereed by the review panel:

Prof Paul Chamberlain, Lab4Living

Irene Mabbott, Sheffield Teaching Hospitals NHS Foundation Trust

Kirsty Christer, Lab4Living

Dr Rebecca Partridge, Lab4Living

Dr Claire Craig, Lab4Living

Heath Reed, Lab4Living

Dr Remi Bec, Lab4Living

Prof David Swann, Art & Design Research Centre, Sheffield Hallam University

Prof Derek Burke, Medical Director, Sheffield Children's Hospital

Julie Walters, University of Lincoln

Dr Eve Stirling, Art & Design Research Centre, Sheffield Hallam University

Jonathan West, Helen Hamlyn Centre, Royal College of Art

Nick Dulake, Design Futures

Dr Gemma Wheeler, Lab4Living

Nathaniel Mills, Paediatric Programme Manager, Devices for Dignity

Prof Sabine Wildevuur, WAAG-CARE

Dr Joe Langley, Lab4Living

Dan Wolstenholme, NIHR CLAHRC YH and Lab4Living



## Conference Themes and Strands

### Design for Health?

With increasing pressure to rethink our healthcare systems and set against complex and interconnected global challenges, we particularly welcome contributions that interrogate meanings and assumptions relating to the terms 'design' and 'health', and offer the following words / terms as provocations:

Design?	Taboo?	Risk?
Health?	Value?	Change?
Care?	Success?	Technology?

For instance:

What do we mean by the term success? Who determines what constitutes success (designer, clinician, patient, policy maker, industry partner). How do we measure it and report it?

Where do the conflicts and opportunities lie? What is the difference between success and failure? Is failure always negative?

What do we understand by health? Who decides what it is to be healthy: person, medic/clinician/designer? How does design shape health (positively and negatively), and how does health shape design?

How have notions of health shifted in relation to time? scientific advancement? philosophies of what it is to be human? And where might future health paradigms lie?

Participants were invited to interrogate and play with the terms in relation to their research and practice in their conference submissions. The conference paper presentations were then organized into the following strands for the conference programme:

Behaviour Change	Communication through Design	Design Cultures
Empathic design	Service Design	Technology & Ageing
Co-Design	Dementia	Designing within Complexity
Implementation	Spaces?	Technology & Design
Co-production	Democratization & Design	Education
Product	Stigma	Visual communication

## Acknowledgments

We gratefully acknowledge the following whose time, creativity, energy and support were essential to the conference:

### Keynote Speakers

Dilys Price OBE

Charlotte Bright, Deputy Director, UK Department for Health and Social Care

Patrick Bonnett, Development Director, National Innovation Centre for Ageing

Jayne Wallace, Professor of Craft and Wellbeing, Northumbria University.

Gavin Munro, Full Grown

Sue Walker, Professor of Typography, University of Reading.

Gary Hickey, Senior Public Involvement Manager at INVOLVE

### Session Chairs

Paul Chamberlain Heath Reed

Claire Craig Christine Smith

Cheryl Grindell Sarah Smizz

Gary Hickey Julie Walters

Gail Kenning Jonathan Wheat

Joe Langley Gemma Wheeler

Irene Mabbott Dan Wolstenholme

Alison Mayne Alaster Yoxall

Rebecca Partridge

## Stewards

Janet Paske

Remi Bec

Janet Ulman

Julie Roe

Nantia Koulidou

Annie Dunsmore-Dawson

Cathy Slorensy

Alison Mayne

Helen Fisher

Henry Cossingham

## Design Team

Helen Fisher, Nick Dulake, Gemma Wheeler, Rebecca Partridge, Nicola Alexander, Pete McQueen, Andy Stanton, Ryan Baird, Matt Willox and John Kirkby

Finally, we thank the following for making the conference space a welcoming, intriguing, stimulating and relaxed environment over the three days:

Wellbeing Space: Dr Alison Mayne; Double Agents: Sarah 'Smizz' Smith, Julie Walters, Laçin Aksoy, Debbie Michaels; Ghost Tour: Mr P Dreadful; Reception: Catherine Lawry.

## Conference organisers

Prof Paul Chamberlain, Co-Director,  
Lab4Living

Heath Reed, Lab4Living

Kirsty Christer, Conference Co-ordinator

Julie Roe, Lab4Living Co-ordinator

Dr Claire Craig, Co-Director, Lab4Living

Dan Wolstenholme, Lab4Living



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## A Design-led Process for Disseminating The Concept of Shared Decision Making

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**ABSTRACT** *Design researchers and practitioners have started to collaborate with experts in diverse areas such as healthcare, education and business especially during the last two decades. In healthcare, design researchers and practitioners have been exploring ways on how to involve patients more actively in engaging in their own healthcare and wellbeing. In this respect, patient-centred care and shared decision making are timely approaches in modern healthcare systems, where designers can leave a stamp by collaborating with stakeholders such as clinicians, patients and relatives to create better healthcare services.*

*Starting from the above perspective, this paper explores the role of design in raising awareness and disseminating the concept of shared decision making based on patient campaigns in Vejle Hospital in Denmark so that patients and relatives would seek for a higher degree of involvement in making decisions for their own treatment and/or examinations. The study that is presented here is part of a 3-year collaborative project which includes enhancing clarity and understanding of a patient decision aid via design and creating ways for successful implementation through involving patients, relatives and clinicians in the design process between Vejle Hospital- The Patients Cancer Hospital and Design School Kolding in Denmark.*

Keywords: shared decision making, co-creation, patient campaigns, patient decision aids

## Introduction

Contemporary design research calls for involving all stakeholders as design partners to ensure that needs are met and ideas and knowledge of relevant actors are incorporated in future design solutions (Sanders and Stappers 2014; Manzini and Coad 2015). Healthcare is one of the significant fields where design can support advance through timely co-creational methods. Shared decision making (SDM), a central column of patient centred care, is exemplar for a co-creational design approach: without participation of patients, relatives and clinicians, no shared decision will be taken. SDM concerns cooperation between patient and clinician when decisions are to be made about diagnosis, treatment or follow-up which are preferable for the patient. This includes use of evidence-based information concerning options, benefits, harms, uncertainties and medical counselling and support to explore the patient's own values and preferences (Barry and Edgman-Levitin 2012) However in order to being able to implement SDM in clinical practice, it is fundamental that stakeholders share the vision of SDM (Coulter 2017; Stiggelbout et al. 2012). 'Patient activation' is thus found to be vital to create a patient push and request for SDM to consequently oblige clinicians and management to implement SDM into clinical practice.

The partnership that this paper covers is a long-term collaboration between Design School Kolding and The Patients Cancer Hospital in Denmark. Cancer care is a complex and on-going treatment process involving multiple health professionals and with a treatment trajectory where patients are facing difficult decisions at multiple time points. In such circumstances, it is considered important to inform and involve patients, to engage them in decisions about their care wherever possible and to help them retain a sense of control (Katz, Belkora, and Elwyn 2014). The collaboration of the two institutions contains the design of a general patient decision aid, adaptable to different types of cancers as well as its successful implementation into clinical practice. For the latter task, four main steps have been carried out: 1) conducting a co-creation workshop on how to implement the concept of shared decision making and make it a success by involving different types of stakeholder groups, 2) testing visual directions of the patient campaigns, 3) conducting a second co-creation workshop for developing campaign prototypes, and a 4) final testing of visual directions of the patient campaigns. These steps formed the basis for a patient campaign to foster the active involvement of patients and relatives and to make sure that SDM is requested from bottom-up. In this context, co-creation enabled a shared value creation as the basic foundation for a project success.

The following sections explore literature on implementation challenges in SDM and research on patient campaigns for SDM, before introducing empirical data following the four-step process.

## Shared Decision Making and Challenges in Implementation

In recent years, efforts to implement SDM have been made (Coulter et al. 2015; Steffensen et al. 2018). Nevertheless, SDM is not widely used in clinical practice, including in cancer care and

several studies suggest that oncologists often do not involve patients in the decision-making process to the extent the patient desires (Tariman et al. 2009; Stacey, Samant, and Bennett 2008).

In addition, little attention has been paid to organizational and system level factors in which these interactions and decisions are embedded, and how to modify these to ensure that SDM becomes part of routine practice. Successful implementation of SDM in routine care is dependent on a number of factors including attitude, culture, skills, knowledge and management support to be realized (Müller, Hahlweg, and Scholl 2016). Not only it is important to involve key stakeholders (clinicians and hospital executives), but also to inform and teach patients about SDM and to validate that it is reasonable to ask for involvement in health care decisions about their own treatment. Although research shows that implementation is a key challenge in SDM, surprisingly little research points to co-creational methods as a way to address the well-known barriers such as the necessity for shared value generation or the harmonization of different stakeholder perspectives.

## Co-creation to Support Implementing Shared Decision Making

Co-creation is explained as an act of cooperative creativity with the goal to create something together (Sanders and Stappers 2008). An essential aspect of it is the participation of stakeholders at the same time in the same context to generate ownership for the solutions (Brandt, Binder, and Sanders 2012, 145). A variety of studies cover patients and clinicians as co-designers of healthcare services (Robert et al. 2015; Mannonen, Kaipio, and Nieminen 2017; Rothmann et al. 2016; Bate and Robert 2006). However, when applied to SDM, we did not find studies on the methodology and value of co-creational approaches to improve the implementation of SDM. We would thus like to point to two studies that address design as a vital element in relation to the implementation of SDM. In the first study, the role of service design has been addressed and iterative design research approach has been put forward as an influential way to foster the implementation of SDM since it differs from typical social scientific methods based on a linear tactic by Griffioen et al. (2017). They especially point to five foundational principles of service design such as user-centeredness, co-creation, sequencing, evidencing and holism as possessing potential for the implementation of SDM. The paper is positioned as 'a call on service designers and healthcare professionals to combine their efforts to improve the implementation of shared decision-making in healthcare' (Griffioen et al. 2017, 194), but does not give insight into patient campaigns specifically. This is done by another study, AskShareKnow, as part of the Magic Program in the UK. In this research project, targeted to support SDM in the National Healthcare Service, a patient campaign was launched. AskShareKnow involves the following three questions: What are my options? What are the possible benefits and harms of those options? How likely are each of those benefits and harms to happen to me? Including 'What will happen if I do nothing?' (Shepherd et al. 2016, 1161). A study on the effect of the campaign showed that 'Enabling patients to view a short video clip before an appointment to improve information and involvement in healthcare consultations is feasible and led to a high uptake of question asking in consultations.' (Shepherd et al. 2016, 1160).

In this study, the format of a video clip was used to convey the information. The methods for designing the campaign or its co-creational efforts remain unclear though.

Based on the challenge of implementing SDM and the relative lack of research on adequate methods to do so, this paper explores how a design-led co-creative process could contribute to raising awareness and disseminating the SDM concept through patient campaigns: How can a design-led co-creative process raise awareness and support the dissemination of SDM through patient campaigns? What methods/methodology help(s) to create a shared value and vision among patients, relatives and clinicians?

## Empirical Data

Creating the patient campaigns consists of the following four main phases in which 120 patients and relatives have participated:

- 1) Co-creation workshop I: Implementing the concept of SDM by involving patients, relatives and clinicians;
- 2) First round testing for the visual directions ;
- 3) Co-creation workshop II: Prototyping communication strategies to create better dissemination of SDM for patients, relatives and clinicians ;
- 4) Final testing for the visual directions.

This process led to three design outcomes: a) Posters, b) Postcards spread out in the waiting rooms, c) Two videos introducing the concept of SDM and the generic patient decision aid to be played in the waiting rooms and on the Centre for Shared Decision Making's website.

### *1) Co-creation workshop I*

The first workshop aimed at creating mutual empathy and learning among patients, relatives, doctors and nurses. It fostered the development of first implementation ideas based on the different needs of the participants who have been recruited by the Centre for Shared Decision Making and thus had ties with the institution as former patients/relatives and current employees, ages between mid-fourties and mid-seventies.

The main themes put forward by the patients and relatives were: more information about SDM and patient decision aids; patient campaigns using different types of media such as TV advertisements, information letters to be delivered to patients' homes and posters in the hospital waiting areas were needed; the style of information was preferred to be in a more informal way to increase the level of understanding.

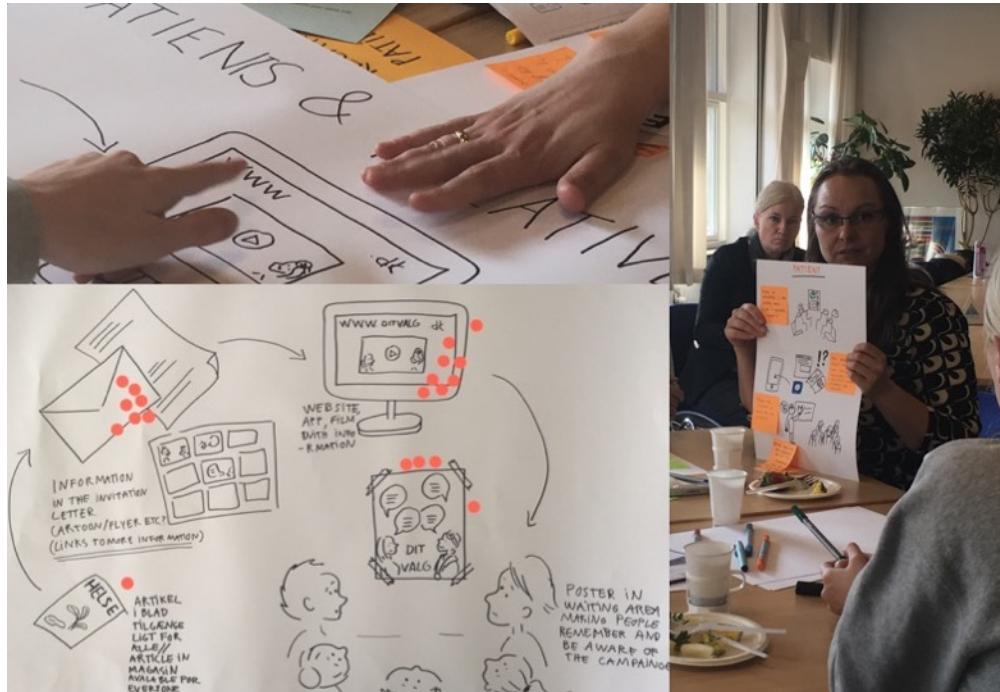


Figure 1: Patients, relatives and clinicians working on implementing the concept of SDM

In the patient and relative group (which clinicians participated in as well), the topic of preparation ahead of the clinical encounter with the healthcare professionals was discussed as essential for a successful implementation of SDM (Figure 1).

## *2) First Round Testing for the Visual Directions*

Based on the findings from the first co-creation workshop, posters with different visual options were developed and tested with 47 patients and relatives through voting and mini-interviews in the hospital.

The main findings of this test phase were using calming colours and images of human beings (instead of illustrations). This choice was explained by enhanced trustworthiness and empathy that would lead to welcoming and friendly information for patients and relatives especially while they waited in a quite vulnerable situation in the hospital.

## *3) Co-creation workshop II*

The purpose of this co-creation workshop which 10 clinicians, 2 patients and 1 relative participated in was to create ownership and prototypes of posters explaining the concept of SDM. The workshop also aimed at ensuring that the dissemination of SDM considered the plurality of different stakeholder voices to build a straightforward communication mode.



Figure 2: Highlights from the workshop process; patients, relatives and doctors working together

#### 4) Comparing The Two Finalist Visual Styles

In this testing phase, two options were compared by 73 patients and relatives through votes and mini-interviews (Figure 3).



Figure 3: Two options to be tested for finalizing the visual direction

The patients and relatives found the use of real people imagery more personal and trustworthy, stated that having real clinicians or patients and relatives pictured on the posters was not necessary. Instead, creating a message for the fundamental concept of SDM was of core importance. The second option (illustrations) was found less relevant and more childish.

*Final Version*

The final version consists of co-created dialogues among patients, relatives and clinicians. Having a co-creative approach in creating the dialogues for the patient campaigns provides an equal and common space for the participants to discuss and share what type of questions and/or explanations would they have and which statements would be more comfortable for them to see.



Figure 4: The final version of the patient campaigns; posters, cards and screenshots from the video (from top to bottom- partly translated into English)



Using a design-led co-creative approach to develop a shared value and vision helped the design development team to receive different feedbacks and expectations from the relevant stakeholder groups. Working closely with all stakeholders supported the process of generating ownership and thus created a basis for a successful implementation in this specific project.

## Discussion and Conclusion

This study aimed at exploring the role of design in raising awareness for the concept of SDM and its implementation through a co-created patient campaign. It thereby explored the two main research questions: How can a design-led co-creation process raise awareness and support the dissemination of SDM through patient campaigns? What methods help to create a shared value and vision among patients, relatives and clinicians?

A design-led co-creation process for creating patient campaigns resonates the core concept of SDM which is 'without participation of patients, relatives and clinicians, no shared decision will be taken'. The patient campaign per se was developed with the goal in mind to raise awareness and disseminate SDM, however through the design-led and co-creative approach already the development process itself fosters the active generation of a potential core group of testimonials. Those stakeholders involved, ideally happen to be 'lead users', with a greater knowledge base and background information on SDM to spread among their peer groups. Consequently, this approach has the capacity for positive implementation trade-offs such as improved acceptability. A potential drawback is to attract a balanced set of participants (physical and cognitive capabilities, socio-economic background, age) and to make sure that stakeholder voices are considered on equal terms to truly create potential ownership and ambassadors for the dissemination and implementation of SDM. The limitations of the design-led co-creation approach not only concern its dependence on a management environment that welcomes different stakeholders' views, but also on patients, relatives and clinicians who would be willing to actively engage throughout the process. Patients with cancer are likely to be a vulnerable situation and might not be able to spend extra time to work on this topic.

In turning to what methods help to create a shared vision, we suggest that creating a mutual understanding among different stakeholder groups and providing a space for them to learn from each other (perspectives, experiences, etc.) build a common ground first. In contrast to top-down approaches as well as more traditional social science approaches (e.g. interviews with each stakeholder group separately) the setting of co-creation workshops enables diverse expertise to form one solution jointly in the same room. Potential methodological additions to raise the level of evidence and evaluation of co-creational approaches would be: testing options that interpret on the outcomes of the previous phases through voting, short-written feedback and mini-interviews could potentially give clarity about the choices of patients and relatives; another co-creation workshop for generating the messages of patient campaigns could contribute to foster ownership and ambassadorship not only for patients and relatives but also for clinicians.

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## Alternative uses for democratized tools of design: Young patients can now play with the tools used by their surgeons

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**ABSTRACT** *Microtia is a congenital deformity of the external ear which occurs once in every 7000 births. Growing up with a visible deformity can negatively impact a child's confidence and self-esteem. Reconstructive surgery is now offered to children at the age of 10. This process uses a 3D scanner and 3D printer to produce a template from which the surgeon can carve cartilage. This research explores the potential of providing microtia patients with the opportunity to use 3D printing technologies in a playful way while attending their appointments. This paper is based on qualitative observations over the past 12 months, which suggest that the provision of 3D printing sessions as part of the wider microtia clinic builds confidence, positive associations with the hospital and a greater understanding of the process of their surgery. This puts them in a better position to make a decision about surgery.*

Keywords: 3D printing, Microtia, Self-esteem, Surgery, Decisions making

## Introduction

The democratization of design and manufacturing tools is often discussed in relation to Maker Culture, where people take control of production for themselves and repair or create their own products using their own capacity, in terms of knowledge and tools available to them (Anderson 2013). With tools such as 3D printers and laser cutters becoming cheaper and more widely available this community is impacted by the new power that is available to them (Gershensonfeld 2005). However, apart from within maker culture, there are more applications for these democratized tools and the potential of such have not yet been fully explored. This paper discusses the beginning stages of a study, with some early results, which explores the potential of using 3D printers as a tool of empowerment for young patients, when 3D printing is involved in their treatment, specifically for microtia, a congenital deformity of the external ear. The study will use patient outcome surveys to evaluate the use of the tools. However, due to the study being at the relatively early stage of 12 months, these surveys are not yet available. This paper will instead focus on qualitative evaluation by means of ethnographical observations and feedback forms for the charity which funds the sessions. These suggest that children who use 3D printing technology for play understand the process more and are more interested in being part of the decision to get the surgery. Additionally, parents report that the sessions are a good way of encouraging the children to come for their appointments and even to look forward to them.

### *Microtia and cartilage reconstruction surgery*

Microtia is a congenital condition which results in the absence or under-development of the external ear at birth. The impact that microtia has on a child can be minimal in terms of functionality but it can significantly impact self-esteem and confidence levels as children become aware that they look different from other children (Hamzelou 2018).

Since 3D printing became available, cartilage reconstruction surgery has provided more successful prosthetic ears. The process involves 3D scanning the child's developed ear and 3D printing this as a model which has the skin removed. The child then has two ribs removed to use the cartilage to carve an ear that will look as close to what they would naturally have as possible. The surgery can be invasive but because it uses the child's own cartilage there is a greater chance of success as their body recognises it as its own. The other draw backs to this surgery is that it cannot be performed before the age of 10 as the ribs are not long enough before then and this introduces other ethical implications including the decision of surgery and who has the right to make this choice. Additionally, research shows that a child is approximately three years old when they notice that they look different (Isar 2018) which means that they grow up feeling that way for many years before it is repaired which can impact self-esteem and confidence at important stages of development.

### *3D printing*

This paper details the use of 3D printing technology through the use of a 3D scanner, 3D printers and 3D printing pens. The 3D printers discussed in this study produce plastic models made from a 3D scan of the ear. This produces a digital model of how the ear looks. Software is then used which breaks this digital model down into thin layers which can then be printed using melted plastic. The 3D printing pens are hand-held 3D printers which are similar to glue guns. The participants feed plastic into one end and then it is pushed through a heated chamber and is extruded from the pen nozzle like ink.



Figure 1: Patient using 3D printing pens at Microtia Clinic

### Ethics Statement

A research protocol between Wee Replicators, the company through which the research was conducted and the charity who fund the sessions along with the staff on the clinic was agreed in line with the Edinburgh Napier University research integrity protocols. Informed consent was obtained from the parents of all of the participants discussed in this paper. Additionally, the observations have been fully anonymized to ensure that the participants cannot be identified. Participants were invited to take part in this research and were free to leave at any time.

### Method

Typically children attend the Microtia clinic twice per year. At their appointments they are given a check-up and discuss the option of surgical reconstruction, which is offered but not actively encouraged. The clinic takes place in several rooms where they will see a surgeon, audiologist, paediatric psychologist among other specialists who try to involve the children as much as possible in their decision regarding surgery. The researcher and author of this paper has a

workstation set up in the waiting room where children can come and play with 3D printing pens and learn about 3D printers. Children can spend anywhere between 10 minutes taking part up to 1 hour, depending on appointment times and interest levels.

The researcher provides an informal space in which children can learn about 3D printing and play with the technology. She watches the children and engages them in conversation but allows the child to guide the topic of conversation.

Everyone who attends the clinic can take part and most do; for this study up until June 2018 this amounts to 31 children. Notes are taken throughout these sessions and these are used to complete evaluation forms, which must be submitted to the charity who funds the sessions. These forms are design and issued by the charity. The form asks the following questions:

1. Describe what you did
2. Describe some particularly positive moments that happened in the session
3. Was the activity a new experience for any of the children and young people?
4. Did you witness the activity bringing the children and young people together socially and did this continue beyond the session?
5. Did family members engage with the activity?
6. Describe any unforeseen challenges (activity/environment)
7. Relevant quotes and/or suggestions from yourself, children, families or staff.

The forms from the sessions, which started in June 2017 will be used in this paper to provide a qualitative evaluation of the provision of these 3D printing sessions as part of the wider microtia clinic. For the purposes of this short paper, a selection of specific observations from the sessions in the clinic will be detailed, these illustrate behaviours which were noticed more widely and have been repeated by many children across the sessions.

## Observations

### *Observation 1*

Child A approached the table and asked if they could join in. They sat down and after a brief explanation of how the 3D printing pen works they began to trace around a drawing of an elephant. As they were drawing, Child B approached; Child B has taken part in the session before. This child had had cartilage reconstruction since the last time they had taken part. Child B excitedly showed the researcher the outcome of the surgery and explained how the surgery went. They said they were excited for the next procedure which would result in the ear being pulled out so that it was not flush against the scalp. Child A looked on with interest but when Child B looked

over, they looked down and carried on using the pen before saying that they could not get the plastic to stick to the paper and so layering was difficult. Before the researcher could help, Child B demonstrated that the pen needs to be held against the paper and moved slowly when trying to make loops or curves. Child A thanked Child B and then asked if the surgery was painful. Child B said that it was sore when they woke up but that they got medicine to take the pain away and the ear was worth the pain. Child A smiled and looked at their Mum who asked if they thought the reconstruction was good. Child A nodded before chatting more about the elephant. After Child B demonstrated how to make the layers stick better Child A managed to successfully produce a plastic elephant. The surgeon came out and called Child A's name and they happily got up, took the elephant and followed the surgeon. The surgeon asked what they had made and they proudly showed him the elephant and explained that it was difficult to make at first but then after practicing more they got it working.

### *Observation 2*

Child C, Child D and Child E were sitting around the table using the 3D printing pens. Child C was making the outline of a fidget spinner. The researcher had made one earlier and demonstrated that they could make moving parts by spinning the fidget spinner made using the 3D printing pen. Child C asked how they were going to make it spin. Child D joined in and said that they would need a ball bearing. Child E had a fidget spinner in their pocket and pulled off a finger pad to reveal the ball bearing underneath. The researcher explained that the fidget spinner they were making did not use a real ball bearing but a little cylinder in its place. First the child would draw the shape of the fidget spinner without the centre ball bearing, they were to fill in the shape and build up the layers until they were happy with the thickness. It was explained that when drawing layers to build thickness, this is what the 3D printer does. Then Child C was shown that they had to draw two individual circles (the finger pads), fill them in and build to the desired thickness. Then the researcher showed them that they had to very carefully draw a circle onto one of the finger pads, one on top of the other until there was a cylinder long enough to fit through the fidget spinner outline and then the other finger pad was melted on top- this fused the central cylinder in place. Once cooled the fidget spinner could be spun. By working through each of the stages of making a fidget spinner Child C was copying the 3D printer in its technique. Child D asked if that was how the surgeon would make their ear. The researcher explained the process that the surgeon would use, referencing the production of Child A's fidget spinner. One of the parents who was sitting nearby said they had not realised it was this simple and that understanding it in terms of how the fidget spinner was made made it more relatable for them and the children. Child D and Child E became determined to make their own fidget spinner too. They both stayed behind after their appointments were finished to complete their fidget spinners. As Child E was leaving they showed their parent the middle section and told them to look closely so they could see the lines. They then said that those lines were the edges of drawings, because a 3D object is split up into hundreds of two dimensional drawings and these lines represented the edges.

### *Observation 3*

Child F is the youngest participant who has taken part in these sessions. They were reluctant to follow their doctor into the room so the researcher gave them a pre-made 3D printed robot to take and told them that they could come and play with the 3D printing pens as soon as they were finished with that doctor. Child F quietly agreed and followed the doctor. When they came back out of their appointment they sat down next to the researcher who demonstrated how the pen works and passed it to them to use. Child F quietly started doodling with the plastic. It did not stick to the paper well because they were moving the pen so fast, however Child F did not mind and instead appeared to be fascinated by the texture of the plastic that came out. They drew it up into the air where they were delighted to find that it stayed up without falling down, they did not make anything specific but just played with the pen. Each time they drew into the air and the line stayed up by itself Child F squealed with excitement. When Child F's Mum told them it was time to go they shook their head. Child F's Mum said that it took her all morning to convince the child to go to the appointment. She said she was happy that Child F had a positive association with the clinic now and hoped it would be easier to encourage them to come in future.

## **Results**

Going into the clinic can be an intimidating experience for a child and when the specialists come out to talk to them children will often be reserved. However, as shown with the elephant in observation 1, when children have what they have made themselves in their hands they tend to be happy to show off their creations and will more naturally engage in conversation with their doctor, a phenomenon also observed by Gauntlett 2011. The doctor can use this as a way of making the process more friendly for the children. By fostering positive relationships between doctors and their patients, children are more at ease and better equipped to be part of the decision of surgery.

Additionally, observation 1 showed that by having an activity that children can participate in together this gives them the opportunity to talk to other children who have the same condition as them, thus providing social engagement and encouragement that they are not the only ones who have the condition.

Observation 2 demonstrates that by letting children play with the technology they understand the process of their surgery better. This empowers them as the process becomes more transparent.

Children have a positive association with coming to hospital as they get to play with a fun and engaging technology and make something for themselves. The personal empowerment and self-esteem they get from this, echoes other research on maker technologies and its impact on the user's sense of capability (Nascimento and Polvora 2016). This applies to all children who take part, not just those who opt for cartilage reconstruction, and so the results of these children are in line with maker education as a whole.

## Conclusion

In conclusion, this paper highlights key benefits of having 3D printing session as part of the Microtia clinic. The activity provides a distraction for children while they are waiting for their appointment and allows for positive associations with the hospital to be made making it a more appealing place to visit in future. Apart from being used as a distraction activity, the sessions allow for social interaction between children who have microtia, which allows them to see that they are not alone and have the opportunity to talk casually about their experiences, which is something that Ratto (2016) also observes in patients who attend 3Dprintability prosthetic workshops to design prosthetic for leg amputations. By playing with the technology and being guided through the process of 3D printing, children are engaging in heuristic learning as they begin to understand more clearly the processes that will be used in the reconstruction surgery if they opt for it. Finally, by making their own pictures and toys using the 3D printing pens the children are empowered by witnessing their own capability in producing something they are proud of and they will excitedly explain what they have made and how they made it. Their doctors can use this to engage the children in conversation making their relationship more relaxed and friendly, which fosters a positive environment for children to feel comfortable in expressing their feelings and wishes regarding their condition and surgery. This study is just in the early stages and when the data is available, patient outcome surveys will also be used to understand the experience of the patient before, during and after their involvement with the Microtia clinic. However, these qualitative observations suggest that having the 3D printing sessions as part of the Microtia clinic provides a positive environment for children to learn, socialise and play, which will benefit their self-esteem and put them in a better position to be part of the decisions about what happens to them in terms of agency and greater transparency of process.

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## Designing in Health: Developing Shared Knowledge through (Un-)Prototyping

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**ABSTRACT** Design and Health are two distinct disciplines that have their own way of thinking, yet they both aim to generate new knowledge. Designers do so by making things and developing prototypes that are tested in context, with the end users. The interactions that take place between the end-users and the tested prototype(s) enable knowledge to emerge about the context, the challenge, what works and what does not (Figure 1). However, the development and testing of prototype(s) in health contexts can be challenging, particularly when it involves clinical professionals who already have large demands on their time.

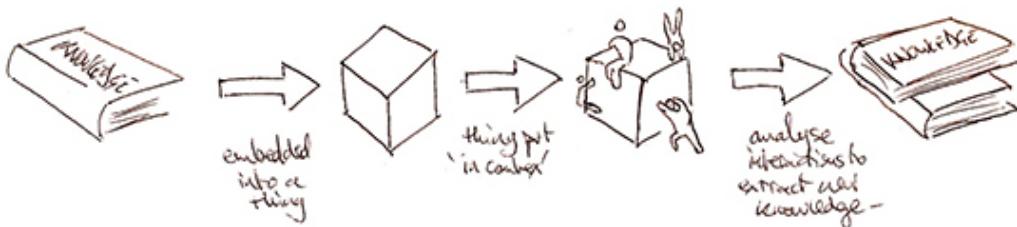


Figure 1: Generating knowledge through testing in context

To illustrate these challenges, three case studies are described. The first highlights the compromises designers make when prototyping to overcome constraints (e.g. time and financial resources) while ensuring responses from the end-users. The second case study demonstrates the role prototypes have as boundary objects to engage hard to reach end users and support them in co-design. The last case study consists of 'undesigning ideas' as a way to understand the knowledge they embed to develop prototypes. In each of the three case studies, prototypes with various degrees of fidelity were used at different stages in the design development process, for different purposes and challenges, and with a range of stakeholders.

Regardless of these differences, prototypes share a common aim: to develop new knowledge that is then embedded into the next iteration of the design development. In each of these case studies, we will share our experiences of how prototypes and prototyping can support meaningful co-design practices, eliciting and integrating the expertise of multiple stakeholder groups with the aim of promoting innovation in healthcare or for health outcomes.



Keywords: prototyping, prototypes, knowledge, levels of fidelity, engagement, participatory, co-design

## Introduction

Brazilian theatre activist Augusto Boal (2004), who created the 'theatre of the oppressed,' once said:

'Words are emptinesses that fill the emptiness (vacuum) that exists between one human being and another. Words are lines that we carve in the sand, sounds that we sculpt in the air. We know the meaning of the word we pronounce, because we fill it with our desires, ideas and feelings, but we don't know how that word is going to be heard by each listener.'

If words are limited, it seems worthwhile investigating other ways of communicating when conducting research, especially when working with vulnerable people. Design uses prototypes and making as a means to communicate, for different purposes, which may be applicable in different contexts and/or with other disciplines, such as health. Yet, Design methodology and methods are very different from those usually applied for health. Designers' approach to developing and/or testing prototypes with key stakeholders can be challenging, especially in such a demanding context. Such challenges are illustrated through three case studies below.

## Background

Design and Healthcare have two distinct ways of approaching the world and conducting research. However, Bec's thesis (2015) demonstrates the potential for these two worldviews to work together. By conducting a design-led research methodology that is highly informed by the knowledge and expertise of health professionals, novel outcomes and new knowledge were generated. In his research, Bec developed a series of games promoting physical activity and identified a range of factors to engage the target audience. In this case, the games reflected the factors identified as engaging yet the latter could be used to generate interventions to promote physical activity among this audience.

Design is different from Science and has developed its own methodology and 'designerly way of knowing, thinking and acting' (Cross 2007, p55). The fields of Health and Design research can be differentiated by their methods of interacting with the end-users (e.g. patients, hospital staff) since Design uses making as a method of inquiry. As stated by Sanders (2002), diversifying the method of investigation when interacting with the end-users leads to developing different types of (tacit) knowledge (Figure 2).

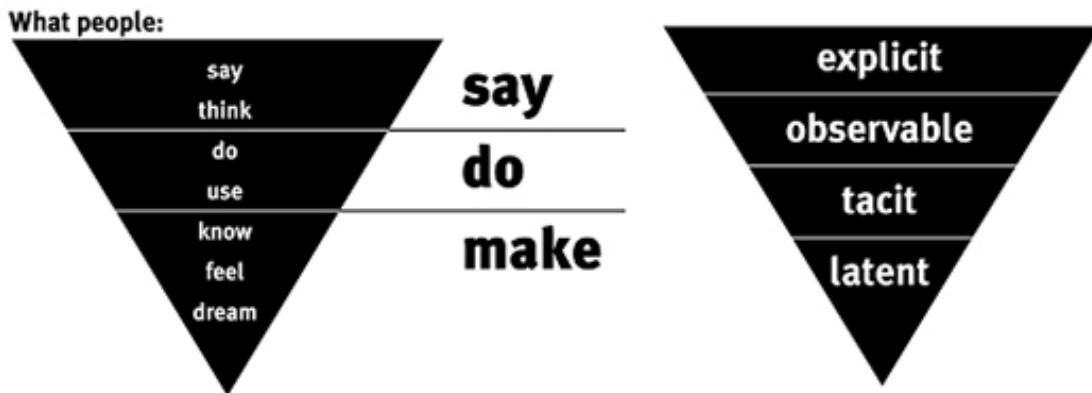


Figure 2: Different ways of inquiring reveal different types of knowledge (Sanders 2002)

Described by Bec (2012), designing through making 'things' is a way to synthesize the (tacit) knowledge gained so far and combine the theoretical and practical understanding. The understanding taking shape (i.e. the thing(s) being made) is then tested in context, with the end-users, allowing knowledge to develop. Figure 1 shows how the interactions that take place between the end-users and the thing(s) can develop insights and knowledge. That knowledge is enriched when thing(s) are tested in context iteratively.

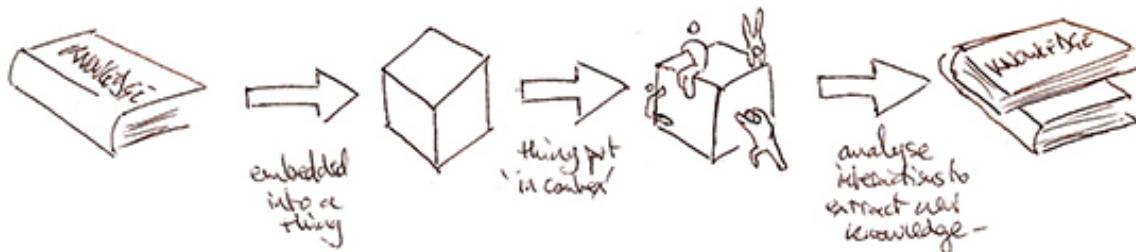


Figure 1 - Generating knowledge through testing in context

We can consequently say that 'knowledge' in Design implies making or prototyping and testing those prototypes in context, with end-users. In the context of this paper, a 'prototype' can be defined as the representation of an idea or a concept using a medium of communication that is either in 2D (e.g. drawings, visuals) or in 3D (e.g. tangible artefacts or objects).

It is crucial to highlight prototypes can have different levels of representation of the reality, which refers to the levels of fidelity as defined by Houde and Hill (1997). A low degree of fidelity refers to prototypes that can be very simple (e.g. using a match box to represent a computer mouse), whilst a high degree of fidelity would include more details. Choosing to create a low- or high-fidelity prototype depends on the audience and on its purpose. Houde and Hill (1997) explains there are three main aspects prototypes can cover: the 'role' (function of an artefact in the users' life), the 'look and feel' (sensory experience of using an artefact), and the 'implementation' (techniques and components). They suggest a number of prototypes are created to explore the three aspects

independently, then an 'integration' prototype (Houde and Hill, 1997) is built (after a number of iterations) as a way to synthesize those three prototypes.

## Case Studies Description and Findings

This paper outlines three case studies in which prototypes of different fidelities were used to enhance the designer's understanding about the potential or effectiveness of the imagined solution among the end-users. In each case study, the designer was part of a wider multi-disciplinary team composed at least one person from a health background (e.g. research nurse).

### *Case Study 1: Prototyping with High-Fidelity to Engage*

The first case study (CS1) describes the main author's PhD study entitled 'Using design-research methodology and games to promote physical activity among adolescents'. This research comprised a series of three interventions in secondary schools in Sheffield (UK). The first intervention explored participants' tastes and preferences to imagine solutions (games promoting physical activity) that would fit the end-users' profile and lifestyle. After analysing the data, an imagined solution was developed and tested through a second intervention. Using feedback obtained from the second intervention, an integration prototype was created and tested across a third intervention. In the context of this paper, we will focus on prototyping at two stages within the development of the games: 1) when testing the concept of the imagined game throughout the second intervention; and 2) when developing an integration prototype to test in the third intervention.

1. The aim of the user-centred intervention was to clarify what the imagined solution might be (in this case, a game concept) and what the solution might look like to ensure engagement. The key here was to create a series of activities that would be of a high enough fidelity to sufficiently engage the target audience, whilst also using minimum resources. Therefore, a series of workshops taking the shape of 'micro-experiments' was conducted to find out how engaging the concept of the imagined game might be (e.g. types of games, duration) before creating an integration prototype. To inform the design of the integration prototype, participants were engaged in 'Saying' (through focus group discussions), in 'Doing' (playing existing games) and in 'Making' (creating their own game). These activities were facilitated by testing existing games (which therefore have high levels of fidelity) to explore graphics, game mechanics, and style. These existing games were used as stimulus to investigate the three aspects named by Houde and Hill about each component of the game. The micro-experiments in this context are seen as a range of activities (i.e. focus group discussion, play testing, creative) led to inform the design development of the game, not to find similarities in the results.
2. Following the data analysis of the intervention described previously, the designer developed a component of the integration prototype of the game (i.e. the currency



dispenser). Based on the knowledge built until then, an 'ideal currency dispenser' was created (left on Figure 3). This 'ideal currency dispenser' was manufactured in plastic (ABS) using a 3D printer to design a dispenser that is robust enough to be carried around and to limit cheating. However, this ideal prototype was expensive and slow to manufacture, raising issues for delivering the right amount of boxes (one per player and fifteen players) in time for testing. A more affordable prototype was therefore created (right in Figure 3). Therefore, only the core system (i.e. buttons with beads) was manufactured on the rapid prototype and inserted into a card-board box, which considerably reduced cost and manufacturing time.

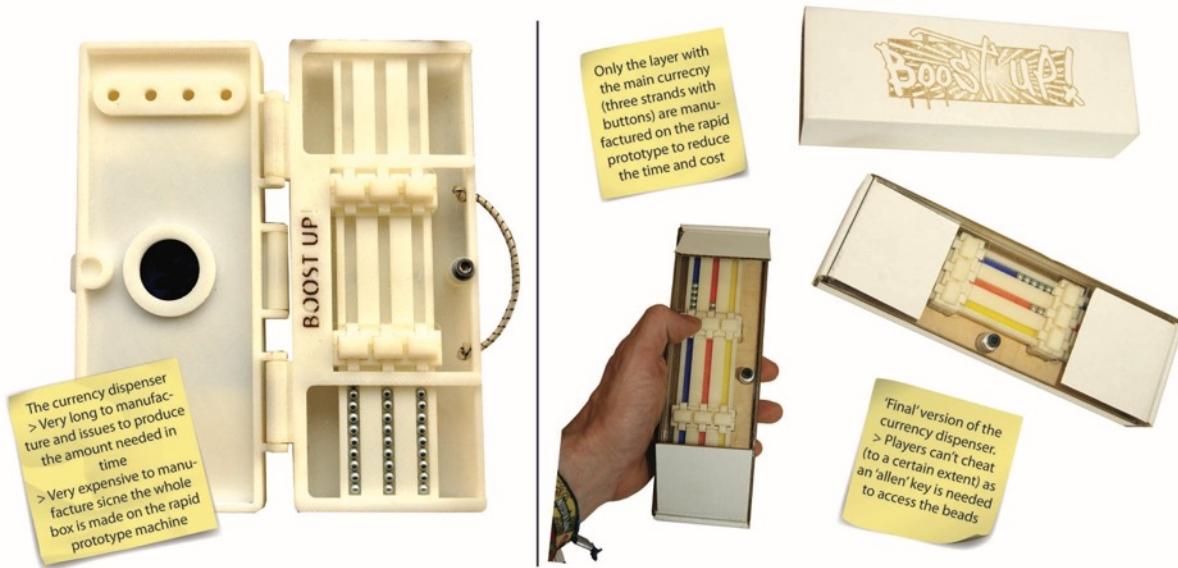


Figure 3 – Reducing the cost of manufacturing the currency dispenser

### *Case Study 2: Prototyping with High-Fidelity to Communicate Effectively*

CS2 is a project that took place in a northern city in the United Kingdom which explored ways to improve the experience of people going through treatment for a heart attack, from admission to the hospital through to receiving rehabilitation after discharge. A series of six co-design workshops were conducted, involving a mix of staff from the local cardiac ward and participants who had experienced a heart attack. A total of six participants attended the workshops; four patients and two patient representatives from the Public and Patient Involvement group - shortages on the ward meant no staff could attend many of the workshops. Despite this, the ideas developed throughout these co-design workshops were aimed at both the patients and the ward staff. For this paper, we will focus on an idea for a booklet developed for the staff and to facilitate their interactions with patients. The designer iteratively developed two integration prototypes at different levels of fidelity which were introduced to the ward staff to elicit their feedback. This input from staff was used to modify and refine the prototypes further.

In CS2, the co-design activities led to the development of an information booklet concept. The booklet was to be used by the staff as a guide to provide the right information at the right time in the healthcare process. Since this booklet was imagined by the patients, it was crucial to also gather feedback from the staff. The booklet was made of A3 pages that were printed in colour on a normal paper (80g) and inserted into a coloured A4 folder sourced from an office supplier. As a first integration prototype, it was the first time that the data generated throughout all the workshops was put together, yet further information was needed. Since no members of staff attended the workshops, the team went to the ward to look for staff members during their working hours to introduce the prototype and receive feedback from them. After leaving the booklet in the staff room for four weeks, the design team found that only a few (superficial) responses had been gathered. Based on the feedback gathered from both patients and staff, the designer developed a higher-fidelity prototype (with more refined visuals, better quality paper and a new custom binding for removable pages). When this prototype was re-presented to the staff members, feedback was very positive, highlighting the huge potential for this booklet and its application to other scenarios (e.g. in the ward or other hospitals). As such, this example highlights the need for careful consideration of prototype fidelity when creating mock-ups and prototypes, as the people testing them may not share the designer's imagination of 'what could be.'

### *Case Study 3: (Un)Prototyping to Develop (Tacit) Knowledge*

CS3 concerns people diagnosed with neutropenic sepsis, a life-threatening complication that can develop following the treatment of a cancer. There is a need for patients identified with neutropenic sepsis to self-assess a range of symptoms they might have on a daily basis (e.g. rise of temperature combined with increased tiredness) and to report them to their health professional. Some preliminary research was conducted prior to the design team joining the project, which defined its scope as to ensure the self-assessment and reporting by the patients of the symptoms described above. Then the multidisciplinary design team has facilitated a series of on-going workshops, four having been completed to date. Two patients diagnosed with neutropenic sepsis were involved in the first workshop along with a core team of four nurses specialized in cancer services, who were the only participants involved in the following workshops. The first workshop triggered ideas among the nurses, and the role of the design team was to structure these ideas and develop prototypes to test in context, with the future end-users.

CS3 was different from the two previous cases since in this project, the participants (nurses) were generating concepts through brainstorming/ideation activities, the idea being that the designer would create an integration prototype(s) by the end of the project. Throughout the workshops the facilitators used 2D visuals to explore the three aspects an integration prototype must cover (i.e. 'role', 'look and feel', 'implementation'). However, the participants often developed new ideas without really understanding the reason(s) behind each idea. Facilitators therefore used a series of tools and frameworks (see 'COM-B' from Michie et al. 2011), to better understand the core message(s) and purpose around each idea. This led to realising that some ideas such a 'welcoming chemo box' was not created for clinical reasons, but more as an empathic tool or a 'nice gesture'

given by the staff to patients when diagnosed with neutropenic sepsis. Facilitators had to deconstruct each idea generated by the participants to better understand the meaning behind them. Un-prototyping the prototypes was becoming a way to develop understanding of the requirements and problem(s) to build an integration prototype(s).

## Discussion

Throughout these case studies, interesting aspects are raised about prototyping and the use of prototypes to develop understanding and knowledge.

CS2 suggests the (integration) prototypes created (of the booklet) and left in the staff room acted as 'boundary objects', a term used in knowledge mobilisation to describe the transfer of knowledge, in this case embedded into a booklet. Often, designers (especially in the early stages of prototyping) tend to be in the field to develop a full understanding about how users react to the prototype(s) (see Figure 2). This relates to Archer who posits it is crucial to:

'have a comprehensive knowledge of the primary sources' (Archer 1995, 8).

Being part of the primary research is therefore a way for designers to gather and use the (tacit) knowledge developed in the field to create the next prototype(s) version. However, due to time and human resource constraints (e.g. involving clinical staff who have many demands on their time), this is not always possible. It is crucial for designers to find ways to engage those giving feedback, one aspect of which is consideration of the level of fidelity of the prototype(s) to ensure the feedback given informs the design of the following iteration.

As mentioned previously, the prototype(s) presented to users don't always represent the vision designers have in mind. Even if the prototype(s) do(es), users might not be able to create the leap between what is presented to them and the designer's vision. This is partly due to the (tacit) knowledge developed up until that point in the design development process and combined with a process of imagining what the world might be rather than what the world currently is (more specific to health research). It is therefore useful to diversify ways of communicating and/or to have faith in what is being created. For instance, prototyping an idea at a low level of fidelity might receive little or negative feedback when the same idea prototyped at a higher level might be received much more positively.

Hence in certain situations designers may have to find creative ways of engaging participants to ensure gathering feedback. This is particularly true when testing an idea early in the design development process. There is a need to evaluate how viable and engaging a concept might be without having to develop an integration prototype that demands higher budget and time. As presented in CS1, one way to do so is through hacking existing products (here games) to get a sense of effectiveness without relying on high resources. Depending on the context, the use of physical objects can be used creatively by designers to reach the aim(s) set, yet as presented in Bec (2015) this creativity can also be applied when developing methods to interact with participants in



co-design activities (e.g. use of playful tools such as dice to engage participants in generating ideas/giving feedback).

The outcomes in user-centred interventions are therefore highly influenced by the designers, whether their role is to facilitate (end-users led) or to design (designer-led). Even in CS2, where end-users are the main driver to designing an outcome, the designer still has a lot of influence in the project, whether it is about planning the workshops activities, facilitating them (e.g. use of drawing to visualize the discussion taking place between participants), analysing the data coming out from them, or prototyping. As CS3 demonstrates, prototypes embed a form of knowledge, whether they are created by the designers or the participants. The visual and/or tangible nature of prototypes enhances participants' reaction to them (e.g. genuine, instant reaction or discussion) and therefore engagement, as discussed by Kelley (2012), IDEO founder.

## Conclusion

Making and developing prototypes is inherent in Design. Visual and tangible prototypes allow a range of stakeholders to communicate in an engaging manner. They therefore seem particularly suited when applied in multidisciplinary projects, especially health-related. Prototypes replace the written or spoken language that is traditionally used to communicate and it is from that perspective that they become powerful, as an alternative language to develop understanding and knowledge.

There are different degrees of fidelity (varying from low to high) to take into consideration when developing prototypes based on the outcome wanted and at what stage in the design development process the prototypes are used (e.g. getting feedback about a concept vs an integration prototype). Furthermore, designers must take into consideration the various forms of resources available (e.g. human, financial, technological). Therefore, designers must make compromises between the availability of these resources and the level of fidelity of the prototype(s) to promote engagement and meaningful feedback from the stakeholders involved.

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## MakeToCare. Designing an ecosystem of actors and user-centred solutions for healthcare innovation

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**ABSTRACT** The paper presents the model and the results of the research MakeToCare (MTC). It is a research project ([www.maketocare.it](http://www.maketocare.it)) conducted in Italy aims to define and investigate an emerging area of innovative healthcare products-service - the MakeToCare Ecosystem - developed by the collaboration between patient innovators and caregivers (Oliveira et al. 2015), healthcare research system, med-tech companies, advanced manufacturing and Do-It-Yourself practices. The first part of the paper describes the research questions representing the basis of the MakeToCare research model and process and the fundamental of the MakeToCare Ecosystem in terms of actors, categories and roles. Nowadays, healthcare is a sector characterized by a great technological transition (Butter et al. 2008; Brynjolfsson and McAfee 2012; Lehrach and Ionescu 2017). An emerging open and exponential innovation (Gabriel et al. 2017; Wass et Vimarlud 2016) wave stimulating the digital transformation of products and services, the servitization of healthcare and the rise of predictive medicine. Moreover, collaborative participation and human enhancement are redefining the boundaries of care and disability. The second part of the paper shows the main results of the research analysing an ecosystem of 180 subjects and 120 projects mapped. The results are focused on the following topics: 1) dimension, composition and scales of the MTC Ecosystem (actors' perspective); 2) macro-areas, regions and urban attractive poles of MTC (territorial perspective); 3) relationship, coalitions and alliances creating MTC healthcare solutions (network and community perspective); 4) design approaches, skills and capabilities within MTC Ecosystem (innovation perspective); 6) kind of MTC product-service systems (solution perspective). The third and final part of the paper synthesizes the results of MTC research evidencing limits and opportunities and reflecting about the perspective in the development of new forms of open and distributed healthcare. In particular, the conclusions are focused on defining the approach and the processes that characterize the MakeToCare Ecosystem and new research disciplinary perspectives for design.

Keywords: User Innovation, Healthcare, Med-tech, Advanced Manufacturing

## Introduction

MakeToCare (MTC) is a research initiative that started as a spinoff of the homonymous contest organized by Sanofi Genzyme at the European Maker Faire Rome 2016. MTC aimed to identify, map and represent an emerging ecosystem of patient innovators, independent researchers, research institutions, start-ups and new entrepreneurs, makers and digital fabrication labs that experiment, design and materialize solutions to improve the everyday life and health of persons living in situations of disability. The first MTC report (released online in December 2017, [www.maketocare.it](http://www.maketocare.it)) proposed a first exploration and mapping activity developed in two directions:

1. the set-up of the research and the definition of MTC as an Ecosystem for research, experimentation and innovation, characterized by collaborative practices developed between patients, caregivers and patient associations, research centres, designers, makers, makerspaces, tech start-ups, advanced manufacturers;
2. the first mapping of the MTC Ecosystem referred to the Italian context, identifying a first representative sample of 120 innovative healthcare solutions created by 188 subjects considered in the Ecosystem.

Data and information on projects and subjects have been analysed and re-processed through infographic maps that supported the multilevel reading of the MTC Ecosystem. The results of this phenomenological analysis have a value of an exploratory work that produces qualitative elements of knowledge without the pretence of representing statistical and quantitative value. The results of the research have been used to introduce the MTC Ecosystem in institutional, cultural, and scientific contexts and then validate it as possible new scenario for the development of innovation in the healthcare sector.

## Set-up and definition of the MakeToCare Ecosystem

The preliminary part of the research was based on a two levels literature review aimed to provide concrete inputs and themes for the analysis and mapping of the MTC research. The first multidisciplinary literature review<sup>1</sup> has explored the main social and technological transformations in the healthcare sector in order to contextualize the MTC research. The results of this work define the following topics:

- *healthcare tailored to an aging population.* Is the topic of aging analysed from the perspective of its social implications on an individual and collective levels (impact on patient and familial caregiving and social sustainability of welfare);

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<sup>1</sup> Literature review includes: *i)* books, papers and articles written by experts in technology for healthcare, healthcare management, STS; *ii)* official reports developed by international organizations like OECD and by global agencies like Deloitte and McKinsey.

- *healthcare for the new generations (between prevention and prediction).* It concerns the digital transformation of healthcare, the virtualization of medicine, new forms of health literacy, and new levels of knowledge and awareness of the human body from external manifestations to genetic structures;
- *healthcare on a metropolitan scale.* It concerns the increasing concentration of population in the cities seen from the new perspectives of citizens-patients and the perspective of the care system.
- *technologically enabled and enhanced healthcare.* It concerns the technological development that 'enhance/augment' persons and products-service systems for care changing the body's limits and barriers, and extensions of the objects and care environments. In that sense, disability can be 'simply' considered as a gap between the person and the environment, a situation that can be reduced or closed with design-focused interventions.

To sketch out the MTC research we considered the role of the patient and the impact generated by his activism in an extended and inclusive way. Starting from this statement, the literature review and research of cases studies was developed in two directions. The first one identifies grassroots innovation models where the patient is the activator or where there is an open and participatory activity between patients and other subjects with different expertise<sup>2</sup>. A specific focus was on the birth of the citizen-designer as evolved forms of user participation, and finally, the rise of the patient innovator (Kanstrup et al. 2015; Olivera et al. 2016; Sienkiewicz et al. 2017). The second one identifies some research projects and experimental initiatives in which the user-patient is involved and where there is a propensity to the use and experimentation of innovative technologies or independent development of technology solutions (e.g. [patientinnovation.org](http://patientinnovation.org)).

Considering the stimuli and inputs provided by the set-up activity, the framework of the MTC research has been articulated in five phases:

1. *Definition of the first model of the MTC Ecosystem* (Figure 1) starting from the interaction between three areas of subjects: 'Patient & Caregiving System', 'Healthcare & Research System', and 'Making, Manufacturing & New Entrepreneurship System'<sup>3</sup>.
2. *Scouting of projects and subjects to refine the first MTC Ecosystem model.* A desk and field research has identified projects aligned with the MTC Ecosystem, facilitating its definition.
3. *Data gathering and the interpretation of projects.* The projects identified have been analysed and interpreted using three different focus (*subjects, design process, and technology*);
4. *The populating of the MTC Ecosystem model.* The subjects identified have been classified within the MTC Ecosystem.

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<sup>2</sup> Literature review on grassroots innovation models has been considered participatory innovation, frugal innovation, open innovation, maker and hacker culture, and Responsible Research and Innovation.

<sup>3</sup> This area includes advanced, social and professional DIY practices, med-tech companies that prototype and materialize solutions for healthcare.

5. *Interpretative analysis of the MTC Ecosystem.* Subjects and projects of the MTC Ecosystem have been re-analysed (*geographical distribution, polarizations, coalitions and collaborations, projects products developed*).

The first result of the research was the definition of MTC Ecosystem:

*'MakeToCare is an ecosystem that enables bottom-up innovation dialogue with applied scientific research in the healthcare sector and that finds in the technology of digital manufacturing an enabling platform for the democratization and diffusion of product-service solutions dedicated to care. MakeToCare is an area of convergence between activities of research, experimentation and (co)design based on the collaboration and coalition between patients and groups/communities of interest, family members and caregivers, operators and centres/laboratories of healthcare and medical research, designers, independent innovators, workshops for shared manufacture, innovative start-ups.'*

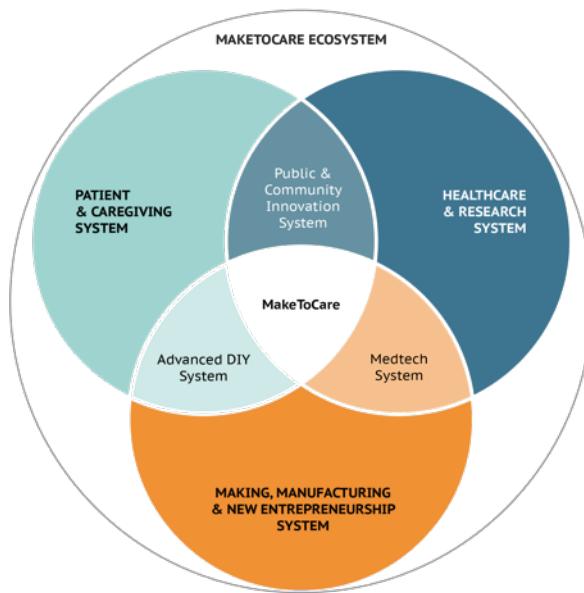


Figure 1. Model of the MTC Ecosystem with its primary and secondary areas

## Studying the MakeToCare Ecosystem

The phase of reporting of the MTC Ecosystem cases began, by narrative logic, with the analytical representation of his subjects and their projects<sup>4</sup>. The 180 subjects mapped have been analysed in order to study their roles and relevance as specific systems and areas within the MTC Ecosystem. The different dimensions of the MTC Ecosystem have been measured to understand what are the system of subjects mainly involved in the development of the projects (Figure 2). At the same time,

<sup>4</sup> The allocation of a project to one or more areas of the Ecosystem was made taking into account the category to which the subjects who developed it belonged, who naturally may also belong to different categories (and areas) when it comes to coalitions of actors.

also the categories of subjects populating primary and secondary areas of the Ecosystem have been measured (Figure 03). A second level of analysis concerns the geography of the MTC Ecosystem. The mapping of the regional distribution evidences a non-homogeneous presence of macro areas and regions with a large gap between contexts with small and large concentrations of subjects. In this context, Lombardy region largely emerges among all the others ones, and at the same time it is relevant to evidence the presence and the role of urban and local systems actively involved in design-materialization of MTC solutions.

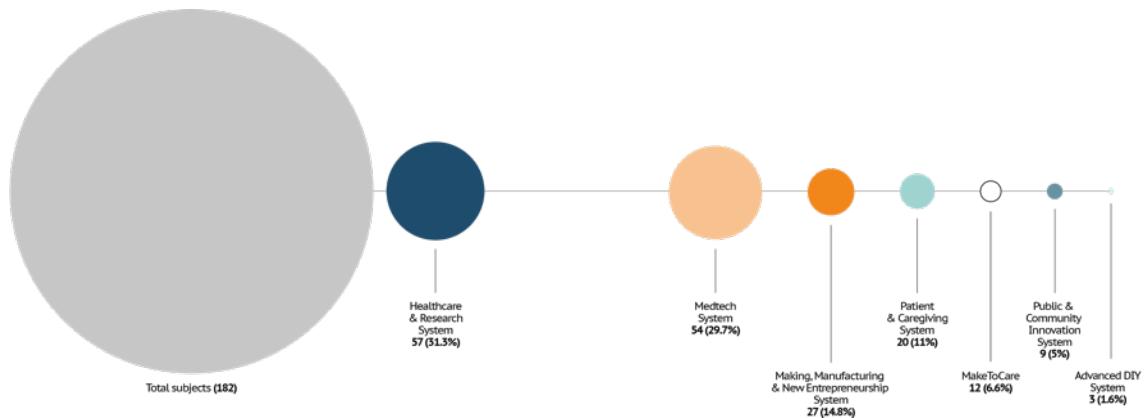


Figure 2. The dimensions of the MTC Ecosystem (base data: 182 subjects)

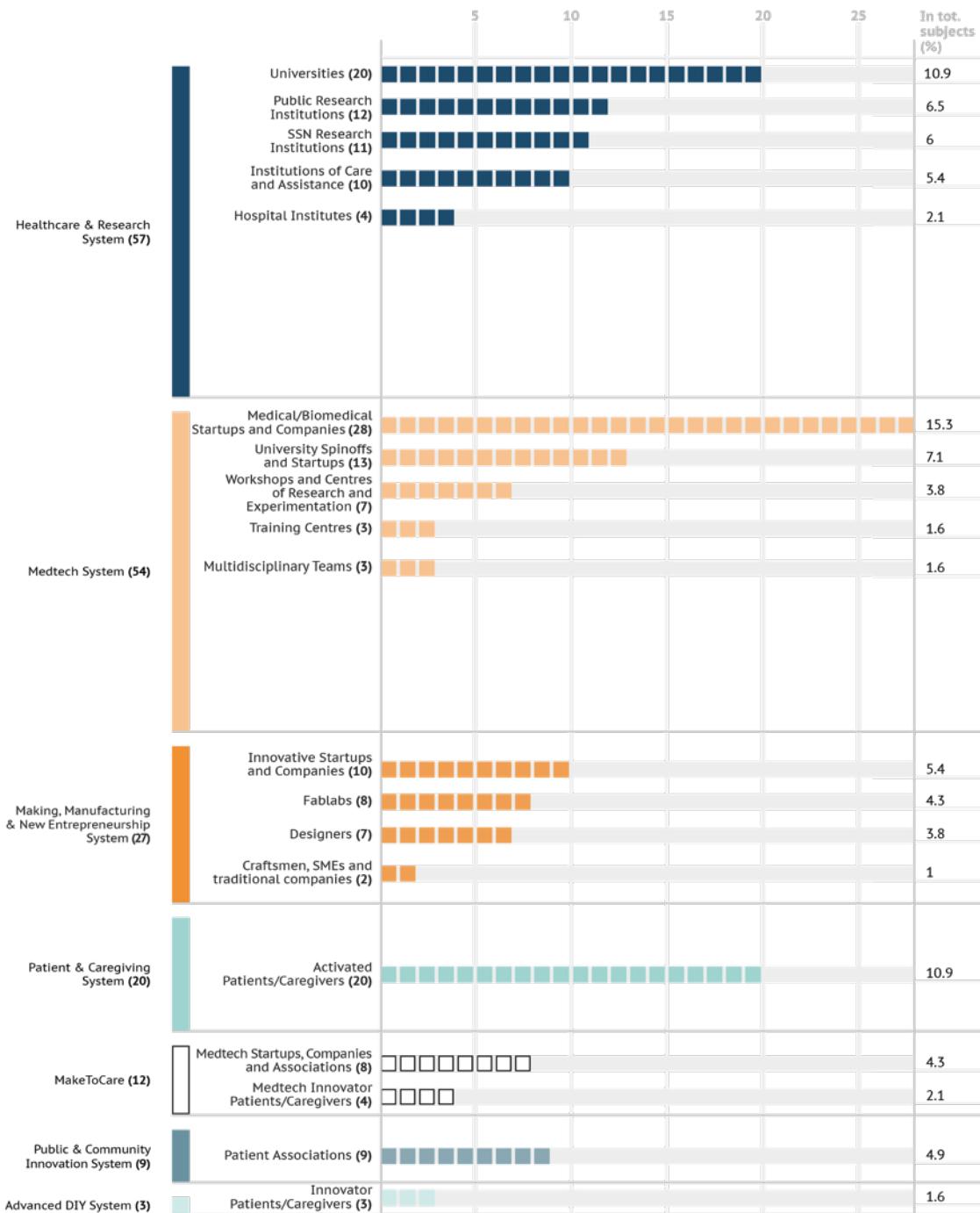


Figure 3. MTC Ecosystem: systems, a mosaic of categories and subjects (base data: 182 subjects)

The MTC Ecosystem has been considered as a special lab with 120 projects. Using this metaphor, distribution of the projects within the MTC Ecosystem has been mapped evidencing the structure of the coalitions that give life to the MTC solutions (figures 4 and 5). Another level of analysis concerns the relevance of relationships in the MTC Ecosystem in order to map the attitude of some categories of the ecosystem to relate to others to develop projects (figures 7 and 8).

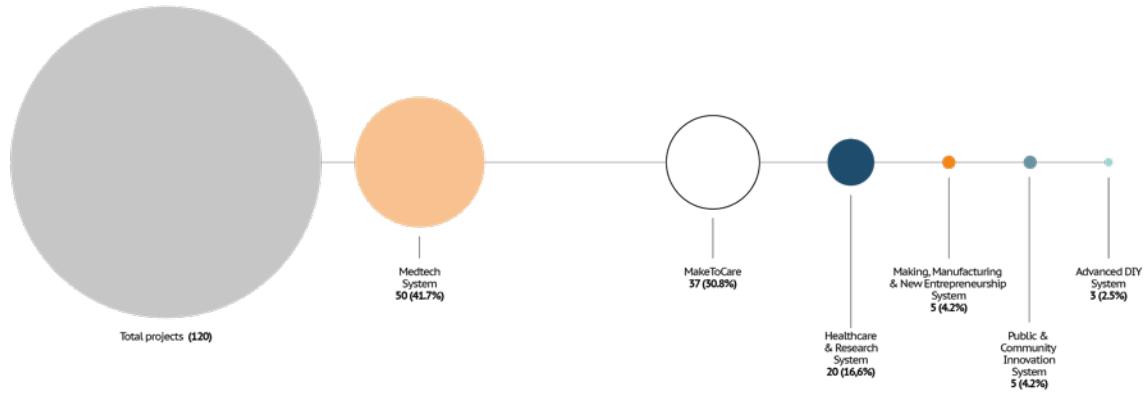


Figure 4. The distribution of projects in the MTC Ecosystem (base: 120 projects)

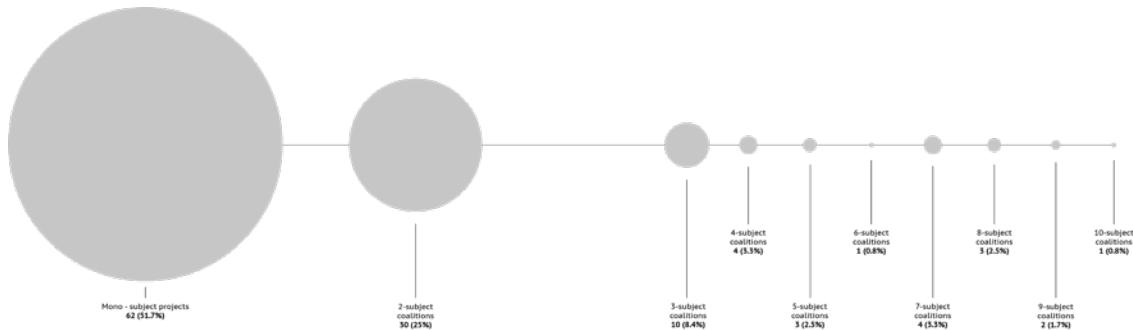


Figure 5. MTC Ecosystem: structure of the coalitions (base: 120 projects)

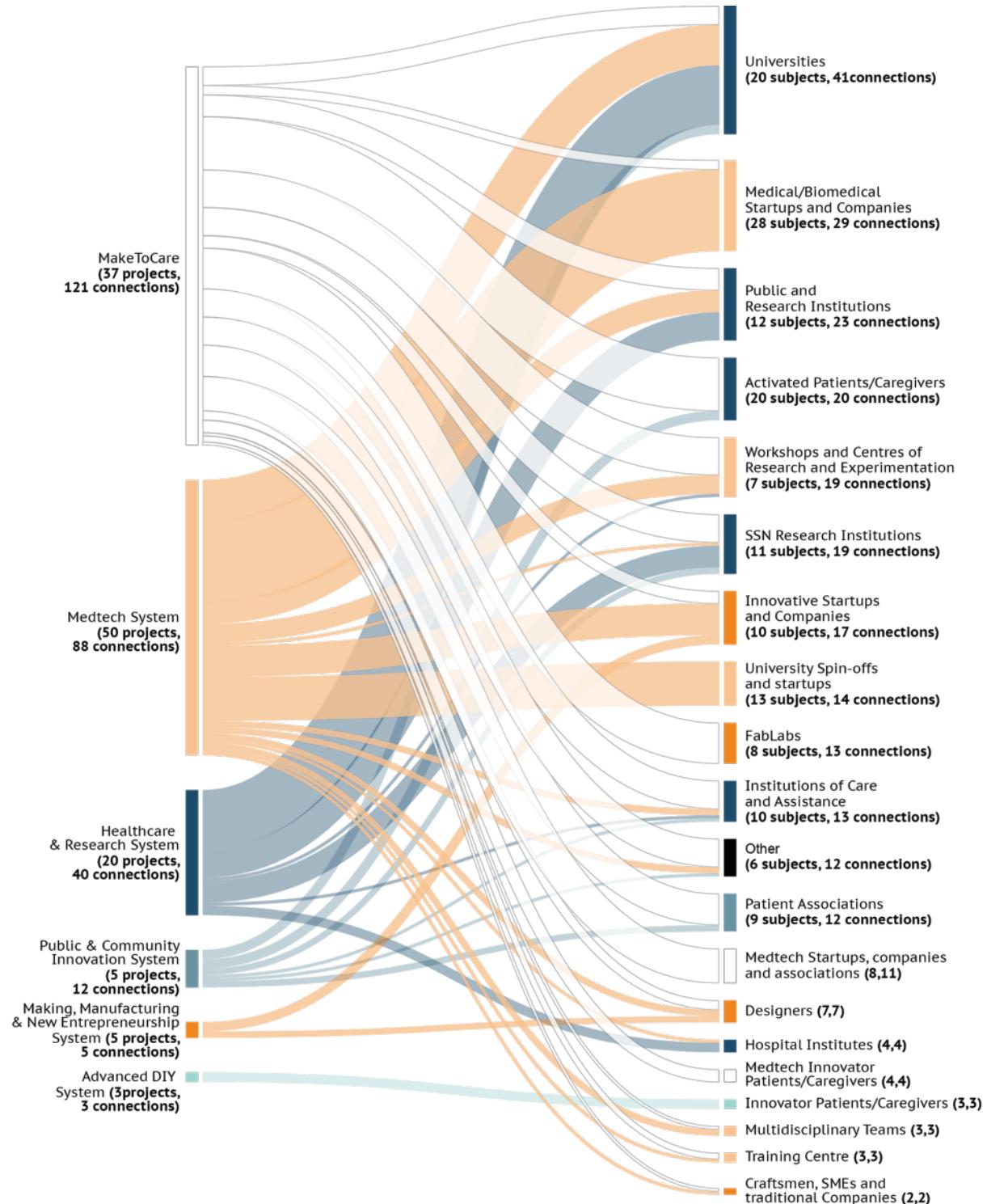


Figure 7. MTC Ecosystem: type and weight of the coalitions



Figure 8. MTC Ecosystem: type and weight of the coalitions

An additional analysis classified all 120 projects (figures 10, 11) based on the positioning and proximity of the solutions compared to the areas of the body (and outside the body), thereby allowing a typological reading and interpretation of the project outputs<sup>5</sup> (figure 9). The construction of the typological reading occurred in two phases. The first step concerns the classification of the design solutions based on an official national source<sup>6</sup>, then integrated with other categories that emerged from the mapping: aids, prostheses, orthoses, devices or medical-health equipment, and digital platforms or applications (apps). The second step positions the MTC solutions on the human body developing a design-driven classification scheme (Archer 1995; Cross 2006) and identify four levels of positioning of the solutions on the human body: *inside the body*, *on the body*, *with the body*, and *outside the body* (involve the surrounding environment).

<sup>5</sup> 37 design solutions of the MakeToCare Area that have been extrapolated, visualized and studied in detail.

<sup>6</sup> see *The rate table of prosthesis and disabled aids*, distributed by the Italian Ministry of Health.

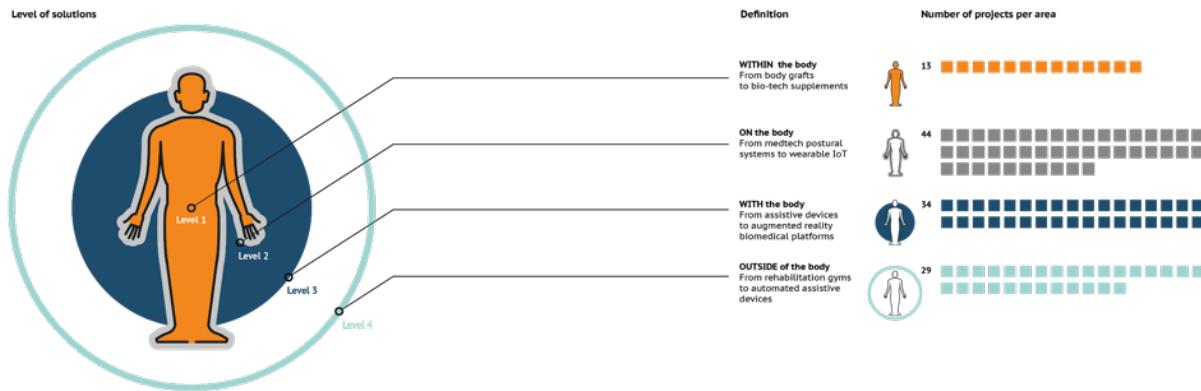


Figure 9. MTC Ecosystem: positioning of the solutions (base data: 120 projects)



Figure 10. MTC project: Open Rampette (source: <http://rampette.opencare.cc/>)



Figure 11. MTC project: Mirrorable (Source: [www.fightthestroke.org/mirrorablecover](http://www.fightthestroke.org/mirrorablecover))

The final synthesis of the MTC research evidences the following aspects:

- the MTC Ecosystem is as an extended area of design biodiversity. Many projects identified are solutions capable of bringing out and materialising emerging needs that are unspoken, unsatisfied, hidden or unmet by the official care system.
- the MTC Ecosystem is an aggregator of models and processes. It is a public-private, territorially open and distributed lab, that brings out a large repertoire of forms of collaborative design: from those of patients to Fab Labs, from research centres to entrepreneurial experiences.
- the MTC solutions are characterized by a human (user)-centred approach to innovation that reduces distances, difficulty, bureaucratic and human barriers, pushing the direct and pragmatic contact between persons, enterprises and institutions. This aspect increases the agency of citizens-patients assigning to them new forms of awareness and co-responsibility in the improvement in the healthcare sector. This means that the organizational and power hierarchies can be transformed: patients can become partners and collaborators of the MTC Ecosystem subjects, stimulating them to design and materialises new solutions;
- the MTC Ecosystem is a individual-collective system of advocacy where the solutions are accomplished through specialized forms of communication that generates information, networking, storytelling and accessibility to the documentation on the processes and results. All of this makes this area a favourable location to incubate evolved citizen-centric forms of health literacy.

## Outcomes, limits, and next steps of the research

The first thing that we learned is that the MTC Ecosystem model and its areas has a more blurred aspect. The second thing is that two different dynamics co-exist in the MTC Ecosystem: on the one hand is the force of some medium-large coalitions<sup>7</sup>; on the other hand, is the individual activism of single subjects (62 projects out of 120). Among these, we can certainly include 15 patients-innovators and companies, start-ups and/or associations involving patient innovators. Regarding patient innovators, the MTC research evidences patients that are activators-generators of a change in the product-services offer for care. Moreover, someone of them are also able to evolve themselves into entrepreneurs and providers of self-designed and self-made products-services. In practice, some cases suggest the idea that may even be a *patient-enterprise* (Maffei and Bianchini 2016), or a patient who can be considered as an individual-organization who develops processes of care through an entrepreneurial creation process (Sienkiewicz and van Lingen 2017). The final consideration concerns the role of public bodies to form an enabling culture and system that achieves a condition of balanced subsidiarity in stimulating the possible actions of private

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<sup>7</sup> 4 or more individuals involved in 58 projects, with an average of 8, and 10 large coalitions for a total of almost 120 subjects involved

subjects. Subsidiarity interpreted as the construction of enabling operational, economic and social conditions that produce an environment favourable for the growth and distribution of the bottom-up innovation processes of MTC. Processes that can penetrate the logic of the traditional system and produce what patients need. These same processes, while working already at the experimentation and prototype level, are not yet sufficiently generative in the construction of the system of management and diffusion of knowledge (shared) and of new forms of entrepreneurship. The MTC research brought out and tried to define an ecosystem that had not been planned and designed, but that emerged thanks to the convergence of enabling conditions. This does not mean, however, that the public actors are not attentive or active on this front also in thinking about initiatives involving the other two areas. The research has in fact shown some evidences in this regard: there are actions implemented by public subjects who mediated the requests of public and private sectors, building a new approach for the production of subsidiarity.

Finally, the first edition of MTC summarizes two insights to identify possible new directions of development that will be explored the second edition of the research:

- the (social) entrepreneurial potential of the MTC Ecosystem, in particular the capability of individual patient innovators and coalitions to evolve into design, productive and economic organizations-platforms operating in a circular *from-patient-to-patient* logic (subsidiarity).
- the innovation time: from service culture closer to the patient, for both personal and market needs, the need to accelerate the times of development and application of innovative solutions emerges. Often, in fact, we found that these timelines do not tally with those of the procedures of scientific-clinical official validation exactly in the sector of healthcare, that expects or requires lengthy, structured and bureaucratized processes given instead urgent and specific needs.

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## Value in the Unspoken: Collaborating Beyond Words

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**ABSTRACT** The NHS is placing increased value on patient centred care. There is a risk that relying on conventional, language-based methods for communication between patients and providers excludes populations who find it difficult to engage with written and spoken words. Co-design principles enable users to have a voice without relying on words, by engaging with objects, images and other tools that represent the systems and concepts being explored.

*The Unspoken Voices Project is concerned with learning from the experiences of people who use communication aids. Communication aids support people who are unable to speak clearly and range in technicality from simple paper-based tools to complex computer systems.*

*The population who use communication aids is varied; this is reflected in the group of experts who have been gathered to advise on the project. Some experts have additional difficulties in understanding word-based communication and/or physical control. Their one similarity is that they experience difficulty in verbal speech.*

*Participatory design principles have been applied within the expert group meetings to promote inclusion and generate meaningful collaboration between the researcher and experts in order to realise the true value of their experience. The experts rejected text-heavy materials in favour of audio-visual and picture-based ones. The lead researcher shifted the focus of the meeting from discussion to practice, encouraging experts to feedback using objects, images and gestures. Collaboration with designers and artists has enabled creativity to inform and record the expert meetings, replacing written words whilst maintaining communicative integrity.*

Keywords: communication aids; communication disability; patient and public involvement; participatory design; collaboration

## Introduction

The past decade has seen an increase in the importance placed on listening to the patient voice in healthcare. Patients should be engaged in discussion and be part of decision making concerning their care (Coulter and Collins 2011); information, both relating to health services and contained within patient records, is expected to be accessible (Department of Health 2012a); patient experience is a core component of healthcare quality (Department of Health 2012b); patients are also considered 'essential partners' (rather than simply participants) in health research (NIHR Research Design Service 2014). There are clear benefits from this shift towards patient-centredness in healthcare. People are more likely to trust their clinicians and adhere to treatment guidelines if their care has been patient centred (Coulter 2013). Greater understanding of people's personal and environmental contexts facilitates the rehabilitation process (Leplege et al. 2009) and, within the field of assistive technologies (AT), there are links between level of engagement of the AT end user and the overall use of AT solutions (Wherton et al. 2015). Methods for engaging patients in healthcare are frequently language-rich however; consultations are based on dialogue, information is provided in text-based leaflets and feedback is gathered via written questionnaires. This can lead to 'seldom heard' groups, who may find it difficult to engage with these media, being excluded from engaging in decision making and overlooked from involvement in health research (Ryan 2013).

Among the 'seldom heard' population are people who have difficulties with speech, language or communication (SLC). SLC problems directly affect up to 20% of the population at some point during their lifetime (Scottish Executive Social Research 2007). Augmentative and alternative communication, otherwise known as AAC or communication aids, are a range of ATs that can be used to support people with SLC difficulties. Communication aids may take the form of simple strategies such as pointing to picture or word charts but also included complex electronic or computer-based systems which convert messages inputted into synthesised speech.



Image 1: Examples of types of communication aids



The population who use AAC is diverse and consists of people with multiple and complex physical and cognitive difficulties. The inherent difficulties that this group experiences with engaging in research is one possible explanation for a lack of qualitative literature exploring their experience of and perspectives on relying on communication aids (McNaughton and Light 2015). The Unspoken Voices Project is a research study which aims to develop a greater understanding of what people's hopes, expectations and priorities are about their communication aids. This information will inform the development of a tool that will facilitate patient-involvement in decision making and evaluation of communication aids. Data will need to be gathered from people who rely on communication aids in a way that enables participation.

## The Experts

An expert group of communication aid users were recruited to advise on suitable methods to support participants to engage in the project. The group members have varying degrees of literacy, but all can read simple words and/or sentences. This paper explores the overlapping philosophies of participatory design, patient-centredness and the central tenet of the Unspoken Voices Project: placing the people who rely on them at the heart of decision making about their communication aid. It also reflects on the impact of employing participatory design methods with people who have communication difficulties, within the expert group as well as contemplating possible future directions for employing co-design in later stages of project.

## Participatory Design

Participatory design (PD) was born out of the social and civil rights movements of the 1960s when people started to demand an increased say in decision making. Its original application was within the workplace, creating more conducive technology-abled systems by engaging workers in the design process (Robertson and Simonsen 2013). More recently it has been applied across a range of design problems from environments to products and in a variety of contexts, including community projects and healthcare (Bratteteig et al. 2013). The underlying principles of PD include the premise that involving end-users in design will improve outcomes (i.e. successful use). At the foundation of PD methodology is the idea of mutual learning i.e. that designers learn about the context and problem from people with a lived experience of them (the end-users) and end-users learn about the process and technical possibilities from designers (*ibid.*). This echoes the symbiotic relationship between research and patient at the core of collaborative research. Andersen et al. (1990) argue that a coherent participatory design method should consist of:

- Application area
- Perspective
- Guidelines:
  - Techniques

- Tools
- Principles for organization

The role of patients and the public as experts in health care delivery and research is evolving. Recent guidance relating to patient and public involvement (PPI) in research (Involve 2018) represents a shift from 'involvement' to 'co-production'. Approaches to PPI now acknowledge the need for a more synergistic and mutually beneficial relationship between researchers and experts. PD has been acknowledged as a potentially useful tool for engaging people with SLC difficulties in designing technologies to support, enhance or overcome challenges with functional communication. Hamidi et al. (2015) co-designed a speech interface for people with dysarthria; people with aphasia have been engaged in designing therapy tools (Galliers et al. 2012) and a collective of researchers are intending to develop a set of design methods specifically for people who have communication difficulties at the Participatory Design conference in Belgium in August 2018 (McNaney et al. 2018). The use of PD as a framework to promote collaboration during PPI with people who have communication difficulties has yet to be reported however. There are also some specific challenges to working with people who rely on communication aids due to the potential for co-occurring complex physical and/or cognitive difficulties.

## The Collaboration

The expert group for the Unspoken Voices Project was initially organised in accordance with guidance from Involve (<http://www.invo.org.uk>) which provides advice about engaging the public in NHS, public health and social care research. The agendas were written in simple language and sent to the experts in advance of the initial meeting. Participant recruitment materials, constructed using guidance from the Health Research Authority and a local University template, were also sent in advance along with a list of questions intended to elicit discussion during the group meeting. The inaugural meeting felt largely unsatisfactory however and the general atmosphere was rather flat. Most of the interactions occurred as a result of questions posed to individual members by the group facilitator (primary author); very little discussion was held between group members; and their overwhelming response to the materials sent in advance, both pertaining to the group meeting and materials for use during recruitment to the research study, was that they were too language and text-dense. A fortuitous meeting and subsequent discussion with Dr Joseph Langley and Dr Claire Craig (Lab4Living, Sheffield Hallam University) directed the group facilitator towards the principles of co-design which were subsequently employed in the expert group meetings. The 'application area' for PD was the expert group of AAC users and the 'perspective' (Andreson et al. 1990) was the need to engage them more in actively participating in the group. During Meeting 2, a range of tools and techniques were used to promote inclusion. Artefacts were employed in the form of images and blocks to focus group members through activity and foster reflection. They were offered visual rating scales as a technique to capture feedback on the new recruitment materials presented.

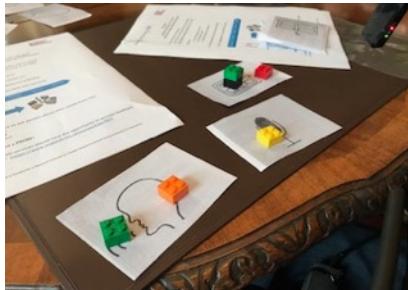


Image 3: One of the artefact-based activities employed in Meeting 2

The 'principles of organization' of the group shifted from language-based to image-based materials and resources. Text-rich resources were one of the barriers to participation during the first group meeting so, for subsequent meetings, more accessible formats were developed. The agenda for Meeting 2 was created using pictures from the internet (with creative commons license), key words produced in bold and supplemented with an audio-visual presentation, accessible via a YouTube link.

The participant recruitment materials and consent forms were also produced in a similar style, using images, key words and with an audio-visual tool to support comprehension. One group member's feedback was: 'How you talk in that video was brilliant. I wish everybody who works with people who use AAC or whatever was so clear.'

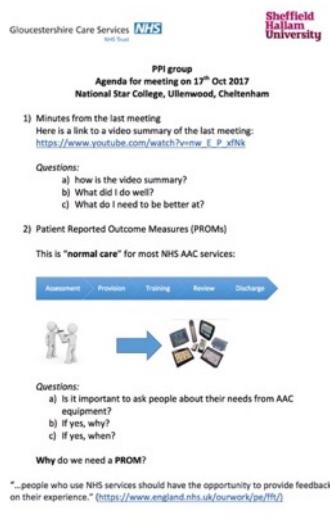


Image 2: Example of the image-rich agenda for Meeting 2

There was a noticeable increase in the level of participation of group members in the meeting and, consequently, a reduction in the dominance of the facilitator. However, experts tended to interact with those communication partners who did not have SLC difficulties when engaging in the tasks and their physical limitations resulted in them being dependent on the communication partner to interact with the blocks, pictures and images.

After further discussion with Dr Craig, aimed at widening the ways in which the expert group might use alternative methods to communicate, an artist researcher (Sarah 'Smizz' Smith, [sarahsmizz.com](http://sarahsmizz.com)) agreed to minute the following expert meeting, using graphic contemporaneous story drawing. Additionally, during Meeting 3, emphasis was placed on visual media to focus and record the discussion. Images projected onto a screen enabled the facilitator to reduce reliance on words further and allowed group members to consider the context for the discussion visually. Changing images allowed the discussion to be moved forward or re-focused when necessary.

During Meeting 3, there was a noticeable improvement in the group dynamic. Experts reacted to one another's comments rather than to the facilitator. Using communication aids can be time-consuming due to the time taken to construct a message before it can be synthetically uttered. During this meeting, the images on the screen and the pictures produced by Smizz gave participants space and pause for reflection while others constructed responses. The final graphic recording, pictured below, was then used to create the minutes for the group and an audio-visual version was produced based on the images contained within it.



Image 4: Smizz' drawing of the events of Meeting 3

## Discussion and reflections

'Design is not understood as the achievement of pre-defined goals, but is guided by insights emerging in the actual process' (Floyd, Reisin and Schmidt 1989)

Participatory design is a reflective process that builds on a foundation of mutual learning (Robertson and Wagner 2013). Public and patient participation in research should also be concerned with establishing an equal relationship in which the skills and experience of all parties involved in the project are respected and people are enabled to provide valuable contributions (Involve 2018). The Unspoken Voices Project is research motivated by the philosophy that the impact of health care professionals is greater when priorities are aligned with the patients we are



working with and that engaging people who rely on communication aids may be challenging but also rewarding. The synergies between PD, PPI and the Unspoken Voices project are concerned with empowerment and emancipation. Using PD is therefore a natural fit within the expert group for this project and using it as a framework for organization has highlighted its potential for other research activities with people who rely on communication aids. Employing PD principles has enhanced the group dynamic and level of inter-member interaction. It has also enabled experts to be actively engaged during the meetings, which has fostered a greater degree of reflection, resulting in increased depth in the discussions.

People who use communication aids can have co-occurring physical and/or cognitive challenges which can limit their ability to interact in the design process. During Meeting 2, participants were given pictures to sort and blocks to allocate to images based on preference. Although using this method increased the focus of the group members, many of the experts were reliant on communication partners to actually interact with the artefacts as their physical limitations impaired them from doing so. The visual tools used in Meeting 3 were successful at focusing and moving forward the group discussion. The pictures produced by the artist to record their meeting were an excellent resource for providing coherence as they were used for both organizing the minutes and reflecting on the discussion. Visual tools are not strictly a mechanism for participation however. A participatory design practice entails tools and techniques that combine telling, making and enacting (Brandt et al 2013). These three facets are all challenging for people who rely on communication aids and innovative approaches to PD will need to be identified if the system for organizing the expert meetings is to be truly co-designed.

PD has the potential to empower AAC users, and the wider population of people who have SLC difficulties, by removing the emphasis on words/language. Redressing the power imbalance with the expert group meetings for the Unspoken Voices Project and enabling experts to engage in the meetings by providing activities and frameworks that promote participation has reaped significant rewards in terms of the quality of the content and discussion. Further work is needed, however, to identify tools and techniques that are suitable for the population of people who rely on communication aids. Future collaborations with artists and designers will seek to identify such mechanisms so that the effectiveness of the group can flourish.

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## Communication through pictograms – judgement test on drugs messages for international purposes

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**ABSTRACT** Medication errors have long been a challenge. The World Health Organization launched a global effort to reduce medication-related errors over the next 5 years (WHO 2017).

In a previous interdisciplinary study, we analysed and evaluated the readability and comprehensibility of pharmaceutical symbols, based on a corpus of over 1,000 symbols collected from more than 20 countries. 75 pharmaceutical linguistic messages were identified. Messages were often confusing, illogical, and graphically incoherent. We developed a pharmaceutical pictogram system (PictoPharma, IP registered 2013).

The next step was to carry out a survey of pictograms for the 75 messages, including PictoPharma and other related non-medical ISO warning symbols, in order to identify the images more accurately understood and reaching a larger cross-cultural consensus. A judgement test for a minimum of 50 respondents per country was designed according to ISO 9186-1 norm (ISO 2007). We started with Portugal. Given its length, the survey was divided into 5 sets, each stage with 15 messages (7-14 symbols per message). It was conducted in 5 hospitals. Preliminary results show very different graphic choices by respondents. Visual literacy appears definitely related to cultural background and familiarization and learning decisive for decoding images.

The survey will now be conducted in 11 more countries in order to obtain 1,000 worldwide responses for each of the 75 messages. Our great challenge will then be to apply the key visual elements selected in the survey to PictoPharma.

Keywords: drugs instructions, cross-cultural pictograms, symbols evaluation



## Introduction

Medication errors have long been a challenge. For several decades, pharmaceutical researchers have been working on the dangers of medication related errors due to interruptions, misinterpretations, and mistakes. In parallel, mandatory information on drugs leaflets and packaging has been growing immeasurably.

Instructions may not be hard to follow. However, people all over the world misinterpret them every day. Data collected in 2003 by the World Health Organization revealed that adherence to long-term therapy for chronic illnesses in developed countries averaged 50%. In developing countries, the rates were even lower (WHO 2003). In 2017, a global effort was launched by the WHO to reduce by half avoidable medication-related errors over the next 5 years (WHO 2017). As 2020 approaches, international concerns regarding Global Health and well-being are changing attitudes in relation to healthcare and health information, namely by focusing on the needs of the patients and their empowerment. Graphic communication, by improving the readability of medicines instructions and making them easier to understand, has a crucial role to play in that effort to increase safety in medication, prevent hazards, reduce waste and to promote patients' autonomy and health literacy.

The need to ensure equity in health for all people across borders and the intensification of social and cultural global movements compel us, in addition, to consider medicines instructions cross-culturally. Pharmaceutical researchers have pointed to evident differences in the comprehension of symbols according to patients' cultural group, age and education level. But we believe that, in spite of those differences, an international system for medicines instructions is not only needed and desirable, but possible. In many other areas where cultural differences are obvious too, international symbols are already in current use – on packaging, labels, leaflets, signage and displays, in sectors such as food, toxic products, clothing, tourism, vehicles and machinery, way finding, traffic signs.

At the same time, technology offers us a multitude of different digital tools that may be used to help patients with prescriptions and to highlight specific warnings regarding the medicines. But this technological growth also brings with it an overflow of information, often contradictory or confusing, which reinforces the need for a coherent system able to function across cultures.

## Methods

In a previous interdisciplinary study, now updated, we analysed and evaluated the readability and comprehensibility of pharmaceutical symbols, based on a corpus of over 1,000 symbols collected from more than 20 countries. We found that messages were often confusing, illogical, and graphically incoherent (Figure 1).

Our research showed that the symbols and written captions on the medicines instructions collected were often inadequate in terms of graphic communication and likely to confuse or

deceive the patient, thus compromising any educational value of symbols. Cultural differences in representations were evident in some images and not at all in others and we found a great variety of representations for the same therapeutic concepts.



source: 1st hor. row – 1 (USP, 1989), 2 (Dowse, 2001), 3 to 6 (FIP, 2004), 7 (PharmaGlyp, 2010), 8 (Camacho, 2013); 2nd hor. row – 1 to 4 (Health Care Logistics, 2005); 3rd hor. row – 1 to 3 (Health Care Logistics, 2005); 4th hor. row 1 to 3 (Target inc, 2009), 4 and 5 (Knapp, 2005), 6 (RAD-AR Council, 2006), 7 (HELPix, 2009).

Figure 1: Diversity on one message

We analysed and assessed the graphic readability and comprehensibility of the pictograms collected, and identified and constructed 75 main pharmaceutical linguistic messages (Figure 2) by means of a participatory linguistic study (2010, updated 2017; Camacho 2013). Meanwhile we developed a pharmaceutical pictogram system (PictoPharma, IP registered 2013). Our focus was not just on highlighting and clarifying medicine instructions in order to reduce medication errors but also on contributing to supported health autonomy through people-centred design by creating a coherent system for all.

01 DO NOT APPLY TO THE EYE	16 DO NOT OPEN CAPSULES	31 TAKE 1 TIME A DAY 24 IN 24 HOURS	46 WASH HANDS BEFORE	61 TAKE ONLY WHEN SYMPTOMS APPEAR
02 DO NOT DRINK ALCOHOL WHILE TAKING THIS MEDICINE	17 FINISH ALL THIS MEDICINE	32 TAKE 2 TIMES A DAY 12 IN 12 HOURS	47 SUBLINGUAL TABLET - DISSOLVE UNDER THE TONGUE	62 DO NOT SHARE YOUR MEDICINES WITH OTHERS
03 STORE IN THE REFRIGERATOR (1°/8°)	18 DO NOT TAKE WITH MEALS	33 TAKE 3 TIMES A DAY 8 IN 8 HOURS	48 INSERT INTO RECTUM / ANUS	63 NEVER TAKE WITH OTHER MEDICINES
04 DO NOT INGEST	19 SHAKE WELL BEFORE USE	34 TAKE 4 TIMES A DAY 6 IN 6 HOURS	49 INSERT INTO VAGINA	64 INJECTION
05 DO NOT TAKE WITH MILK OR DAIRY PRODUCTS	20 DO NOT CHEW	35 TAKE WITH WATER	50 FOR THE NOSE	65 HEART DISEASES
06 DO NOT TAKE IF BREAST-FEEDING	21 TAKE BEFORE MEALS	36 DISSOLVE IN WATER	51 FOR THE EAR	66 FOR HYPERTENSION
07 DO NOT TAKE IF YOU ARE PREGNANT OR IF YOU THINK YOU ARE PREGNANT	22 TAKE AFTER MEALS	37 DO NOT FREEZE	52 MOUTHWASH - GARGLE	67 RESPIRATORY / LUNG DISEASES
08 DO NOT GIVE THIS MEDICINE TO BABIES 0-3 YEARS OLD	23 TAKE WITH MEALS	38 DO NOT STORE IN THE REFRIGERATOR	53 FOR BABIES	68 STOMACH / INTESTINAL DISORDERS
09 DO NOT GIVE THIS MEDICINE TO CHILDREN 3-12 YEARS OLD	24 TAKE BY MOUTH	39 DO NOT SHAKE THE BOTTLE	54 FOR CHILDREN	69 FOR HEADACHES / MIGRAINES
10 KEEP OUT OF REACH OF CHILDREN	25 TAKE IN THE MORNING, AT WAKE UP	40 EYE DROPS	55 AVOID UV EXPOSURE	70 CHECK THE HEARTBEAT
11 DO NOT TAKE WITH CAFFEINE	26 TAKE AT NIGHT, BEDTIME	41 EYE OINTMENT	56 DO NOT STORE NEAR HEAT OR IN SUNLIGHT	71 READ THE INSTRUCTIONS CAREFULLY
12 DO NOT DRIVE	27 TAKE IN THE AFTERNOON	42 TO CHEW	57 KEEP DRY	72 DO NOT TAKE WITH GRAPEFRUIT JUICE
13 DO NOT DRIVE IF THIS MEDICINE MAKES YOU SLEEPY	28 DAYS OF TREATMENT	43 ORAL INHALER	58 REMOVE THE CAPSULE FROM ITS PACKAGE	73 AVOID GREEN AND YELLOW VEGETABLES
14 DO NOT BREAK OR CRUSH TABLETS	29 EXTERNAL USE ONLY	44 TAKE WITH MILK	59 APPLY TO SKIN	74 ABOUT THE SAME TIME EACH DAY
15 DO NOT TAKE AT BEDTIME	30 DO NOT DRIVE IF THIS MEDICINE MAKES YOU DIZZINESS	45 IF YOU HAVE QUESTIONS, CALL THIS NUMBER	60 CREAM / LOTION	75 NO EARLIER THAN 4 HOURS AFTER INGESTION

Figure 2: 75 linguistic messages identified and constructed



People-centred design needs people to validate and understand their choices. The next step was then to carry out a survey of pictograms for the 75 messages in order to identify the images more accurately understood and able to reach a wide cross-cultural consensus. Non-medical ISO warning symbols were included in parallel to the pharmaceutical pictograms. This implied a new and wider image research and collection.

At this stage, our study consists in the application of a worldwide judgement test with real users, involving the implementation of innovative criteria. Our first results come from Portugal.

### *Judgement test - procedures*

The judgement test for a minimum of 50 respondents per country was designed according to ISO 9186-1 norm (ISO 2007).

We considered about 30 pharmaceutical systems/collections, gathered in the previous interdisciplinary study and including PictoPharma, updated, and also other related non-medical ISO international warning symbols collected from a wide spectrum of areas of everyday life.

To the 75-main therapeutic linguistic messages corresponded 75 groups of symbols. From each of those groups we selected for testing 7 to 14 symbols, organized by key visual elements.

Some of the 75 groups only offered 2 pharmaceutical symbols, others had up to 39 varieties. The groups that had only 2 varieties of representation (e.g. for the message 'DO NOT APPLY TO THE EYE') were completed with non-pharmaceutical symbols related to the key visual elements of the message in order to reach the minimum of 7 options. In the overrepresented groups (e.g. 'DO NOT DRINK ALCOHOL WHILE TAKING THIS MEDICINE'), a maximum of 14 representations were selected for each referent, according to ISO 9186-1 recommendations (2007). The reduction from 39 to 14 symbols was done taking into account their graphic elements, independently of legibility, size, author or source. We are aware that the selection may be controversial, at times subjective, but there was no alternative. For the 75 messages/groups, a total of 626 symbols were presented in the test for judgement and election of 75 symbols.

All images were opened in Photoshop CS5, in order to be in black and white (grey scale if originally coloured). Indication of sources was eliminated and any words in the image were blurred. Images kept their original external shape (within a square, rectangle, circle, or triangle), but were separated from their captions and background, and were limited by 4 square corners in order to be all consistently unified, as recommended by ISO 9186-1 (2007).

As regards size presentation, variants were displayed sufficiently large to be distinguishable but as small as possible to prevent reading details in excess (Neurath 1936) and considering the size of their future applications. This means that they were presented in 15mm squares (and not 28mm, the minimum according to ISO 9186-1 (2007)) and finally grouped in horizontal A5 size (Figure 3).



All of this symbol are supposed to appear in Medication Instructions.  
You might find them printed or on a sticker on patient leaflets, on medicine packaging and in posology prescriptions.

Please judge the comprehensibility of ONE SINGLE symbol by writing the percentage of the population that you expect WOULD UNDERSTAND this meaning, choosing only one:  (100%);  (80%);  (60%);  (40%);  (20%);  (0%). Please note that 100 % means everybody would understand it, with no one failing, and 0 % means nobody at all would understand it. Remember that what we want is your estimate of the percentage of other people in the general population who are likely to understand the symbol correctly. Please DO NOT CONFER when making your estimates as it is your response which is important.

2. Each symbol is supposed to mean "DO NOT DRINK ALCOHOL WHILE TAKING THIS MEDICINE". The symbol is intended to communicate its meaning to the general population.



source: 1st hor. row – 1 (USP, 1989), 2 (Dowse, 2001), 3 (Camacho, 2013), 4 to 7 (FIP, 2004); 2nd hor. row – 1 (Target inc, 2009), 2 (RAD-AR Council, 2006), 3 (ISO), 4 (Hanson, 1995), 5 (Mwingira, 2006), 6 (Target inc, 2009), 7 (ISO).

Figure 3: Judgement test - Group 2 from 75

For each individual message/group of symbols, we asked for the choice of the symbol that the respondent thought might be expected to be 100% understood by the general population. It is not pertinent in comprehensibility tests, in view of the desired results, to categorize symbols from best to least appropriate or in different levels. Survey respondents could nevertheless select the % of comprehensibility they attributed to the one symbol they had elected (100%, 80%, 60%, 40%, 20%, 0%). They were asked not to go back in the questionnaire while answering, not to check responses already selected or to answer items that they had left blank. The general context 'Medication Instructions' was given in the front page, as well as the context in which the symbols would be presented (PILs, medicines packaging, stickers or posology prescriptions). Date and information on age, gender, education level, cultural group and possible disabilities was asked for.

Given the length of the survey (75 messages/groups, 626 symbols to read), it was not practicable to have each person answer the whole questionnaire. The survey was therefore divided into 5 sets, each comprising 15 messages. Each respondent was handed only one set, comprising 15 groups of symbols displayed on 8 A4 pages (2 A5 groups per page).

Paper or digital support for the survey was discussed. Although both supports were possible, we opted to start in Portugal with a face-to-face paper survey.

The use of an extra question as a reinforcement of the symbol chosen was considered, where respondents would be asked to indicate in words the key visual elements of their choice. Given the length of the questionnaire, this option was discarded.

### *Judgement test - Portugal*

Our aim is to involve countries from Asia, Africa, North America, South America, Europe and Australia, so as to reach the largest cross-cultural consensus, according to ISO 9186-1 norm (2007). Contacts have been made and the application phase will start very soon. In Portugal, the survey was conducted in the 5 hospitals that make up CHUC (Coimbra Hospital and University Centre): University Hospital, General Hospital, Children's Hospital, Bissaya Barreto and Daniel de Matos Maternity Hospitals (Figure 4). CHUC is one of the largest hospital centres in Europe, with strong links to the University of Coimbra, one of the oldest European universities (founded in 1290).

As CHUC serves an extensive geographical area and is used by people from all over the country and from abroad, we were able to obtain a significant sample, covering a large variety of groups. Respondents came from urban and rural areas, belonged to different age groups (from 15 to 90 years), had diverse education levels and a variety of occupations. A number of respondents had disabilities (sight, hearing, physical mobility, neurological).



Figure 4: Surveys in CHUC

I had the help of three collaborators to apply the survey in CHUC, authorized by the administration. Each collaborator aimed to obtain 50 surveys (ISO minimum), but a total of 500



was achieved. The survey had an unexpected good acceptance; people were very motivated to respond. The response rate was almost 100%. In 500 questionnaires, only 21 people answered incorrectly or incompletely. 20 to 50 questionnaires per collaborator were applied per day. Response time was not controlled, but each respondent took from 5 to 15 minutes to judge 15 groups. Older people often asked for help to fill in the questionnaire, but were quite certain of their pictorial choices.

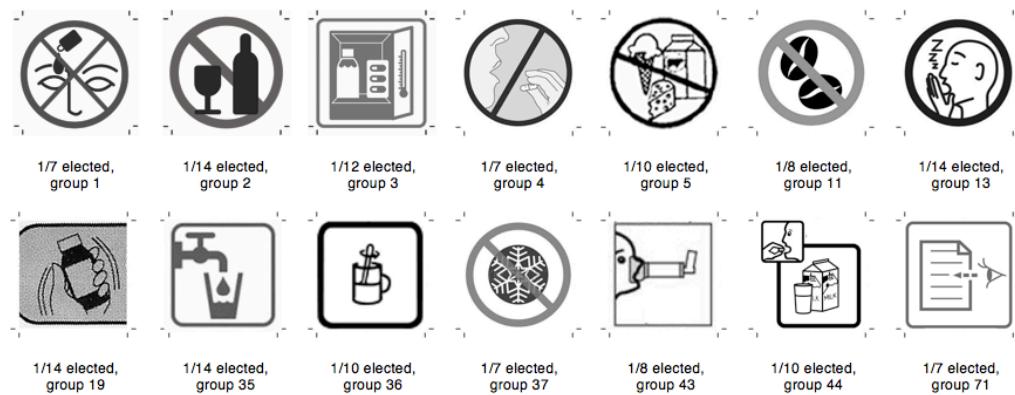
From 8am to 3pm on weekdays the hospitals were full of people, patients for appointments, tests or treatments and visitors. We approached respondents in the patients' waiting rooms and visitors' halls. After 3pm, some health professionals were also interviewed and we also applied some surveys outside, in the nearby streets.

## Results

In this first phase in Portugal we obtained 100 outcomes for the 75 messages/groups. The analysis of the elected symbols in each of the 75 messages/groups is still ongoing. If, on the one hand, the use of paper support for the survey appeared more viable than a digital support, on the other hand the analysis of the 7,500 groups of messages (500 questionnaires x 15 groups/answers) on paper takes much longer, and has not been completed yet.

At this stage, it is still premature to contemplate final results, since our aim is to involve a significant number of other countries, representative of different cultures, all over the world. Nevertheless, our sample was significantly varied socially and culturally for the results to be informative and productive.

Outcomes analysed so far show a variety of graphic choices by respondents (Figure 5). We believe that respondents' choices were mostly based on the key visual elements of the symbols and did not take into account either design legibility or contrast. Those aspects are to be evaluated at a later stage by a final validating test comprising the elected 75 symbols.



source: 1st hor. row – 1, 3 (RAD-AR Council, 2006), 2 (Camacho, 2013), 3 (RAD-AR Council, 2006), 4 (unknown), 5 (unknown), 6 (unknown), 7 (FIP, 2004);  
2nd hor. row – 1 (HealthCare Logistics, 2005), 2 (Design Indaba), 3 (FIP, 2004), 4 (unknown), 5 (HELP ix Pictograms 2009), 6 (USP, 1989), 7 (RAD-AR Council, 2006).

Figure 5: Judgement test results - 14 of 75 elected symbols (Portugal, March 2018)



In some groups a considerable number of different judgements were made, and the elected image for the group was chosen by a narrow margin, which means that most of the symbols in the group could be chosen for the final design. In these cases, only when results came out through Microsoft Excel did we realize which symbol had been in elected and how fragile some of the choices were (decisions made by comprehensibility % in ex-aquo cases).

Meanwhile, people talked with us a great deal (I guess this may be very cultural too), thus compensating orally the final reinforcing written question we had eliminated. A sample of their comments is given below in Figure 6, some related to the judgement results in figure 5.

GROUP MESSAGE	NUMBER SYMBOLS	COMMENTS CHUC – PORTUGAL
03 STORE IN THE REFRIGERATOR (17/8) 38 DO NOT STORE IN THE REFRIGERATOR	12 7	"Thermometer scales are unclear", "the ice star is not fridge but freezer", "these fridges look more like cupboards".
09 DO NOT GIVE THIS MEDICINE TO CHILDREN 3-12 YEARS OLD	7	"It is not obvious: if it is not for children, it is not for babies either".
10 KEEP OUT OF REACH OF CHILDREN	14	"A shelf is what characterizes reach".
11 DO NOT TAKE WITH CAFFEINE	8	"A cup could be a cup of tea and not of coffee, coffee grains are certainly coffee".
13 DO NOT DRIVE IF THIS MEDICINE MAKES YOU SLEEPY	14	"The hand in front of the mouth is fundamental, forget the rest".
19 SHAKE WELL BEFORE USE 39 DO NOT SHAKE THE BOTTLE	14 7	"Curved lines represent shaking better than arrows".
35 TAKE WITH WATER	7	"The faucet is essential because it has to be a glass of water".
36 DISSOLVE IN WATER	10	"Images to dilute and images to self-dissolve are different instructions".
37 DO NOT FREEZE	7	"The ice star is undoubtedly the synonym of freezer".
44 TAKE WITH MILK 05 DO NOT TAKE WITH MILK OR DAIRY PRODUCTS	10 10	"These packs can be juice or wine, the package has to have a cow on it", "For dairy products we must include: milk, ice cream and cheese".
62 DO NOT SHARE YOUR MEDICINES WITH OTHERS	7	"There are medicines we can share".
71 READ THE INSTRUCTIONS CAREFULLY	7	"Reading instructions is often extremely difficult, instruction pictures are welcome".

Figure 6: Judgement test results – sample of comments offered by respondents during the process

Some of the most important conclusions so far were given by the comments and 'guidelines' offered by respondents during the process, while they were reading the pictures aloud and making their own choices. Consequently, respondents' feedback about the survey was crucial, and notes taken by collaborators were collected and registered at the end of the day. This situation had not been predicted but was very positive and reinforced the importance of applying a face-to-face paper survey.

It should be emphasized that it is our intention, after the final choice and redesign of the symbols, to keep symbol and written caption grouped (as in PictoPharma, initially designed in 3 languages).

## Conclusion/ Way forward

Our aim is to have the 75 messages identified in the participatory study (2010, updated 2017) support the development of a coherent and logical linguistic and pictorial system for the most



relevant therapeutic instructions and warnings. The pictograms/symbols are to be chosen cross-culturally through a judgement test as recommended by ISO 9186-1 (2007), in order to create a uniform and transversal international visual communication system. The challenge of a worldwide judgement test is fundamental for people-centred design and for the creation of sustainable dialogues.

Portugal first results showed very different graphic choices by respondents. The results reinforced our assumption that visual literacy appears definitely related to cultural background, and that familiarization and learning are decisive for decoding images.

The judgement test will now be conducted in 11 more countries in order to obtain 1,000 worldwide responses for each of the 75 messages.

Once the judgement test is completed, we will apply the key visual elements selected in the survey to update, improve, complete and redesign PictoPharma. Design legibility and contrast will then be tested according to ISO methods for testing comprehensibility.

Finally, we aim to submit PictoPharma to international standard organizations in order to have it considered for international use.

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## Design with Care - From Art to Applied Design to Income Source

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**ABSTRACT** *In the last half-century, the perception of disability as a fundamental human right enabled legislation to be passed ensuring equal access to mainstream education, employment, and public services. Human rights encompass social inclusion - for which the benchmark has been heavily weighted towards independent living and mainstream employment. For people with severe learning disabilities or mental health issues, it has been hard to secure mainstream employment and financial security. In Japan, in preparation for 2020 Tokyo Olympics / Paralympics, the government and charitable foundations are striving to provide creative opportunities for disabled people. This paper focuses on how the linkage of creative activities by disabled people and the strategic use of co-design methods and inclusive processes can enable new forms of financial independence and social empowerment for people who would otherwise have difficulty gaining mainstream employment.*

Keywords: Co-design, Inclusive Design, Social Welfare, Collaboration, Disability



Figure 1. Examples of assembly, packaging and products from SWOs in Japan

## Introduction - Design Background

Over 5000 social welfare organizations (SWO) in Japan provide work and care for severely disabled adults (beneficiaries from hereon) - such as cleaning, bread making or simple assembly which generates individual income ranging from £50 to £5 per month (Fig.1). Art activities are run primarily as therapeutic activities falling under the category of care, thereby generating no income. As of April 2018, the Japanese Ministry of Health and Welfare changed Japan's *Disability Independence Law (Shogaisha Jiritsu Shien Ho)* to *The Disability Support and Protection Law (Shogaisha Hogo Shien Ho)*. Unlike its predecessor, the new legislation sets annual profit margin targets for organizations with funding assessed and provided annually, according to the organization's profitability (Ministry of Health, Labour and Welfare, 2018). This puts greater pressure on organizations to produce high-quality income-generating goods even where such expertise is absent. Simultaneously, they must balance the need of care for beneficiaries with severe cognitive issues encompassing learning disabilities, autism or mental health issues.

## Designing Creative Processes

The author - a graphic designer - initiated the cited design-based projects as a designer, project facilitator and creative director using the following methodology:



## *Process 1: 8 Methods for Creative Growth (8MCG) - Assessing and expanding on existing creative abilities*

Research has shown that art can have great therapeutic value - reducing negative moods and anxiety (Bell C.E. & Robins S.J. 2007) while reducing stress, agitation and depressive symptoms to improve the brain's psychological outcomes (Flett J.A.M., Lie C., Riordan B.C., Thompson L.M., Conner T.S., Hayne H. 2017).

*8 Methods for Creative Growth* were developed by the author in collaboration with staff from SWO Ayase Himawari-en which employs adults with severe learning disabilities. The author worked with class of 10 to 15 beneficiaries with varying creative and cognitive abilities for over a year to develop the methods (Table 1.).

Table 1. Description of 8 Methods for Creative Growth

	Method	Details	Benefits / Changes
1	Changing the size and Material you work with	Changing the drawing size or drawing material the artists works with to further highlight already existing artistic strengths	helps artists to see good qualities in their own works. Gives new sensation which can lighten self confidence and motivation
2	Converting Movement into Art	Converting the person's favorite sensation and movement into a creative act	Helps people with severe cognitive ability or limited movement to create through the sensation of actions and movement
3	Making colour & shape templates	Colour-in templates with prime shapes and simple with thick outlines or black surrounding backgrounds	Better understanding of colour and composition. Many transitioned into drawing freely. Also has Therapeutic benefits (less aggressive behaviour)
4	Creating new tools	using everyday material and products to create art tools which can enabled new sensations and unexpected results	Expands creative ranges by introducing new tools and methods with different shapes and textures
5	Giving Encouraging words	guiding the person trough the creative process using encouraging words, and enabling independent decision making	Better self confidence and willingness to challenge new things. enabled more independent decision making
6	Selecting high quality inspirational material to work from	Provides new inspirational sources that matches the person's interest	expands creative horizons by providing material through personal interest and existing creative traits
7	Understanding the true meaning behind an artwork	understanding the meaning and reasons behind what they draw trough observation over a sufficient span of time.	making sure the appropriate supportive methods are provided without harming the person's self development
8	Using grid templates to encourage further drawing	teaching basic 3D shapes trough the use of guides and gridded paper. slowly adding primary shapes within the shapes to create drawings	Encourages people who have difficulty in drawing from imagination to draw freely without the fear of making a 'mistake'

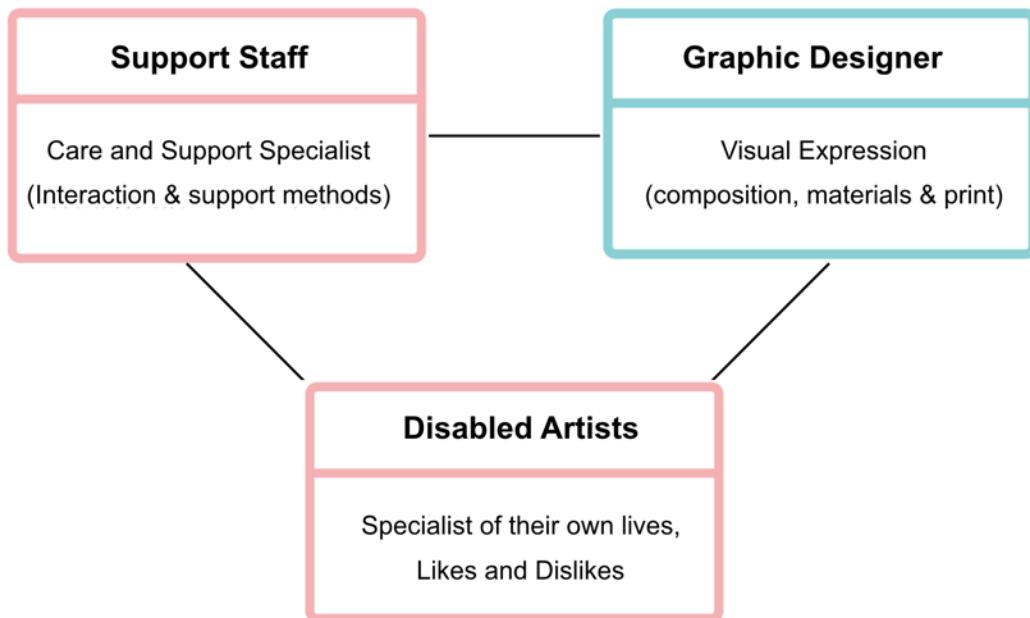


Figure 2. Combining skills diagram

Combining the author's visual design skills, the staff's specialist care and support skills and one-on-one knowledge of the beneficiaries and their abilities or interests (Fig.2), eight basic methods were developed. The methods support the beneficiary's cognitive needs whilst expanding their creative abilities - ranging from such basic strategies as changing the materials they work with to creating templates or sensation-based creative tools. The benefits have been significant - increasing the quality of artworks (Fig.3) which have been converted to high-quality design-based goods that can be sold as mainstream products (Fig.4). It has also helped staff and carers to discover creative opportunities within the SWO and reduce troubled behaviour. This has significantly reduced staff's stress levels, enabling greater focus on individual ability and care.



Figure 3. Artworks before (left) and after (right) using methods



Figure 4. Design Goods

## Process 2: Challenge Workshops Model (CWM)

The Challenge Workshops model (CWM<sup>i</sup>) was developed by Julia Cassim whilst at the Helen Hamlyn Centre for Design at the Royal College of Art. This knowledge transfer programme uses inclusive design as a tool for exploring innovation and developing techniques in co-design practice using different design-led mechanisms (Cassim and Dong 2013). The model provides opportunities for disabled or socially marginalized groups, to work as design partners with designers during the design process. The workshops range from 24 hours, 72 hours to 5 days, and enable initial design prototypes which act as a starting point for the development of finalized products.

## *Process 3: Designing Production Processes (DPP)*

Many SWOs with which the author has worked desire to develop products in-house over the long term but lack any expertise in how this can be achieved. Designing production processes that combine pre-designed templates and design elements using the organization's pre-existing skills base, (e.g. assembly skills<sup>ii</sup>) enables them to fully or partially create the final product. Successful



creative direction and in-house assembly and/or production can reduce production or marketing costs incurred by the need to use outside expertise thereby increasing overall profit margins.

## Projects using Design-led Processes and Methods

### *Commercial Collaborations: Shiro Labo Sendai*

*Processes used: CWM*

*Author's Role: Workshop Facilitator / Art Director*

**Project Outline:** *Shiro Labo* project was initiated by the Able Art Company<sup>iii</sup> and the author connecting local designers and disabled artists in Sendai Prefecture. 48 Hour Challenge workshops were held to produce design goods. The 2016 workshop at Sendai Zoo (Fig. 5-1), developed animal-based merchandise (3 designs x 30 units of each) which was sold in pop-up stores. In 2017, *Shiro Labo* collaborated with national baseball team *Rakuten Eagle*'s CSR department to develop official merchandise (3x30 units) which were sold in their official shop (Fig. 5-2).

**Result:** All goods sold out by April 2018 - with a percentage of the profits going directly to

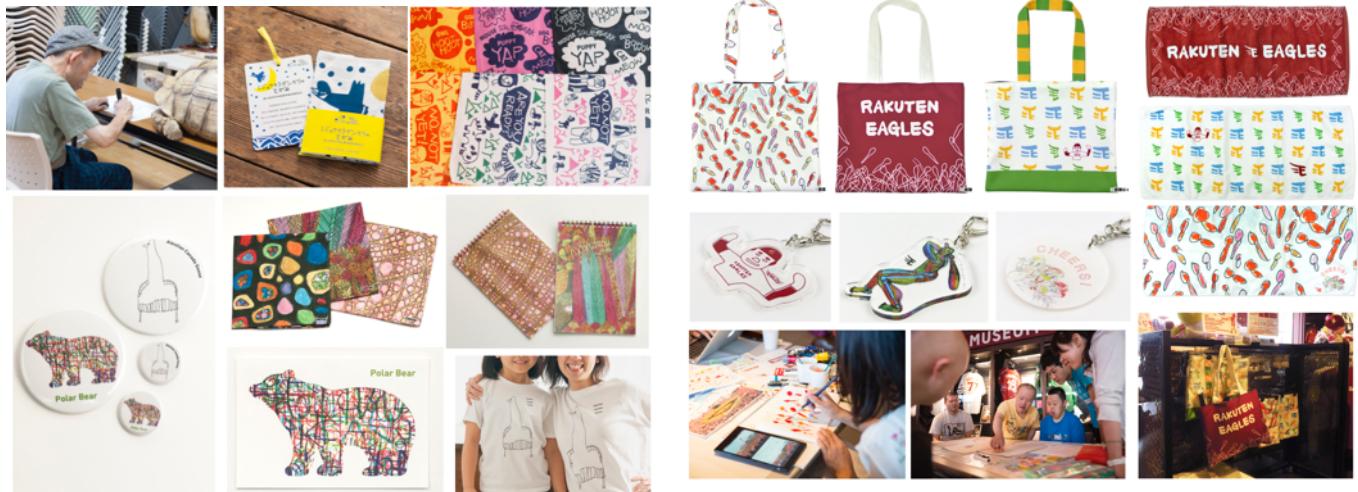


Figure 5-1. Sendai Zoo merchandise

Figure 5-2. Rakuten Eagles merchandise

beneficiaries.

### *Self-Produced Products 1. Shibuya Font Project (2016 -)*

*Processes used: 8MCG, DCW, DPP*

*Role: Creative Director*



Project Outline: Shibuya ward in central Tokyo funded a three-year project to develop open source digital data and souvenir goods specific to Shibuya. The aim was to promote diversity and inclusion



Figure 6. Students developing artwork with artists

through creative activities in Shibuya SWOs. Students from Kuwasawa Design School were paired with 6 SWOs to create digital patterns, fonts and product prototypes. Students worked for two



Figure 7. 48 Hour workshop held at Fab Cafe MTRL

months with their paired SWOs under the author's direction to develop art work (Fig.6) which was used in a 48 Hour Challenge workshop to develop design prototypes using digital fabrication technology (Fig.7).

**Result:** High quality prototypes produced in a short time frame using digital fabrication technology (Fig.8). From 2018, the teams have started to develop product lines that can be made within the SWOs.

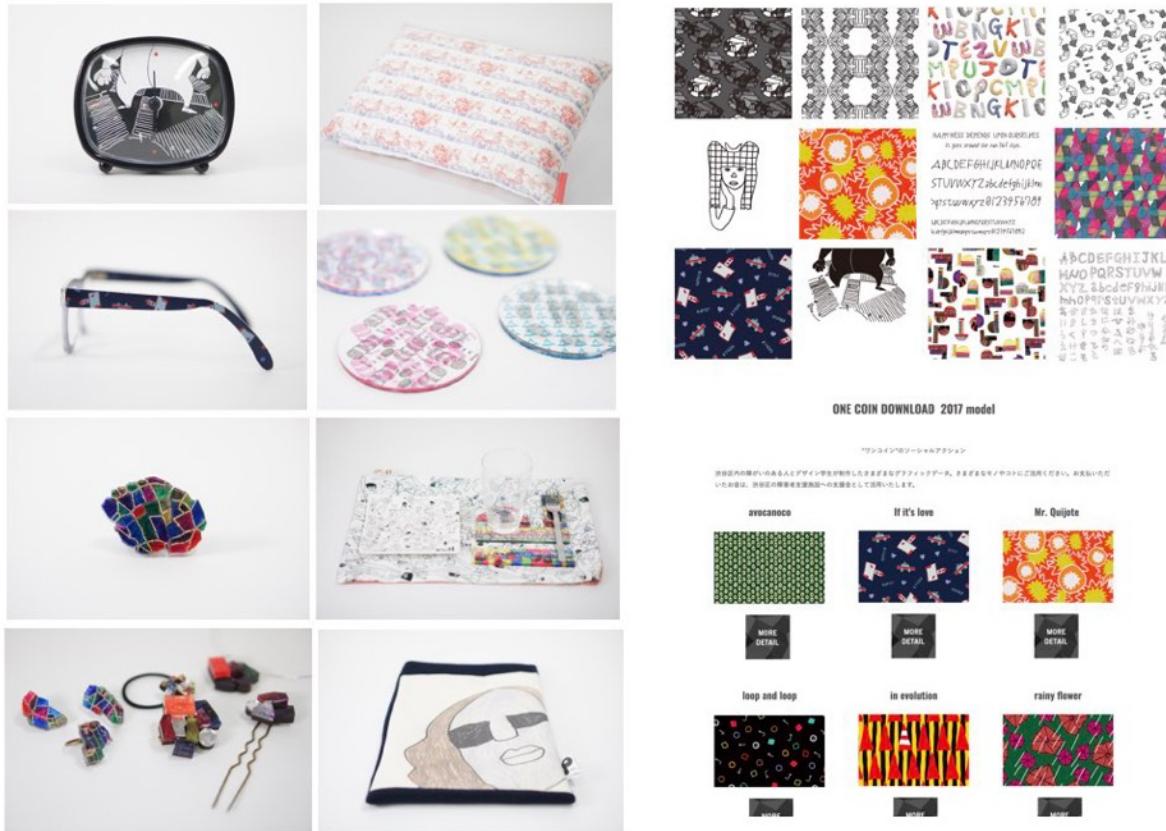


Figure 8. Prototypes and online digital material from 2017

## Self-Produced Products 2. Gencho Moso Karuta by NPO Harmony

*Processes used: 8MCG, CWM, DPP*

*Role: Lead Designer*

**Project Outline:** to design and develop production methods for the 3rd edition of the *Cho Gencho Moso Karuta (Guess the 'Hallucinatory' Story Card Game)* (Fig.9) by Harmony - a SWO offering basic living support, counselling and employment for members with severe mental health issues. Episodes from weekly group counselling sessions where members share personal events (including their visual and auditory hallucinations) are transformed into stories as a coping



Figure 9. 3rd Edition of card game (Harmony, 2017)

mechanism. Stories are then converted into a *Karuta Card*<sup>iv</sup> game. The first edition (2011) was created with a publisher but Harmony received a fraction of the profits. The second edition (2014) was produced completely in-house but had high production costs (Fig.10).

The author worked with members to help generate high-quality visual design materials (Fig.11), using creative support methods. The packaging was designed to be assembled by members and linked to their regular hourly assembly wage of £1.40 per 30mins (Fig.12). This helped provide work for people regardless of their mental state and physical ability - since conditions in mental health although manageable can change unpredictably. 1000 sets of the 3rd Edition were put on sale in June 2018 via online shop. All profits become the members' income.



Figure 10. 1st edition (left) and 2nd edition (right) of card game]

The Result: Creating sustainable in-house assembly methods and financial revenue through sales (100 box-sets sold in two weeks).



Figure 11. Workshop developing visual material for the 3rd edition

## Conclusion - The impact of design-led projects

The impact on beneficiaries has been significant with increased motivation and self-confidence, and reduction of stress or troubled behaviour. Understanding amongst the beneficiaries' families and surrounding community has increased whereby understanding of their hidden abilities can be gained through looking at the artworks.

Through post-workshop survey and interviews, all participating SWO staff noted the importance of design as a '*tool to help expand the reach of products to a wider audience outside of the social welfare community*'. Communities surrounding SWOs are small, limiting the market which in turn affects profits. Therefore, a design focus that aims for mainstream market acceptance is vital to expand their creative and financial opportunities.

Many also stated the importance of setting design goals to enable staff to plan strategically with designers on how to implement creative activities into the final products.

Collaboration with industry can gain the widest exposure. Having a pre-established design format, enables organizations to collaborate with designers for the first time but can reduce design flexibility. However, even where production costs are covered, profits can be marginal to sales.

Therefore, it is important to have projects like *Shibuya Font* where designers can explore creative opportunities within each SWO's context and link these to future products, in parallel to finding avenues through industry collaboration. Utilising skills from within can kickstart (fully or partially) self-produced products.

To enable this, designing production methods utilizing digital fabrication techniques and pre-existing skills in the SWO are vital. The author hopes the design-methods introduced, can become a template and reference for non-profit organization to create their own design goals long term - ones that will bring financial independence and social inclusion benefits where the beneficiaries' abilities are viewed as an asset.

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i Inclusive design - co-design methodology whereby designers and people marginalized from the mainstream design process, develop products or services that are accessible to many regardless of background or ability and used within the mainstream market

ii Many organizations undertake low-income assembly-based work commissioned by small manufacturers such as, clothes hangers, food or goods packaging. Average income ranges from £0.2 to £5 per unit.

iii Able Art Japan - NPO supporting people with disabilities to make a living through art. Main aim is to represent the artists and manage commercial use of their artworks which are licensed for advertisements and product designs. They host advocacy events and workshops across Japan.

iv Traditional Japanese card game where players have to guess the meaning of picture cards associated with narrated stories



## Recovery by Design: Design tool innovation to engage dependant drinkers

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**ABSTRACT** *It is estimated that 94% of dependant drinkers are not engaged with support services (Ward and Holmes 2014). This statistic suggests that recovery innovation is lacking, with novel designed strategies most needed to engage the most resistant, entrenched and challenging drinkers. A group which is responsible for a substantial strain on public service funding by impacting emergency and social care services (Anderson 2013). This research therefore aims to adapt existing design tools to innovate in the alcohol recovery field.*

*A cultural probe (Gaver et al. 1999) was deployed with service users to inspire new intervention ideas. This involved creative task based participatory workshop activities and co-design sessions, with staff and service users at a rehabilitation facility in Brighton during 2017. The data and feedback from the cultural probe uncovered therapeutic value for the participants reporting that whilst challenging, completing the tasks was an enjoyable alternative exercise, which helped highlight where their addiction had taken them.*

*Using this initial pilot knowledge, a revised tool called a Creative Recovery Kit was developed and tested. This aimed to harness creativity in a structured treatment setting, using the principles of the cultural probe to allow participants to discover insights about themselves. This version was designed to assist in the building of creative confidence (Kelley and Kelley 2012) and develop recovery capital (Granfield and Cloud 2001), to provide a smoother pathway out of addiction and reduce the chance of relapse. The structure of the kit was intended to encourage and empower participants to find new ways to understand, be creative with and design their own recovery, by connecting them with creative groups in the wider recovery community.*

Keywords: health, alcohol, addiction, recovery, creativity, toolkit, engagement, signposting

## Introduction

It is estimated that 1.2% of the population are likely to be dependent drinkers (those who present AUDIT - Alcohol Use Disorders Identification Test scores of 20 or more) (McManus et al. 2014), with around 94% of this group thought to not be engaged with support services (Ward and Holmes 2014). This statistic suggests that innovation in this area is lacking, with new strategies most needed to engage the most resistant, entrenched and challenging drinkers. This group is responsible for a substantial strain on public service funding, due largely to frequent accident and emergency visits, involvement in the criminal justice system, committing acts of anti-social behaviour and regular arrests or dispersals (Anderson 2013). Heavily dependent drinkers are often faced by a complex web of issues alongside their addictions, for example: insecure housing, mental health issues and unemployment. Navigating such a landscape to develop impactful outcomes is a significant challenge and could be described as attempting to address a wicked design problem (Buchanan 1992).



Figure 1: Cultural probe research kit

## Cultural probe

### *Design*

The initial aim for developing a toolkit was to work directly with individuals in the middle stage of substance misuse recovery to discover more about their lives, networks and desires. The principle objective for this was to discover insights for future design interventions.

It was considered essential that participants felt part of the project rather than simply being required to retell their recovery story. An alternative form of engagement was therefore proposed through a self-reporting style cultural probe research kit (Gaver et al. 1999). This approach rather than ethnographic observation, was considered appropriate in such an emotive setting and respectful of the personal nature of the issues faced by the participants.

### *Initial pilot and development*

The cultural probe was piloted with 8 service users at a substance misuse rehabilitation centre in Brighton during March 2017. Participants worked through a series of creative tasks resulting in an unexpected but significant finding of therapeutic value inherent in the process. As feedback from service users suggested that although challenging, completing the tasks was an enjoyable and engaging exercise, which helped them see where their addiction had taken them.

Data was analysed using thematic coding and content analysis , presenting an opportunity to develop the cultural probe into a Creative Recovery Toolkit, which could be useful both as a research tool for services and to provide therapeutic value for participants.



Figure 2: Creative Recovery Toolkit



## Creative Recovery Toolkit

### *Design*

The developed toolkit aimed to elicit information useful for services and provide therapeutic creative activities for participants, alongside involvement in a research project. Objectives were to trial the tool with a different group of clients who also suffered from mental health issues (dual diagnosis) and explore the building of creative confidence and recovery capital.

The toolkit was also self-contained with a simple low tech / cost design, which included all the required materials: Task cards, a disposable camera, coloured pencils, a pen and emoji stickers. The wording of the task questions was carefully designed not to lead responses and ensure the tasks were straightforward and easy to understand, with participants encouraged to be messy and creative. Tasks were split into two halves: Past and present, to allow a comparison of life words before and during recovery.



Figure 3: Workshop space for pilot

### *Tasks and initial findings*

The Creative Recovery Toolkit was undertaken by five participants in residential treatment during November 2017. Each of the five one and a half hour sessions began with an introduction by the

researcher (as facilitator) followed by time to complete tasks and a summing up group discussion. Participants were involved both in the live testing of the toolkit and through an ideas generation session on how the prototype design might be developed to be more engaging and effective.

Example responses are illustrated below and are chosen from across all the participant responses.

DT

**ABOUT YOU**

1

I was born in Brixton I was brought up near the Sea which makes me happy so I had a happy childhood playing down the beach with my friends. I love playing and watching Brixton play trying to go to most home games as I can with my friend which makes me happy I worked in the building trade for 30 years then I became ill in my later life which was a big shock to me I did not see this coming I just walked out my job and never went back and stayed in for six months could not go out I was staying with my dad and he could not understand what was going on a friend of mine got in touch with the right people with our immediate difficulties and saw me and I ended up in hospital which was a shock to me

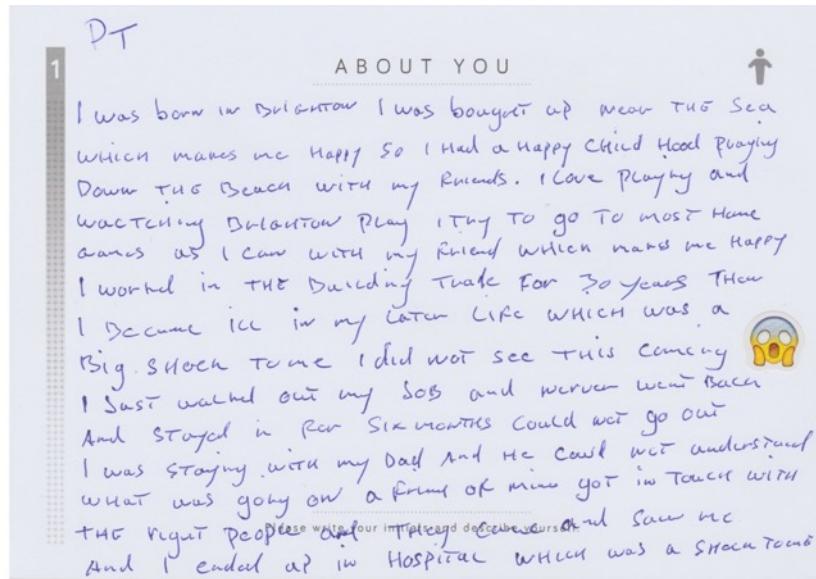


Figure 4: About You task

### Task 1 - About You

This task gave participants the opportunity to introduce themselves however they felt comfortable.

2

**PLACES**

PAST

1 I lived here and suffered symptoms here. I was sectioned here.  
 2 I experienced severe anxiety here.  
 3 I worked here and experienced anxiety here.  
 4 Severe anxiety here.  
 5 First contact with mental health services here.  
 b anxiety when shopping  
 7 Struggling to get to the corner shop  
 8 Anxiety on the way to work  
 9 council house here that I never stayed the night in because of anxiety.

Mark up to 10 places you visited whilst experiencing symptoms, on the map on the next card. Number them and describe the importance of each place on this card.

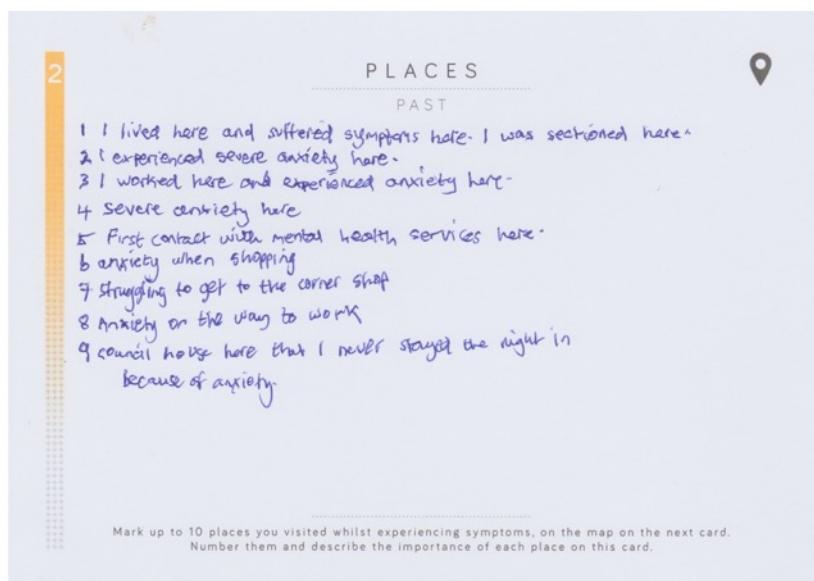


Figure 5: Places (past) task



6 PLACES PRESENT

Computer Club  
Activity Group  
Foot Ball Group  
wood work Group  
Recovery Group  
Friday Cafe  
Church  
watching Blossom play with my friend mat  
watching foot ball in the pub  
going out with my sons  
Having Breakfast with my dad on a Saturday

Mark up to 10 currently visited places which symbolise recovery on the map on the next card.  
Number them and describe the importance of each place on this card.

Figure 6: Places (present) task

### Task 2/6 - Places

This task was designed provide an understanding of the places which influenced each of the participants during their addiction and into recovery.



Figure 7: Participant photograph

### Task 3/7 - Photography



This activity aimed to give participants a more objective eye through which to view their identified places. They could then challenge and explore their emotional attachments to these places as they move through recovery, with regularly visited places taking on new meanings.

Figure 8: Day Diary (past) task

The form is titled 'DAY DIARY' with a subtitle 'PRESENT'. It features a vertical timeline from 6 am to 4 am. Activities listed include: Walking up ~ cup of coffee (6am), Online Facebook ~ coffee (8am), lunch (12pm), Meet Possibility People (1pm), Work at Possibility People (2pm), Possibility People, work (3pm), Meet Coffee with a friend (4pm), Dinner (5pm), Email / read things online (6pm), Sleeping (10pm), and 12midnight (12midnight). There are emoji icons for each activity: a coffee cup for morning coffee, a computer for online Facebook, a sandwich for lunch, a person for meeting people, a fork and knife for dinner, and a sleeping face for sleeping. The bottom of the form has handwritten text: 'In Recovery? @ Orion ways?' and a note: 'Describe your activities on a typical day now that you are in recovery. Compare these activities to the PAST day diary.'

Figure 9: Day Diary (present) task

### Task 4/8 - Day Diary

This task was designed to show a clear contrast between previous and present daily habits and activities. Clearly illustrating a change in behaviours as recovery is developing.

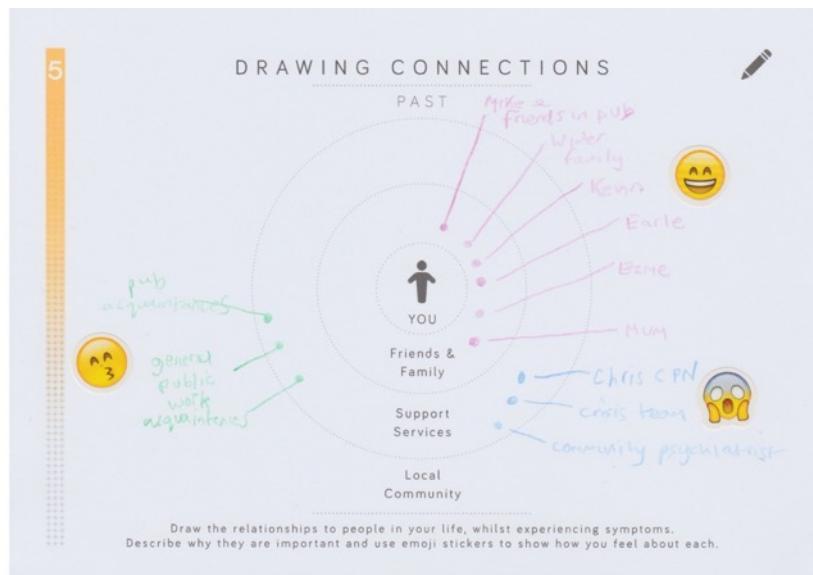


Figure 10: Drawing Connections (past) task

### *Task 5/9 - Drawing Connections*

This task assisted participants with mapping and identifying damaging and supportive relationships and community connections and therefore explore their attitude towards them.

### **Ethical considerations**

Due to the vulnerable nature of the individuals involved in the research it was critical to protect them during participation. Service users were chosen who were in the middle stages of recovery and therefore established and stable, which minimised the danger of relapse through reliving difficult past experiences and visiting sites of previous damaging and/or illegal behaviours.

Anonymity was provided to those taking part to promote confidence, encourage strong engagement and minimised the potential for anxiety about the activities revealing uncomfortable truths. The session facilitation was overseen by experienced support staff, as the process would elicit difficult past experiences and feelings. The staff could then manage any personal discoveries which may be challenging for the participants to deal with on their own as part of their formal recovery process. As mentioned above, the cultural probe method was considered appropriate to discover more about this group. As in such a sensitive setting traditional ethnographic observation could feel intrusive and may even interfere with service users' treatment (Crabtree et al. 2003). A self-reporting style approach would therefore empower participants to engage with a research project and provide an activity which felt novel and clearly contrasted with traditional recovery assignments or assessments.

### *Staff and service user feedback*

It was suggested by staff and service users that the kit was an excellent reflective tool and really helped to elicit activities and places which were triggers and instigate conversations around recovery. The workshop facilitator suggested that an approach exploring unique recovery journeys was valuable in a treatment climate where assessment and recovery measurement are increasingly being standardized.

Discussion with participants themselves suggested that the process, whilst at times challenging, really helped to highlight the progress made in recovery and allow self-expression of their personality in a non-clinical or assessment based manner. The group stated that the toolkit felt like a process designed for service users, rather than for researching or assessing recovering individuals 'as guinea pigs' as one participant described a previous experience of participating in support service research.

### *Discussion and conclusions*

Overall the responses provide a clear contrast between previous and current behaviours, illustrating the progress being made in recovery, this was particularly evident in the thematic coding of the data undertaken. The photography task and drawing connections task responses helped participants identify their support network and the people or services which could be instrumental in their long-term recovery. This activity therefore helps develop awareness around the importance of building networks and recovery capital generally, to sustain abstinence and avoid future relapse (Granfield and Cloud 2001).

The toolkit facilitates the generation of co-produced data with participants, which can increase a sense of involvement and empowerment (Bayley and Thickett 2013) and shows potential to inform the way in which services tailor support by helping to identify specific needs and interests of participants. Needs can be supported and interests encouraged in ongoing treatment, as participation in creative (non-recovery related) activities and involvement with community groups can help to reduce social isolation and are considered essential by those in recovery to avoid relapse (Duffy and Baldwin 2013). Therefore, tasks which can assist in highlighting the importance of building these connections and interests whilst resident in structured treatment are valuable, especially if the tasks themselves contain a reflective and creative element. As once structured treatment has ended, it is vitally important for individuals to have enjoyable and accessible activities to attend in the community and places to go to socialise and meet new people (Daddow and Broome 2010).

The pilot demonstrated that the variety of activities increases inclusivity, as participants felt able to engage with the activities they feel safest undertaking. The range allows for a participant to miss one or two activities during the process of completing the series but still feel part of the process. This helps to overcome exclusion from participation due to language barriers, alcohol induced brain injury, lack of creative confidence (Kelley 2012) or mental health issues such as anxiety.

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## The ecopsychosocial complexities of acute psychiatric wards

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**ABSTRACT** *In the past, buildings for mental health have followed experimental, uneven patterns. That hindered the creation of established design methods. The gap was addressed with a user-inclusive model, the 'SCP model'. Its application to successful (awarded) psychiatric facilities indicated that staff and patients questioned this success. This hiatus between top-down versus bottom up perception of therapeutic environment, generated the need to investigate the socio-spatial context of psychiatric wards. This research aimed to promote our understanding of psychiatric space in relation to social interaction.*

*The locus comprised two acute wards, each evaluated using the SCP model. Parallel, they were analysed using Space Syntax to identify the social logic of their layout in terms of hierarchies, staffs control of the ward in terms of supervision and opportunities for social engagement.*

*The juxtaposition of medical architecture, an area specializing in patient-focused environments and the more generic space syntax methodology highlighted common factors being perceived differently between these two disciplines. It also identified challenges for space syntax. The latter produced inverse results when used for mental health premises compared to other building types, raising questions for the applicability in healthcare settings. However, these inverse results could be interpreted by Goffman's theory on total institutions and listing community mental health wards as such.*

*The findings questioned the appropriateness of generic methodologies for healthcare. It highlighted their lack of sensitivity in perceiving limitations to spatial movement and human co-presence resulting from illness. Integrated approaches of evaluating healthcare settings need to be developed. Use of medical architecture, as a discipline, and patient involvement, as opposed to clinician and architect only, are essential to achieve comprehensive understanding of ecopsychosocially supportive environments.*

**Keywords:** Mental Health, hospital architecture, healthcare design, institutionalization, psychiatric facilities

## Introduction

The diversity in psychiatric service provision combined with limited interdisciplinary relations between architecture and health sciences brought about an experimental, intuitive approach for the design of psychiatric buildings. The model that dominated the programming, planning and design of psychiatric facilities after the 80s was normalization theory and was borrowed from learning disabilities (Wolfensberger and Glenn 1973). This lack of a direct link between design and patients' pathology became more obvious after an array of findings on community psychiatric facilities in France and the UK (Chrysikou 2003). One of those was that even awarded psychiatric buildings could demonstrate institutional building features. This agreed with data from service users and staff in these environments (Chrysikou 2015). The implementation of normalization to mental health compromised the needs of psychiatric patients accommodated in the most acute spectrum of care-provision. The balance between privacy and surveillance constituted the major dilemma for psychiatric architecture (Smith 2002). Normalization could not address it. However, synchronous research (Sheehan et al. 2013) on UK psychiatric facilities linked the built environment to staff satisfaction, yet questioned the importance of observability for staff. Finally, there was absence of service-user involvement and vertical advocacy of staff in decision making at planning stages. This resulted in disparity between principles of psychosocial rehabilitation, architecture and end-user expectations or even the adequacy of available human resources. To address this, an alternative model to normalization was developed in University College London (UCL as a tool tailored for psychiatric facilities (Chrysikou 2014). It was named 'the SCP model' and could depict the quality of the environment and its' consequences to patients' life. It employed earlier theories for psychiatric hospitals (Vavyli 1992), principles of patient focus care (MARU 1991) and concepts of Medical architecture (Davies 1988; Scher 1996), research in psychiatric environments by environmental psychologists (Baker et al. 1960; Ittelson et al. 1970; Sloan 1992) and work conducted in the broader field of disability from the end-user perspective (MacIntyre 2018). The model corresponded to key issues behind mental illness expressed by the three dominant models of care: the jurisdictional, the medical and the rehabilitation model. The SCP model comprises three parameters that correspond to a pyramid of needs (Figure 1).

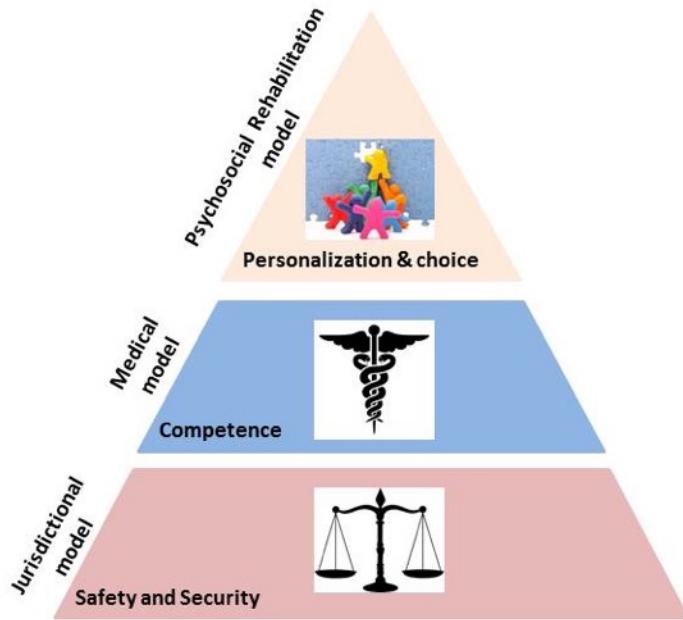


Figure 1: The SCP Model and the pyramid of needs: each tier represents a parameter of the model and corresponds to a model of mental health provision

All topics on mental health environments could be classified according to: a) safety & security, b) competence and c) personalization and choice. These derived from the basic needs related to the priorities relevant to the main objectives of mental healthcare:

- a) harm and self-harm prevention, existence-related
- b) medical and nursing provision, competence-related
- c) social reintegration, wellbeing-related.

Yet, this bottom up and patient focused model, could not cover social aspects in depth. This requires methodologies detached from individual perspectives. So, how could the social element be introduced and therefore help us develop a more integrated framework? Hillier advocates that society and space are interlinked (Hillier and Hanson 1984). He suggests that one produces the other and vice versa and we cannot distinguish between the two. He developed the theory of Space Syntax. This theory of architectural morphology investigates socio-spatial relations. It has been used for the understanding of institutions (Marcus 1993) but never juxtaposed with the end-user perspective in mental health contexts.

Combining the approaches of medical architecture and architectural morphology, this research set to investigate the social dynamics of institutional space and the socio-spatial angle institutional environment generate, in relation to the perspectives of end-users. For the first time, the two frameworks came together. The first was designed especially for mental healthcare and the other covers all spatial scale. By combining the two, the research investigated both patients' relation to the therapeutic regime and social relations to the spatial configuration.

## Methodology

The locus involved two secure acute facilities, operated by different London Trusts and chosen according to pre-set criteria and permission granting. Acute wards have been linked to poor service user experience and high staff burnout (Sweeney et al. 2014).

For evaluating patients' needs and the compliance to care regime, patients and staff were interviewed using semi-structured interviews of 30 and 23 main sets of questions respectively. Data on the environment and sense of place of the wards derived from a systematic architectural account for spatial organization, therapeutic regime, building qualities that enhance health (Ulrich 1984; Zeisel 1984) such as daylighting, art, natural views, access to nature, gathered from visits, photographic auditing and plans. Regarding plans, architectural blueprints were compared on their analogies of areas per use and user group. Third, a detailed checklist of 212 building traits based on one by Robinson (1984), identified institutional physical characteristics in a comparative scale to the local norm as defined by the neighbouring or local residential buildings in parameters related to the exterior, the layout and interior design. Regarding architectural morphology, each facility has been analysed using Space Syntax (Table 1). Space Syntax tools used involved social solidarities, social relations diagrams, and integration values. The morphological analysis was performed for the interior of the facilities, using Depthmap software and blueprints of the wards. The tools used comprised convex analysis, axial analysis, visibility graph analysis and JASS Software for justified graphs.

Table 1: Methodology in relation to main research objectives

Methodology for a psychosocially supportive design of mental health facilities		
Objective (reference to main research objectives)	Methodology	Tools
Personal Milieu	Evaluation of patient's needs and compliance to care regime	Semi-structured interviews of 30 (for patients) and 23 (for staff) sets of questions
Place-making for mental health	Data on physical environment and sense of place	Visits, photographic auditing and architectural blueprints for calculation analogies of areas per use and user group
Domesticity vs institutionalism	Architectural checklist	212 traits on building exterior, layout and design of interior



Social Milieu	Space Syntax analysis	Convex graphs, axial graphs, visibility graphs and justified graphs
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## Results and Discussion

Despite the UK having officially closed its psychiatric hospitals both wards were situated inside larger psychiatric complexes. Their facades bear strong visual references to non-residential architecture even though both are part of Care in the Community. Case study A (Figure 2) was part of a former fever hospital campus, yet it has been converted for mental health use four decades ago. The entire campus presents strong institutional characteristics. Ward condition is poor. In contrast, case study B (Figure 2) sits in a recently remodelled Mental Health Center. Both wards sit on the ground floor and do not have direct access outdoors.



# DESIGN4 HEALTH



Figure 2: Floorplans of Wards A and B, color-coded according to functions

Both wards, present strong institutional character: an average of 60.85 and 54.72% according to the Institutional vs Domestic checklist for Ward A and B respectively. Moreover, they are at the institutional end or very close to it when compared to UK wards investigated using the same checklist 15 years ago (Table 2). Overall, Ward A showed wear and tear and demonstrated institutional traits such as dormitories and shared toilets, now considered obsolete. By contrast, Ward B was maintained in an excellent condition. However, its number of institutional traits was comparable to that of Ward A. This was the result of an extensive use of anti-ligature fixtures and fittings. This agrees with the National Service Framework (NSF) for Mental Health (Department of Health 1999).



Table 2: Mean institutional percentages for Wards A/B compared to earlier UK sample

Percentages of institutional features per building	
Facility	Mean
Ward A (2016)	60.85
Ward I (2002)	56
Ward B (2016)	54.72
Ward II (2002)	48
Ward III (2002)	47
Ward IV (2002)	44
Ward V (2002)	26

The research produced a significant volume of data, deriving from the checklist, architectural auditing, space syntax analysis and interviews. These generated a comprehensive series of findings regarding architectural features of the buildings, therapeutic regimes, layouts, relationship to care models and to users' preferences, plus their relationship to the data of the earlier UK study that used the SCP model and generated a comparable amount of data that could not be presented in a single paper (Figure 3).

Ward A bore considerable resemblance to institutions, yet scored close to Ward B which incorporated several elements of the state of the art technologies in psychiatric design, especially those related to anti-ligature. Thus, in the same geographical area, i.e. London, we could have two distinct models of care provision: one pre-normalization providing low stimulation, limited privacy and sociofugal design of sitting arrangements (Osmond 1970), and one post-normalization featuring specialized psychiatric design. The latter could be described as a re-introduction of the psychiatric ward of the general hospital in the community: emphasis on infection control, anti-ligature, central nursing station, provision for various degrees of gender segregation, general hospital policies such as non-smoking policies in all hospital outdoor areas etc. This agrees with the conclusion of Kilaspy (2007) after reviewing psychiatric literature on de-institutionalization that community services could not completely replace hospital care resulting in increasing re-institutionalization.

The qualitative characteristics are mostly depicted by the analysis according to the three parameters of the SCP model, the architectural morphology analysis and in particular the analysis



of user hierarchies and policies such as gender segregation, smoking policy or access to the existing outdoor areas. Parallel, interviews provided important qualitative data.

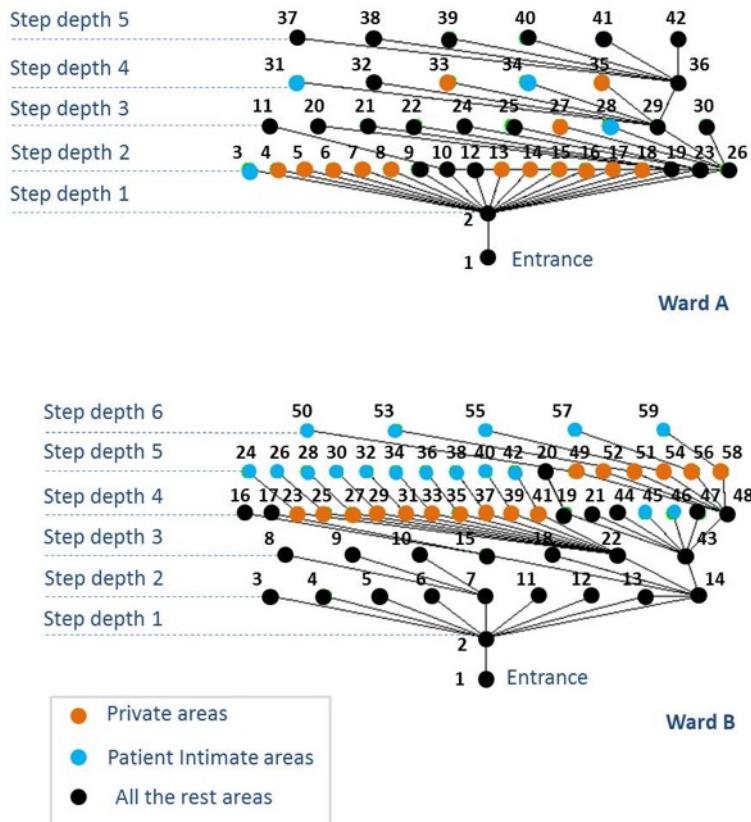


Figure 3: Justified graphs of Wards showing depths of private/intimate areas

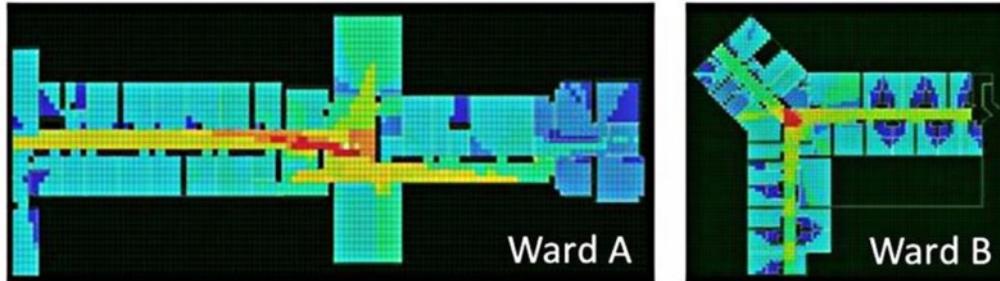
Regarding layouts, the two Wards presented similarities and differences (Table 3). From those differences, it is worth looking at smoking policy. Ward B prohibits smoking in the campus so patients had to get escorted leave to smoke, one at a time. This resulted in long queues, unrest and incidents of violence outside the nursing station and had been the reason behind the fire according to ward manager. This was an indication that policy and buildings in mental health facilities are interrelated, affecting the spatial use and experience considerably.



Table 3: Layout similarities and differences for Wards A/B

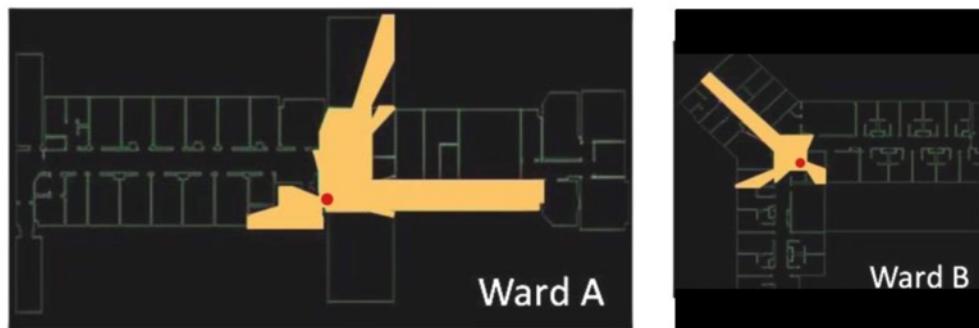
Similarities and differences in the layout of the two Wards			
	Description	Ward A	Ward B
Similarities	Ground Floor	+	+
	Single-storey	+	+
	Access to fully protected courtyard	+	(+)
	Centrally positioned nurse station	+	+
	Centrally positioned clinics	+	+
	Double loaded corridors	(+)	+
Differences	Office area: Offices integrated (as opposed to segregated or at the far end)	-	+
	Self-contained ward (vs dependent)	-	+
	Single bedrooms (vs sharing)	-	+
	Toilets: Individual (vs shared)	-	+
	Gender segregation: Single gendered ward (vs female only area)	-	+

From the previous point in relation to integration of the nursing station and unrest around it, we could generate food for thought for the application of Space Syntax in institutions. What would be described by Hillier and Hanson as social logic (1984) appears in this case severely compromised by rules restricting movement. Yet, Space Syntax appears to pick the location of violence outbreaks, if we do not expect these to be areas of socialization as space syntax assumes. In both wards, the most integrated spaces appear to be the spaces outside the nursing station (Figure 4). They are also areas of very good visibility (Figure 5). And indeed, patients gather outside nursing stations in total institutions putting themselves in the surveillance 'radar'. Visibility from that point might have been a brief requirement. Yet, most staff were not actually there. Patients did not gather outside the staff office of Ward B, which was at a segregated part, neither outside the entrance connecting the ward corridor to the staff only part in Ward A, which was also segregated. Patients gathered at the most integrated point. It remains uncertain whether that was a demonstration of an institutional behaviour or a human need of meeting people at the most integrated point of the ward.



Colder shades indicate fewer human co-presence and warmer shades higher human co-presence , with dark blue indicating fewer chances to dark red indicating higher chances.

Figure 4: Integration of Wards A/B. The most integrated space in both cases is the area outside the nursing station coloured in red



Position of the observer in the ward, just outside the nursing office door



360°- vision from the given point (red dot)

Figure 5: Visibility from the nursing station at Wards A/B

To the above we could increase the complexity of the argument by involving the visibility from the nursing station. The purpose of a nursing station is surveillance (Figure 5). However, the visibility from windows of nursing stations to the corridor had been partially blocked by staff and, moreover, staff had their backs to corridors. Thus, they lacked visual control. This questioned the centrality of the placement of the nursing station in terms of a briefing priority. Further research in wards that present high integration characteristics in activity or in social areas, such as the common room or the activity room might increase the potential for social interaction in relation to the demonstration of passive behaviours and staff and patient satisfaction might provide new insights on psychosocially supportive ways.

## Findings and Conclusions

Findings highlighted potential connections between regimes, spatial configuration and social fabric in psychiatric institutions. Architectural morphology methods indicated areas attracting people, because of layout (Figure 4). However, this derived from institutionalization, confirming Goffman's theory of total institutions (Goffman 1961). Psychiatric hospitals have been classified as such. Yet, community psychiatry allegedly de-institutionalized psychiatric provision. The inverse effect of the integrated spaces being those who fostered anti-social behaviours, demonstrate that de-institutionalization remains incomplete. The high scores in institutional points supported this.

Space Syntax presented strong limitations on understanding space inside psychiatric facilities, unless it was justified by Goffman's theory. However, this is something outside space syntax core theory. So, it should be juxtaposed to other tools and used cautiously, to prevent misunderstanding phenomena. This finding agrees with scholars who question the validity of space syntax for healthcare (Peponis 2017; Van der Zwart 2018). Insights from healthcare architecture field of research should be essential to outline institutional undercurrents. The combinations of both methodologies might lead to more elaborate research tools both for healthcare architecture and architectural morphology. In any case, a generic methodology of architectural theory, including space syntax, should not be used on its own because, differences on perception and on physiology that derive from an illness conflict with generalized principles. Therefore, it is imperative that the understanding of healthcare spaces needs to derive from integrated methodologies combining healthcare and spatial tools and from multi-disciplinary and patient inclusive research consortia.

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## What do 'Life Cafes' tell us about dying and end of life care?

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**ABSTRACT** *The World Health Organisation (WHO) estimates that the number of deaths worldwide will increase from 56 million to 70 million by 2030. Within the United Kingdom this equates to an increase of 20% over the next five years. Not only will palliative and end of life care services be required to meet the needs of an increasing number of people who are dying but we must also respond to an increasing number of people who are dying from complex, long-term conditions such as cancer and dementia. This paper reports the findings of the first phase of a study undertaken by design researchers at Sheffield Hallam University to inform the development of new and flexible models of care that are responsive to the needs of an ageing population with increasingly complex end of care life needs. Taking the method of 'exhibition in a box', a form of object elicitation developed by Chamberlain and Craig (2013) as the starting point this study curated a series of creative activities, named the 'Life Café' to scaffold thinking and to prompt conversation.*

Keywords: Design, End of Life, Object Elicitation, Method, Conversation, Communication



## Introduction

The last two decades have witnessed a demographic change on an unprecedented scale. Medical advances and the treatment of infectious diseases have led to significant increases in life expectancy and the phenomenon of global ageing. However, demographically the world is now at a tipping point and those individuals who have extended their lifespan by 20 and 30 years are now dying. Within the United Kingdom it is estimated that the number of people requiring end of life care services will increase by 20% over the next five years (ONS 2015).

These demographic shifts are placing increasing pressure on existing services, which are already under considerable strain. The fear is that as pressure increases the quality of care people receive may be compromised. These concerns have been fuelled by a number of recent studies. For example, in one study (ONS 2014), it was found that only 50% of bereaved relatives felt that their loved one had died in their place of choice. In another government commissioned, Review of Choice in End of Life Care (DoH 2015) found that 30% of people who died in hospital received care that was rated by family members as 'poor' or 'fair'. The same review also reported that 40% of those interviewed felt that their family member had not received the dignity or care they deserved.

Research highlights that excellent care is synonymous with a personalized approach where the decisions and personal preferences of the individual are taken into account. However, this is predicated on a system where parity in relation to the quality of care exists across all services. The conclusion of the Ambitions document that '*people want their choices to be real choices based on high quality end of life services being available in all areas and in all settings*' (DoH 2016, 7-8)

In spite of the ambition of government and numerous attempts from health and social care to respond to these challenges, no solution currently exists and a radical rethink is required.

In light of the size and complexity of this challenge, design is well placed to address the issues facing services that address end of life care. Design has always played a significant role within this field but this has tended to focus on environmental design, reflecting a growing body of research that has repeatedly highlighted that the design of the physical environment in hospital and care homes '*can have a direct impact on the experience of care for people at end of life*' (DoH 2008, 17).

This widespread acceptance of the significance of architecture and interior design in relation to physical and psychological wellbeing is perhaps most clearly manifested in the King's Fund '*Environments for Care at End of Life*'. This initiative, funded by the UK Department of Health, was undertaken as part of the broader Enhancing the Healing Environment programme and included over 20 projects focusing on the redesign of specialist and non-specialist hospital and palliative care settings including prisons and mental health units.



However environmental design is just one facet of what design might offer and there is a growing recognition by the broader health community that the potential of design has not yet been realised. Indeed a rapid review of the literature undertaken by Borgstrom and Barclay (2017) highlighted that despite good evidence demonstrating the value of co-design and experience based design methods in capturing patient experience and improving services only 12 papers utilizing these approaches were identified in the context of palliative and end of life care.

## About the current research

The study described in this paper is part of a broader enquiry: the Marie Curie Design to Care Programme. The overall aim of the two-year programme is to create the foundations for the future of innovative and tailored palliative and end of life care. A focus of the enquiry is the development of new and flexible models of care that are responsive to the needs of an ageing population with increasingly complex end of life care needs. These models seek to create a system where there is a parity of care across the United Kingdom where different levels of health and social care provision exist.

This paper reports the first phase of the study undertaken by design researchers at Sheffield Hallam University. This research has used design methods to build understanding of the factors community living individuals identify as positive care experiences.

This is very much in accordance with Ambition 6 of the national framework for palliative and end of life care: which places emphasis on community involvement, stating 'each community is prepared to help: people are ready, willing and able to have conversations about living and dying well and to support each other in practical ways' (Ambitions for Palliative and End of Life Care: a national framework for local action 2015-2020).

Taking the method of 'exhibition in a box', a form of object elicitation developed by Chamberlain and Craig (2013) as the starting point this study curated a series of creative activities, named the 'Life Café' to scaffold thinking and to prompt conversation.

Whilst traditional qualitative research methods using structured and semi-structured interviews can preference the views of the researcher, who can make assumptions about what the issues are, the creative activities contained in the 'Life Café' can offer individuals the space to reflect, discuss, explore and define the real questions. The activities offer scaffolds for communication because at one and the same time they are both concrete and abstract.

## Study Design

Convenience sampling was used and 141 people were recruited for the study from community groups and faith-based organisations including: the Salvation Army, Age UK, Police and Fire Service, local older people's groups and groups from BME communities.



Each session followed an identical structure. After giving written consent, participants were invited to participate in the creative activities that comprised the Life Café. These included interactions with objects / tools to stimulate conversations, word cards, and activities focusing on elements considered important in the context of life and care.

The consent process included permissions to video record/tape the workshop and these recordings were transcribed and analysed using thematic analysis. In order to triangulate the data, the themes were embodied in a series of images and objects that were shared with other groups and stakeholders to check the findings against the views of experts and researchers within palliative care. Where particular objects and images were found to be especially helpful in eliciting conversations these were fed back into the Life Café methodology. As a consequence the Life Café was effectively designed in partnership with participants over the duration of the study.



Figure 1: Life Café set up



## Findings

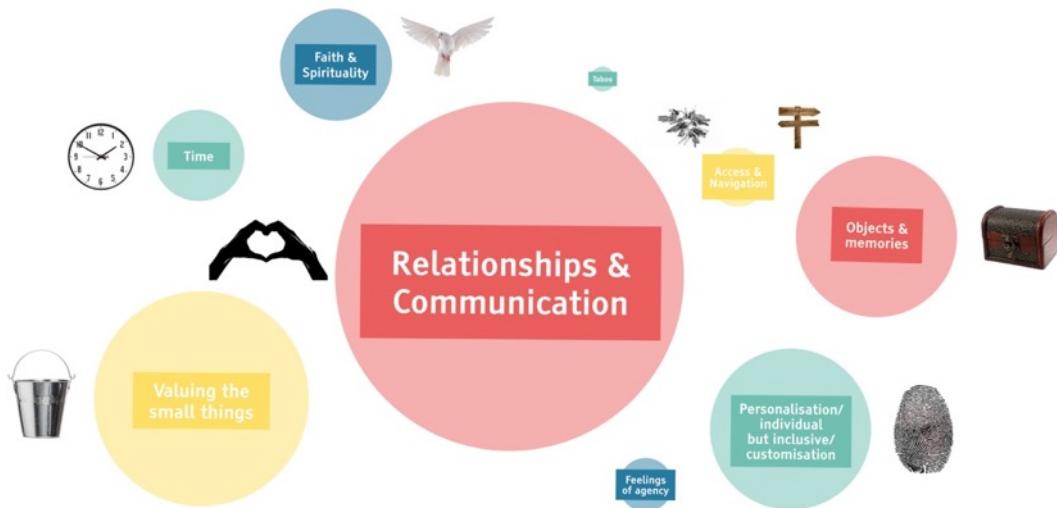


Figure 2: Themes

The strength of the Life Café methodology was that it led to the generation of rich discussion in relation to the importance of meaning and to an articulation of care and the centrality of relationship-centred support. Analysis of the data identified the following themes:

### *Relationships*

Good care was synonymous with relationship-centred care and this emerged as by far the most significant theme within the data. Caring for another person both shaped and was shaped by the relationship. Sometimes this could be positive:

'It was actually a privilege to care for her [mother]. I learned more about her in those last few days than I had a lifetime before.'

At other times this could be difficult:

'We were exhausted in the end, emotionally and physically which meant that we said things we didn't mean and which I really regret now.'



Participants described the impact of wider friendship groups within caring relationships. Two of the most powerful examples of relationship-centred care came from descriptions of community networks. Both related to being cared for in the context of mental health. The first reflected the value attributed to friendships of existing groups individuals were part of; the second described a relationship that was not close and where the person who had taken the role of 'carer' was unaware of the impact they had.

Analysis of the data showed that the broader theme of relationships contained levels of complexity and nuances between notions of care and how these intersected with personal beliefs about value systems and who should offer care:

'There are two types of care; one is looking after your family and children, the other is looking after others that need care.'

The challenge was that care offered through formal health systems could sometimes be regarded as less genuine, and less focused on the person.

## *Navigation*

Navigation and way finding were strong themes that emerged across the research. There were a number of dimensions to this. One the one hand this related to navigation of services and how people found their way through the maze of health care provision to access the care and support that best met individual needs. For example, one individual expressed this in the following way:

'We had been told that my mother had literally days to live. She was very ill by that point but I remember driving from hospital to hospital trying to get a commode to preserve what little dignity she had and all the time feeling that time was running out'

This was linked closely to the importance of understanding where people were within systems and having an overview of what was available at different points in people's journeys through end of life-care services '*knowing what is available when*'.

Within this theme it was not always enough just to know the service but also knowing who to ask, when to ask and how to ask in order to unlock the most appropriate resources.

On the other hand navigation linked to a more existential dimension, less about navigation of services and more about how to navigate the disease in the context of life. One very powerful description was about 'feeling your way' through the experience: navigating the emotional aspects of living with or caring for someone with a life-changing or life-limiting condition, and closely linked to this the more spiritual aspects:



## *Faith and spirituality*

Faith and connection to faith communities was significant for many individuals in our study. Spiritual and religious beliefs shaped individual perspectives of care, particularly end of life care. For some participants these beliefs acted as fundamental motivations for caring for others. For others, faith enabled participants to make sense of events as they unfolded.

## *Feelings of agency: the ability to adjust and accommodate change*

This at times linked to a broader theme around feelings of agency and the ability to exert control over small things even when in the midst of illness. This was not always easy as tensions could arise between letting others in to care whilst still maintaining a sense of agency and maintaining valued roles. Participants regarded seizing opportunities to grow and develop in the face of illness as important. This necessitated making changes to the way particular activities were performed in order to accommodate illness.

The unpredictability of illness and its impact on energy levels, which could vary massively from one day to the next, was seen as having a significant impact on sense of agency. A number of participants spoke then of the value of practical support that came in the form of internet enabled shopping services and telephone banking.

## *Communication*

These emotional and social needs were seen in this study as equal to or even taking precedence over physical needs and a strong theme throughout all the life-cafes was the importance of a holistic approach which recognised and valued the person beyond their illness. Finding a way to hear the voice of the person and the importance of communication was key to this. Indeed, there was a broad consensus across the groups that a key component of good care was communication. The following comment was indicative of many of the broader conversations and responses from participants across the research:

Good care is 'talking, listening, communicating, trusting, consistency, choice and time.'

## *Personalization /individual but inclusive / customization*

Good care was ultimately about listening to and responding to the person's story. Within the Life Cafes participants expressed the notion that it was impossible to describe a set formula for good care as it should be personalised. A metaphor for good care was a chameleon since good care simply blended into the rest of the person's life and was literally invisible, seamless. Finding ways to elicit this understanding was regarded as being part of the service itself.



## *Valuing the small things*

Inevitably tensions existed in ensuring how to create care services that are responsive to individual needs but have the scope to be applied to a broad population. The study highlighted a number of ways through which care was enacted. Within the workshops individuals described concrete examples of good care; significantly this was not always focussed on major interventions but frequently on detail and small acts of kindness. These aspects did not just relate to care given by family and friends but there were instances where participants who had formerly worked as health professionals who also attached importance to these aspects:

'When I was a nurse I sat with a man that was in the last few hours of his life, there wasn't anything I could do but sit, it was a privilege to be there. This was a huge thing for the family but all I did was sit there and give the time to be there for him.'

Another participant summed up this theme in the following words:

'You don't need huge amounts of electronics, technology or resources, sometimes it's the simple things that make a huge difference.'

## *Not much about place of care but awareness of value of sensory element*

Few conversations during the Life Café workshops related specifically to the site of care although many participants spoke of the value of qualities in the environment that promoted quality of life with particular reference to sensory elements. Individuals spoke of the value they placed on music, on touch and being held.

## Discussion

The themes identified in analysis of the data sat well and were congruent with other research in this area. For instance the need for systems to support individuals in navigating services, the importance of seeing the person beyond the label of patient and of the need to find ways to offer individuals facing end of life a sense of agency reflects the broader literature (Kjellgren et al 2015). Relationships within care were seen as central to care and to quality of life.

What was also clear from this phase of the research is that individuals living in communities were a rich source of support and had many resources to offer. Participants attending Life Café workshops not only described the qualities that they valued in the context of care but detailed examples of care they had both given and received. Emotional and practical supports were regarded on an equal footing to addressing physical needs. This adds further credence to the Government's Choices document (DoH 2016) which recognizes the need to work with and within broader communities to equip individuals and develop their capacity in offering services, 'reaching out

beyond the usual networks of organisations and communities to call upon contributions, ideas and actions from a wider spectrum of people' (Choices Document, 4)

Significantly individuals who participated in the Life Cafés identified the value of feeling heard within the research and the method itself offered people the opportunity express this:

'This has made an incredible difference to me today, to be able to share these things and to listen to you all.'

Death is a taboo subject, and attendees at the Life Cafés spoke of the need for more education and awareness. The objects and activities contained within the Life Café had immediate resonances with participants and prompted very personal discussions, unique to the individual. The value of objects and materials in promoting and supporting positive memories was seen as important and this was reinforced in the methodology adopted through the Life Café. Objects spark conversations, stories and hold memories. People talked about things that they had kept, not because of the monetary value, but because they held important memories - often memories of people and relationships.



Figure 3: Objects of importance

Through the iterative cycle, the objects and conversations themselves became part of the methodology and were embodied in the final Life Café Kit which is now being developed so that it can be purchased and independently facilitated in community settings.



Figure 4: Life Café Kit

## Conclusion

The Life Café methodology was found to be extremely useful in creating a space where conversations about living and dying well could occur. The enquiry highlighted that care and particularly end of life care is complex and nuanced where great importance should be attached to the details of how care is enacted. Finding ways to build understanding of the experiences and interpretations that individuals have in relation to care is something that practitioners and policy makers need to take into account. The challenge of palliative and end of life care is to find ways of accessing and creating understanding of factors that individuals in receipt of care find important and at the same time creating service models that can accommodate such differences in preferences, values and experiences.

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## **Of Other Products: Marginalized Perspectives, Speculative Heterotopia and Health Debate**

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**ABSTRACT** All lives are shaped by their health. However, the lives of people with disabilities are routinely shaped by their conditions and their relationships to the medical and social interventions that their health necessitates. More particularly, while many people with disabilities rely on prescribed and generic chemicals for everyday functioning and survival, society's narratives position disability as the site of a precarious, dangerous, imperilled or obliterated future. At the same time as people with disabilities suffer erasures in and through techno-ableist culture, health is developing as a locus in future-focused speculative and critical design practices such as design fiction. In response, Thinking with Chemical Stories: A Design Fiction Pilot brought together disabled artists, designers and academics ( $n=9$ ) to explore possible futures at the intersection of chemicals, health and disability through the co-creation of design fictions. In the five-day workshop hosted at Ryerson University, Toronto in July and August 2017, we made use of Foucault's six principles of heterotopia to explore design concepts, shape diegetic prototypes and frame potential design fictions. Our discussions led to the PainSonic diegetic prototype and the world building that sprang from it explored the relational nature of chronic pain.

We found that the principles acted as an effective cognitive heuristic that aided participants in the construction of a possible future world – a design fiction that may be understood as a speculative 'heterotopia of deviation'. The principles of heterotopia were also an effective aid in centring marginalized perspectives, while the process of generating design fictions was both a challenging and an enjoyable way for participants to explore and discuss their own health experiences. While noting that in use researchers should be open to the exploration producing unexpected insights, we conclude that participatory design fiction has potential as a method for the wide-ranging exploration of health-related topic areas.

Keywords: design fiction, participatory research, speculative design, health debate



## Introduction

All lives are shaped by their health. However, the lives of people with disabilities are routinely shaped by their conditions and their relationships to the medical and social interventions that their health necessitates. More particularly, while many people with disabilities rely on prescribed and generic chemicals for everyday functioning and survival, society's narratives position disability as the site of a precarious, dangerous, imperilled, or obliterated future. At the same time as people with disabilities suffer erasures in and through techno-ableist culture (Kafer 2013), health is developing as a locus in future-focused speculative and critical design practices such as design fiction.

Speculative Design is an approach encompassing design fictions that enables us to think about the future prospectively and critically (Auger 2013). Concerned with progress and ideas for the better, Speculative Design claims to take into account that better means different things to different people (Dunne and Raby 2013). However, this claim is contested from a number of standpoints, including economic and ethnic diversity, de-colonialization and feminism (Tonkinwise 2014; de O. Martins and de Oliveira 2016).

Despite such critiques and the tendency of design fiction to orientate toward mainstream conceptualisations, such as the Ikea Catalog from the Near Future (Bleecker 2015), Participatory Design has traditionally eschewed speculative practices. Instead, Participatory Design has favoured the use of insights generated by speculative and critical designers over the development of its own participatory speculative practices (Simonsen and Robertson 2012).

## Related Work

Recently, explorations have begun to be made into the value of combining Participatory Design and fiction (Knutz, Lenskjold, and Markussen 2016) and also for methods of participatory design fiction to explore social futures, what Sanders calls 'collective dreaming' (2017, 222). In the area of health Tsekleves and Darby have piloted participatory approaches to design fiction (2017; 2018). These projects have worked with older people in critiquing policy and shaping health debates in specific settings as a way to centre marginalized perspectives.

These factors lead us to recognize a need to develop and establish participatory approaches to design fiction and also to create design tools to aid participants, particularly those from marginalized perspectives, in imagining, building and exploring future worlds that place them at the centre.

## Methods

*Thinking with Chemical Stories: A Design Fiction Pilot* brought together disabled artists, designers and academics (n=9) to explore possible futures at the intersection of chemicals, health and

disability through the co-creation of design fictions. In this section, we provide an overview of project information, including the project leadership, funding and partnership arrangements, followed by a description of the number of sessions and their timings, and an outline of the recruitment strategy. We go on to outline a map used to introduce key concepts and the workshop process before describing the ways in which the concept of heterotopia (Foucault 1984) was used in the workshop and the ways in which provocation and triggering are interrelated in participatory design fiction practice.

### *Project Information*

The five-day *Thinking with Our Chemical Stories: A Design Fiction Pilot* workshop was held in Toronto, Canada in July and August 2017. The venue was The Responsive Ecologies Lab (RE/Lab) at Ryerson University and the sessions ran over 10 sessions with two per day, S1-S8 (n=10) and S9-S10 (n=8). The group was made up of 5 participants from the arts and 4 participants from Ryerson University and the University of Sheffield (UK). Participants were recruited by Creative Users and Ryerson University. They were purposively selected based on their likely interest in design fiction and their ability to offer insight into the chemical lives topic.

### *Workshop Process*

In advance of workshops an access audit was conducted and shared with the facilitator. After introductions and access check-ins, participants proceeded to discuss their chemical lives, imagining YouTube videos that shared their significant stories – quickly capturing the domain (title), potential interest levels (views), and topic extent (duration). Next, a map (See Figure 1) of process was introduced, which at its centre featured a diagram outlining the concept of heterotopia, 'sites which are embedded in aspects and stages of our lives and which somehow mirror and at the same time distort, unsettle or invert other spaces' (Johnson 2013). This was followed by a set of prompts intended to aid design fiction development. It is beyond the scope of this paper to give a detailed explanation of every prompt and principle; however, the prompts relating to heterotopia are listed below, as follows:

- Crisis and deviation
- Spatial juxtaposition
- Gatekeepers
- Transition and accumulation
- Functional mutability
- Illusion and compensation



We then introduced an example diegetic prototype, the Soulaje euthanasia wearable, from the ProtoPolicy project. Diegetic prototypes are technologies that exist only in a fictional world, they are used as part of the world-building apparatus in design fiction. We gathered the dimensions at play within the participants' understandings of chemical lives. We developed several design concepts that might act as the diegetic prototypes for design fictions to develop our understandings of the possibilities that such product and service concepts afford and to grapple with the nature of provocation in speculative practice. We then focused on developing one of these concepts as a group, exploring the alternative possible worlds that might arise, prototyping and designing.

As noted above, a map was used with workshop participants to outline the concepts at play in the workshop before the more detailed prompts were introduced. Maps are a common metaphor in futures discourse (Slaughter 1996). Taking up that metaphor, our map, A Portolan Chart of utility to the creators of Participatory Possibilia in navigating the seas of Possibility as they seek to lay eyes upon the edges of Near Future Possible Worlds, is a navigational aid designed as a way for the lead author to overlay a number of understandings of the future in order to outline a worldview in support of the use of participatory design fiction interventions into futures debates. Those understandings were developed by reflecting on the practices employed in ProtoPolicy (Tsekleves et al. 2017) and the preparations for the What If? Project (Darby and Tsekleves 2018).

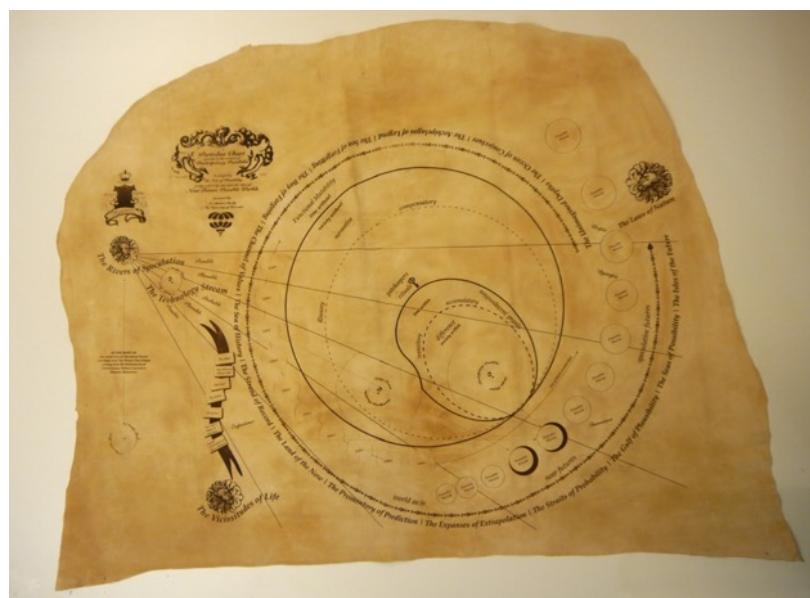


Figure 1: A Portolan Chart of utility to the creators of Participatory Possibilia in navigating the seas of Possibility as they seek to lay eyes upon the edges of Near Future Possible Worlds

The navigational aid introduces three controlling dimensions; *The Rivers of Speculation*, *The Vicissitudes of Life* and *The Laws of Nature* that together describe how our futures are fermented at the intersection of the world's physical limits, the vagaries of our own lives and the futures dictated to us by those with power. Temporal concerns are introduced through the *longue durée* (Armitage 2012) which spirals out from the past unfolding, with a poetic turn of phrase, from *The Unimagined*



*Depths to The Isles of the Future.* Intersecting this expansive temporality and diverging out from just below The Rivers of Speculation the lines of *possibility*, *plausibility* and *probability* (Dunne and Raby 2013) open across the width of the map. The expected fourth term, 'preferability', is purposefully omitted as it is itself under question as part of the process. At the centre of the map the concept of heterotopia is mapped out in order to give attention to the consideration of how products and spaces are formed around, and construct, both normative and non-normative experiences in the world. Wrapped around the diagramming of heterotopia, represented with small circles on the left and right respectively, are a number of possible ethical positions and a number of alternative possible worlds. Two possible worlds highlighted by dark shadow are positioned as being in the near future and connected by a dotted line to design fictions related to the normative and non-normative. The non-normative alternative possible world, formed from the design fiction, is linked by a dotted line to a circle representing a discursive space, which in turn links to the triumvirate of powerful futures influencers that are at the source of *The Rivers of Speculation – Academia, Industry and Government*.

Cognitive heuristics are commonly used in design ideation as they 'employ idea triggers that assist in creating concepts using simple prompts' (Yilmaz and Seifert 2010); they also provide strategies for guiding variation in developing design candidates. Throughout the workshop the principles of heterotopia were explored as heuristic prompts through variations on questions, such as – Who is in *crisis* and what is the nature of that crisis? Who *deviates* from the normative and what is the nature of that deviation? How does the heterotopia function as *illusion* in relation to the remaining space? How does the heterotopia function as *compensation* in relation to the remaining space?

The exemplars and design concepts introduced and created during the workshop were critiqued making use of these questions and ideas to introduce them fluidly into the design process.

## Discussion and Findings

During the workshop we developed five design concepts, one of which was prototyped with basic materials and used as a diegetic prototype to build a fictional world.

### *Triggering and Provocation*

Through the workshop process it became evident that the line between provocation and triggering is thin. When the *ProtoPolicy* project's central diegetic prototype was introduced to demonstrate how artefacts can generate a 'world' about them, most participants positively engaged with the euthanasia wearable, however one participant had to leave to regain their composure having been triggered by the topic. Triggering occurs when a person has a strong emotional reaction to an external stimulus and though the access audit was intended to manage this possibility the participant, unfortunately, hadn't declared the issue. The audit did highlight issues regarding racism and colonialism so when the 'Go Native' water bottle concept, a filter system to add E. Coli to bottled water (See Figure 2) inspired by workshop conversations and the



Walkerton incident in 2000, was created and offered to the group as an ad hoc provocation during the workshop, it was done so carefully with the facilitator having assessed the likely impact. Both the concept and the language used to describe it were usefully challenged and interrogated by the group through a discussion regarding the relationship between provocation and triggering. As a result of these discussions we laid out in-workshop guidelines to include topic warnings before presenting any potentially triggering concepts to the group. We were also able to debate what it meant to attempt to form a world from a diegetic prototype and to shape a discursive space from a provocation in a design fiction.

The group continued their discussions of their chemical lives and developed three design concepts of their own which explored their understandings of provocations and responded to previous discussions. These concepts were: The Baby Want to Be – a talisman and necklace that aids genetic manipulation for a narrow set of preferable traits and warns of congenital defects, A beach bench – recycled street furniture made from tampon applicators that are collected from the shoreline by the public as part of a monetized recycling initiative, and After Effects – a system that monitors a users' physiological response to a performance and directs users to locally provided support services if they are triggered by an event.



Figure 2: The ad hoc provocation 'Go Native' – an E. Coli filter for a water bottle

### *Heterotopia as a Cognitive Heuristic*

Having explored the basics of design fiction and discussed and debated their understandings of their chemical lives the group began to develop their ideas toward a diegetic prototype. They



focused on the use of chemicals in pain management and began to develop their diegetic prototype, a vibra-tactile modular suit that would provide relief for those with chronic pain without the need for chemical interventions.



Figure 3: Participants prototype the modular arm of the PainSonic pain-suit from cellophane, tape and paper

The prescription system was seen as a gatekeeping process, which would allow many people with disabilities to access the technology, but it was also subverted through discussions about DIY constructions and bespoke high-cost suits to attend 'cool' pain parties.

The pain-suit itself was the entrance ticket allowing the wearer to penetrate the *gateway* to the speculative heterotopia of the pain party. The party featured a 'DJ' mixing the various experiences of pain in the room. The *functional mutability* of the pain party was considered a progression from a sadomasochistic party, with discussions about the possibility of riding the contours of pain in both negative and positive ways and extensive discussion about the nature of pain as relational.

The chronic pain sufferer was centred as deviant from the healthy norm and the heterotopic space was intended to function as a *compensation* to their negative experiences of pain, a place where pain was transformed into a positive attribute. *Spatial juxtapositions* were left underexplored, however the externalising of human pain into a social construction might be considered an

incompatible spatial juxtaposition. *Temporality* was understood as fluid as it related to the experience of chronic pain within and without the pain party.

Not every question was answered, or even posed, however those that were helped to shape a unique experiment in participatory design fiction and gave a structure to expose relations that may have gone unimagined otherwise.

## Conclusion

We found that when working with participatory approaches to design fiction its essential relation with provocation needs to be considered carefully and facilitation modified appropriately to avoid triggering participants.

In addition, when conceptualized from a deviant, or rather marginalized perspective, the design fiction method through its world-building approach generates an alternative possible world that may be understood as a speculative heterotopia. As a result, Foucault's principles of heterotopia are not only a potentially useful way to explore a design fiction, but they are also an effective cognitive heuristic to aid in the construction of future worlds – a heuristic that may be of particular use when taking a participatory approach to design fiction world-building.

Beyond the workshop, the group have continued to iterate on and develop their initial ideas launching [www.painsonic.com](http://www.painsonic.com) in May 2018 and initiating physical prototyping of vibra-tactile technologies and generating designs for networked garments toward preparing a design fiction film.

## Acknowledgement

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## **A Pictorial Interviewing Method Designed to Effectively Include the Voice of Residents of Care Homes for Older Adults.**

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**ABSTRACT** We report on an ethnographic research method devised to examine the impact of the built environment of care homes on the health and wellbeing of their residents. Care home residents represent some of the most vulnerable people in our communities yet are key stakeholders in the life of residential care homes. We were therefore keen to capture their voices.

There are recognised problems associated with interviewing older adults and other vulnerable groups (Willcocks 1984). Thus, the views and experiences of care home residents remain under-represented in comparison to the voices of experts such as practitioners, academics and care deliverers (Burstow 2014; O'Dwyer 2013). Their choice-making strategies may be influenced by others (family, service providers) or affected by time and changing circumstances (Hillcoat-Nallé tamby 2017). The tendency by care facilities to address management information needs in the guise of resident involvement has also been reported (Baur 2013).

This essay describes the visual method we used to engage residents in conversation. The method is flexible, a potential co-production method and transferable to different study topics. It was also designed for participants with low levels of cognitive decline. The ability of residents to not only participate but also offer solutions to problems they identify, was evidenced in the findings.

The negative impact of lengthy and academic consenting procedures on the inclusion of vulnerable populations in research, is also briefly described.

**Keywords:** Wellbeing, Interviewing, Ageing, Vulnerable Groups, Inclusion, Care Homes.

## The Research Challenge

Our research approach was developed following regular relationship-building visits to six care homes over two years, getting acquainted with all stakeholders including management, staff and visitors. Becoming known to, and familiar with, the local environment and culture we noted the importance of activities to break up routine, creating other activities ourselves (Nevay and Lim 2015).

Our objective was to develop an accessible method to conduct supported conversations focusing on residents' knowledge and experience. We adapted a 1980s research method whereby residents were given cards illustrated with line drawings and text labels, similar to government information leaflets of the period. Each image represented a built environment element and they were used with cognitively able older adults (Willcocks 1984). However current care home residents are generally much older than in 1984, often 'in care' through circumstance, not choice, following a crisis, either health related or through the loss of a spouse or carer.

A pictorial approach to engage with individuals was devised. The intention was to emulate an inclusive 'game' interaction and neutralise the effect of an interview-like situation. The topics for the images (Figure 1) were based on care home observations, interviews with visitors and previous literature. The method was designed to encompass responses ranging from limited, to full engagement. This was to respect the sensibilities of people with low levels of cognitive decline and avoid participants' feeling failure, especially since ability could not be predicted until they participated. Our second pilot confirmed that we could use the 'game' without using the results (if necessary), and not undermine any participant.



Figure 1. Card Images used to stimulate discussions with residents

Following feedback from visitors to care homes we had produced a visual map of '*a journey through a mythical care home*' (Figure 2) resulting in the 'journey' framework which informed the narrative we employed giving structure, context and meaning to the cards as we used them with residents.

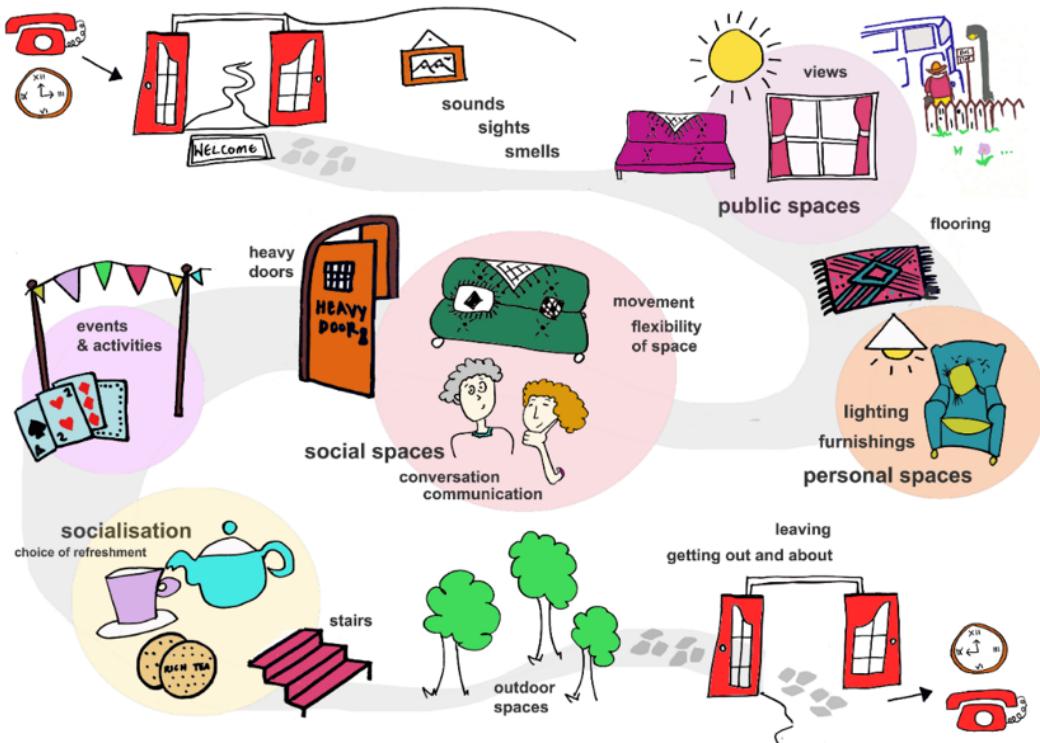


Figure 2. 'A journey through a mythical care home'

### Ethical Constraints

From previous work with older adults we perceived a further constraint to full engagement was an overly academic and long ethical consenting process (Dee and Hanson 2016). Initial adjustments to standard university processes received ethical approval but our first pilot participants still found the process too inaccessible. Normalising language use, and 'lightening' academic processes, without threatening research ethics, was important to create a 'level playing field' for these participants. In our second approved version the consent form was reduced to six verbally accessible bullet points which participants responded to with ease. We included images from the test stimuli on A5 information cards (Figure 3) with a photograph of the lead researcher and contact details. Designed to be large enough to be noticed and easy to read, they were widely available to changing shifts of staff, visitors and family members so all stakeholders were informed. Trust was maintained within the care home and the researcher easy to contact. It also proved useful as a prompt for conversations between participants and these other stakeholders. This approach proved successful in the second pilot study (including two residents with cognitive impairment) and with final study participants.

**BESIDE** Evidence for Built-Environment Design  
Towards Better Care Environments for Ageing

  
**Marianne**

**'IDEAL HOME' GAME**  
*What makes a good care home environment?  
Asking residents about the building they live in – gathering expert information*

**Who are we and why are we asking you questions?**  
 We are researchers from the University of Dundee. We are here to learn more about your building.  
 We want to understand how the building can be made to feel more like your own home  
 We want to know what you like and do not like about the building you live in.  
 You can ask us any questions too. If you do not want to talk to us we will stop asking you questions.

**What do residents think is important in an 'ideal' care home?**  
 Your opinions matter and can help architects and designers understand what makes a good care home building  
 Only YOU know what works and what fails because this is your home.  
 You are the experts.  
 We want Residents to tell us about the building they live in.

Please play our card game and tell us what you think.

**CONFIDENTIALITY**  
 We are not collecting any personal information.  
 You can speak freely knowing everything you say will remain anonymous.  
 We do not share your information with anyone else.  
 We will record our discussion with you to make sure we remember what you said. We keep the data in a secure place at the University of Dundee and all of the information will be destroyed after 5 years.  
 You can say NO at any time and we will stop.

**What are we going to do?**  
 We will play an Ideal Home Game (using pictures) and have a chat about what you like, don't like and what you think is important:

*Think about the building and what you like about it:  
 Think about what is important to you  
 Does any part of the building or the outside make you happy?  
 What could be made better?*



We can stop at any time if you don't want to play or don't like the game.

Thank you for talking to me - Marianne Dee  
 If you want to talk to someone else about the project you can phone Ian Harrison BESIDE Admin on 01382 384787

Figure 3. Information Cards for Residents' Ethical Consenting.

Ethical consenting procedures and the research method were tested and validated by an experienced care home activities organiser and approved by care home managers.

## Method

Our use of images was based on the need to encourage conversation but also reduce the potential of social desirability bias. Previous work draws attention to ways that institutionalised people in particular want to please their interviewer, search for the right



answer and are, understandably, reluctant to criticise the service they depend on for their everyday care (Peace 2002).

The use of objective images, bearing little resemblance to reality, was designed to allow negative feedback and counter the reluctance of a generation unwilling to complain (Pearson et al 1993). A symbol is neutral and simpler to comprehend, whereas photographs can be interpreted in an absolute way and lead to over thinking or fixation on a single aspect of an image, such as style or décor. Alternative communication practitioners report symbols as effective shorthand for those with cognitive conditions affecting communication or memory (Murphy 2015).

Thus, 39 A5 study cards displayed deliberately bright graphic images without text labels. The A5 cards were arranged into 13 topics to illustrate both the built environment (9 topics) and care home lifestyles (4 topics). The latter were included to encourage discussion around daily life which the built environment could impact upon. Each conversation was audio-recorded.

Sixteen residents across six care homes participated. Care home managers identified potential participants who met with researchers to check willingness to participate. Daily care home patterns were respected, interruptions expected and tea breaks or informal chatting were supported. All sessions took place in the care home at a time best suited to the resident and in an area identified by staff but influenced by the study needs; usually in a quiet space and always with a table to lay out the cards.

The cards were tested in pilot studies to ensure accessibility for people with low vision, hand tremors or wheelchair users. The A5 size addressed visual limitations and participants were happy using them on a table. The card sets acted as a prop to maintain the flow of conversation and the 'journey' provided a common framework and sequence.

One set of cards was shown at a time, each image described, and any questions addressed. Descriptions were literal -e.g., '*this is an outside bench next to a tree*'. Each image triggered a conversation and all responses were valid.. A window image for example provoked comments on indoor heating levels as well as light levels and views of the outside world.

After discussing each set participants were asked to place the cards in one of three boxes: '*important*', '*not important*' or '*don't like*'. This was a staged device to mark the intervals between sets, signalling the start of the next set of images and creating a participatory feeling. Box choices were not analysed, findings lay in detailed analysis of the recorded conversations in conjunction with the reaction maps.

Reaction maps were prepared forms on which participants' body language, facial expressions and strength of feeling were captured by a second researcher. Extreme enthusiasm or lacklustre responses were recorded, or participants pointing at examples, when terminology failed, was captured. Only overt non-verbal responses were recorded. A Likert-type scale recorded strength of feeling, gauging positive and negative responses to 10 topic sets and 39 images. The scale also noted disinterest or doubtful responses as being 'on the fence'. Following this live coding the two researchers immediately debriefed, sharing their collective experience to check each reaction map.

## Conclusions

Two researchers were important for the smooth operation of the game, observing residents' feedback and welfare, and good practice working with vulnerable participants.

The artefact 'trappings' (Figure 5), roused curiosity from other stakeholders making participation attractive and providing substance for later in-home discussions. Discovering that the re-designed Information Cards (Figure 3) became prompts for interactions between all stakeholders was a bonus.

The visual method proved effective in engaging in conversation. An established sequence enabled efficiency, held the correct discussion point, but allowed diversions. Exploiting face to face time was important as elders can tire but sociability was an important aspect of this activity. 'Talking while doing' is noted as therapeutic permitting diverse conversation whilst appearing to be active (Milligan et al. 2013, 12).

Participating then choosing a box replicated a game construct and recreated activity familiar in care homes. Residents found choice difficult and were torn between individual versus communal importance, with the latter tending to over-ride personal feelings.

Some images worked better than we imagined, e.g., 'seating' provoked a wealth of detail, while 'furniture layout' stimulated conversations about wider personal issues regarding the impact of communal living on socialising, privacy, choice and conflict.

The first set was deliberately small (Figure 1, Images 1 and 2) to ease participants into the method but proved unintentionally controversial, provoking early debate. The blue chair was criticised as lacking care home function, setting the scene for sharing personal expertise.

The rich detail from these single sessions suggest we tapped the surface of knowledge, elders in care homes, if enabled, could contribute to research and their communities.



The visual method required significant resources and time to develop, test and deliver in order to ensure a relaxed participatory experience.



Figure 5: Box Options

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## What moves you? Designing a walking app for and with older adults

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**ABSTRACT** *Older adults define keeping busy and enjoying hobbies as a valuable contributor to successful ageing. Walking is a popular hobby amongst older adults, and often their social network is a strong motivator for physical activity. Therefore, we designed a walking application in close collaboration with older adults to enable them to record walked routes and to share these routes with peers. With a prototype of the walking app, we conducted a pilot study with sixteen older adults, who used this app over a period of four months. During the pilot, we conducted focus groups and interviews to gain a deeper understanding of their experience with the application. In the design process we found that hobbies are a concrete design vehicle to brainstorm on future use together and the UI should match previous technology experience. With respect to the walking application we learned that the participants were more interested in the nature and quality of the routes taken by others as opposed to recording everyday walks, and that the intended other users of the application were influencing which routes they would record and share. These findings can guide designers in developing meaningful technologies for older adults.*

Keywords: co-development, older adults, leisure activity, familiarity, smartphone application

## Introduction

For older adults, there are continued health benefits of regular physical activity (PA), this is influenced by multiple factors such as self-efficacy, daily life integration, social support, financial resources and awareness of PA programs (Ory et al. 2018). Smartphones can influence people's physical activity, but recommendations should be contextualized and personalized (Stuckey, Carter, and Knight 2017). In the Netherlands, as of December 31, 2017, the national statistics agency (CBS) listed on its website that in 2017 an increasing number of older adults are using internet outdoors: 61% of 65-75 year old internet users and 33% of the 75+ year old internet users, while five years ago this was 16% and 4% respectively. As these numbers are increasing, we see the potential to empower older adults through internet-connected applications.

Previous research shows ways to motivate older adults to increase their physical activity, for example by environmental factors of their neighbourhood (Barnett et al. 2017; Lockett, Willis, and Edwards 2005). Furthermore, walking applications have been explored, such as a group walking game and a group walking program where users could collect stamps (Takahashi et al. 2016). However, in this study, we aim to let users determine where they want to walk. Social support is one of the most important motivational factors for older adults to be more physically active (Smith et al. 2017) so therefore we integrated social triggers in a walking application to stimulate people to walk more.

Successful ageing is most commonly seen as life satisfaction, high morale or the subjective assessment of well-being (Baltes and Carstensen 1996). While health is seen by older adults as the main contributor to successful ageing, keeping busy and enjoying hobbies are the second contributors (Kahlbaugh and Huffman 2017). The walking application aims to integrate both of these aspects. Literature also suggested that by shaping the meaning of technologies together in communities, older adults can adopt the technologies more easily (Righi, Sayago, and Blat 2017). Based on these arguments we envision to design a community-driven walking application for older adults.

In this study, we will describe a design process of the application with older adults, and investigate via a pilot the usability and experience of using this application in context.

### *The walking application: Ommetje*

The walking application 'Ommetje' (meaning: 'small walk' in Dutch) stimulated people to increase their walking activities by allowing them to record their walked routes and share these with peers in their (walking) community. The community serves as a social reminder and trigger to go for a walk. In the design of the application, we aimed to keep a low threshold to start using it. Therefore, the application was provided for free, and it was usable without the cumbersome set-up of an account. Users only need to fill in their usernames (if wanted), and then their location is automatically found by GPS.



The main menu serves as a safe point of return for the users, consisting of four functionalities (Figure 1, left):

- 1) recording routes, to track your walks.
- 2) reviewing your personal walking history including distance and when the walk was made. Also, it is possible to send and receive these walks to and from an individual user.
- 3) seeing the shared routes of others in a Twitter-like wall (Figure 1, right), to get inspiration from your walking community to explore new places. Users have the option to turn off the community sharing per walk and only display personal walking history.
- 4) creating a list of routes you plan to walk, to downscale the list of walks into the most interesting ones.

The two remaining tiles are for settings and closing the application.

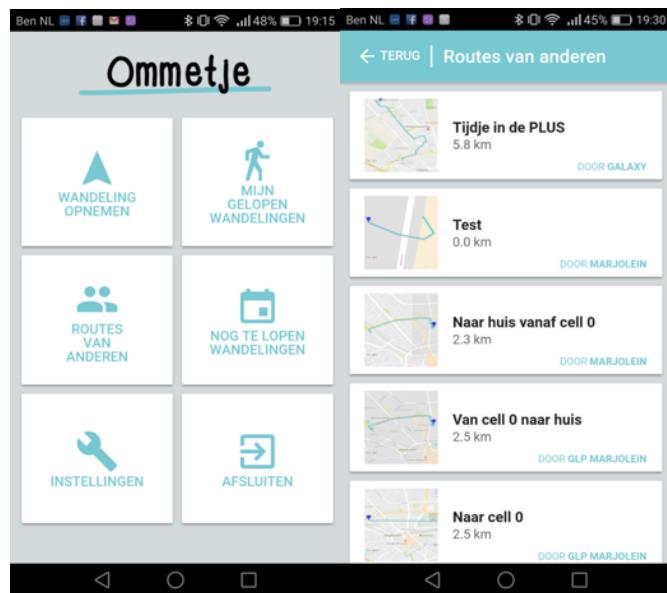


Figure 1: The main menu of the walking application (left), the Twitter-like wall showing routes of others (right).

## Approach

This section discusses the mixed-method used in the design process which consisted of two stages: 1) Three concept discussion sessions with 42 users in total, from May 2017 till August 2017 and 2) A pilot evaluation in which sixteen users, aged 63 to 83 (average 72), used the walking application for four months from November 2017 till February 2018.

During the concept discussions, firstly, we organized a session in which we presented the idea to understand people's willingness to use it (N=20). In this session, the screens of the application

were presented (Figure 2, left) as well as a related context picture to enable people to familiarize themselves easier as users of the application (Figure 2, middle). First, three main functions were presented, namely recording a route, seeing personal walking history and sharing routes with friends. Then people were asked for remarks and feedback. Second, two more advanced functions were presented, namely uploading a picture on a route and seeing highlights on a map when visiting a city. Again, these functions were discussed in a group setting.



Figure 2: Screenshot of application (left), contextual picture of the presentation (middle), the concept cards (right).

Secondly, we created eight like/dislike cards with concept statements (Figure 2, right), such as: 'I definitely do not think my walking information is interesting (e.g. walking speed, distance, and calories)'. From these cards, the participants ( $N=10$ , Figure 3, left and middle) individually selected which ones to answer to give more detailed feedback on specific functionalities. Drawing on the postcard design probe by Burrows et al. (2015), these cards were created to support participants in providing concrete remarks. After writing down their reflection on the cards, everyone shared a comment about one card.

Thirdly, a contextual inquiry (Dell'Era and Landoni 2014) with an early prototype was executed ( $N=12$ , Figure 3, right) to observe people's behaviour and discuss the logic of the interface. The researcher made a walk with every participant in the neighbourhood, which was created by the participant. The researcher had a passive role in providing hints to the participant if he or she was confused but took notes on troublesome interactions and steps. This preliminary testing was extremely valuable as we could implement the suggestions before the start of the pilot.



Figure 3: Using the like/dislike cards to determine functionality preferences (left), a dislike card (middle) and early prototype testing (right).

After the design process we conducted the pilot test, in which the focus group method (Barrett and Kirk 2000) was chosen to facilitate four group sessions over the course of the pilot 1) to guide them in learning the application and 2) to better understand people's experience and opinion of the walking application and how they used it. Finally, we concluded the pilot with a 1-on-1 interview to learn exactly how a person feels and thinks about the application, without others influencing this opinion, which could be the case in a group setting (Ireland 2003). Also, this gave us the opportunity to observe how people interacted with the application.

## Findings

We first present a summary of the collected data on the concept discussions of the design process. Secondly, we present the analysis on the focus groups and final interviews conducted during the pilot test, by the two facets of the walking application design: ease of user interface and user experience.

Concerning the three concept discussions, we first report on the session in which we presented the idea. Our participants saw potential in sharing walks with others, yet were concerned about privacy: 'who can see my walks and can I share anonymously?'.

Furthermore, people wanted the application to show deviation from the original route and wanted to use it for other purposes as well, such as cycling tours. It was interesting for us to see that people defined new use cases, so they could already in this early stage brainstorm on future use.



Secondly, from the concept cards, we got enthusiastic responses that people were interested in the application providing information on important places to visit in an unknown city. People particularly find it valuable to rely on other people's knowledge and experience with routes and are open to trying new things. One barrier a full-time caregiver experienced is that she had limited spare time and preferred to have walks in the neighbourhood. Some improvements suggested for the walking application were to 1) show what surfaces you come across (sandy, branches, etc.) 2) extend the application towards cycling (again) and 3) provide information on the width of the path (e.g. when riding a tricycle). These showed that our participants could indeed brainstorm on additions to the current design.

Thirdly, in the contextual inquiry, we looked at user interface and user experience. We observed some mismatches in the User Interface (Figure 4): 1) the dark orange record button was perceived scary and for emergencies only (figure 4, left), 2) some icons were different than expected e.g. heart icon for saving a route and the WhatsApp icon for sharing a route (Figure 4, middle) and 3) it was unclear how to get to the keyboard to type a name, so people immediately wanted to press the start button (Figure 4, right). Also, when starting a route from someone else in a different city than your current location, it was difficult to see because the application only shows your current location.

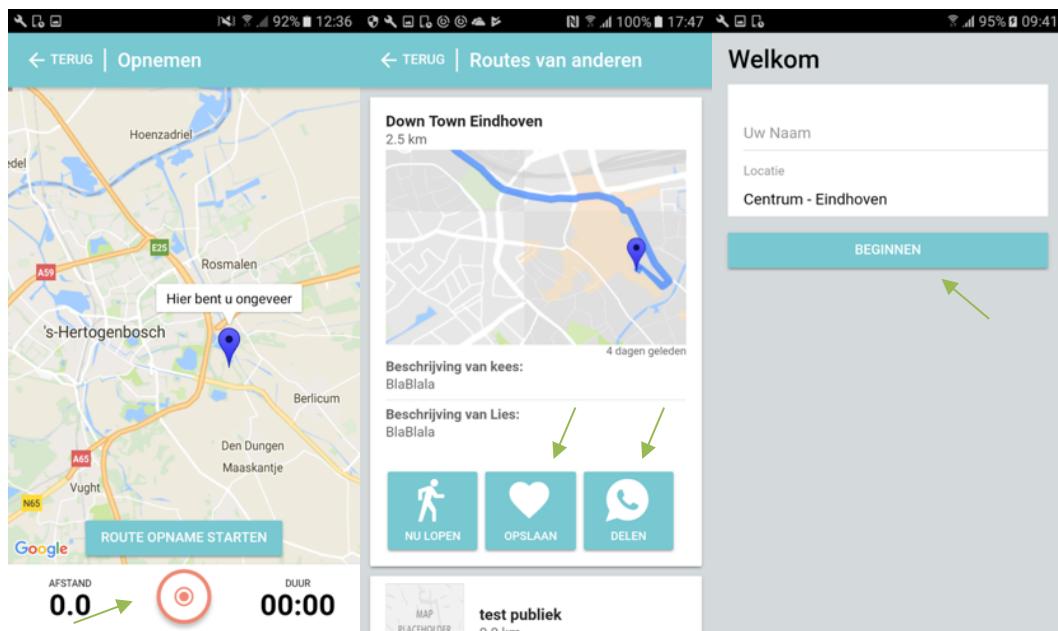


Figure 4: Mismatches in the User Interface: orange button (left), icons (middle) and keyboard (right).

To conclude the three concept discussions, we implemented the feedback and altered our design for the pilot test. From these we implemented, for example, a new sharing option where people could select to share in the community, with one person or don't share at all. Furthermore, extra information concerning a walk can be added to a route. In addition to this, the overall performance of the system was improved as well, the routes were recorded better, and the distance measurement was improved.



From the pilot test, we learned about the use of the walking application in context. From the sixteen participants, three dropped out due to health issues. A larger middle group used the application only sporadically with an average of two walks per person. Three users were very active as they recorded 8, 14 and 16 walks in total, and continuing to do so even after the research. Overall the recorded number of walks was lower than expected, though, the potential of the application could be seen by the participants as they were actively brainstorming on future use.

### *Ease of use: previous technology experience*

In the pilot test, we have observed people comparing their previous smartphone experience with the application, for example 1) the awareness of a limited phone memory so similar to a photo gallery they wanted to remove unnecessary routes from others, 2) the affordance of a map being an interaction possibility and 3) the critical mindset of more purposeful icons they are familiar with.

Leonardi et al. (2008) mention language spoken by the technology used to be unfamiliar to older adults, as it was from outside of their culture. However, we see this trend is changing now, and older adults start reflecting on the User Interface themselves. There are still considerable differences between older adults in this respect, and this complicates future UI development.

### *Experience of use: quality over quantity and sharing with community*

Our assumption was that people would use the application to track any walk they made and therefore have an activity overview, and be socially motivated to walk more due to sharing these walks. For one participant the application indeed grew, because of this overview, to a core reason to use a smartphone. However, for many participants the core function of the application was only recording and sharing routes outside the village. They assumed that routes in the village were known by the villagers (their peer participants). This is somewhat surprising as people could also decide to track their routes but keep these only for themselves in their personal walking history.

Though it became apparent that our participants were currently more interested in the quality of the route, a nice nature experience outside the village, than the quantity of the walks they made, for example by recording every walk to the supermarket. In hindsight, this is in line with Kahlbaugh and Huffman (2017) who suggest we might focus on evaluating the number and frequency of activities, while for older adults the perceived quality may be of higher importance. Or as one user strikingly mentioned: 'I would like to see pictures which show me what a nice route is, so you know a little bit more if you come across something nice, specifically if you are visiting another village' (Participant 3, final interview). Therefore, we see the potential to design for collecting these valuable experiences.

This focus on sharable routes outside the village only, may be due to our framing of the application within this community, because both learning and sharing were promoted with



people from one village. As Righi et al. (2017) suggest we should design for people and their community, as 'the meaning of technology is shaped in dialogue with everyday practices'. So, this influences the use of the application a lot and we could hypothesize that if we enlarge the community of the walking application, people would be more willing to contribute nice routes in their surroundings for people outside their social network as well.

## Conclusion

By designing and evaluating for hobbies together with older adults, we intended to gain further insight into what sparks their enthusiasm and how we can address this better in future designs. By involving our participants in the design process and use this concrete walking application, they were able to reflect on it and we learned we should focus more on quality rather than quantity of the walks. We addressed two dominant factors while designing for older adults: 1) to match a new design with the user's previous technology experience and 2) to be aware of the user's environment in which they use the application, both the physical environment where you are, and the social environment with whom you use the design together and thus also what is valuable to them.

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## Framework for technology engagement and adoption in older adults

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A wide range of technology products including health-related items such as blood pressure monitors, electronic medication reminders, and other off-the-shelf products such as smart phones and tablets could help older people to look after their health and wellbeing. However, older people have been slow in adopting technology products. Previous studies on technology adoption in older adults focused on factors contributing to behavioral intentions towards adoption of specific technologies such as mobile phones (Wang, Chen, and Chen 2017) and interfaces and smart technologies in automobiles (Lee et al. 2015). The findings revealed relationship between behavioral factors such as physiological limitations of ageing, anxiety, intrinsic motivation, perceived usefulness and ease of use to behavioral intentions to technology use. However, these findings do not reveal implications to design and thus there is a need to study design factors that initiate an engagement with technology products and factors that ultimately result in technology adoption. A one day participatory workshop was conducted with older adults, caregivers, healthcare providers, industry representatives, researchers, policy representatives and community partners, to examine factors that influence older adults to engage with technology products. This facilitated workshop comprised several interactive sessions utilizing TUNGSTENTM tools. Among these was Technology Interaction, an activity designed to encourage participants to share their thoughts about technologies "out-of-the-box". Participants from different backgrounds were allocated to each table, with at least one older person assigned to each table. A 'mystery box' consisting of store-bought technology products in the original packaging was placed on each table. Working in pairs, participants selected mystery box items to try out. Each pair in turn then fed back their perspectives on their interactions with the products. The Technology Interaction session was video-recorded and analysed using Noldus Observer XT to examine user engagement and barriers to technology adoption. Overall six themes emerged from this study, five relating to product design features - affordances, aesthetics, typography, familiarity and product interactions and one accessibility theme related to the use of these products such as access to resources (for example WIFI, smartphones), remembering passwords and assumed previous knowledge and expertise. The outcome of this research study is a new framework that outlines factors that influence older people's engagement and adoption of technology-based products.

## Design + Nursing: Transforming Concussion Prevention Through Inter-professional Education

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**ABSTRACT** In 2013 our university publically supported a university-wide research initiative addressing the need for concussion prevention among student athletes. As a response, faculty from Industrial Design and Community Health Nursing joined together to conduct three years of collaborative studio experiments addressing the risks and preventative solutions for concussion. While the original call was for college athletes, it became apparent that our study should include various age groups including elementary, secondary, and collegiate levels.

This experiment was a true collaboration of unlike minded faculty and students who combined their expertise, formed teams and worked together utilizing both the design and nursing processes to identify at risk populations and develop solutions. Using our 'touch and go' collaboration process, the student teams conducted in-depth stakeholder analysis and underwent an iterative process producing several solutions directly targeting vulnerable populations. The student groups performed lab testing of products and transformed these into actual or conceptual products that were designed to benefit the end user. Since our involvement in this initiative, our student teams have focused on concussion prevention in high-risk associated sports, including American football across all student age groups, hockey, as well as cycling. Recently, we addressed concussion prevention among college-aged athletes participating in women's soccer, women's lacrosse, and cheerleading. Our student teams worked closely with patients, caregivers, doctors, and therapists to develop a clear understanding of how concussions occur in each of the sports. With this information, these students develop primary, secondary, or tertiary prevention strategies including education systems, virtual awareness training, and wearable product solution to name a few. Since this time, projects have been included in several upper level grant applications, and an across campus appreciation for the completed work.

**Keywords:** Community health, collaborative design, collaborative methodologies, prevention



## Introduction

In 2009 our collaboration began its journey. It started when faculty from the University of Cincinnati's Industrial Design and Nursing: Community Health programs were collaborating in an existing university centre focusing on aging. During this, it became clear that the methodologies of design and nursing were more closely linked than anyone had thought. Because of this, and with support from our deans and university president, we spun out the Design+Nursing collaboration. Since then we have been solving problems ranging from over bed tables to mild traumatic brain injuries. Not only have we exposed our students to great projects, we the faculty have also learned much to expand our research base and inter-university opportunities based on our expanded professional network.

In 2013, following a university-wide research initiative addressing the need for concussion prevention among student athletes, our collaboration unanimously agreed to focus efforts on this topic. While the original call was for college athletes, it soon became apparent our scope should include various age groups adding elementary and secondary levels.

This Visual essay will focus on how the Design + Nursing collaboration was assembled and positioned for success.

### *The Basics*

When developing our collaboration's workings, we hit several roadblocks including: How one class would be offered in two colleges, crowded curriculums, and student recruitment. We found each program had student populations appropriate for this type of experiential learning. Nursing's schedule proved to be more flexible and could parallel industrial designs'. Our plan was to have the community health clinical meet at the same time as Industrial Design's 3<sup>rd</sup> year design studio. This solved logistical issues. To address cross discipline course addition, we decided to use courses already offered for each program and adapt them to a collaborative experience. This also solved our recruitment issues. We housed the collaboration in a studio setting giving nursing students an experience different from a typical classroom.

The professors had taught collaborative courses outside of this arrangement but not as focused. While developing student-learning outcomes, concerns arose regarding total immersive collaboration and the inability to have specialty specific time. To address this, we developed a 'touch and go' collaboration model. This model's hypothesis was 'collaboration can be effective by interval interactions'. Our student level required time to have discipline specific discussions to ensure their design and nursing fundamental skills were on track. We scheduled our classes to meet collaboratively every Thursday afternoon. Discipline specific interactions were set up outside this time. For homework, students were required to meet outside the collaborative time. This schedule was set up early in our collaboration and has proven effective over the past nine years. Success couldn't have occurred without the willingness of one collaborating partner to alter their schedule. Compromise was key in finding our collaborations foothold.



Finding the right combination of collaborating students has been challenging. Early on we used 3<sup>rd</sup> year Industrial Design students and Nursing students studying in Traditional and RN-BSN tracks. After running 4 studios using this model we found there were several pros and cons

Table 1. The basics

Design Pros	Nursing Pros
High enthusiasm	Experience in nursing
Good ideas and skills	Experience working with other disciplines
Design Cons	Nursing Cons
Did not understand collaboration value	Community health was not priority for all students
Did not see collaboration as an asset	Competing curriculum priorities
Lacked design maturity	Check the box mentality for most students
Had to take the course	Had to take the course

## The perfect combination?

Moving into the middle stages of the collaboration we began our focus on concussion prevention. To be impactful in this area, two aspects of our student participants needed changing.

We needed students with a higher maturity level who understood the inherent value of collaboration.

The course should be chosen not required.

Keeping our course structure, we moved from fall to spring semesters. This enabled us to take advantage of higher level, 4<sup>th</sup> year, design students and recruit accelerated graduate masters nursing students.

At this level design's curriculum requires participation in interdisciplinary design courses. Students from Fashion, Visual Communications, and Industrial Design majors are allowed to take studios in each other's disciplines.

The accelerated graduate nursing students came from various backgrounds that did not always include health and wellness. This combination of student body appeared as a perfect fit. Not only did students have better skills and maturity, they also would have to sign up to take this particular topic out of a list of many offerings.



During this phase we defiantly saw differences in output and quality. From the nursing perspective, the accelerated students were perfect for this type of collaboration. They understood the value from past experiences and were passionate about the topic. Issues did arise surrounding our design students. For most, this was the first time they'd worked in an interdisciplinary environment. Not only were they working for the first time with students from a different field they were also working with designers from different disciplines. It was also the first time they had worked in a team construct. These factors caused an adjustment period that was unexpected and effected design outcomes. This arrangement lasted two years. During this time we overlooked an important fact: Design students had approximately nine studio topics to choose from and many times our studio was their 2<sup>nd</sup> or 3<sup>rd</sup> choice. The pros and cons are shown below

Table 2. The perfect combination?

Design Pros	Nursing Pros
Higher skill sets	Self selected course
Advanced understanding of the design process	Passion to work on concussion prevention
	Previous professional experiences
	More mature
Design Cons	Nursing Cons
Not their 1 <sup>st</sup> choice	Heavy course load
Minimal collaboration and team experience	Troubles meeting after class.

## Moving to the graduate level

Recently we experimented with teaming Masters of Design students with the Accelerated graduate nursing students. This did not work as well as hoped. The nursing students were a perfect fit but design students were challenged. While the maturity level of the MDes students was high, skill sets varied to extreme levels. Meeting times were another issue. MDes students only meet once a week and did not allow for discipline specific teaching. These issues proved to be success deterrents. Below are the pros and cons

Table 3. Moving to the graduate level

Design Pros	Design Cons
High maturity level	Extreme skill level variation

Knowledge from various backgrounds	Communication: English as second language
Very good collaborators	Breakout time eliminated
	Some were novice designers
	Heavy course load
	Not a self selected course

## The Future

Looking forward, we will revisit the Industrial Design undergraduate student population. We will run our collaboration in summer where senior designers will be taking their final studio before capstone. In this semester, students are given the choice of picking one of four studios and many look for wellness topics. We feel this will be a great student pool due to their maturity/skill levels, experience, and ability to self-select. We will run this studio every other year to match faculty summer teaching requirements. We will also give student teams more independence and flexibility to choose community health topics rather than focusing solely on concussion.

## Our process

Early in this writing it was said

‘it became clear to us that the methodologies of design and nursing were more closely linked than anyone had thought’

This directly related to similarities of Design and Nursing processes. These processes had parallel objectives but were titled differently. We learned that certain process tasks were more advantageous to execute in a collaborative environment than others. This formed our ‘Touch and Go’ model.

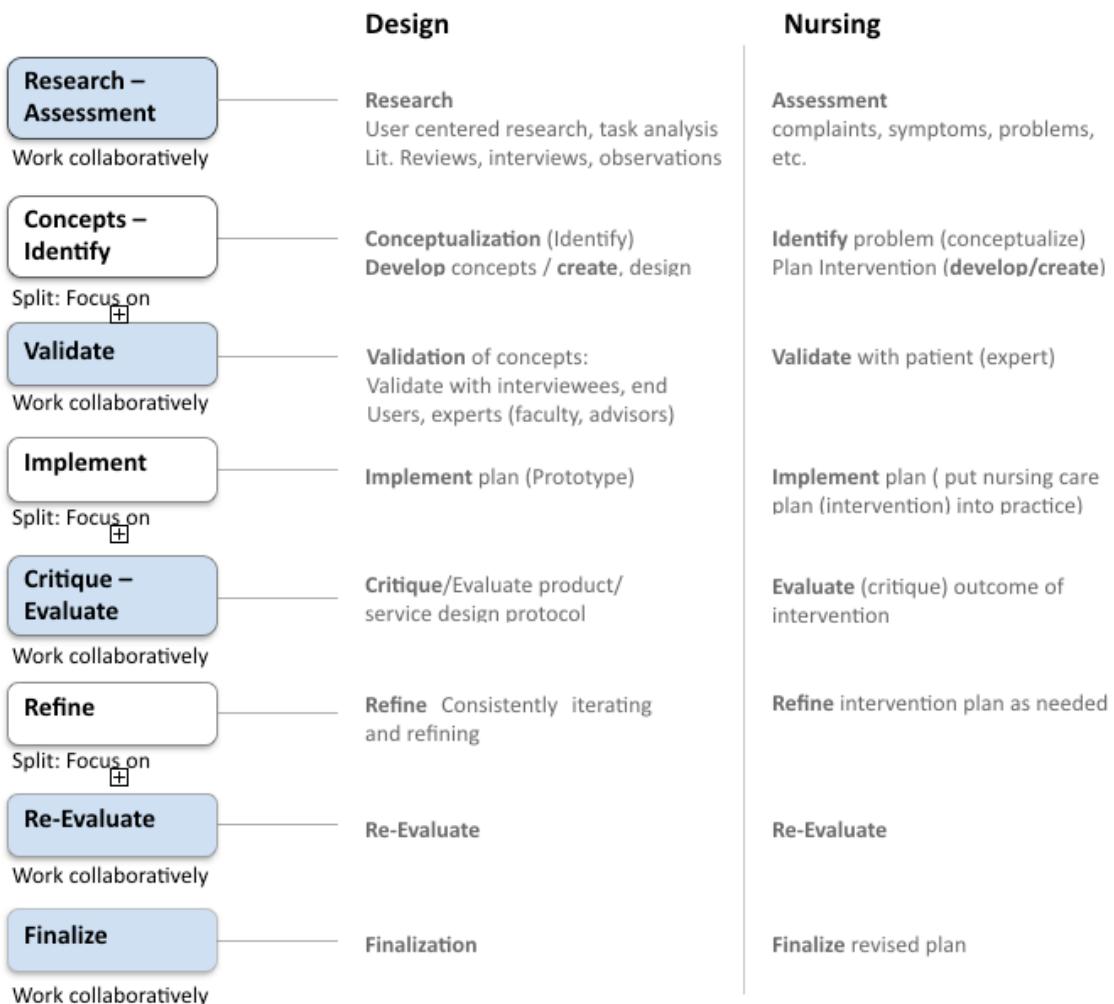


Figure 1: Each step requires collaboration while developing discipline specific deliverables. Each phase ends with an integrated presentation. Blue boxes represent full collaboration.



Figure 2: Research/Assessment; Design and nursing students collaborate to gain an in depth understanding of their community through primary and secondary research. Main deliverables from nursing are population pyramids and design develops info-graphics based on key findings

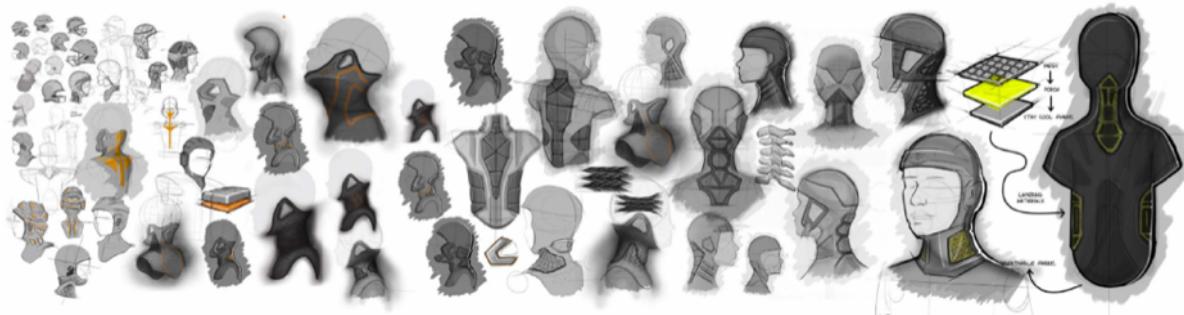


Figure 3: Concept and Identify; Students loosen their collaboration and focus on discipline specific activities.

Designers begin iterations based on research. Nursing uses design concepts as stimulus, identifying methods for intervention strategy development. End deliverables: 3-6 comprehensive solution directions with a conceptual intervention strategy.



Figure 4: Validation; Using concepts and intervention strategies as tools. Our students re-join in a tight collaboration going back to those originally interviewed and gaining concept related feedback. End deliverables: comprehensive oral report and a plan for refining to one final direction.



Figure 5: Refinement; During this phase students loosen their collaboration and focus on refining one direction that integrates all Validation feedback. End deliverables: designers make minor revisions and begin final build. Nurses refine their conceptual intervention strategy to match product refinements.

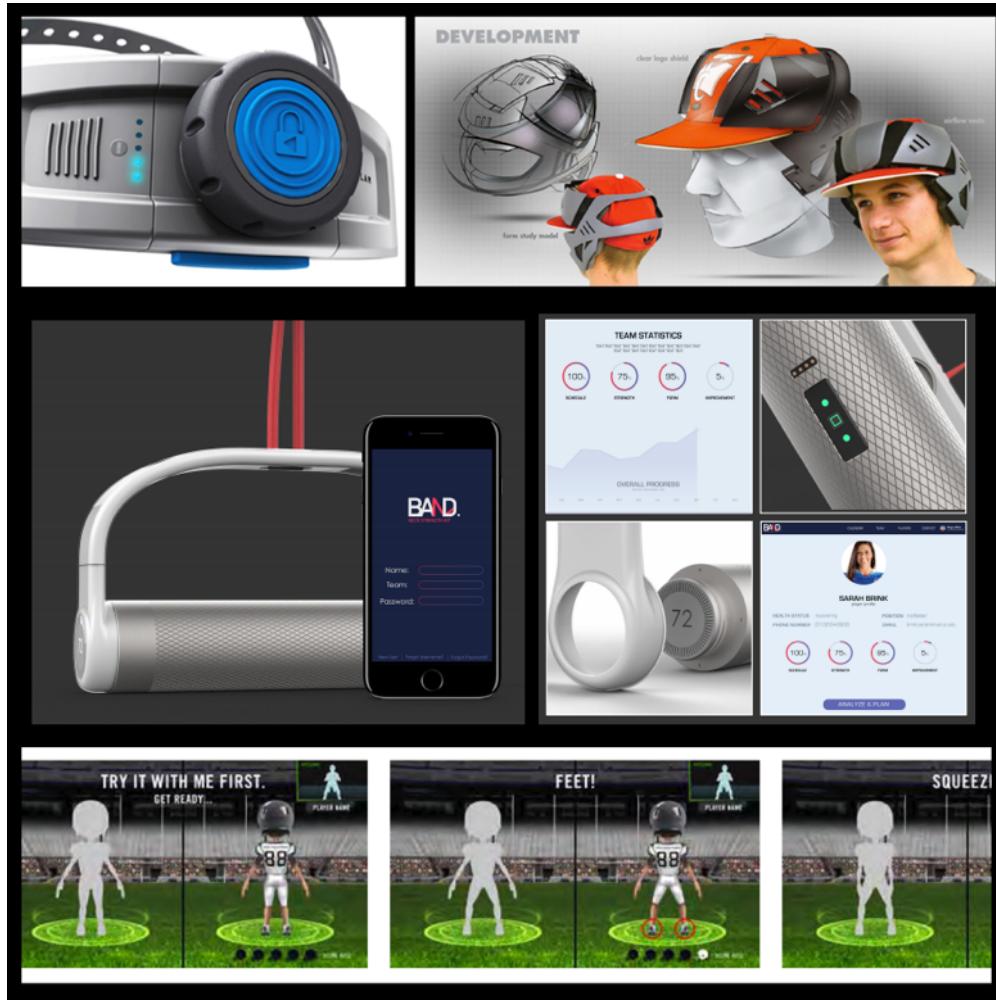


Figure 6: Finalization; high quality concepts that are clinically back, stakeholder validated and ready for public option



Figure 7: Presentation; we invite our areas investment community to review student work. This has resulted in student employment, grant integration, and commercialization funding

## Conclusion

It is evident that this collaboration is a win-win for students and faculty, both groups benefitted from the interprofessional collaboration experience. Upon completion of the course, many shared that they gained community empathy for those utilizing their project and appreciated the impact their solutions could have. Students expressed increased confidence in their skills and gained more from the experience than they gave. Students also shared that they had an increased appreciation for the value of collaboration when solving big challenges.

Faculty involved in this course increased collaboration skills as well, as they experienced professional growth and network expansion as new relationships were formed with colleagues outside of the college and university. Each faculty intimately learned the process and mind-set for the other discipline, and over time, became competent to guide the direction of the entire collaboration. Our collaborative course is positively recognized in both colleges, and will continue to be an option for students in the future.

## **Product Representations as Mediating Tools in the Development of New Medical Technology**

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**ABSTRACT** *Involving users in the design process of new products and services is generally disputed as a prerequisite for fulfilling users' needs and requirements. The importance of user involvement has been argued also regarding the development of new medical technology. Collaboration between users and developers/designers is however not without problems due to differences in, e.g. background, training, perspective, and vocabulary. In order to address these differences, the need for different 'mediating tools' has been emphasized. One type of mediating tools is product representations (PRs). Earlier studies have most often focused on the type of PR that should be used in different phases of the development process in order to get input on different designs. This paper describes instead how and in what situations different PRs mediated communication and collaboration between professional users (medical experts) and designers in an innovation project targeting a solution for long-term monitoring of brain activity based on electroencephalographic (EEG) signals.*

**Keywords:** user involvement; mediating tools; product representations; smart textiles, EEG monitoring

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## Introduction

Long-term monitoring of the brain activity (EEG) is part of the routine treatment of prematurely born infants (Figures 1a and 1b). Today's method requires single electrodes to be positioned on the infant's head according to international standard. The method has however several drawbacks as it is time consuming, complicated and requires specially trained staff. An additional drawback is that the electrodes' position is undermined if **the infant moves its head, resulting in disrupted monitoring**. Even more problematic is that the currently used electrodes often lead to complications in terms of severe pressure damage to the skin on the infant's head. EEG-monitoring is therefore limited to intermittent use which does not correspond to the clinical need (ideally 24/7).

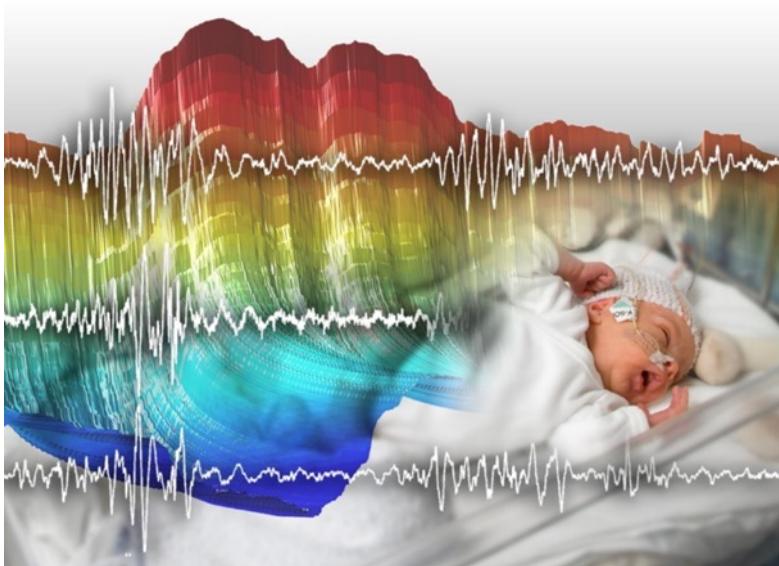


Figure 1a: A new-born baby at neonatal intensive unit, monitoring EEG-signals. 1b: Pressure marks from electrodes after short time usage. Copyright permission from Johan Löfhede.

A cross-disciplinary project was initiated to explore if and how new textile materials (that respond to stimuli from the environment) and techniques (an innovative 3D weaving technique) could address the problems described. The project team consisted of different key competences: one clinical expert (neurophysiologist), two biomedical engineers (one in signal processing, one in electrophysiological signals monitoring), one 3D weaving specialist and one specialist in textile engineering. Thus, each team member also represented either a 'professional user' perspective (i.e. the clinical expert and the biomedical signal-processing specialist) or a 'design' perspective (i.e. the textile competencies and the specialist in electrophysiological signals monitoring). The project team met nine times during the nine months project, iterating between discussions of users' needs and requirements and potential design solutions and tests of the same by the user in the use environment (Figure 2).

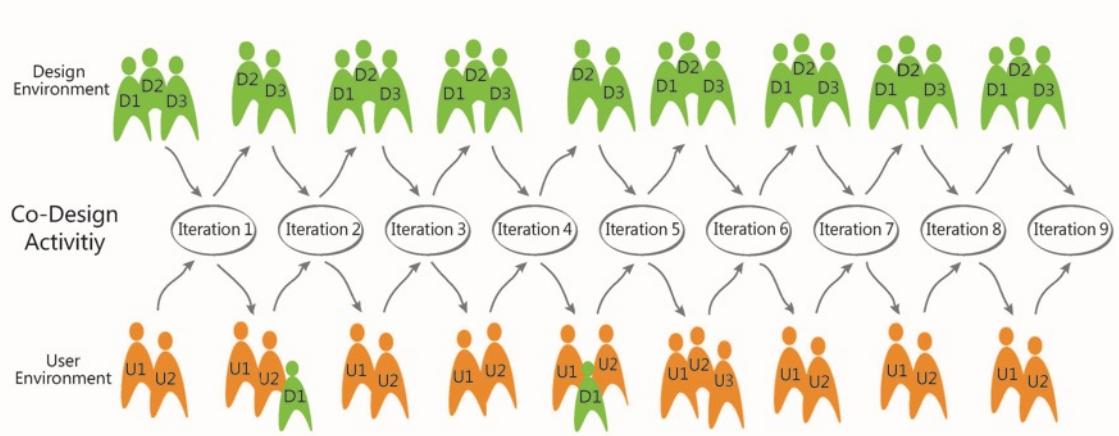


Figure 2: The iterative co-design process (D=designers, U=users)

Involving users in the design process of new products, including new medical products, is generally disputed as providing benefits in terms of, for example, ideas for new and innovative products (von Hippel 2005), identification of deficiencies and potential problems in current and future products, as well as suggestions for solutions to these problems (Engelbrektsson 2004). However, several barriers have been found to collaboration between users and designers such as differences in background, language, and terminology (Moody 2015) as well as in goals and perspectives (Chamberlain and Bowen 2006; Karlsson et al. 2011).

In order to address these obstacles, the need for mediating tools has been emphasized (Star and Griesemer 1989; Carlile 1997). These are stimuli that enhance reflection, facilitate discussions and support focus on a specific topic (Engelbrektsson 2004). One type of mediating tools is product representations (PRs), i.e. something that represents any kind of feature in a (future) product. Examples include design specifications, hand-drawn sketches, mock-ups and physical or digital prototypes. PRs are though not per se synonymous with mediating tools, rather it is the manner in which the PR is used that distinguishes a PR as a mediating tool (Söderman 2001).

In the cross-disciplinary project different PRs were introduced (Figures 3a; 3b; 3c).

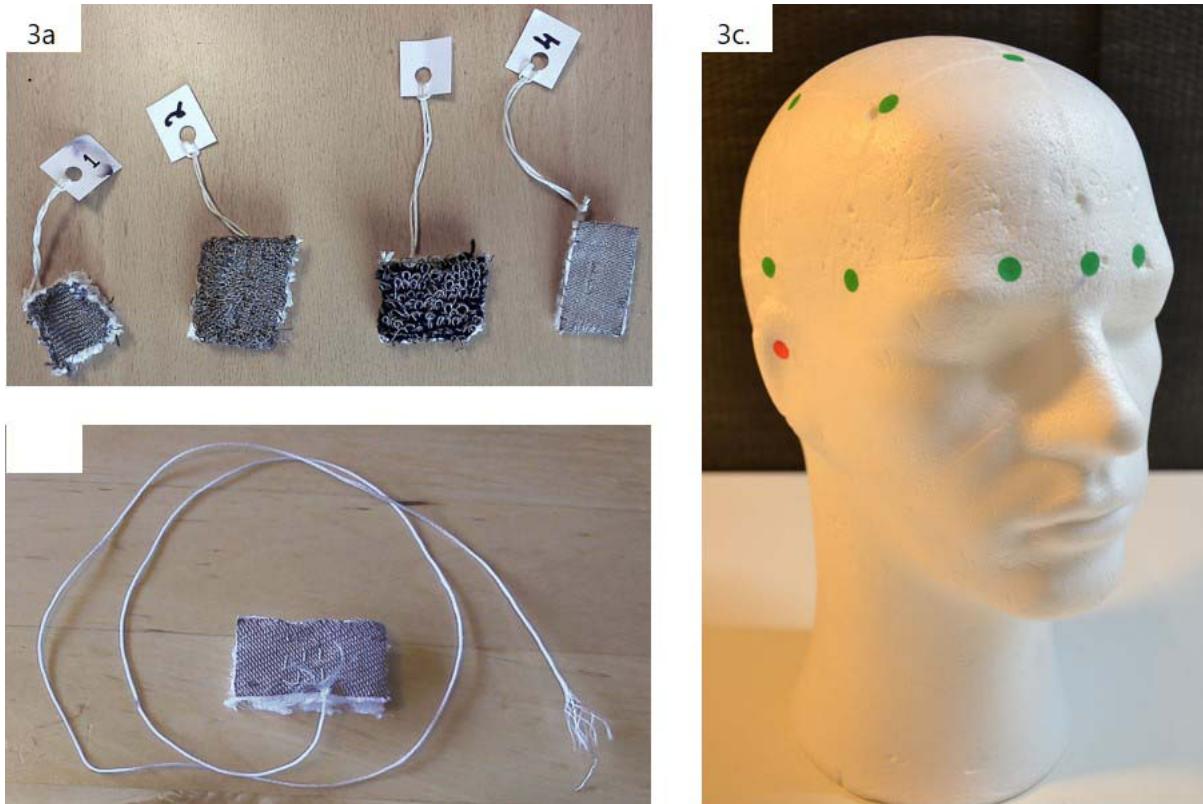


Figure 3: Examples of PRs used (3a) Various textile electrodes (3b) Electrodes with integrated textile cable. (3c) Dummy head illustrating electrode positions.

Whereas earlier studies have most often focused what type of PR that should be used in different phases of a design process in order to get input on different designs (Houde and Hill 1997; Stompff and Smulders 2015), the purpose of this paper is to describe how different PRs mediated communication and collaboration between the professional users and the designers in the project.

Findings are based on content analysis of notes, transcripts of recorded dialogues and participatory observations at the nine sessions. Posed questions and answers, confirmed understanding (or not) related to technical matters, social dialogues and the PRs' role in different situations constituted the coded themes in the analysis.

## Findings

The analysis showed that a substantial part of the dialogue between users and designers was characterized by questions and answers. The questions posed were initially fairly general but as the process progressed more specific and considerably more detailed questions were asked. The PR appeared to stimulate (in particular) the users' curiosity and desire to understand what was represented and hereby understand the proposed technical solutions. Examples of typical questions were: 'Is that plastic?' and 'That is insulation against humidity I guess?' but dialogues could also develop as follows:



User 1: What signifies this coaxial? What does it really mean?

Designer 2: That it... here it has a core and then isolation and conductivity to shield... and then it is a shield...

User 1: It's one centre and then it is insulated?...thin and delicate...that can be very practical in this for us.

Similarly, the PRs were often used to replace words or 'filled in' where words were lacking. In these situations, multimodal communications in terms of using deictic gestures and being able to, for example point at part of or details of the PR appeared essential: 'Here ...', 'There ...' or 'This is ...'.

The analysis also revealed several situations characterized by certain leaps in understanding of perspectives. For example, the designers had consistently used terms such as 'net' or 'ribbon structure' to describe the new concept while the users had used 'cap' or 'helmet' – but no one had paid attention to, or to the implications of, these differences. However, this changed when one of the users wanted to share a new experience he had made, visualized by his own hand-drawn sketches of the design of another and more complete prototype for EEG-monitoring. It became obvious to the designers that the sketches illustrated some differences but also similarities between the designers' ideas and the ideas presented by the user which the designer, mediated by the PR, could explain. More importantly though, faced with the sketches, the designers as well as the users understood that their respective image of the final design differed. The PRs used up until this point in time had been samples of separate electrodes or improvised sketches visualising details to be potentially included in the final design and it is possible that none of the PRs had challenged the individuals' mental model of the solution and hence both users and designers could persevere in their respective idea of the design solution. It appears that the user needed a more complete prototype to fully understand the designers' idea while the designers needed the user's own representation to grasp that the user had not fully understood their concept. Hence the PR mediated an integration not only of terminology but of perspectives which helped form a common mental image of the design solution.

Another example of integration of perspectives and formation of a common goal concerned product properties. A number of user requirements had emerged over time, such as that the solution should apply a 'soft pressure' and be 'smooth' and 'elastic'. To one of the sessions, a prototype, including many of the features asked for and assembled as a functioning whole, was demonstrated to the users:

Designer 1: ... this is to adjust the size (showing an adjustable part in the prototype) but we have to have a material that is ...more elastic but not very much...

User 1: (exploring the prototype)... As you said it is probably a good thing to have...in the end...more elasticity to improve the contact ...

Designer 1: ...and...we actually put in all 21 electrodes...



User 1: Feels good... (touches and evaluates the feeling of resilience, and surface haptics of the electrodes).

These requirements, expressed as 'soft pressure', 'smooth', and 'elastic' are requirements referring to individuals' experience of a certain property, with limited possibilities to describe in technical terms. The tangibility of the PR enabled, in this case the users, to handle and explore the properties and thus evaluate if the proposed solution fulfilled their requirements. The physical and tangible PR became the common reference for the specific properties discussed, and thus facilitated the formation of a common objective across the team members.

To be able to take part in a design process, users have to acquire some knowledge about the possibilities and limitations of (new) technology while designers need to acquire detailed knowledge on use, in this case the practice of EEG, to understand how to fulfil users' requirements. The different PRs played an important role in this type of knowledge transfer. For example, even though the designers had received verbal instructions and schematic sketches illustrating the electrodes' correct position on the head, when a physical prototype was to be jointly tested the users' comments made it obvious that the designers had misinterpreted parts of the instructions and the prototype did not fit properly: '... It is supposed to... a bit wider so... further down...' However, the situation also probed the users to reveal that: 'But... if you really want to know... you should bring one of the specialists which do this all the time'. Another specialist was therefore asked to join the session to demonstrate the correct position of the electrodes. In this situation, the interaction with and the joint manipulation of the PR elicited information that could be characterized as 'sticky' (cf. von Hippel 1994) but fundamental to enhancing the designers' knowledge of the use situation, hence users' requirements for future solution.

The users' understanding of the potential technical solution grew throughout the project and the PRs mediated new insights of the possibilities provided by the technical solution but also played an important role in creating trust. In the following example, PRs, consisting of various, previously used PRS had supported the designer's explanation of the final design. A long discussion of how the proposed technical solution could be designed and function in use proceeded users' responses:

User 1: So, it is not entirely science fiction to imagine that you can weave everything in one piece ... with conductor ... surfaces ... everything ...

The comment may indicate that the user had not until this moment fully grasped the potential of the proposed innovative technology but more importantly, that he had been hesitant regarding the feasibility of the suggested solution. However, the PR supported the user to develop a more comprehensive understanding of the proposed technology. The same discussion continued with a sudden follow up comment from the second user:

O, yes ... several layers ...the circuit boards are made like this (referring to his own domain knowledge) ....

Thus, the PR did not only represent the technical solution but rather mediated a link between one domain and the users' own and enabled the users to gain more confidence and trust in the proposed technology (i.e. 3D smart textile technology) as well as in the designers' competence.

The various tests and explorations of PRs seemed to support the users to develop a deeper understanding of the technology. Over time they became more active as when a user asked the designers if humidity (replacing contact gel) from one electrode could be transferred to another. As no one knew the answer to this question, the user proposed to perform such test, concluding that the risk was minimal. The user's contributions led to important solutions regarding the choice of materials. In this case, the PR triggered the user to take initiative to contribute with his own domain expertise to identify critical design solutions.

## Discussion and Conclusion

The analysis identified several situations in which the PR played a significant role, in mediating communication and in mediating collaboration (the former considered a prerequisite for the latter).

Previous research on PRs has mainly focused on the manifestation of the design, and consequently on the degree of fidelity, what type of PRs to be used, and when in the design process different PRs are more suited (Stompff and Smulders 2015). Moreover, research on design communication has often overlooked the mediating role of PRs in favour of other aspects of collaborative design such as verbal communication or organizational structures (Eckert and Boujut 2003).

While PR is suggested to facilitate communication and collaboration (Söderman 2001) their effects have earlier been described in fairly general terms, for example to 'span the language over different disciplines' (Engelbrektsson 2004) and 'support the development of a common language' (Brandt 2007). The findings presented in this paper develops on these claims. The PRs facilitated multimodal communication and combined with deictic gestures substituted words when words were missing and facilitated explanations of terms when terms were not understood.

Carlile (1997) defines mediating objects as 'tangible and concrete and loose enough in its manner to be manipulated and negotiated to reflect one's individual knowledge and make it explicit and understandable cross design teams'. Brant (2007) discusses that tangible prototypes, though without manipulating abilities, becomes 'things to think with' when users are involved. In this study, PRs became a common reference for users and designers, thus facilitating the formation of a common objective for specific properties (such as elasticity, softness, and resilience) as well for the design solution as a whole.

In addition, the access to physical PRs allowed various tests to be performed that provided the evidence the users needed to trust the design idea, but probably equally important was that the various, and over time modified, PRs were also manifestations – not of user feedback, which is the most common theme in literature (cf. Rhinow et al. 2012) but of user input.



Whereas earlier research has shown that mediating tools, such as prototypes, can enable users to formulate requirements for a new technical product or system at the early stages of the design process (Karlsson 1996), the study presented here emphasizes the roles of PR in creating important leaps of understanding and shift in perspectives to identify knowledge gaps, trigger queries, and provide answers, summarized as the PRs mediating a learning process between designers and users. The situation with the PR placed in a use situation created an opportunity for the team members to share an experience and to learn from one another, not only for the designers 'teaching' the users design solutions and processes but also the user teaching the designer user needs and requirements from a use(r) perspective.

This can be described as though the PRs mediated the users to take steps, evolving from rather passive evaluators to becoming active co-designers and hereby fully contribute with their specific domain knowledge. However, the designers were also enabled to take important steps in grasping the users' needs and requirements and evolved into a kind of 'co-user'. It can be argued that the users needed to become co-designers and the designers to be influenced to become co-users, before a genuine, common objective was possible to obtain (Figure 4).

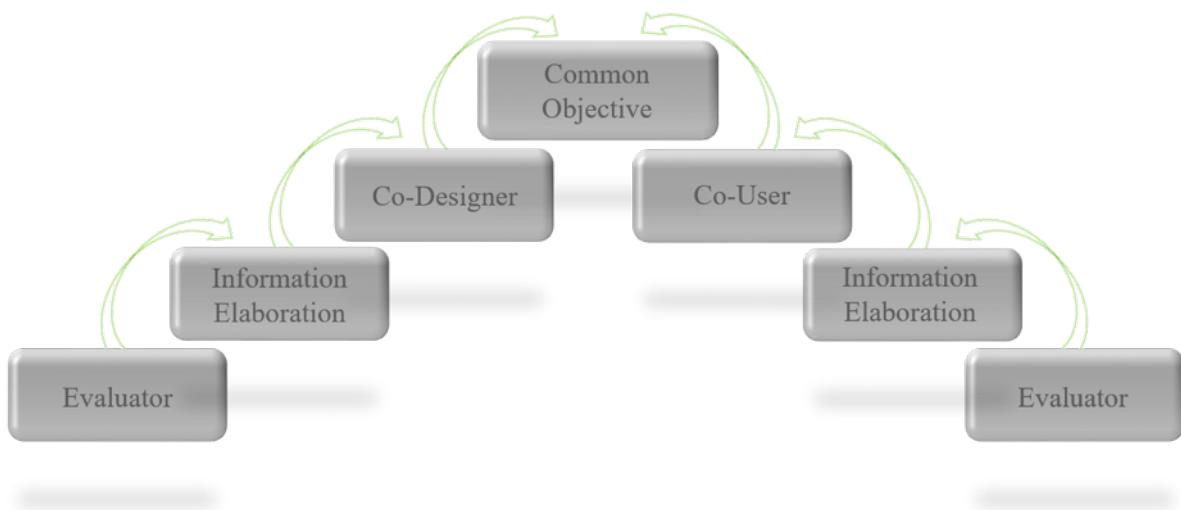


Figure 4: The process from evaluator to co-designer and co-user forming common objectives

In conclusion, the PR mediated communication by facilitating understanding of users' and designers' respective terminologies and thereby the creation of a common language. Furthermore, the PR mediated collaboration between the team members by knowledge generation, integration of perspectives and the formulation of common objectives.

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## **Staying in touch as partners – creating islands of normality for couples living with dementia**

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*[ABSTRACT only] This research focuses on the nature of supporting dyad relationships in which one person has taken on the role of a carer for the other who is living with dementia. While most technologies are designed to consider either how the carer can be supported in this role or the memory can be improved, this research explores specifically how technology can support the relationship between the carer and person living with dementia.*

*Our review looks at two living situations and show how fun, intimacy and equality might be rediscovered and nurtured through the aim of creating contact in meaningful ways. One situation looks at residents in aged care homes being visited by their partner; the other setting considers couples living at home where the partner is the formal or informal full-time carer.*

*Case Study 1 was conducted in collaboration with Dementia Australia and Lifeview Residential Care. Results from the residential homes propose that visits are threatened by implicit expectations and emotions, in particular from visitors' perspectives. What used to be 'normal' life become precious moments of togetherness and intimacy. The data demonstrates the possibility of shared interactive games to shift the responsibility of the visiting partner away from a constant carer role to an enjoyable emotional and entertaining event. Case Study 2 explores technology as support for couples living together. Similar to Case 1, shared experiences and activities are crucial to couples feeling engaged and connected beyond patient/carer roles. However the biggest impact on the relationship when living together is the opportunity for the carer as well as for the person living with dementia to maintain their life and identity away from the caring–cared dyad.*

*The research shows how this engagement and activity fosters wellbeing and healthy dyad relationships beyond the principles of clinical or medical care. The presentation makes suggestions for evaluating the impact of technology-supported activities through the lens of dyad relationships. Further the presentation proposes that traditional paradigms on measuring health, wellbeing or mood are not suitable in the complex interaction of two people having shared their lives up to 65 years.*

Keywords: Living with Dementia, evaluation, impact of technology, caring-cared dyad



## Designing a better visit: Touch-screen apps for older people living with dementia and their loved ones

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**ABSTRACT** This paper presents interactive touchscreen apps (games and activities) co-designed with older adults living with moderate and advanced dementia and their visitors in residential care settings. The project, in collaboration with Dementia Australia and Lifeview Residential Care, aimed to enable increased and meaningful social activity through a yearlong co-design process. Eighteen residents living with dementia and their main visitors (often partners, children and carers) were recruited from three separate residential care centres. The project consisted of three phases; (i) understanding the needs of both residents and visitors during a visit (exploring interests), (ii) systematic co-development and investigation of interactions and (iii) iterative evaluations. Here we focus on phase two and the first round of evaluations. Many of the participants had no previous technology experience and a range of conditions including loss of touch and tactile sensitivity, restricted vision, aphasia, and shortened attention spans. Hence a wide range of interaction solutions needed to be found to accommodate these challenges to achieve an enjoyable and social experience including exploiting multiple and accidental palm touches, registering button presses on touch-offs, removing edge zones and supporting interactions with music. A suite of two player apps were created including a picture guessing game and a dance hall version of tic-tac-toe; Skill games include a gyroscopic tilt marble maze and bowling; and art and music activities where participants trace pulsing colour lines to music, clean windows which reveal high definition photos and co-colour animated images. The apps were found to facilitate equal engagement and mutual social interaction with the visitors and residential staff. They provide new social opportunities with volunteers, or other people unknown to the older adults, yet.

Keywords: co-design, advanced dementia, game apps, touch screen interaction, quality of life



## Interpersonal interaction

Touchscreen-tablet computing (Tyack and Camic 2017) (Upton et al. 2011) has been quietly contributing in the dementia sphere for over a decade and in many cases has demonstrated clear benefits to quality of life through supporting and maintaining a sense of *personhood* (Kitwood 1997) for people living with dementia. In particular, scaffolding, i.e. one carer to one person with dementia, has been shown to promote interpersonal, intergenerational interactions, activities and communication (Upton et al. 2011) (Tyack and Camic 2017). The demand for dementia specific touchscreen apps to promote interpersonal interactions has seen a number of projects exploring art, games and music activities.

A tablet touchscreen computer itself affords an interaction to be supported by film, photo-media, animation and music, each capable of stimulating minds, memories, stories and conversations. Tablet-touchscreen music apps have used to promote reminiscence activities between people with dementia and their carers (Riley, Alm, and Newell 2008). Apps have also been used to form collaborative music ensembles for older people with dementia demonstrating skill development (Favilla and Pedell 2014).

More recently apps designed specifically for *cognitive stimulation* (memory, attention and concentration training) have been trialled in centres where the residents and their carers increased their average ‘time on activity’ and puzzle completions over a six month period (Yasini and Marchand 2016). Of particular interest in each of these studies is how the apps themselves promote a shared interaction *dyad* between the person with dementia and their carer. Also of great interest is how to best design for this specific *dyad*. Westphal et al. (2017) demonstrate the value of user-centred play-testing in the development of a tangram puzzle game alongside design inputs from other stakeholders including occupational therapists, doctors and geriatric psychiatrists. User-centred design introduced customisable difficulty, auto-snapping pieces, multi-touch and multi-user interaction. The design of game art to promote reminiscence and storytelling also greatly benefitted from play testing with the dyads. Importantly, multi-user interactions emerged from observations of interpersonal dynamics during play-testing sessions.

### *The dementia dyad*

Certainly, stakeholders have much to contribute, but can the person with dementia themselves be brought into the co-design process throughout? Most apps focus on a single or *scaffolded* use, rather than supporting a dual use, and do not specifically support an equal relationship. Many existing apps including cognitive stimulation brain training apps do not support the interests of people living with moderate to advanced dementia, while many other games can be perceived as patronising. Research has shown that older adults are more motivated to use technology, in particular touch screen technologies, when it supports and maintains their interests (Beh, Pedell, and Doube 2015; Pedell et al. 2013). How can an app acknowledge varying interests and also be



suitable to differing levels of dementia? What is the role for creative expression to elicit meaningful and active engagement?

## Co-design based on interest

Co-design is a design process which focuses on including all stakeholders in the design process to ensure that the results meet the user needs (Taffe 2015). Co-design is highly beneficial for designers, as it provides unique insights into user needs, preferences and ideas. Co-design carefully organized and implemented, can result in a sustainable product and enhance quality of life for the future (Sanders and Stappers 2008).

We saw an opportunity to co-design touchscreen apps (games and activities) specifically for the dementia care centre setting and the dyad of visitor (life partner/carer) and resident (person with dementia). Our aim was to develop games to be played by two or even three people. These games are not suitable for the resident to be left alone with (as an occupational tool) OR to be played in larger groups. We wanted to create a positive pleasurable shared experience between the resident and visitor(s) hence promoting – a better visit.

Our project was undertaken in collaboration with Dementia Australia and Liferview Residential Care and spanned a yearlong co-design process. Eighteen residents living with dementia and their main visitors (partners, children and carers) from three separate residential care centres across Melbourne contributed to the design. The project consisted of three phases: (i) understanding the needs of both residents and visitors during a visit (exploring interests), (ii) systematic co-development and investigation of interactions and (iii) iterative evaluations.

We specifically wanted to learn about the interests of the residents – in many cases about the hobbies or activities they had pursued in earlier years. Our rationale was that the iPad apps should not cater primarily for people with dementia, but for people with certain interests who also live with dementia. At the same time we considered it to be relevant to cater for the interests of the visitors supporting shared experience. However, for the visitors (without exception) it was more relevant to find things that their loved ones cared about and would engage with as this would make their visit rewarding and give them the feeling to be part of a relevant shared interaction.

## Touchscreen solutions for dementia

Overall, there was a lack of technology experience amongst the group. However there was no fear of technology. Amongst our participants we discovered typical age and dementia related barriers to touch screen interaction (Favilla and Pedell 2014) including diminished eyesight and hearing, loss of touch and tactile sensation, short attention span and cognitive impairment. Loss of connectivity to the iPad's touchscreen was frequently observed during our preliminary trials using existing apps. Later, during the development of our first prototypes we observed how this intermittent connectivity could result in tens of fast multiple touches being registered by the iPad, creating significant lag in interaction flow and even leading to software crashes. For button



pushing and simple switch interactions we found an excellent and robust solution; setting our software interactions to register touch-offs rather than touch-ons.



Figure 1: **Co-colouring:** User's colour-in a black and white outline. At the end users are rewarded as the image magically animates.

Accidental touches through other fingers and resting palms on the screen also proved very challenging with our first prototypes. These accidental touches would often activate interactive edge zones resulting in the app window closing. Even with these zones deactivated and multi-touch gestures deactivated, accidental touches would still unexpectedly and critically interrupt play. A single menu and navigation button was situated in the top left hand corner and the apps were developed to work only in landscape mode. We also decided to embrace accidental and palm touches. Our challenge then became how to build successful apps that would utilise and even reward these touches.

To do this we designed a series of games based on accidental and multi-touch gestures. **Co-colouring** (fig.1) is an app that presents a black and white picture outline which the users magically colour in touching anywhere on the screen. The app rewards the participants by coming alive through animation once the screen is completely coloured over. In the app **Washing-**



**windows** (see fig.2 below) the users work together to wipe off a white foreground to reveal a 'view through the widow' underneath.



Figure 2: **Washing-windows** reveals a high-definition photo prompting conversations through discoveries.

### *Interactions for music and memories*

Throughout our regular co-design sessions we collected life-stories, images and experiences. These we integrated into our game mechanisms through high-quality design. Many Australian themes such as wild life and flowers, animals, favourite and habitual activities, family holidays at the beach, BBQs and even mundane everyday products such as Vegemite, decorative biscuit tins and the Hill's Hoist washing line. A guessing game was soon designed which we simply named **Reveal** (see fig.3) which was resourced by a rich photo library exploring themes such as animals and wildlife, food, destinations, interesting objects and Hollywood actors. The interaction is easy with users clicking to remove large tiles revealing a picture underneath. Touch-offs register reliably in case a user leaves their finger resting on the screen and upon completion a prompt for a conversation is added with the answer to stimulate conversations. Through the co-design process we captured information and insights spanning three generations prompting rich



communications between the visitor and resident dyad participants. This information was then brought to the design content to maximise intergenerational interactions.

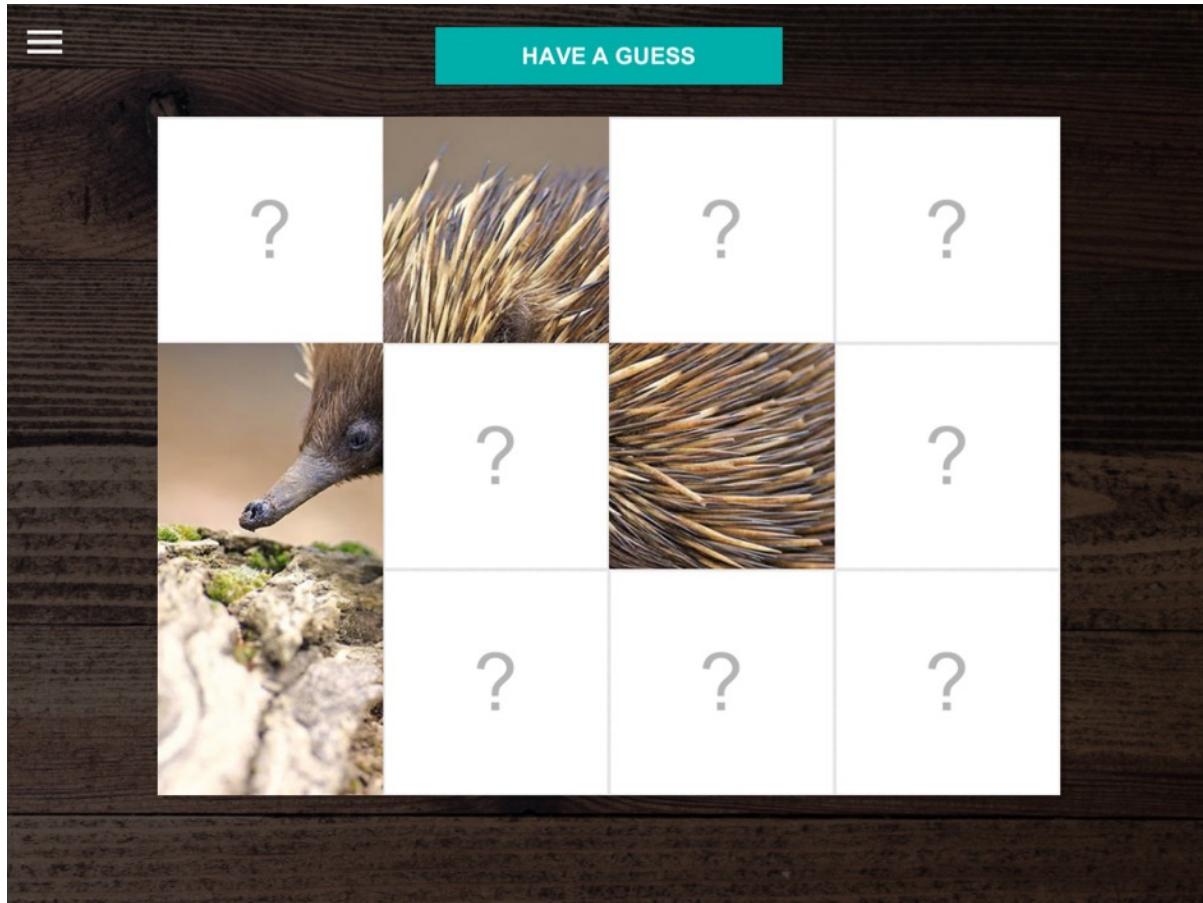


Figure 3: **Reveal:** A collaborative interaction prompting rich stories and discussions.

Through our design sessions with the dyads we realised music could support our interactions in several ways. Friday afternoons at the centres would see all the centre's residents come together for happy hour during which time a musician would play songs over the speaker system by request. The residents became animated, sang and talked so jovially amongst themselves some even dancing that we knew music had to play a large part in our design solutions. Music is effective at prompting memories and stories, yet also stimulates attention and engagement. Favourite songs would create positive emotions lifting mood and raise activity levels.

A hit list of favourite songs was compiled from the three residential centres and produced by a professional musician for the project. Care staff contributed their knowledge of the residential community's song preferences and music was played during co-design and play-testing sessions. Each song was remixed as both an upbeat and ambient relaxation instrumental track with the aim to support reminiscence and attention.



For people with moderate and advanced dementia music can be an extremely effective cognitive warm-up as our perception of music touches on many areas right across the brain. **Traces** is an app developed for people with advanced dementia and is intended as a fun stimulating music and animation show. Once again all touches are rewarded by the app as participants explore together combinations of touches and full-screen gestures. Traces then replays the users' gestures gradually fading ready for the next gesture. The number of loops can be set by the users themselves. Background music animates the traces creating surges and pulses of brightness and colour. Although intended for advanced dementia users, **Traces** was popular amongst all participants and provided an excellent collaborative exercise and warm-up app prior to the other games (fig.4).

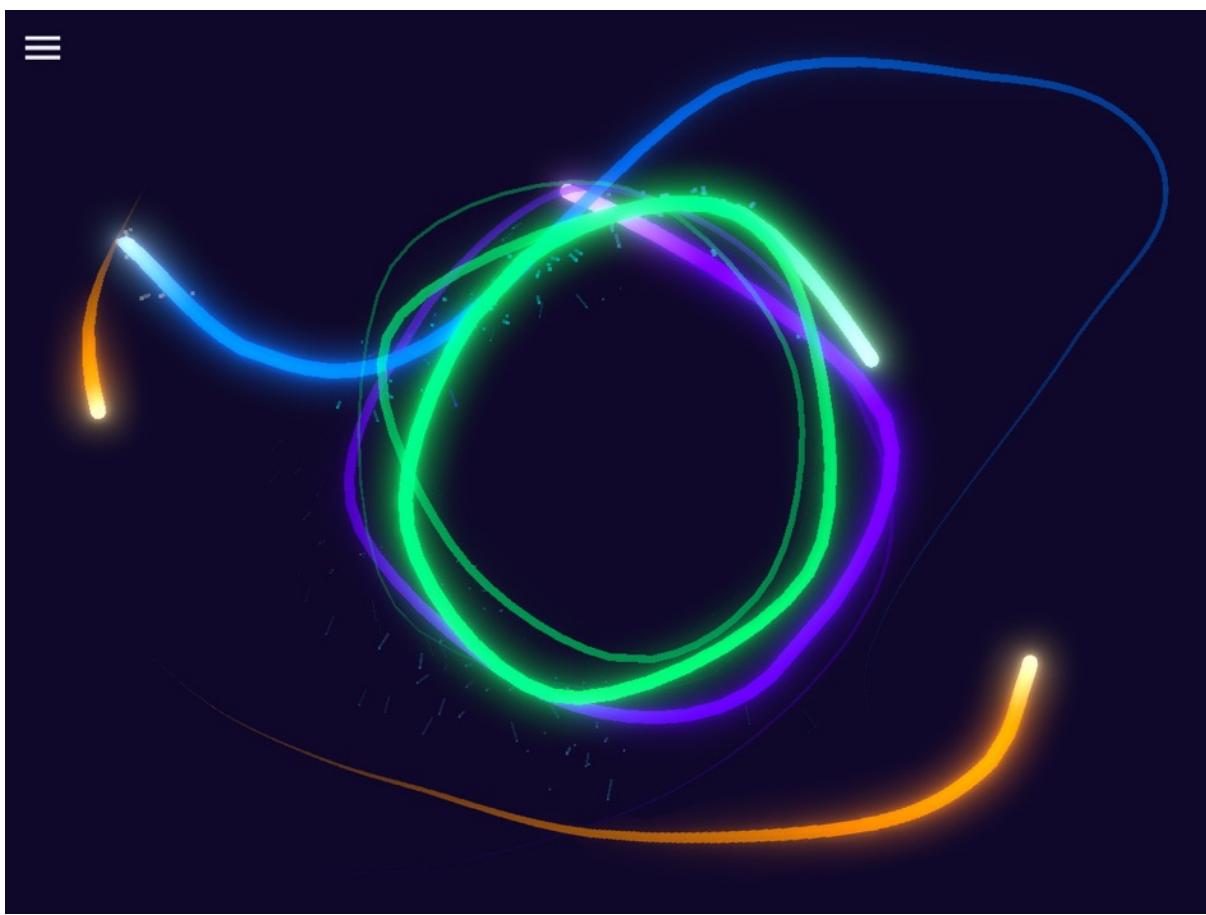


Figure 4: **Traces**: users' gestures looped over and over revealing a brilliant colour and music show.

### *Competition and skill*

During our initial play-testing phase we observed how all the participants enjoyed skill and competition games. Frustratingly many existing commercial games although visually stimulating and appealing, are not playable by people with moderate to advanced dementia. Games that focus on complex scoring, goals and fast competitive action are not suitable either. Playing a simple tic-tac-toe game can be challenging as the symbols of o's and x's can become confused.



During our initial observations we noticed many times the surprise and joy experienced by the visitor when the resident would win a game of tic-tac-toe. We discovered this would happen after the visitor lost concentration, which would consistently occur. Trialling different mechanisms, we noted how colour became a much more dominant cue than the symbol for prompting whose turn it was. We decided to support this app with dance hall music styles and beats that would layer up as players took their turns. This game we called **Tic-tac-tango**.

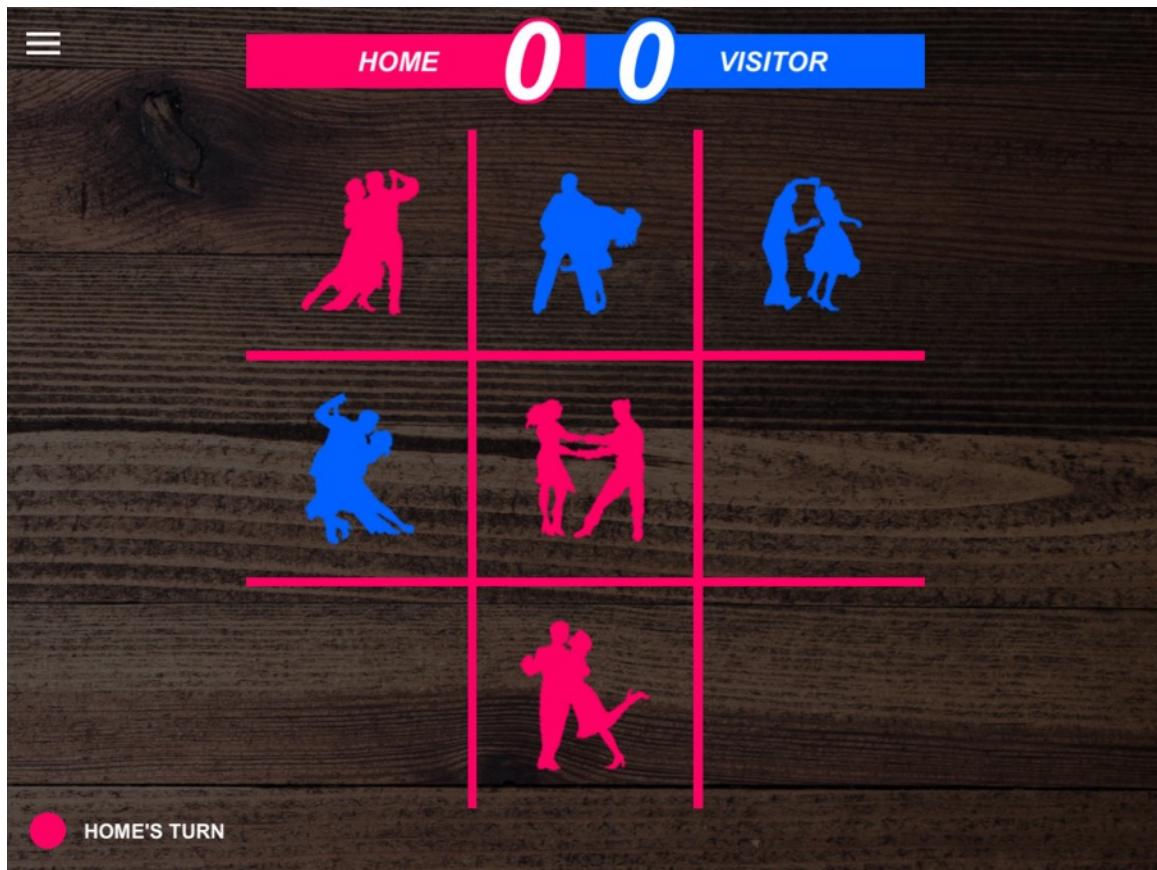


Figure 5: **Tic-tac-tango:** colour based interaction exploring ballroom dance culture

Bowling (including lawn and indoor carpet bowling) remains one of the most popular activities of older adults in Australia and also amongst our participants. We created the app **Bowls** as another competitive game accommodating various levels of player skills. Occasionally children would visit our participants and we wanted to create some games to really engage them. Providing the home team (resident) with some gravitational assistance and the option for a one touch shot (to include advanced dementia participants too) we created a game that is quite challenging for a visitor to win (fig.6).

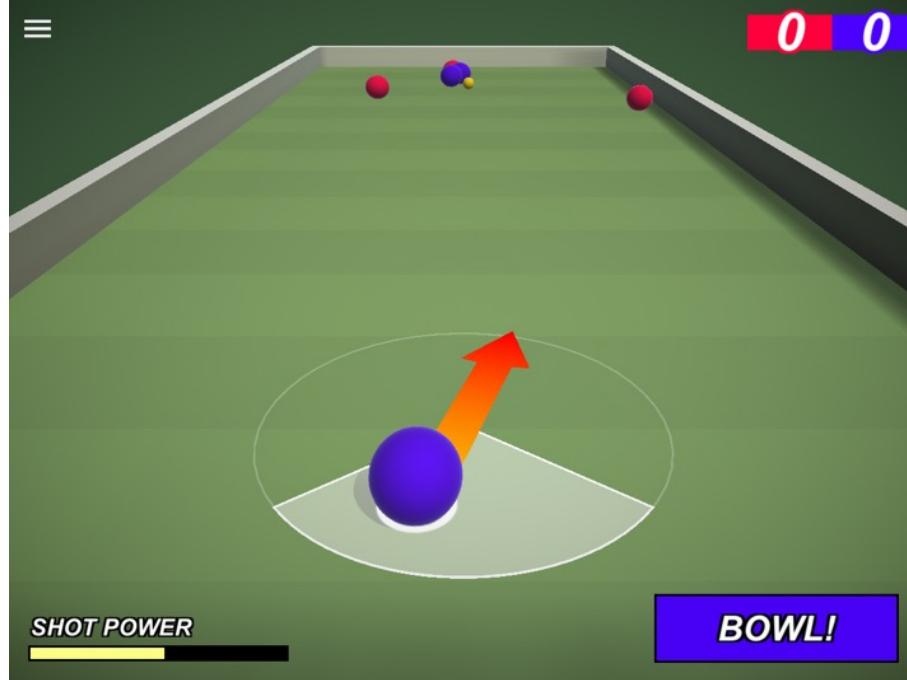


Figure 6: **Bowling** assists all residents to bowl beautifully.

We also explored interactions where the resident would pick up and hold the iPad either seated or standing the idea being to encourage some upper body mobility, coordination and exercise. Marble-maze uses the accelerometer and gyroscope sensors of the iPad and although the residents enjoyed the fun interaction it was probably the least successful of our solutions.





Figure 7: **Marble-maze**: Single-player interactions requiring attention can be antisocial.

This is largely due to the single player nature of the interaction and the concentration required by the user to play it. In short this app was antisocial and did not promote any interpersonal interaction.

## Conclusions – designing the better visit

Currently the apps are still undergoing their final evaluation phase, which we will report in future publications. However, we feel strongly that they have achieved our aims of promoting a better visit through interpersonal, intergenerational interactions, activities and communication. After initially planning to design four apps our final set offer a much broader range of activities.

As a result of our project we offer the following recommendations on co-designing for interpersonal interactions for dementia.

**Always design for two:** The greatest visitor's pleasure is seeing their loved one do something well. Cognitive warm-ups with music and reminiscence activities can set the scene for unexpected and profound moments.

**Find the right activity at the right time:** This is about providing both an enjoyable experience and wide range of activities both participants can choose from. There might be games the resident is not interested in or days where an activity away from the iPad is preferred. This is okay and should be respected.

**Play as much as possible together:** While you might read out instructions and questions try to play together as equal players. Explain how it works, but don't just take on the role as an instructor. Engage the resident as much as possible in showing by demonstrating, gently guiding, encouragement and part taking.

**Be flexible and explorative:** There is no right or wrong way or the need to finalise certain games or sections. Come up with ways that engage both of you. The main purpose is to have fun together. Hence don't insist on playing according to rules. Of course you can point out cheating or when you feel you have been left out with your turn...

**Engage in conversations:** Ask one question at a time (even if there are several listed). But also don't leave all the questions to the resident. Just show initiative and tell some stories yourself.

**Encourage active engagement versus passive consumption:** Art and music making activities promote active engagement over passive consumption (watching television). Where possible offer the opportunities for creative expressions and skill development.

## Acknowledgements

We would like to thank all Ann Lafferty and all the staff from Lifeview Residential Care for their input in this project and their support throughout. We also wish to thank Tanya Petrovich from Dementia Australia for initiating this collaboration with the Future Self and Design Living Lab. A special thank you to all the participating residents from Lifeview and their visitors co-designing these app with us.

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## **Clothing and Dementia: Exploring the sensory experience.**

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**ABSTRACT** *The World Health Organisation has identified the challenge of caring for those with dementia to be made a public health priority. Increasingly, literature from dementia care advocates creative approaches to aid those with dementia to live well. Greater importance is being placed on the significance of the physical and social aspects of dementia care environments, yet little attention has been given to clothing in the care setting. Moreover, social scientists posit that the body is sentinel to experiencing the world. This research seeks to address the under-researched area of clothing, embodiment and dementia and, in turn, investigate the potential of clothing in the holistic care of people with dementia. Findings may be harnessed to alter care practices around clothing and to investigate clothing design in the care setting. The qualitative methodology; sensory ethnography will be employed to conduct interlinked cycles of study. The methodological focus on the embodied and nonverbal experience necessitates an interdisciplinary approach. Drawing on the researcher's background of textile design and psychology, a range of methods will be used to support the needs of participants living with dementia. Cycle 1 will be conducted in a care home with people living with dementia and will involve observations and interviews. Cycle 2 will consist of focus group discussions with creative practitioners. Cycle 3, will use a series of 4-6 object handling sessions to explore thematic findings from Cycles 1 and 2. The sessions are based on both object elicitation interview methods and object handling interventions for people living with dementia. Objects such as; clothing, textile samples and photographs may be used in the sessions. Film will be used to capture verbal and nonverbal responses. All data will be thematically analysed at an interpretative level.*

**Keywords:** dementia; clothing; embodiment; qualitative research methods



## Introduction

Dementia is an umbrella term for a number of diseases that affect the brain, the most common of which is Alzheimer's disease (Alzheimer's Society 2015). The syndrome is characterized by a number of symptoms including: problems with both short-term and long-term memory and other executive problems, such as problem solving (NHS Choices 2016). It is currently estimated that there are 850,000 people living with dementia in the UK and, with the UK's rapidly ageing population, it is estimated that over 1 million people will be living with dementia in the UK by 2025. At present there is no cure for dementia. The World Health Organisation has identified the challenge of caring for those with dementia to be made a public health priority, stating that enabling wellbeing is imperative (WHO 2015).

Increasingly, literature from dementia care advocates creative methods to aid those with dementia to live well. Notable examples were provided in the All-Party Parliamentary Group on Arts, Health and Wellbeing 2017 report, in which the arts were outlined as having significant benefits to the lives of people with dementia. Moreover, greater importance is being placed on the physical and social aspects of dementia care environments (Davis, Byers, Nay, and Koch 2009). In 2015, The Department of Health (NHS 2015) issued comprehensive design guidance on the layout and sensory aspects of dementia care environments.

Furthermore, material objects are increasingly used in the care of people with dementia. Several writers have outlined that people with dementia can benefit from being offered an object (Groulx 2005; James, Mackenzie and Mukaetova-Ladinska 2006; Perrin and May 2000). Moreover, Stephen, Cheston and Gleeson (2012), posit the use of tactile objects in the care of people with dementia. Furthermore, the LAUGH (Ludic Artefacts Using Gesture and Haptics) research project design devices to facilitate playful and engaging interactions for people with dementia. Despite objects being used in the care of people with dementia, limited attention has been given to clothing in the lives of people with dementia. This is surprising, given that clothing is in such proximity with the body; clothing can be considered a person's most immediate environment (Twigg 2013).

## *Clothing and dementia*

Despite assumptions in both literature and the media that a loss of interest in appearance (including clothing) is symptomatic of dementia, Downs (2013) highlighted the emerging and compelling argument that the body, and its appearance, are critically important for theorising and researching the lived experience of dementia. In their research, Dementia and Dress, Twigg and Buse (2013) found that clothing remains significant in the lives of people with dementia. They reported multifaceted findings, exploring the significance of clothing in the care setting and the home. Their study found that bodies become contested territories within dementia care, with the appearance of the 'cared-for' invested with meanings that reflect perspectives of caregivers. Moreover, tensions can arise between practical care provisions and maintaining continuity of clothing to the person with dementia.



Clothing in the care home is often subsumed into formal caring routines, thus meeting the needs of the institution. For example, clothing such as polyester easy-care fabrics that require no ironing, trousers that are permanently fastened to prevent exposure, and clothing that opens at the back for ease of toileting are often used (Iltanen-Tähkävuori, Wikberg and Topo 2012). This, in turn, results in the 'classic' look of the dementia patient (Twigg 2013). This is notable as Gove (2013) found that dementia became stigmatized when it was visible, most notably through a person's appearance.

Clothing in the care home is often also restricted due to limitations set by the institution. Armstrong and Day (2017) reported care home guidelines that stated, 'numerous clothes are not necessary' and 'clothing should reflect the resident's current lifestyle'. Such practical restrictions could be said to meet institutional priorities, rather than the needs of the person. Additionally, clothing in the care home is labelled out of practical necessity to ensure that, when laundering, a person's clothing is returned to them.

This research, currently in progress, does not seek to over-emphasise the potential of clothing in the holistic care of people with dementia. Yet, as found by Twigg and Buse (2013), clothing is important in the lives of people with dementia. The aims of the research are to explore the relationship between people with dementia and their clothing, whilst investigating the sensory experience of clothing during wear. Findings may be used to enhance the holistic care of people with dementia and to explore the look and feel of clothing design for people with dementia.

## Methodology

Conducting research with people with dementia can be challenging due to issues around informed consent, varying levels of communication and the progressive nature of dementia. Furthermore, as Ellingson (2017) posits, research methodologies and methods are often entrenched with the Western notion that the mind takes precedence over the body. As such, social scientists have traditionally conducted research as though knowledge were produced without involvement of the body. This could be considered particularly important when carrying out research with people with dementia, as employing traditional research methods could be deemed as limiting and restrictive, due to a focus on verbal communication. Kontos and Martin (2013) claim that an embodied approach to research, whereby sensory, visual and participatory research methods are used, can empower people with dementia to participate.

Due to the focus of the research, and an attempt to empower participants living with dementia, the qualitative methodology Sensory Ethnography will be employed to carry out interlinked cycles of study. Sensory Ethnography (SE) is a form of traditional ethnography that focuses on sensory and nonverbal meanings (Pink 2009). SE does not involve prescriptive methods; the approach emphasises the creative role of the researcher in exploring the lived sensorial experience of participants. Pink (2009) advocates drawing upon and adapting traditional research methods, such as observations and interviews, whilst also using novel methods to collect data, such as designing an activity for research participants. When employing SE, researchers seek to empathise with



research participants. Moreover, the researchers are acknowledged within the research process and, as such, knowledge is co-created between the researcher and participants. Additionally, this links to the notion of decentralizing the researcher in the research process (Liamputong 2007), meaning that research is conducted 'with' research participants rather than 'to' research participants. Thus, data or knowledge is co-created, rather than the researcher being the expert.

The SE approach does not seek to generalise or generate one truth, rather the researcher and participants co-create findings that are situated within the specific research setting. In the case of this body of work, research will be carried out in one large care home that provides specialist dementia care and is a registered charity.

Reflexivity is an important component of the SE approach. The researcher will engage with written reflections and will use a visual journal (Figure 1) to document creative responses to the research process and the developing research findings.



Figure 1: Examples from the researcher's visual journal.

*Ethical Considerations.* Carrying out research with people with dementia, living in a care home, raises multiple ethical considerations. The research team are experienced at working with people with dementia and those who support them. This research has received ethical approval from the University of West London's College of Nursing, Midwifery and Healthcare on the condition that a favourable opinion is gained from NHS Research Ethics Committee.

## Methods

Drawing upon the work of Pink (2009) and the interdisciplinary background of the researcher, a range of iterative methods will be used. Figure 2: Interlinked Cycles of Study, is a visual representation of the approach to research.

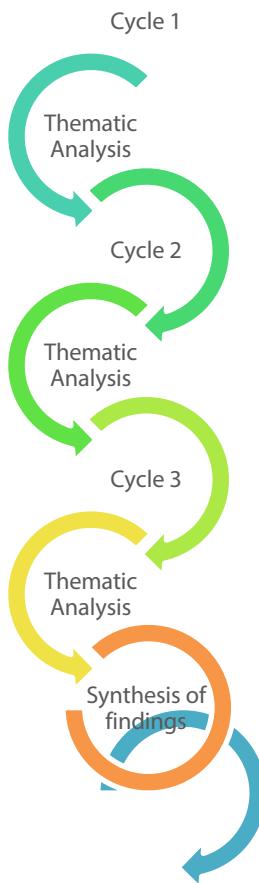


Figure 2: Interlinked Cycles of Study

### Cycle 1

The first cycle of study explores the experience of clothing wear in the care home. Drawing on SE methods; observations and interviews will be carried out. Observations may involve; sitting with, walking with, and taking part in activities with participants. Due to the SE approach, the researcher will attend to the multisensory care home environment whilst carrying out observations. Interviews will be carried out alongside observations. Hubbard et al., (2003) recommend conducting interviews alongside observations, as interviews are then shaped by everyday situations and thus, are embedded in daily events. Additionally, they report approaching interviews flexibly, enabling participants with dementia to communicate with the researcher on their own terms and using their own pattern of conversation, rather than confining dialogue to the traditional interview setting. As such, a series of prompts will be employed to guide interviews (Guy and Banim 2000; Hubbard, Downs and Tester 2003; Pink 2009). Prompts allow for a flexible approach and leave space for the interviewer to be responsive to the interviewee (Pink, 2011).



Fieldnotes and audio-recording will be used to collect data, that will be thematically analysed (Braun and Clarke 2006).

### Cycle 2

This cycle of study involves the use of focus group discussions. The focus group method involves moderated group discussion, based on the participants' perceptions and experience of a topic. In the case of this research, the focus group will be used explore thematic findings from Cycle 1. The groups will be made up of six creative practitioners (for example, visual artists) who are currently working in health and social care settings, who are either working with people with dementia, or have worked with people with dementia.

Participants will be presented with thematic findings from Cycle 1 and will be asked to reflect and share their thoughts on the findings. The focus group discussions will seek to identify potential objects or images that could be used to represent thematic findings. As such, Cycle 2 will inform Cycle 3.

### Cycle 3

Increasingly, researchers employ creative methods to elicit findings when working with people living with dementia (Bartlett and O'Connor 2010; Buse and Twigg 2013; Moss and O'Neill 2017). Pink (2009) advocates the use of novel methods of data collection when employing a SE approach, positing that researchers could collaborate with participants to, for example; produce a film, write a song, or engage in an everyday activity. Cycle 3 involves a series of Object Handling Sessions. Participants will include; people living with dementia, care home staff, relatives and friends of participants living with dementia.

Twigg and Buse (2013) used objects when carrying out their Dementia and Dress research. For example, they worked with dementia reminiscence groups to explore items such as vintage clothing. Objects can be particularly useful in supporting those who may struggle with verbal communication (Bartlett and O'Connor 2010; Buse and Twigg 2013; Griffiths et al 2016) and so, can be accommodating and flexible, allowing participants to partake at varying levels.

The content, structure and timings of the Object Handling Sessions will be informed by object handling interventions that have been carried out with people living with dementia. The Sessions will be approximately one hour long (Camic et al., 2017; Johnson et al. 2015), and between eight-ten items will be used, as recommended by Camic et al. (2017). Each Object Handling Session will focus on a theme, as related studies have found this a useful way to define the objects used. Griffiths et al (2016) explored a multi-sensory intervention for people with dementia using themed boxes, for example; Childhood. Furthermore, Thompson and Chatterjee (2016) used objects from a museum's collection, separating the items into boxes such as; zoology (horns, shells, teeth), or archaeological artefacts (amulets, flint tools). The themes used will derive from Cycles 1 and 2; items such as clothing, fabric samples and images may be used.



To facilitate understanding, and in order to capture nonverbal responses to items during the Object Handling Sessions, each session will be video-recorded (Reavey and Prosser 2011). Visual analysis will be carried out by the research team. The use of visual methods aligns with the SE approach, and seeks to explore the multifaceted and sensory experience.

*Preparing for the Object Handling Sessions.* The researcher has been working closely with two care homes to devise and deliver arts and textiles workshops. The workshops have included object handling (as pictured in Figure 3) and creative making workshops. Figure 4 depicts wearable pieces designed and created by people living with dementia.



Figure 3: Exploratory object handling workshops with people with dementia

*Cycle 3: Follow-Up Interviews.* At the end of each Object Handling Session, care home staff, relatives and friends of participants living with dementia will be invited to take part in a short semi-structured interview. The interviews will be used to explore responses to the sessions and the potential of clothing and textiles in the holistic care of people living with dementia. This is also likely to make findings applicable to dementia care practice.





Figure 4: Outcomes from an exploratory textiles workshop working with people with dementia.

### *Synthesis of Findings*

After each Cycle of study, data will be analysed thematically using Braun and Clarke's (2006) phases of thematic analysis. Findings will be discussed separately, and will then be presented in an overarching results and discussion section. The synthesis of findings will seek to present and explore the multifaceted nature of the research. Anonymised images from Cycle 3 will be used, with consent from participants, to illustrate and represent findings. Moreover, the researcher will use reflections from her visual journal to further explore the representation of findings (Ellingson 2017).

## Conclusion

There is currently a dearth of research that explores the significance of clothing in the lives of people with dementia. This research seeks to employ a range of traditional and creative methods to explore the significance of clothing to people with dementia. Findings may be used to inform the holistic care of people with dementia and may be developed to inform clothing design in the care setting.

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## Using distributed creative co-design to develop a treatment decision support tool for people with malignant pleural effusion

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**ABSTRACT** *Malignant pleural effusion (MPE) is a common, serious problem predominantly seen in metastatic lung and breast cancer and malignant pleural mesothelioma (MPM). Recurrence of MPE is common, and symptoms significantly impact on people's daily lives. Numerous treatment options exist yet choosing the most suitable depends on many factors and making decisions can be challenging in pressured, time sensitive clinical environments. This project aimed to develop a support tool to facilitate this decision-making process using a creative co-design (CC-D) approach led by the translating knowledge into action (TK2A) team of the NIHR Research Collaboration and Leadership in Applied Health Research and Care Yorkshire and Humber. Pleural teams from three sites in the UK took part in the project.*

*To overcome the geographical distance between the three sites and the ill-health of service users, a novel distributed model of CC-D was used. The TK2A team designed and structured the workshop and its content (including video clips of activities), which was run on each site with clinicians, patients and carers. This approach enabled a local lead with no CCD experience to be able to facilitate the workshop. Following this locally-led workshop, a joint national workshop with representatives from a subset of all stakeholder groups was conducted to consider findings and key messages.*

*Following the national workshop, the design team developed a first prototype/service visualization (i.e. a video representing a web-based support tool) to help people identify personal priorities and guide shared treatment decisions. Further iterative prototype development informed by stakeholder feedback took place, before being handed to a software company in charge of final testing and implementation.*



*We know that CC-D helps to overcome many of the barriers to 'traditional' co-production methods; such as power, language and time. The distributed form of CC-D attempted to address the challenge of delivering CC-D in busy clinical practice. This paper will describe the methods and propose that this is an approach worthy of further research and evaluation*

Keywords: Creative; co-design; distributed

[Abstract only; no full paper]



## Designing to Foster Meaningful Relationships for Families Living with Dementia in Long-term Care

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**ABSTRACT** *Dementia is a disease which challenges family relationships – children or spouses adopt the role of caregivers and advocates for their loved one living with dementia, while that person's cognitive and communicative abilities continue to decline. Accompanying this decline may be the need for long-term care, and this leads to new relationships with staff. This design research project aimed to develop an environmental design strategy to inform the renovation of a dementia care unit at Toronto Rehabilitation Institute (TRI). More specifically, this strategy aimed to create an environment that both orients families to the new home in which their loved one is living, and integrates family into the community of TRA meta-ethnography was conducted to understand the nature of relationships between family members with and without dementia, as well as staff. This synthesis was then thematically analysed in an attempt to gain an understanding as to what fosters or hinders meaningful relationships for families living with dementia in the context of long-term care. Floor observations, attendance in clinical rounds, and semi-structured interviews were also carried out to understand the specific needs of staff, residents, and family at TRI. Following the secondary and primary research, design charrettes, sketches, concepts, floor plans, a 3D model, and renderings were carried out to develop and communicate the design strategy to TRI staff. These strategies were then presented to TRI to inform future renovations of their facility. Ultimately, this research highlights how placing a loved one into long-term care challenges the notions of home, family, and relationships, while also providing environmental design solutions that can help address these challenges.*

Keywords: dementia, ageing, environmental design, experience design, rehabilitation

## Background

Dementia is a disease which challenges family relationships – children or spouses adopt the role of caregivers and advocates for their loved one living with dementia, while that person's cognitive and communicative abilities continue to decline (Ducharme et al. 2009). Accompanying this decline is the inevitable need for long-term care. While maintaining family connections to persons with dementia in long-term care is challenging, this setting can also be extremely beneficial. Long-term care can help preserve the identity, well-being, and quality of life for a person with dementia while also helping staff to better care for, understand and manage the behaviour of a person with dementia (Durkin, Shotwell, and Simmons 2014).

Understanding how dementia impacts families as a whole is a topic that has been explored by researchers all over the world (Lethin et al. 2016; Cronfalk, Ternestedt, and Norberg 2017; Hou et al. 2015; Moyle et al. 2010; Bramble, Moyle, and Mcallister 2009). However, what seems to be lacking in the literature is an understanding of how long-term care environments, particularly physical environments, impact the family experience of dementia.

## Context and Project Structure

Toronto Rehabilitation Institute (TRI) is a leader in rehabilitation care and research, as is notable on their website. One area of their specialized care is geriatric psychology, which is delivered in their 5 South unit. This unit, as explained on TRI's website, aims to improve the quality of life of those living with late-stage dementia who have behavioural challenges, mostly within other long-term care homes. Explained during interviewing, the healthcare team at 5 South works collaboratively to develop behaviour management techniques amongst a multi-disciplinary team, that can be translated back to their long-term care home after their temporary stay at 5 South.

The current design of 5 South resembles that of a generic hospital unit, and has not been designed to support the unique needs of the 5 South community. Recognizing this, TRI developed a request for proposal (RFP) and collaborated with the inaugural cohort in the Master of Design for Health program at OCAD University to develop design strategies for their unit's redesign. This paper will focus on that of the family experience, developed and designed for by the authors (the designers).

## Research and Design Activities

Figure 1 provides a visual overview of the research process, which followed a pattern similar to the Design Council's Double Diamond and spanned the course of 14 weeks. The discovery phase was carried out to provide the designers with an understanding of the 5 South context and their care team's use of the environment, as well as an understanding of dementia as a disease, and how it influences behaviours and existing environmental design strategies. These findings from both primary and secondary research were then thematically analysed to identify a direction for the design strategy that would meet TRI's unique needs (Figure 2).

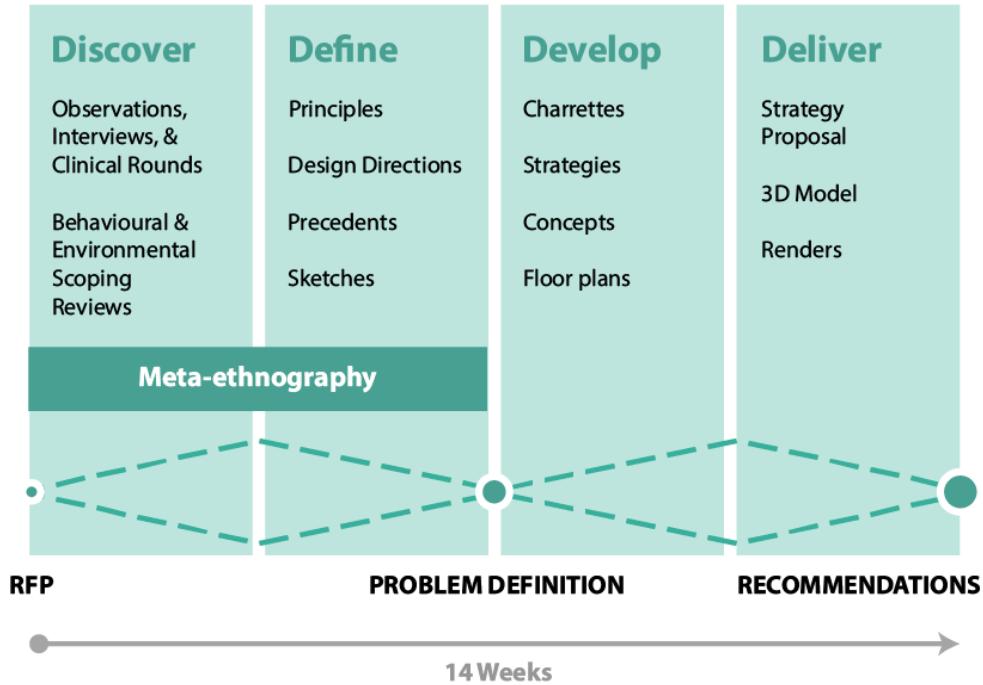


Figure 1: A Double Diamond infographic adapted from the one made available on the Design Council's website. Research and design activities followed a pattern similar to this.



Figure 2: Thematically analysed primary research, conducted by graduates Laura Halloran and Alison Mulvale. Themes pictured here identify roles and associate observations from interviews.



As the discovery phase indicated a need to design for the family experience, a meta-ethnography was conducted to better understand the nature of family relationships when dementia and long-term care become a reality, and to serve as the theoretical framework for the design strategy. As the strategy was being developed, charrettes were held to share findings gathered by all designers in the project which helped to problem-frame and ensure strategy alignment, all with the guidance of faculty. Design activities were carried out throughout the majority of the process to visualize and communicate how strategies might be realized as interventions at 5 South. These evolved from precedents to sketches, concepts, floor plans as shown in Figure 3, 3D modelling, and renders.

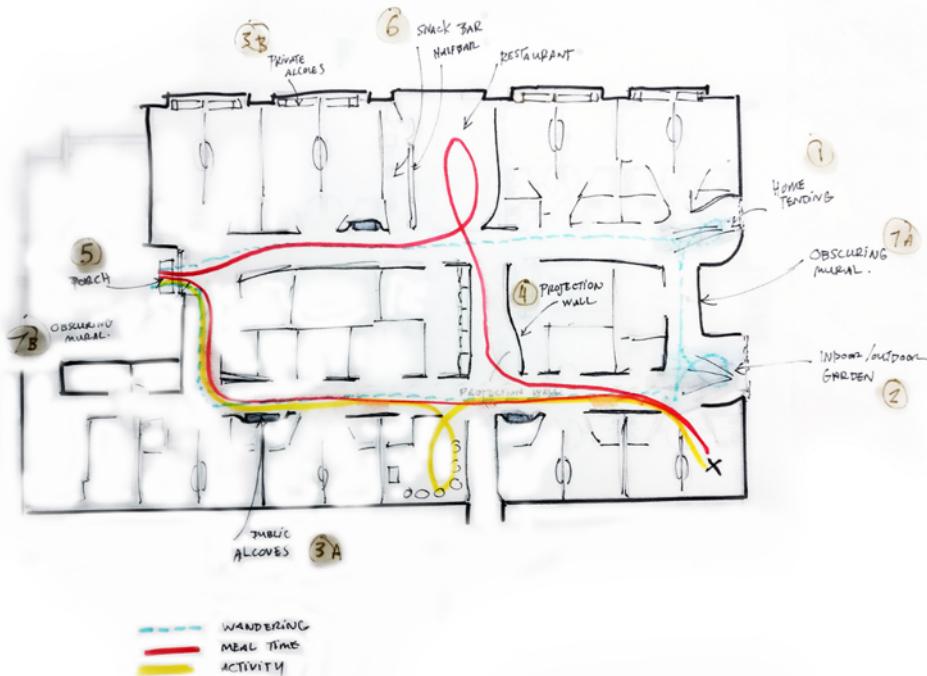


Figure 3: A sample floor plan of the 5 South unit, used to identify potential paths for family visits and the best placements for design interventions.

## The Resulting Design Strategy

A significant finding from the meta-ethnography, noted in Robinson, Reid, and Cooke (2010), indicated that,

'[while the conception of] home is an ongoing dynamic process between the individual and her environment...the meaning of home is embedded in human, and in particular, family relationships.'



This finding was confirmed in 5 South's RFP that expressed a desire to appear less institutional and more 'home-like,' and also in interviews that identified the challenge of building these important

relationships given the short-term nature of their care. As a result, the designers developed a strategy to make 5 South a home by fostering meaningful relationships between a family member and their loved one with dementia (Figure 4).

The results of the meta-ethnography also revealed that families with dementia experience pervasive loss and chronic grief as dementia progresses (Paun and Farran 2011; Graneheim, Johansson, and Lindgren 2014; Førsund et al. 2014; Peacock et al. 2014; Hemingway et al. 2016; Duggleby, Schroeder, and Nekolaichuk 2013; Acton and Wright 2000). Since 2011, Andrew Tarvin has described seven qualities of meaningful relationships on his consultancy website: communication, respect, honesty, dependability, empathy, interdependence, and purpose. How families living with dementia in long-term care communicate, respect and empathize with each other while negotiating new meanings of honesty, purpose, and dependability is important for understanding what constitutes the meaning they find in their relationships. With this in mind, this strategy focuses on the need to orient and integrate families into their loved one's new home of 5 South. This orientation and integration strategy can provide family with tools to learn about the new care environment, introduce family to the new care team, and empower family with knowledge about dementia. These tools, in turn, can help to counter the negative impact dementia can have on meaningful relationships, and encourage more knowledge transfer between family and staff.



Figure 4: A visual summary of design activities that explored the fostering of meaningful family relationships – a strategy developed according to research findings.



## *Orientation*

The orientation focus of the strategy aims to orient families to new ways of communicating, to the reality in which their loved one is living, and to building positive relationships with care staff. As family members are no longer recognized by their loved one with dementia and may no longer be able to verbally communicate and share stories, they can question the very purpose of their interactions with loved ones who have dementia (Chesla, Martinson, and Muwaswes 1994; Bramble, Moyle, and Mcallister 2009; Moyle et al. 2010). Thus, this strategy aims to orient families to new ways of communicating with their loved one with dementia. In addition, whether it is when deciding to place a loved one into an institutional care, or facing their loved one's misconceptions of reality, families explicitly express that they are unsure of how to honestly communicate (Cronfalk, Ternestedt, and Norberg 2017). Thus, this strategy also aims to help orient families to the reality in which their loved one is living. Finally, the orientation strategy also recognizes that care staff play an important role in helping family address feelings of guilt, while also supporting families who may feel lost when trying to connect with their loved one (Bramble, Moyle, and Mcallister 2009). For example, in instances of severe dementia, family members often observe staff for inspiration on how to interact with their loved one (Cronfalk, Ternestedt, and Norberg 2017). Thus, staff ultimately help family members to have more meaningful relationships with their loved ones with dementia (Robinson, Reid, and Cooke 2010; Cronfalk, Ternestedt, and Norberg 2017; Bramble, Moyle, and Mcallister 2009; Strang et al. 2006), and this strategy aims to create an environment that fosters positive interactions between family and staff, while still respecting staff resourcing.

## *Integration*

Transitioning from the family home to long-term care creates a significant discontinuity in the lives of families living with dementia. Intuitively, research indicates that integrating home life to institutional settings can help to minimize this disruption. This includes but is not limited to providing opportunities for homelike tasks (Robinson, Reid, and Cooke 2010). The hospital-like setting further impacts discontinuity by creating a sense of a 'lock-down, [sterile] facility', giving family members a sense of guilt for leaving their loved ones behind (Robinson, Reid, and Cooke 2010, 497). Family members can also struggle with not feeling welcomed into the facility as a result of the clinical setting. Integration, then, aims to respond to this by addressing the discontinuity family members may experience when their loved ones have been relocated to 5 South.

## *Executing the Strategy*

The design strategy described above was used to develop design interventions specifically for 5 South. While a total of six were proposed, only two will be described here.



## Welcome Board

The current entrance of 5 South can play a larger role in helping to both orient and integrate families to the 5 South community. A welcome board, Figure 5, was proposed as part of the redesign of the entrance and is composed of a variety of elements which aim to:

- Improve communication during visits
- Strengthen relationships between family and staff
- Provide a continuous experience from home into 5 South
- Empower families to navigate dementia behaviour



Figure 5: Development of the Welcome Board from sketch to concept, incorporating precedents.  
The quilt that is centrally featured hung in a more obscure window, previously.



Together, these elements aim to orient by equipping families with information and facilitating positive communication between families and staff. For example, group photos of staff are featured, alongside a feedback area for families to 'shout out to staff', to help build avenues for familiar, positive feedback. This not only helps to foster meaningful relationships between family members and their loved ones, but also helps to encourage knowledge sharing between family and staff. In addition, the literature reviews revealed that ending visits can be particularly difficult for family members as it can generate feelings of guilt and betrayal (Førsund et al. 2014). Including an activity schedule on the Welcome Board orients families to the routines of 5 South, and allows them to coincide the end of their visits with the start of an activity to help make this a smoother transition.

## *Hallway Activities*

Family members are not always able to visit during organized activities and meals. Home-like tasks, such as picking flowers from a garden (Figure 6), help families integrate by turning an institutional setting into a more familiar and 'home-like' one. Having these hallway activities readily available to both residents and family also alleviates the need for staff to coordinate and organize another activity. In doing so, it gives family members the opportunity to partake in a familiar activity, and, ultimately, have a more meaningful, enjoyable experience with their loved one. Thus, orientation is also addressed by offering families alternative ways to communicate with loved ones while considering staff resourcing.



Figure 6: A concept for a hallway activity, supported by a precedent found on Creative Art Co's website.

## Conclusion

Primary research conducted at 5 South unveiled a need to develop an environmental design strategy for the family experience. Secondary research revealed that dementia challenges family relationships in long-term care, and this presented the designers with the opportunity to develop an environmental design strategy to foster meaningful relationships at 5 South. This strategy became two-pronged, focusing on integrating family life into the 5 South environment, while also orienting family to the new reality in which their loved one is living. Where current literature confirms the challenges families face, this research hopes to supplement by exploring how design might meet these challenges through the physical environment. As a result, the authors hope to support institutions seeking to renovate existing dementia care facilities for the betterment of family experiences.

## Acknowledgements

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## Zeitgeist Publication: A Storytelling Project with Residents & Design Students

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**ABSTRACT** In Spring 2018, residents in a long-term care facility came together with a class of undergraduate Communication Design students, to co-design and co-write a mini-publication series featuring resident stories.

Through our project, small teams of 2-3 students were paired with 1-3 residents, to create a mini-publication over the course of 6 visits with each other. The purpose of the Zeitgeist project was to create a platform for meaningful exchange and social interaction between students, residents, their families and care home staff through both the design process and the final design outcomes. This project gives voice to residents, providing an opportunity for creative and emotional expression, stimulation of positive memories and the engagement of residents in a unique and meaningful activity. Simultaneously this project offers design students learning opportunities in storytelling, publication design, co-design and participatory design research.

This project was inspired by the Zeitgeist Kollektiv, a public editorial design and storytelling project within a care home system in Zurich, led by the designers Carolyn Kerchof and Martina Regli.

Keywords: storytelling, dementia, communication design, co-design, aging

## Introduction

The changes and challenges that come with later life, including relocation, can constitute challenges to our sense of self (Randall et al. 2015). On an emotional level, the transition into residential care can be overwhelming for seniors. It has been reported that seniors fear losing their independence and being admitted into care more than they fear death (Brownie et al. 2014). From a resident perspective, entry into a residential care facility becomes a major life transition.

Facilitated by a recreational care therapist, undergraduate Communication Design students from Emily Carr University of Art and Design, in Vancouver, Canada, came together with residents in a long-term care facility to co-design and co-write a mini publication series featuring stories of residents' lives, experiences and 'big life questions', such as would they prefer to live on the moon, or on the bottom of the ocean?

Carolyn Kerchof's Turning Nursing Homes into Media Homes project directly influenced the idea for this project. Her stated goals were 'to design a publication that was attractive, readable, and interesting for nursing home residents using participatory methods', while also designing something inspirational and meaningful to the residents that could integrate the residential care facility within the city's culture (Kerchof 2015). This became Zeitgeist magazine which 'combines storytelling, design, and the search for meaning in very old age' (Kerchof 2018).



Figure 1: Students and residents take part in ice breaker activities, facilitated by recreational care therapist

### Aims

Zeitgeist Vancouver is currently seeking ways of developing a project implementation framework within facilities in Vancouver, Canada, while observing how inter-generational communication and resident storytelling can be improved through visual design principles, embracing Kerchof's belief that 'being able to articulate and share experiences is essential to leading a satisfying life for many people, most of all toward the end of life' (Kerchof 2015).



Figure 2: Students and residents engage in storytelling activities

This project seeks to improve the lives of residents, both through the process and intergenerational exchange in which the publications are made, and through the final outcome which enables residents to share their story with their loved ones and care team. While providing benefit to residents, this project also creates a unique learning context for our Communication Design students. Attempting to address some of the emotional challenges of living in residential care we have looked at an empathetic design for a holistic healthcare experience.



Figure 3: Example of resident story translating into visual design by students

### *Methods*

Students were grouped with pairs of residents from UBC Purdy Pavilion and together engaged in a series of activities aimed at firstly building a relationship, before they would together co-design a magazine focused on the resident's life experiences. The project implements the Design+Storytelling framework, using storytelling as a way to improve communication between designers and stakeholders (Gausepohl et al. 2016).



Figure 4: Students review copy and design with residents before finalizing their designs

Content generation takes the form of conversation, storytelling, games and creative activities such as collage, illustration and photography. The narratives provided act as design artefacts themselves that can help in the transition from problem space to solution space and with them the students can begin to develop some initial design concepts and editorial layouts that speak to their resident's individual personalities and experiences. Initial designs are taken back to the residents for a consultation session during which they can express their preferences on copy, editorial design, typography and choice of imagery.

The rapport students develop with residents, as observed in our initial pilot project, can allow them to have nuanced discussions around the visual design of the publications that best speak to the content and taste of the resident, avoiding the cliché approaches, such as simply making the type larger for an elderly readership perceived to prefer this approach. Storytelling allows the user's needs to be more effectively and efficiently communicated around a specific context, allowing for more varied responses than a typical, direct interview technique.

As a society we have never had such a large proportion of elderly people, but being overly concerned with care makes it easy to forget that old people still have a considerable amount to contribute (Diamond 2012).

"Consider the elderly not only as a problem but also as possible agents for its solution; support their capabilities and their will to be actively involved, and optimize use of their social networks.' This initial revolutionary move of considering the elderly not only for what



they need but also for what they are able and willing to do has led to a number of social inventions and enhancements' (Manzini 2015)



Figure 5: Example of resident story translating into visual design by students

## Impacts

Anecdotal feedback from our pilot project indicated the need for both a lead in and lead out to the students working with residents. Some rapport-building was required early in the project to allow the residents to feel comfortable enough to share their stories with the students. In the weeks following the project several residents also asked 'when are the students coming back?'. Further, we began to uncover a range of potential benefits to this project which we would like to validate and gather systematically moving forward.

Initially we planned to unite all of the individual publications within one larger publication with an agreed, unified aesthetic. Observing the process of the students working with the residents soon taught us that the aesthetic and nature of the materials was directly influenced through their interactions with each other and as a result served as a form of documentation of both the experience and the relationship that had been developed. We decided that to unify the design would remove this unique expression of their time together, so instead we sought a way of grouping each of these individual experiences.



The intention for this project was to create a mutually beneficial relationship between students and residents. Communication Design students need interesting and original content to work with and residents need an opportunity to tell their stories. Through this project, design students are able to provide their skills and expertise to residents in order to capture their stories and enhance well-being, while in exchange, the residents provide a rich immersive learning environment for our students. It not only addresses a need for residents but also allows them to continue to actively contribute their skills and experiences in meaningful ways that benefit others.



Figure 6: Collection of finished student and resident co-designed publications

'There is only one solution if old age is not to be an absurd parody of our former life, and that is to go on pursuing ends that give our existence a meaning — devotion to individuals, to groups or to causes, social, political, intellectual or creative work... in old age we should wish still to have passions strong enough to prevent us turning in upon ourselves. One's life has value so long as one attributes value to the life of others, by means of love, friendship, indignation, compassion. When this is so, then there are still valid reasons for activity or speech' (De Beauvoir 1970).

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## Logic models as a form of creative practice in co-production? Sharing learning from commissioning processes within South Yorkshire

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**ABSTRACT** Logic models have been used as a planning tool since the 1960s, but many question their utility. They have not only been criticised for reflecting a 'top-down' approach to designing and evaluating programmes, but also because following the logic of complex programmes is often difficult and thus models can mix abstract aims with more concrete implementation steps. Yet is there still value in using logic models? And, moreover, can they be used in co-production: a more 'bottom-up' process of service design, implementation and evaluation? This paper considers these questions by sharing learning about the use of logic models by a team who aim to co-produce commissioning in health and social care, working across 24 projects in South Yorkshire. We first describe how the team worked with health and social care commissioners and other local stakeholders to define the aims of the initiative and a project brief, and discuss how these were translated into logic models, through a collaborative process and using a common 'crib sheet'. We then move on to discuss the different ways in which logic models were used, to: 1) provide vision for what needed to happen to enable co-production; 2) map interaction with stakeholders at different points in time; 3) reflect on how interaction and activities enabled or constrained co-production; and 4) retrospectively reflect on how process related to outputs and impact. In conclusion, we suggest that logic modelling can be a type of creative practice; whose value lies not primarily in the product (model) that is produced, but in the process of iterative reflection that developing a model promotes. Logic modelling can thus help us design and evaluate with commissioners and service users, and collectively unpack assumptions and evidence about why co-production in particular programmes ought to be, is, or is not working.

Keywords: logic models, co-production, commissioning, co-design, learning



## Introduction

Logic models have been used as a planning tool in the field of international development since the 1960s, but many still question their utility. They are criticised for reflecting a top-down approach to designing and evaluating programmes (Kushner, 2012). Following the logic of the programme is often difficult because the model may mix abstract programme aims and more concrete programme steps (McCracken 2006). Yet is there still value in using logic models? And, moreover, can they be used in co-production: a more 'bottom-up' process of service design, implementation and evaluation?

This paper considers these questions by sharing emerging learning about the use of logic models as part of a participatory evaluation of Co:Create: an initiative based within South Yorkshire Housing Association that aims to support the co-production of commissioning in health and social care. Co:create are working across 24 projects in South Yorkshire. We first describe how Co:create has worked with health and social care commissioners and other stakeholders to define the aims of the initiative and a project brief, and discuss how these were translated in to logic models: through a collaborative process and using a common 'crib sheet'. We move on to discuss different ways in which logic models are being used, to: 1) provide vision for what needed to happen to enable co-production; 2) map interaction with stakeholders at different points in time; 3) reflect on how interaction and activities appear to be enabling or constraining co-production; and 4) reflect on how process relates to outputs and impact.

## Background

The Co:Create team aim to co-produce commissioning in health and social care and are working across 24 projects in South Yorkshire. Co:create works from a starting point that the health and social care commissioning landscape is challenging and requires innovative whole system solutions. The team also works on the basis that existing co-production practice in commissioning is not consistent and needs to take place early in the commissioning cycle and throughout it to be successful. Co:Create has been funded for three years by the Department of Health to experiment with different approaches to incorporating and embedding co-production into the commissioning cycle. Different approaches are being used in the 24 projects that the team have been involved with across health and social care commissioning in South Yorkshire. The team are currently entering their third year of supporting commissioning practice.

## *Co-produced evaluation of Co:Create: a brief overview*

One component of Co:Create is the evaluation of the approaches that are being used to incorporate and embed co-production into the commissioning cycle. The evaluation is ongoing and is a co-produced or participatory evaluation. Participatory evaluation is often used when little is known about how or why an initiative might work (see Cousins and Whitmore, 1998). It involves



input from different stakeholders to interpret how an initiative is working (or not) and why. Importantly, learning is generated in the evaluative process as an initiative progresses, with reflection on progress used to inform and justify changes in approach.

In terms of how this has worked in practice, when Co:Create began as a funding bid, it was mainly an idea; with the bones of an operational model. It took the staff team about 6 months to articulate what Co:Create would do and how. The evaluators supported the Co:Create team by asking questions about the programme and encouraged the team to develop an initial theory of change. From this participatory process, it became apparent that the decisions the Co:Create team made early on about what happened next, the way the team worked and sought to develop relationships, and thus the overall approach, was building the 'Co:Create Way' and would form part of the 'findings' for the evaluation. Building a Theory of Change together helped the Co:Create team and initial bid writers to articulate more broadly how they thought the Co:Create approach would support change. The initial Co:Create theory of change is illustrated in Table 1.

Table 1. Co:Create initial theory of change

IF ~~Co:Create~~ models asset-based approaches and challenges traditional forms of engagement,  
THEN all stakeholders in the commissioning process will be active partners in improving health and social care services.

IF we create the conditions for people to work together in new ways, THEN relationships between commissioners, people who access services and practitioners will be more trusting and equitable with greater understanding of each other's assets and challenges.

IF commissioners meaningfully engage local people and networks, including the seldom heard,  
THEN people will ~~realise~~ the value of their experiential knowledge, increasing their capacity to be genuinely heard.

IF commissioners are enabled to become facilitators of change THEN new solutions for service design will emerge.

### *Development of logic models in participatory evaluation*

Logic models are statements, often presented visually, of how a project, programme or service is supposed to work (Centre for Community Health and Development, 2018). Other words that are used for with logic model include: road maps, programme theory, theory of change and programme framework (Centre for Community Health and Development, 2018). The processes for developing a logic model may vary, but regardless of the label or approach used, all aim to show the logic of how an initiative is supposed to work: illustrating links between what is done (activities), the changes that happen as a result, and the way in which those changes lead to short-



term and longer-term solutions for problems in communities (outcomes) (Kellogg Foundation, 2004). There are different types of logic models. *A priori* logic models capture how a project team hopes an intervention or programme will work. *Post facto* logic models explain how a programme actually worked, thereby explaining the interaction between what a team hoped to achieve and the influence of the surrounding context on the ability to reach the original aims (Rowher *et al.*, 2016). Effective logic models clearly and transparently link activities, changes and outcomes to the underlying theory and assumptions about why a programme ought to work to achieve change.

When developing models, stakeholders often find it easier to list activities and outcomes, and more difficult to articulate how activities will bring about change. Using the analogy of a road map, a map will show a driver which route to take but will not explain how to navigate along that route. Rivers on the map may be prone to flooding. The road may be in poor repair, or there may be junctions which have a high rate of accidents. Logic models that are presented simply as maps do not document these types of potential challenge, nor describe how activities will be constructed to enable change.

In the evaluation of Co:Create, it is unknown territory. The initial theory of change was a hypothesis, based upon staff experiences of working in other contexts, which were not necessarily focused on co-production. Although these experiences may be valid, we needed to start with the proviso that the theory of change was tentative and might need revisiting based on what was learnt while the initiative was being implemented. Logic models became a key part of the participatory evaluation, for several reasons. First, they can be used in an interactive way to reveal why people think activities will work, getting at the theory underneath the project structure (Centre for Community Health and Development, 2018). Second, they can be 'dynamic models': they can be iterated and serve as a record of assumptions for what was thought would work before project inception, as well as what actually worked (Rogers, 2008). Third, they are a useful tool for getting people to reflect together, because focusing discussion on creating 'the visual' can shift people away from traditional ways of interacting, based on everyday roles, towards new ways that require people to communicate differently. Finally, the discussion that occurs while creating a logic model can surface potential issues and risks, leading to critical discussions of what will really work and consideration of contingencies if a project seems to be going off track. Logic models as creative practice are therefore a vehicle for constructing a road map *alongside* a detailed set of directions on how to navigate the pitfalls of co-production, in order to arrive at the desired destination.

### *Developing the evaluation with logic models*

The evaluation is being co-produced, which means that Co:Create staff are involved in documenting how activities were agreed, who participated, and what changes occurred as a result. For each project and set of project documents, a logic model is developed with an initial group of project stakeholders. Co:Create staff were trained by the evaluation team in how to develop logic models by using two Co:Create projects as cases. The evaluation team and Co:Create



staff essentially had a rich and detailed conversation about the two cases and, in the process, sketched out relationships between inputs, activities, outputs and short-term outcomes. As the models were developed, descriptions of the surrounding context were captured alongside reflections on how context influenced progress. The evaluator facilitating the discussion periodically 'stepped back' from the activity to explain why a particular question was being asked, and how the sketch was being used to illustrate the underlying reasoning for the project. Questions were also asked to reveal possible risks, how things could go wrong, and how this might be mitigated.

After developing the two models, the training experience was written up as a logic model 'crib sheet' to provide a reference guide for the evaluation team and Co:Create staff; enabling us all to work with project leads and wider teams to create the models. This presented in **Box 1**.

### *Using logic models for within-case analysis*

The logic models are placed in shared project files, which also contain a set of documents tracking the development of each project *via* meeting records, initial project brief, and the contract. Evaluators review the project documents, extract all information relevant to the logic model and compare what is extracted to the logic model information captured by Co:Create staff. Meetings are being held between evaluators and staff to check the completeness of the models and create a shared understanding of what each project hoped to achieve. The models are also being fed back to project leads to check for differing perceptions of how things work.

The number of times a logic model is revisited will vary depending on the length of the project, the number of changes that occur during it, and the willingness of stakeholders to participate in collaborative reflection. Projects that are completed within 3 months may only have an *a priori* and *post facto* model. Some projects are staged, in the sense that commissioners requested an additional piece of work upon completion of the initial brief. In these cases, the logic models are being constructed to reflect how one stage of work leads on to another.

As each set of models is completed, evaluators are using a realist approach to analyse the learning generated, asking 'What works in facilitating co-production, for whom, in what circumstances, and why?' A similar process is being used to ask what does not seem to work. This sort of realist approach is useful in evaluating co-production because it preserves diverse accounts - which means that all stakeholder explanations are considered equally important in producing explanations. The results of this form of more independent analysis are fed back to Co:Create staff and members of each project for cross-checking, to ensure that all perceptions and explanations for how co-production works have been captured.

Box 1: Questions to guide the development of logic models



#### Context:

How did the project start? What were the issues that needed a co-production approach?  
What were the drivers for doing the work (political, economic, social)?  
What did commissioners hope to get?  
What history was there, in terms of working together? In terms of experience in consulting people?

*Reflection: Were expectations realistic? Did the original brief need renegotiation and if so, why? Were there concerns?*

#### Input:

Which stakeholders had time and resources to contribute to the project?  
What did Co:Create agree to contribute?

*Reflection: Was it difficult to get key stakeholders involved? Did Co:Create benefit from any leadership to promote engagement? Any discussion of risks and dependencies e.g. what sort of commitment and resource was needed for Co:Create to be effective?*

#### Activities:

What did people do together? Who was involved (relates to history of working together above)?

*Reflection: What were their experiences of participating? What went well, what went not so well with the activities?*

#### Outputs:

What happened as a direct result of the activities? What was produced/decided?

*Reflection: Were people able to apply the experiences and learning from activities to the process of co-production? What were the barriers and facilitators?*

#### Outcomes:

What was achieved over the longer term in relation to the aims and objectives of the project?  
Were there unanticipated outcomes – either positive or negative?

Logic models are now being produced for 14 projects. University evaluators are doing in depth evaluation of 3 projects so are interacting directly with project stakeholders - those commissioning the projects - to create models. Co:Create staff are leading on completing the models for the remaining 14.

*Reflection: How did the process at the stages of Input, Activities, Outputs influence the outcomes? What could be done differently in future? What contributed to success and will be used as a strategy in future projects?*

Co:Create is using the process to take stock at the beginning of each project, to see whether the initial plan aligns with the theory of change for the overall programme. In some cases, the reflective exercise has helped to judge whether a project should be continued. The interactive modelling has been a useful tool to refocus individual projects and ensure that everyone is moving towards the same aims. The team are finding that the process works as a clarification and



feasibility check, which can be used to go back to commissioners with a refined and more realistic offer of what Co:create can do to facilitate co-production. The Theory of Change also helps Co:create explain overall ambitions to those involved in health and social care commissioning processes, especially commissioners, and acts as an excellent framework for evaluating the effectiveness of collaboration with commissioners at the end of a project.

### *Cross-case analysis*

Explanations for how co-production works are being examined for cross-cutting themes and patterns. For this stage of the process, we are using a model which explains the processes of partnership working that has been developed and validated by an international team (see Oetzel et al., 2015; Belone et al., 2016). The model includes sections on context, partnership processes for co-learning and co-design, and intermediate outcomes such as sharing power and building capacity. It also contains a section on long-term outcomes, including ability to transform services, enable social justice and health equity (see Center for Participatory Research 2018). We hope to return to some co-production projects at the end of the programme to identify whether Co>Create contributed in any way to achieving these longer-term impacts.

As we conduct the cross-case analysis, the emerging explanation for whether and how a service such as Co>Create facilitates co-production will be compared with Co>Create's initial Theory of Change. This analysis is being completed now and will be used to feed back to commissioners on what works in co-production (and what doesn't). The discussions will be used to develop a plan for how to move forward.

### *Reflections on challenges encountered with using logic models*

The success of logic models as an interactive tool for creating and charting the course of a project depends on the willingness of stakeholders to engage across organisational boundaries, and to prioritise engagement when there are many competing demands on time. In cases where commissioners perceive that Co>Create will be doing co-production *for* them, it has not been possible to engage them alongside other stakeholders to co-produce the model. Where commissioners are actively engaged, they have contributed to the development of *a priori* models and participated in reflection and modelling at project end. Having the wider team, including evaluators, in creating the model has produced richer discussion, demonstrating the importance of including as many different perspectives as resources permit.

Despite varying levels of engagement from commissioners, the models are serving as a useful tool for Co>Create to articulate project aims and rationales for proposed activities. Creating the models has also helped staff reflect that, when it comes to evaluation, the process of designing a project and the reasons for each particular design are just as important as listing the activities that will be delivered, the outputs and outcomes.



## Conclusions

In this paper, we have captured emerging learning about logic modelling and Co:Create; an initiative that is seeking to support the embedding of co-production in commissioning across health and social care, and based on an ongoing participatory evaluation. The production of a logic model 'crib sheet', which incorporates different types of questions, has been useful. Developing the crib sheet as part of a training process provided a common basis to collaboratively develop logic models. The conversations and discussions that happened when creating logic models have been just as important as the model itself; providing rich information to learn from about how people envisage a process leading to coproduction. Notes from logic model development sessions are an additional source of data, supporting the completion of cross-case analysis and therefore identification of the components and processes, across projects, that promote co-production. We therefore suggest that logic modelling is a type of creative practice; whose value lies not primarily in the *product* (model) that is produced, but in the *process of iterative reflection* that developing a model promotes. Logic modelling can help support design and evaluation processes involving commissioners and service users; helping people collectively unpack assumptions and evidence about why co-production in particular programmes ought to be, is or is not working.

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## The discovery and visualization of Human Factors in Healthcare procedures

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**ABSTRACT** Safety and efficiency in the provision of healthcare have become paramount as national health services around the world are coming under increasing pressure due to expanding, ageing, and less active populations. The impact of human factors in the delivery of healthcare and the usage of medical devices is increasingly being recognised as a significant contributor to patient experience and safety (CHFG 2017) with the potential to be used as a driver for positive transformative change.

This paper poses the question of how human factors can be researched in such a complex socio-technical and safety critical system as healthcare, and how the information and insights gained can then be visualized so that all stakeholders can understand the subtleties and interdependencies of the various actors at play.

This research originated from task analysis studies conducted during healthcare procedures as a means to inform the design process. The paper seeks to formalise and expand this knowledge into a methodology for wider dissemination, using theoretical and empirical research approaches, allied to the experience and insights gained from running design projects with healthcare clinicians and medical device companies.

The result is the development of a systematic methodology that can assist designers, researchers, architects and healthcare professionals during the research phase of a healthcare design project. This methodology can be used to uncover user needs, identify potential risks, provide documentation for regulatory adherence and training, inform the development of a comprehensive design brief and ultimately aid the delivery of safer and more efficient healthcare products, interactions and services.

Keywords: Human Factors, healthcare, medical devices, design research, visualization.



## Introduction

As healthcare systems worldwide face increasing pressure from complex and interconnected global challenges, new approaches and methodologies are required to help develop creative, informed and holistic solutions that take the abilities of potential users in to account.

Consideration of the human factors involved in the execution of healthcare procedures is fundamental in the creation of this empathetic user-centred design process. Human Factors is regarded as synonymous with

'ergonomics, human engineering, usability engineering (UE), or human-computer interaction (HCI)' by the US Association for the Advancement of Medical Instrumentation (AAMI) who define it as 'the application of knowledge about human capabilities (physical, sensory, emotional, and intellectual) and limitations to the design and development of tools, devices, systems, environments, and organizations' (AAMI 2013, 1).

This paper presents a methodology that enables the capture, analysis and documentation of the human factors that affect the interactions of both those who deliver and receive healthcare with their environment, equipment, organisational structure, and colleagues across a range of settings from homecare to primary care and acute hospital care. Through the discovery and visualization of human factors during healthcare procedures it is intended to offer different perspectives on current practice, allowing the development of new transdisciplinary dialogues leading to transformative change in patient experience and delivery of care.

## Context

Worldwide, the size, structure and physiological profile of our populations are rapidly changing. The United Nations estimate that from 2018, the world population will increase by almost a billion people by 2030 (7.63bn to 8.55bn - medium variant projection) with an additional 1.2 billion by 2050 (UN 2018). The World Health Organization (WHO) estimates that

'between 2015 and 2050, the proportion of the world's population over 60 years will nearly double from 12% to 22%.' (WHO 2018).

Worldwide, levels of obesity (Body Mass Index  $\geq 30\text{Kg/m}^2$ ) have almost tripled since 1975 (WHO 2017). The consequences for the demand in healthcare workers is stark with estimates that by 2030, the global demand for health workers will rise to 80 million workers, double that of 2013 levels (World Bank 2016). The need, therefore to create a healthcare environment that allows the safe and efficient delivery of care while reducing pressure on staff is obvious.

The potential for human factors to contribute to the improvement of patient safety and experience, healthcare delivery and risk management has been well documented (CHFG 2017). However, for various reasons, adoption of human factors within healthcare has been slow-paced and uneven (Russ et al. 2013). This paper aims to contribute in this area, leveraging expertise



developed in the Product Design Department in the National College of Art and Design, Dublin. The department has run a studio based MSc. programme in Medical Device Design since 2009, during which students work in collaboration with clinicians and industry partners to develop solutions to real world healthcare problems. These projects typically begin with a period of contextual user research. As a result, a competency in the creation and application of methodologies to conduct contextual research in complex environments and to interpret and visualise its results has developed within the department. While developed independently, this approach bears common elements to the work of Mary Beth Privitera in the University of Cincinnati who has published widely on contextual inquiry in medical device development. (Privitera 2015)

## Proposed Methodology

The proposed methodology has evolved over a number of years during the research phase of medical device and healthcare related design projects in both human medicine and veterinary procedures. To date, this approach has been used to study a range of procedures, from those requiring high manual dexterity and high cognitive load to low risk scenarios. The intention is that the methodology could be applied to almost any task performed by healthcare professionals.

The overall approach of the methodology is based on design ethnographic methods for conducting contextual user research. The principle of this approach is that the researcher seeks to gather as much data in the actual usage context in order to fully understand all the various inputs that can affect usage outcomes and that could inform a design intervention. The emphasis is on primary research conducted in the field supported by secondary research that gives an understanding of particular medical conditions and the wider healthcare context.

The methodology consists of four distinct phases:

1. Project briefing and scope
2. Data collection
3. Data analysis
4. Data presentation

### *Project briefing and scope*

As a wide and diverse range of projects can be undertaken using this approach, it is important to establish the start and end points of the contextual research. It can be beneficial in the early stages to allow a breadth of study as tasks completed before and after the procedure being studied can have a major impact on the experience for both patients and staff. The initial broad sweep through a patient experience or procedure should yield insights into those parts which need a greater level



of analysis and particular issues or 'pain points' can be identified. The intent of this step is to create a framework for the analysis of the task or procedure, to establish, in a hierarchical manner, the critical steps from the perspective of both patient and clinician.

### *Data Collection*

1. Secondary research is conducted into the procedure using medical textbooks and journals. If online video footage of the procedure is available this can be used to construct a first stage task analysis.
2. Primary research can be conducted by a number of means depending on the nature of the task or procedure being analysed. Ideally the researcher will observe a procedure in the contextual clinical setting across a number of locations to account for institutional or clinical differences in procedure.

### *Observation*

- a. If more than one researcher is allowed into a procedure then different roles will be adopted such as note taking or videography.
- b. If possible video and audio should be used to record the procedure.
- c. Still photographs can also be used to record particular parts of the procedure.
- d. If cameras are not allowed then an observer may take notes and sketch out a storyboard of the procedure.
- e. For procedures or tasks which are performed over a number of locations, a floor plan should be used and the physical movements of the healthcare staff should be mapped using spaghetti mapping as shown in Figure 1.
- f. It may be possible to get research participants to describe the procedure while performing it for retrospective verbal protocol analysis (Bainbridge and Sanderson 2005). Retrospective analysis allows the researcher to enquire and ask pertinent questions in order to gain insights into the procedure for later synthesis and analysis.

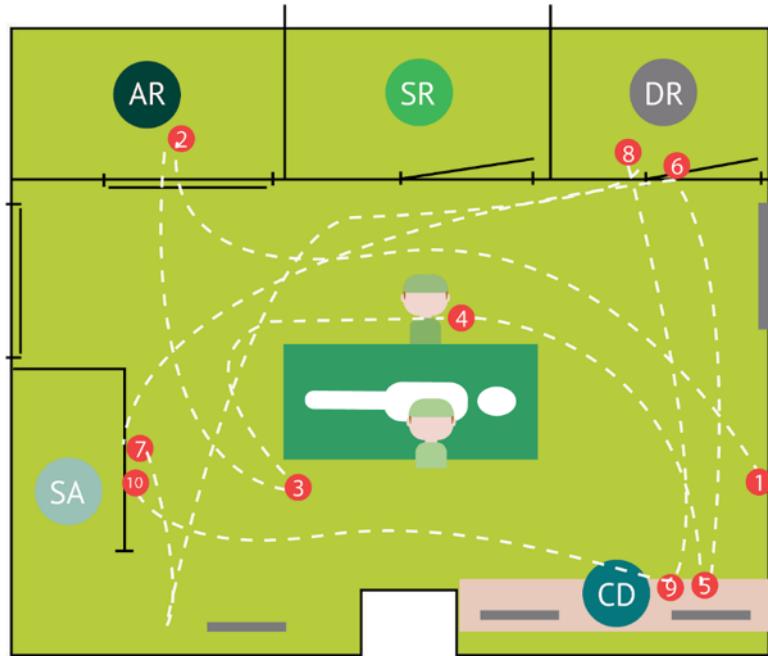


Figure 1: Spaghetti mapping of the circulating nurse in an operating theatre. Image by Nikita Parikh

### *Interview*

Where possible interviews are conducted with the various stakeholders including patients, clinical staff and training professionals. Interviews may be enhanced through use simulation (Privetera 2015), observing videos of procedure or discussion of the rich picture of the procedure shown in Figure 3.

### *Role Playing*

In some instances mock ups of the procedure may be conducted where the researcher role play the various professions as shown in Figure 2. This method is useful for putting the researcher into the shoes of the user and gain insights on what the user may be perceiving, thinking and doing at each step of a procedure.



Figure 2: Role playing a minimally invasive surgical procedure.

### *Data Analysis*

#### *Sense making*

Information from the data gathering phase is used to build up a rich picture of the procedure in an analogue fashion using sketches, storyboards and post-it notes. This can be a useful tool for validation and editing of the task with clinical professionals.

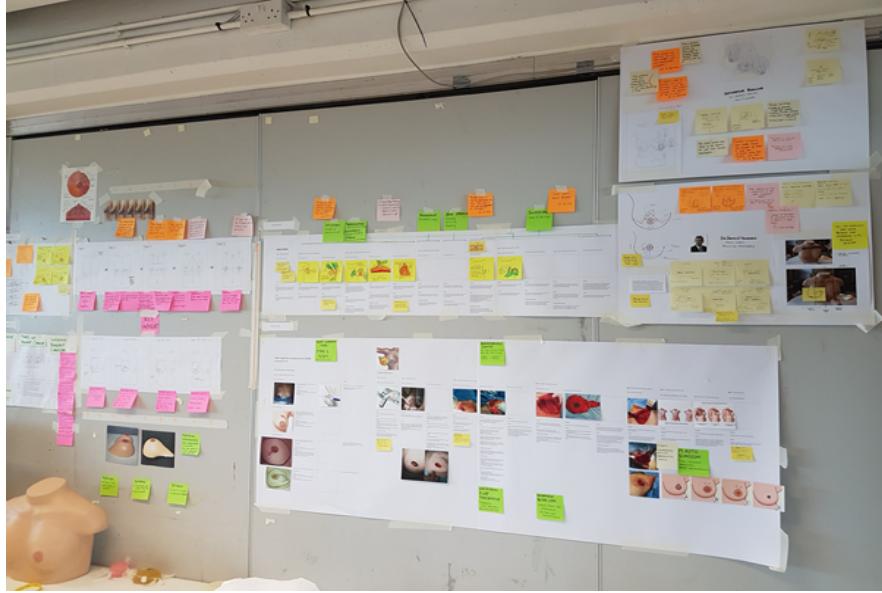


Figure 3: Building up a rich picture of a task using a combination of digital and analogue methods.

#### *Analogue Task Analysis*

The task analysis is initially mapped out in an analogue fashion using sketches as shown in Figure 4. Task analysis is broken down into perceptual inputs, cognitive processing, and physical actions involved in performing the step in accordance with FDA (2016) guidance shown in Figure 5. This detailed task analysis allows the researcher to establish, at critical junctures in the procedure, what the clinician is perceiving from the information available to them, what their understanding of that information is and how it informs their decision-making process given the context of the procedure.



Figure 4: Analogue presentation of task analysis.



This analogue version of the task analysis is then presented to key stakeholders in order to establish its validity, identify key insights and allow the researcher to identify particular moments for further exploration. The user feedback from this presentation can be key to identifying design interventions.

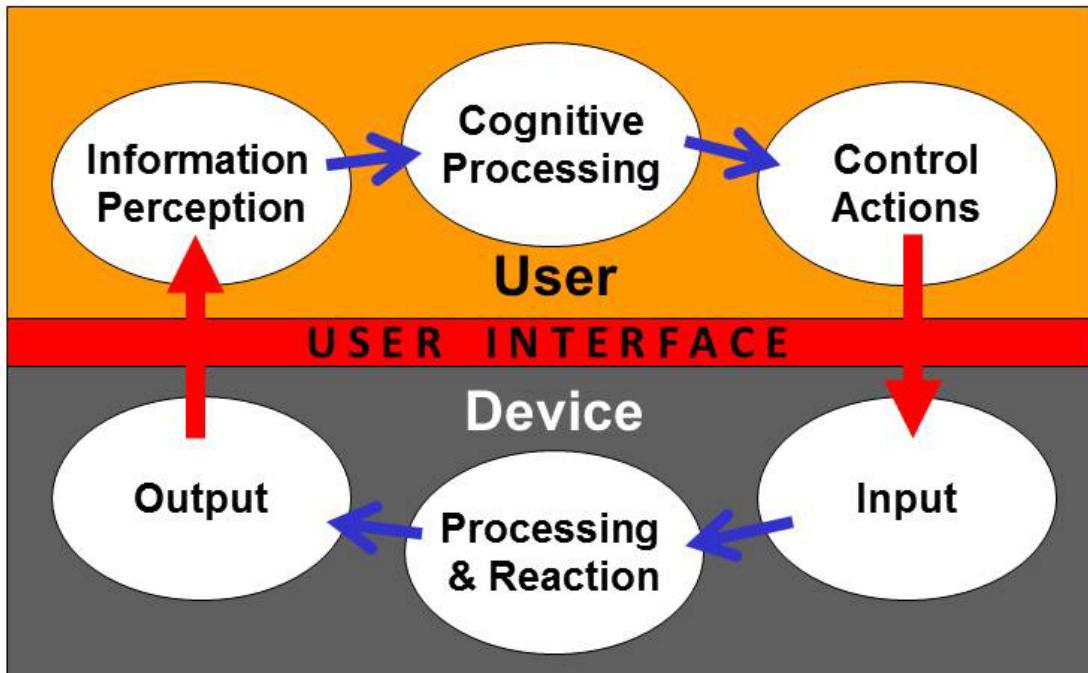


Figure 5: Device User Interface in Operational Context (adapted from Redmill and Rajan 1997). FDA (2016)

### *Data Presentation*

Due to the extensive nature of the data collected and analysed, it is important that information is presented in a clear concise format that only includes relevant key findings and insights. It is important to maintain objectivity at this point and present all the discovered insights rather than just those that point to potentially favoured design solutions.

The final presentation of the research will be dependent on the task or procedure and the level of detail required to execute it. Two potential methods of presenting the information are as a journey-map or a task analysis

### *Journey Mapping*

In procedures which are carried out in a number of locations over a period of time the information can be presented as a journey map. The example shown in Figure 6. is a journey map for an admissions procedure for a hospital ward. This information could be used for training of healthcare professionals, value stream mapping of healthcare procedures or as a discussion document for improving healthcare procedures.

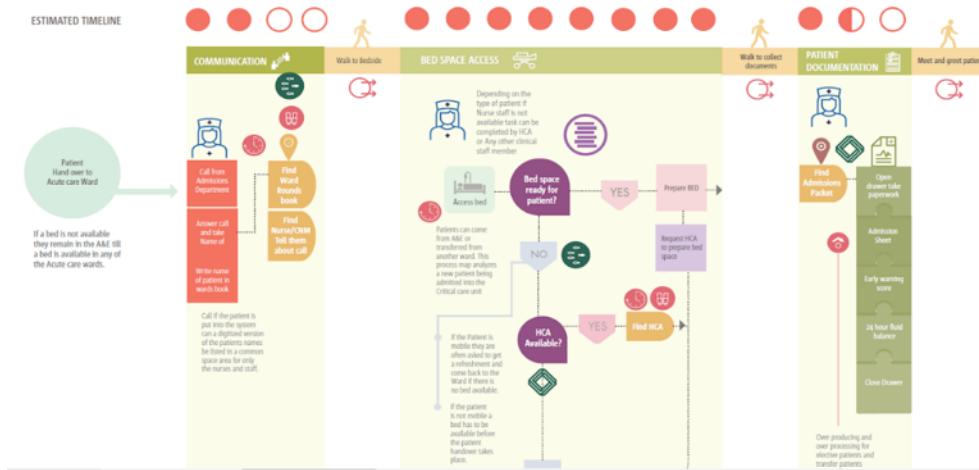


Figure 6: Section of journey map for a hospital admissions procedure

### Task Analysis

For critical procedures requiring manual dexterity and high cognitive load the information can be presented as a task analysis. The final task analysis document should have a visual representation of each step of the procedure. Alongside the visual of each step there is a text description and any insights the design researchers gained when studying the procedure are also noted as shown in Figure 7. The three stage Perception, Cognition, Action (PCA) model of task analysis is used to focus on what the user is perceiving, thinking and doing at each step of the procedure. This information can be used as a training document, a starting point for the development of a medical device or the starting point for fulfilment of the regulatory requirements with regard to human factors.

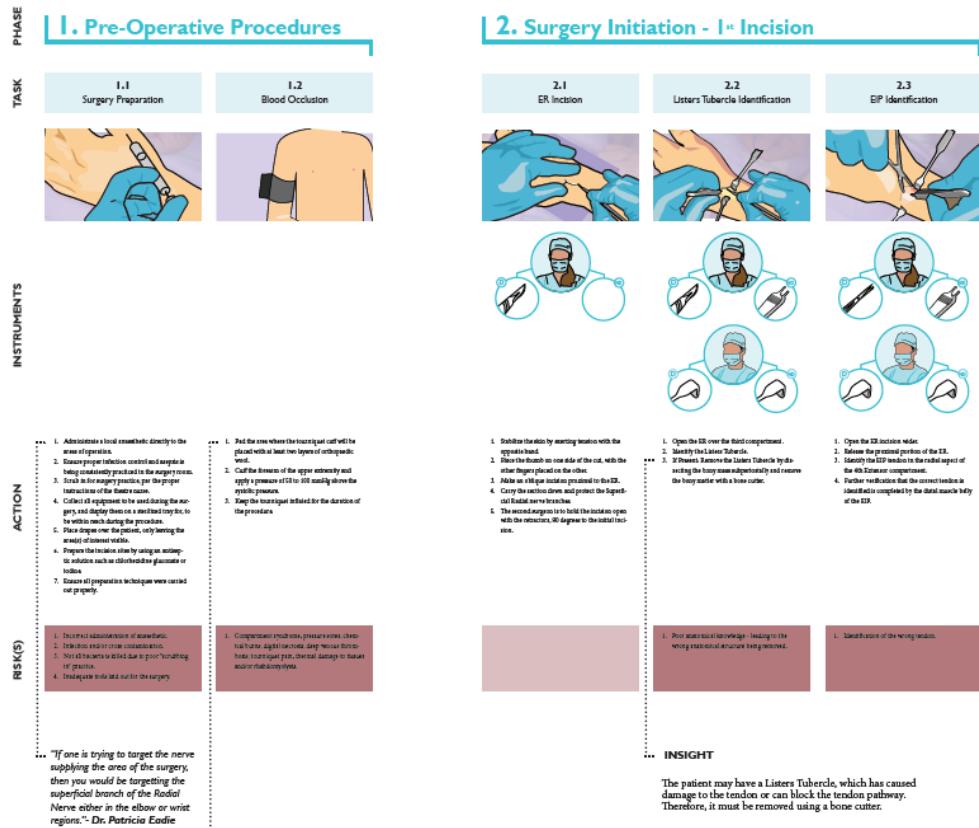


Figure 7: Section of task analysis for a surgical procedure

## Discussion

The aim of the methodology presented above is to incorporate the relevant human factors into the design process of healthcare projects. This approach could be of particular use in the design and development of medical devices. The relevant standard is HE75:2009/(R)2013, Human Factors Engineering – Design of Medical Devices. HE75 is produced by ANSI/AAMI and recognised by the US Food and Drug Administration (FDA) as a general consensus standard related to human factors and the application of human factors to medical devices (AAMI 2013). HE75 clearly details a methodology for formative and summative testing of medical devices in order to discover potential issues through user testing. However, by the time a design reaches formative and summative testing, significant time and resources have already been invested in the product under development which, due to time-to-market and budget constraints, can create a reluctance to deviate from the existing brief or to implement the findings of user testing if those findings indicate major product changes or a pivot in direction are required. To prevent this scenario, the proposed approach aims to ensure that through a rigorous and documented phase of contextual user research, the inputs, requirements and outputs of all stakeholders are taken into account, potential risks and decision making points are identified, and key insights and findings are presented in a clear, unambiguous format from which the criteria of a design brief can be formulated and all the rich detail that informs the design process can be taken.



A key aspect to the discovery of data at the outset of the process is the preparation and mindset of the researcher when engaging in research process. The researcher should have sufficient in-depth knowledge of the procedure, condition and expected outcomes under study, in order to enable them to be credible and to ask the pertinent questions but still maintain the position of a 'naive observer' where tacit information (known to healthcare staff) is not assumed but questioned. This allows the capture of a wide variety of information that may normally be overlooked, for later synthesis and analysis. The analysis of this data allows an objective challenging of the status quo. In the experience of the authors, some of the most valuable insights that lead to transformative change emerged from keen observation of what is happening around and in support of a particular procedure rather than specifically related to the procedure itself. Establishing this viewpoint from the outset requires persistence, rigour and trust that the process will yield results.

## Conclusion

This paper has outlined the background and development of a methodology for the contextual user research and visualisation of human factors involved in healthcare procedures. It is intended that the creation of this methodology will provide a defined framework through which those involved in a healthcare design project can confidently develop transformative healthcare products, interactions and services based on transparent, traceable and accountable methodology.

It is also intended to further refine the methodology and augment it with the development of a set of design research tools to assist in its implementation. With the continuous evolution of technology, new methods for the capture of images and video e.g. eye-tracking glasses, could be integrated into the process to further refine understanding of the clinician experience during a procedure. Applied to the development of surgical trainers, augmented reality or virtual reality could be used to overlay the outcome of the research onto the user experience to assist in decision making, flag risk scenarios and inform progress through a training task. In this scenario, artificial intelligence could be used to map the trainees experience against an 'ideal' path defined by the outcome of contextual user research. There is also potential for formulating the output of the research into pre-existing standardised formats to allow seamless integration with risk management protocols to meet industry requirements.

Therefore, rather than an end-point, the authors would intend that the publication and dissemination of this work is the first step in the creation of a discussion and possible collaboration with interested parties to develop and refine the presented methodology. This will allow closer alignment with the inputs, requirements and outputs of the various healthcare usage scenarios and industry sectors to which this methodology may be applicable.

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## The Design of Digitally Manufactured and Hyper-Personalised Cutlery Sets for Stroke Patients

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**ABSTRACT** We present the design of a digitally manufactured system to produce cutlery personalised for the individual needs of stroke patients. Stroke often results in weakness or paralysis on one side of the body and often in the inability to hold cutlery and eat using the affected limb. While there are some cutlery sets for people with disabilities that offer large foam or rubber handles to improve grip, there are no systems that cater for the many factors that differ regarding impairment after stroke. Our research identified wrist motion, strength of grip, contracture, shoulder strength, and index finger extension, as factors that affect stroke patients' ability to use cutlery with their affected limb. Given the many potential combinations for each individual, our system offers hyper personalisation in the form of a parametric system that can produce over 40,000 versions of cutlery to address the very particular needs of individual stroke patients.

Keywords: human centred design, stroke, participatory research, hyper personalisation, rehabilitation, cutlery



## Introduction

Stroke patients find standard cutlery challenging to use for several physiological, mental and cultural reasons. Using a standard knife and fork at the same time is often too difficult for stroke patients, due to weakness or paralysis resulting from the stroke and the concentration required to operate both concurrently. Wanting to feel normal again, patients will avoid current market solutions in efforts to avoid stigma surrounding existing assistive devices, instead opting to use and struggle with standard cutlery (Bispo & Branco, 2008). This project aims to provide patients with a personalised set of cutlery, making them feel confident.

## Background

A stroke occurs when there is a blockage of blood flow or rupture of an artery to the brain. This results in the sudden death of brain cells due to lack of oxygen. Symptoms can include sudden loss of speech, weakness, or paralysis of one side of the body. Stroke is a common problem, with an estimated overall incidence of first time stroke sufferers of 2.4 per 1000 (McLaren and Perry 2003). Stroke produces a wide variety of physical, cognitive, emotional and social effects that may persist long beyond the acute phase or hospitalisation.

A study on 162 patients admitted for stroke rehabilitation over a period of 1 year (Westergren et al. 2001) found difficulties in eating in 80% of patients; and 52.5% were unable to eat without assistance. 60% would only manage 3/4 of their meal, 56% had difficulty manipulating food on the plate, and 46% had trouble transporting food from the plate to their mouths. This often results in under nourishment of 32% of patients (Westergren et al. 2001), and in compensation, where patients end up using their unaffected hand for every eating action, and avoiding the use of the affected hand. This in turn increases the atrophy of the affected limb, creating a vicious circle.

The use of objects employed to aid in impairment, such as a wheelchair, a walking aid, or cutlery sets with large foam handles often act as a symbol of stigma and emphasise the prejudices to the people who use them (Bispo & Branco 2008). Stigma can be related to the aesthetics of objects (Vaes 2014) and the appearance of and interaction with objects can produce emotions that affect our behaviour (Rodríguez Ramírez 2011, 2014).

Current market solutions for eating utensils for stroke patients or people with disabilities address a wide range of physiological factors, with varying levels of effectiveness. From adding straps to fix the utensil to the hand, to larger ergonomic grips, to bendable adaptive cutlery, there are plenty of existing solutions in the marketplace. Common themes throughout existing solutions include: the stigmatising aesthetic common with healthcare products; the problem that the eating aids will only address one factor or be specific to one problem caused by the condition, meaning that consumers may need to invest in multiple different products to experience effective relief; there are no current solutions customised for stroke patients' individual needs and impairments, meaning that there is no differentiation for instance between left handedness or right handedness, or if the left side of the body or the right side is affected; current solutions don't



address progression in the recovery. As every stroke patient experiences different symptoms (some may have contracture of the fingers, while others may have weakness, some have good wrist rotation, but in others it will be poor); there isn't currently one solution on the market that can be customised to the very different needs of individual stroke patients.

We suggest that a system for producing hyper-personalised sets of cutlery that can be adapted to address progression as the patients recover, will address the individual impairments of stroke patients and make it easier and more acceptable for them to use both hands for eating, therefore addressing the very common issue of compensation and facilitating the use of the affected hand.

## Methods

We followed a Research through Design approach in different iterative phases based on design criteria (Rodríguez Ramírez 2017). In order to define design criteria for a system to personalise cutlery for stroke patients, we carried out a literature review, competitor analysis and semi-structured interviews with clinicians and patients.

User testing sessions assessed the effectiveness of prototypes throughout the design and research exploration stages of this study; protocols are described below. Thematic analysis was used to identify insights from sessions.

### Design Research Phase 1

A semi-structured interview was conducted with an 82 years old male stroke patient. It had been 11 years since his stroke which affected the left side of his body. He spent 6 – 7 weeks in hospital learning to walk again.

When eating out at a restaurant he uses cutlery provided by the restaurant and then normal cutlery in the comfort of his own home. He avoids meals that require two hands to eat due to his caregiver having to cut up his meat for him. He chooses foods he can eat with a fork mainly, avoiding the knife. He pointed out that every stroke patient is different and that he uses customised items for his own needs, such as a bag a friend made him for his wheelchair. He struggles picking up the cutlery when it is flat on the table. His index finger can't stay extended when holding a knife.

### *User Testing Session 1: Use of cutlery by stroke patients*

#### *Procedure*

We tested three sets of cutlery. Set 1 (fig. 1) is a standard and chosen to be control for the testing.

Figure 1: Standard set of cutlery used for testing.



Set 2 (fig. 2) is an experimental set for stroke patients (Chen 2017). There is an additional “ring” attachment for the fork in this set, designed with the idea that it would keep the index finger secured to the top of the fork to practise a more desirable grip while reducing the frequency of dropping the utensil.



Figure 2: Experimental set of cutlery for stroke patients.

Set 3 (fig. 3) has the ability to be easily manipulated through bending and twisting, so stroke patients could tell us what their ideal shape would be. Patients were recruited through a neurological physiotherapist. The inclusion criteria were experience of a stroke at least 6 months prior to the interview, living at home, an active wrist and finger, the ability to walk independently, an age of 40-75 years, and good general health. Exclusion criteria were signs of severely impaired



verbal communication, inability to give consent, severe neurocognitive deficits, experiencing excessive pain in any joint of the paretic arm, terminal illness, or life-threatening comorbidities.

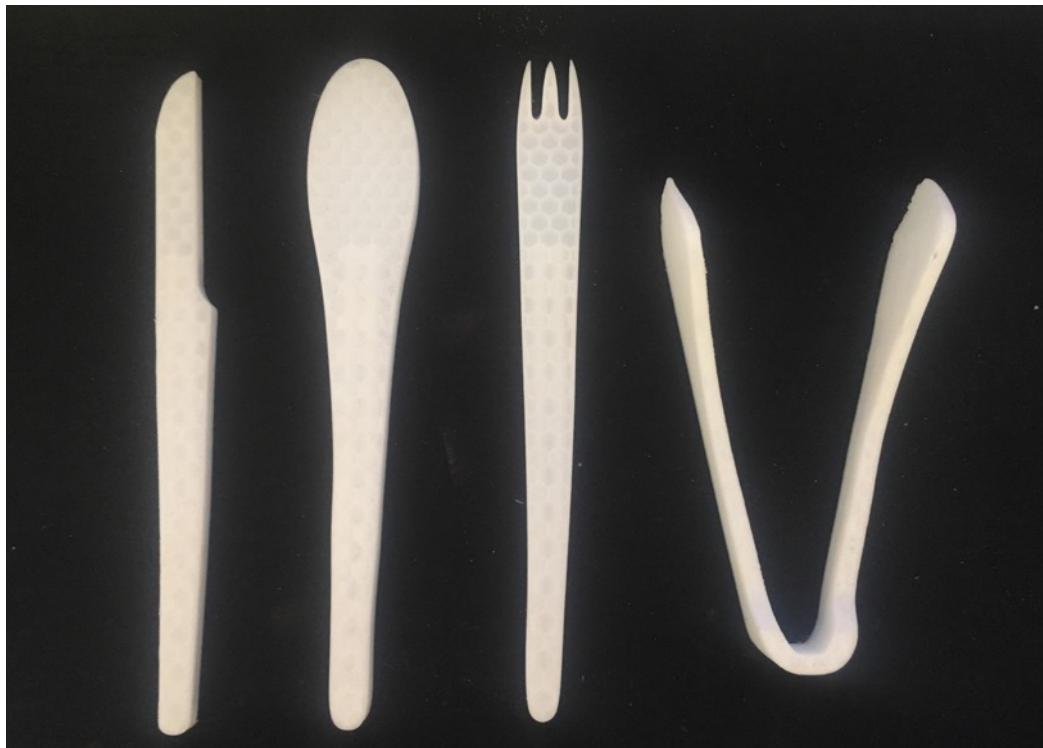


Figure 3: Flexible set of cutlery for stroke patients to modify according to their own requirements.

Four patients were recruited and used on two different occasions, once for phase 1, and again in phase 2.

Each session took 30 minutes. The tasks the patients were asked to perform were:

- Picking up cutlery
- Manipulating cutlery into holding/eating position
- Manipulating/cutting food on the plate
- Transporting food from plate to mouth
- Eating



Figure 4: Observations from testing sessions.

The findings from the testing sessions are summarised as criteria of what the new design should do in the table below. We found, in consultation with clinicians, that the following factors affected the way patients held utensils and could potentially be addressed through individualising the designs for each patient: wrist motion, strength of grip, contracture, shoulder strength, index finger extension.



Table 1. Criteria based on design research phase 1:

Theme	Solution	Influence on System
Lack of control	Improve hand position on the cutlery with emphasis on the index finger.	Larger area to accommodate and secure the index finger along the top of the utensil. A potential groove or indentation.
Difficulty picking up cutlery	Improved position of the way cutlery sits on the table.	An area underneath the cutlery that could leave space for the patient's fingers could be created by a bend in the utensil.
Hard to hold	More ergonomic shape to prevent dropping and improve grip.	Design of ridges and built up areas of mass to fit specific areas of the hands and give the fingers more to wrap around to secure against the palm. System could change the shape of the handle's cross section.
Would not use in public	Cutlery should follow an attractive and standard cutlery aesthetic.	System could offer a choice of colours or materials.
Trouble with stability (waving/tremors)	Increase weight of utensil and improved established hand position.	Weight will be proportional to material and density and could both be informed by the system.
Food falling off cutlery	Modified tines for better hold on food and increased weight to reduce waving.	Prongs could be modified by the system to create a concave form depending on impairment levels.
Difficulty establishing grip with one hand	Cutlery can be stable on table in its rest position in order to let the user position their fingers appropriately before picking up.	An area underneath the cutlery that could leave space for the patient's fingers could be created by a bend in the utensil.



Wrist, arm, and hand position preventing cutlery from reaching plate	Change angle and direction of bend in the neck and handle of the utensils.	The system could change the angle of the handle with the hand in both the x and y planes.
Difficulty using knife and fork concurrently	Cutlery on affected side should be secure and stable enough in the hand to minimise concentration needed to operate both.	The system could implement a left versus right identification method, where it could change the knife or fork depending on which side the user was affected.
Doesn't look normal	Cutlery should follow an attractive and standard cutlery aesthetic.	System will follow a constant curve geometric constraint to keep the aesthetic constant and clean.
Everybody has different needs	The cutlery should be customisable.	The CAD model should be parametric and customisable.

## Design Research Phase 2

Based on the findings from phase 1, we designed through an iterative process sets of cutlery and tested them with clinicians. The resulting designs were tested again during user testing session 2.

### *Design Results*



Figure 5. Final digital parametric system.



Figure 6. Images of final set discussion and description of final set

The final set is a digitally manufactured system that can be hyper personalised to the specific needs of individual stroke patients. Before purchase, clinicians can indicate through a website the different impairments the patient has (including angle of wrist motion, strength of grip, contracture, shoulder strength, index finger extension), and the system parametrically produces the ideal set for that patient. The set has an angle to help the patient pick up the utensil from the table, while also bridging the gap from the hand to the plate and hand to the mouth. This 'bridge' between the handle and utensil is wider, and shaped with a groove to influence an appropriate grip on the utensil by guiding the index finger.

Half of the cutlery is made from food safe stainless steel on the eating side of the utensil, the other half is 3D printed in Nylon. The latter can be replaced for a new one as the patient recovery progresses and their physical abilities improve.

### *User Testing Session 2*

The same participants from User Testing Session 1 were recruited and given a new set of cutlery. We followed the same protocol as in User Testing Session 1. As we knew the physical abilities of each of the participants, we designed and manufactured a specific set for each participant (fig. 7),



based on the variables for which we could control in our parametric system: angle of wrist motion, strength of grip, contracture, shoulder strength, index finger extension.



Figure 7. Final design for participant 3.



Figure 8. Observations from testing sessions.

## Discussion

The following themes were constructed based on the findings from testing session 2.

**Weight:** all four participants mentioned weight as an important factor. Heavier sets even helped with the hand keeping a more stable position. Too heavy was also an issue. Weight should be a variable to personalise sets for.

**Grip:** the size of the grip and its texture were important elements to personalise. One participant said it gave him more control and "agility", potentially because he is only mildly affected he



doesn't need a large grip like the others. He also commented how the larger grip means his wrist movement isn't as free. Patients expressed when going back to a standard forks that there was not enough grip.

Index finger groove: this gave more control to participants, which they liked, as there was a place to help them control the movement of their index finger. One participant still held the knife in a full grip without extending the index finger.

Hyper-personalisation: the value of the hyper-personalisation seemed most evident when one of the participants mentioned that even the smallest change makes such a big difference to the way it feels in his hand.

Length of handle: while this wasn't a variable we controlled for, participants indicated different preferences for handles, which will be another variable for us to control in future designs.

Aesthetics and stigma: while three participants reacted positively to the new design and stated they would be willing to use them in public, one participant said even if it meant he could eat a steak out in public he still wouldn't use them, simply because of the way he is and how vain he is.

Ability to cut with fork and knife: participants were able to cut using fork and knife. One mentioned: "First time I've cut something in ten years, this is quite exciting."

Overall acceptance: three of the four participants expressed acceptance to the new sets, mentioning comments such as "they are infinitely better than the things I tried last time."

## Conclusion

The eating difficulties stroke patients face when using cutlery are an important area to design for. The main findings from this study conclude that cutlery designed for stroke patients needs to be personalised, as each patient has very individual needs according to their very individual impairments. Current cutlery does not address all the issues stroke patients face due to their impairments, and it doesn't allow for personalisation.

People who have been affected by a stroke in their lives will benefit from a desirable practical design solution with a personalised set of cutlery that assists them to feel confident and comfortable using cutlery in situations outside of their homes, as well as assisting as a therapy device. In helping remove the stigma surrounding design in rehabilitation, and individualising consumer cutlery to aid in the long-term, this can contribute towards a more progressive rehabilitation of a stroke patient.

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## Engaging stakeholders as partners: Co-designing a visual toolkit for psychoeducation about anxiety with young people, professionals and carers

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*About 33.7% of people will suffer from an anxiety disorder within their lifetime (Bandelow & Michaleis, 2015) and treatment generally includes professionals directing people to psychoeducational resources containing written information on anxiety. These resources tend to be poorly designed (Demir, Ozsaker & Ilce, 2008) and typically use didactic methods based on professional knowledge (Zelenko, 2012), resulting in text-heavy health messages that exclude the lived experience and de-emphasise the importance of interpersonal dynamics in caring relationships. As a response to these gaps, this research proposed an alternative approach to the design of psychoeducation materials, using visual communication and interaction design to merge evidence-based health information with the lived experience of multiple target users. The proposed design solution is an interactive and visual educational toolkit on anxiety, co-designed and tested with 6 young people, 5 carers and 4 health professionals. This research uses a qualitative, mixed methodology of Participatory Action Research with elements of co-design and design thinking, including visual research methods. The paper reports on the process and findings of co-design, including workshops applied as a site of iterative design of the visual anxiety toolkit. The preliminary findings of testing through co-design of the visual toolkit prototype indicated high level of engagement with the visual tools that aided participants' sense-making and catered for the differences in the communication and education preferences of professionals and the community. This study points to potential benefits of grounding the design of psychoeducational materials in the considered use of visual communication and involving target users in the design process.*



## Designing A Mobile Application To Improve Engagement With Pelvic Floor Muscle Training Amongst Women From Pregnancy To One Year After Delivery

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**ABSTRACT** Women who are pregnant or have given birth are at high risk of developing Pelvic Floor Disorder (PFD). When left untreated, PFD can cause symptoms such as incontinence, organ prolapse and pelvic pain in sufferers. Pelvic Floor Muscle Training (PFMT) is a highly effective means of treating and preventing symptoms of PFD. However, adherence rates to PFMT remain low.

*This study focuses on the development of a mobile application to improve engagement with PFMT amongst women from pregnancy, up to one year after delivery. The goal of the application is to improve engagement with PFMT through addressing barriers to adherence, and guiding performance of PFMT.*

*Initial design criteria were developed based on literature findings. From here, prototypes were developed and tested. These findings were supplemented by a survey and clinician interviews. The study concludes with the development of a mobile application that identifies strategies for addressing the design criteria.*

*This study revealed that a mobile application on its own is likely to be an ineffective means of teaching women proper PFMT technique and our findings suggest that women should work with their therapists to learn proper PFMT technique. However, we report on strategies to successfully improve engagement such as engagement models (e.g. Hooked model) and environmental/contextual triggers to action within the design.*

**Keywords:** pelvic floor disorder, pelvic floor muscle training, engagement, adherence



## Background

Pelvic Floor Disorders (PFD) occur when the pelvic floor muscles become damaged. This results in symptoms including incontinence, pelvic pain and organ prolapse (Haylen et al. 2009), which can often induce feelings of shame in sufferers (Priddis et al. 2013, 252-253). Women who are pregnant or have recently given birth are at high risk for developing PFD, due to the stress placed on the pelvic organs during this time (Baessler and Schussler 2008, 36-37).

Pelvic Floor Muscle Training (PFMT) is recommended as the first line of treatment for PFD (Norton and Brubaker 2006, 62-63). PFMT is recognized as a highly effective method for treating PFD, with short term cure rates of up to 80% (Bo 2012, 5). PFMT significantly reduces symptoms when undertaken during pregnancy (Sangawang and Serisathien 2011).

However, adherence to PFMT remains low. Borello-France et al. (2013, 762) identified adherence rates amongst women at 50% after 12 months. Common barriers include forgetfulness (Borello-France et al. 2010; Priddis et al. 2013), performing exercises incorrectly (Dehlendorff and Tibaek 2014, 666), low self-efficacy (Chen and Tzeng 2009) and stigma (Almeida et al. 2016).

## *Adherence Frameworks*

A number of frameworks have been developed to understand health adherence behaviour. The Health Belief Model (HBM) (Rosenstock et al. 1974) identifies six concepts that predict an individual's likelihood to undertake health behaviours.

The HBM influenced the development of the Information, Motivation, Strategy (IMS) model (DiMatteo et al. 2012). The IMS is designed to improve adherence to healthcare treatments. The model states patients require sufficient information, motivation, and strategy for addressing barriers to adherence.

## *Persuasive Technology*

Persuasive Technology (PT) is a field of research that studies how technology can influence behaviour change. PT strategies have been utilized within the health domain (Oinas-Kukkonen and Lehto 2010).

Fogg's Behaviour Model (FBM) (2009) identifies three requirements for a person to engage with a behaviour - motivation, ability and trigger. Expanding on the FBM, the Hooked model is a PT framework designed to foster habitual engagement (Eyal 2014). The model consists of four stages - trigger, action, reward and investment.

## Aims and Objectives

This study has two central aims:



- 1) Develop design criteria, which identifies user requirements for improving engagement with PFMT for a mobile application.
- 2) Produce a mobile application, which implements the design criteria developed.

This study seeks to achieve these aims through identifying barriers to engagement with PFMT, and addressing these barriers through design. Strategies for addressing these barriers will be taken from health behaviour models, (HBM and IMS) persuasive design frameworks (FBM and Hooked) and other findings from the research/design process.

## Methods

The Postgraduate Research Through Design Model (Rodriguez Ramirez 2017) provides the structure for this study. The model begins with a review of existing knowledge and designs. After this stage an initial design criteria is formulated. (See Table 1) This is followed by a process of iteration and experimentation, concluding with the production of a final design. Throughout these stages the initial criteria evolves in response to findings. Finally, the final design is evaluated against the new criteria.

Interviews with clinicians, a survey and two rounds of user testing were also conducted.

1. Educate users on the condition and the benefits of performing PFMT
  2. Educate on proper PFMT technique
  3. Utilize Engagement Increasing Techniques
  4. Accommodate the differing personal and medical factors that influence engagement with PFMT
  5. Reduce barriers to engagement
  6. Foster the habitual performance of PFMT in daily life

Figure 1: [First Design Criteria]

### *Defining barriers to engaging with PFMT*

Semi-structured interviews with three clinicians were conducted. Clinicians were asked questions regarding barriers to performing PFMT.

We also carried out a 40 question survey with three women aged between 32 and 55. Participants were pregnant/had children. The survey asked questions on barriers to PFMT adherence, and feedback on features for the mobile application.

### *Testing the new designs*

Two testing sessions were carried out to assess how well the app we designed teaches women about their anatomy, the correct way to perform the exercises and whether it helps them engage in PFMT.

Two women between 22 and 24 participated in the first testing session, through semi-structured interviews. Participants were given three existing applications to test. Participants also evaluated a range of metaphors used by clinicians to communicate PFMT technique (Barnard 2017, 36).

The second testing session involved three women between mid 20s to late 40s via semi-structured interview. The participants were asked to evaluate fifteen animated visualizations, in terms of their ability to communicate the 'squeeze and lift' motion, as part of the training for performing the PFMT correctly. Participants reviewed two anatomical representations of the pelvic floor (2D and 3D) in terms of communicating the location of their pelvic muscles.

## Results

### *Clinician and Survey Feedback*

#### *Information and Guidance*

A lack of information and guidance was identified by both clinicians and women as a barrier.

Clinicians stated verbal instructions for performing PFMT were ineffective. Each clinician mentioned that 50% of women who receive verbal instructions for PFMT will perform them incorrectly. The clinicians recommended that an application should refer users to a clinician for assessment.

#### *Perceived Benefits and Susceptibility*

Perceived susceptibility, and lack of perceived benefits (Rosenstock 1974) were identified by both women and clinicians as factors that influence engagement with PFMT. One clinician suggested increasing perceived susceptibility/benefits within the application by 'scaring them with statistics' - e.g. 50% of women who have had a vaginal delivery will have had a prolapse.'

#### *Stigma*

Survey and clinician data identified stigma as a barrier. One woman surveyed stated she felt 'embarrassed' by her PFD. One clinician stated that stigma prevents women from gaining an awareness of their pelvic floor health.

#### *Memory*

Forgetting to perform PFMT was identified as a significant barrier by women and clinicians.



## *Personalization*

Clinicians emphasized the necessity of tailoring exercise regimens to individuals, as every woman requires different care. Clinicians emphasized the need for women to be assessed by a pelvic floor health professional. An assessment stage within the application was suggested by one clinician, to help match women with an appropriate regimen.

## *User Testing*

### *User Testing Session One*

'Squeezing around a tampon' and 'Squeeze as if you are stopping the flow of urine' were the most preferred of the metaphors. One participant commented that they found these metaphors most successful in communicating technique, as they referred to sensations that were familiar to them.

Participants found the 2D visualizations of the pelvic floor confusing. One suggested that an interactive 3D version would better communicate the location of the muscles.

Participants did not like applications that lacked instruction regarding how to perform the exercises.

### *User Testing Session Two*

Of the visualizations presented, participants tended to prefer visualizations that had an organic motion, and that were more abstract over figurative.

Participants preferred the interactive 3D visualization over the 2D visualization noting that the 3D visualization was easier to understand the part of the body it was representing.

For the app, one participant suggested the level of instruction/guidance offered to be customizable. Another suggested the addition of a discreet mode, especially for push notifications.

## *Application Prototype Design*

This prototype was based on the second version of the design criteria, integrating clinician, survey and user testing findings. (See Figure 2) The app is based on Eyal's Hooked model (2014) to establishing habitual engagement.



1. Educate users on the condition and the benefits of performing PFx
2. Educate and guide users on PFMT technique
3. Educate women about pelvic floor anatomy
4. Utilize Engagement Increasing Techniques
5. Accommodate the differing personal and medical factors that influence engagement with PFMT
6. Reduce barriers to engagement
7. Foster the habitual performance of PFMT in daily life
8. Refer women to clinicians for assessment

Figure 2: [Second Design Criteria]

### *Trigger*

The application reminds users to perform their exercises via push notification. This notification can be launched either via an alarm set by the user or when a user is at a certain location (i.e. work). (see Figure 4) This feature addresses point 6 of the criteria, and point 7 through establishing an association between performing PFMT and daily activities.

### *Action*

The application provides a guided workout component where users are provided with timed visualizations to assist with their exercises. The visualizations are based on the feedback received from initial user testing. Brief written instructions are provided to help guide the workout. The guided workout component addresses point 2 of the criteria through using metaphor and visualizations to guide PFMT.

### *Reward*

This application utilizes reward mechanisms to promote engagement. Users can achieve high scores, set exercise goals and track progress. Other reward mechanisms include ratings at the end of workouts and praise messages (i.e. 'Great! Keep Going'). These components address point 4 of the criteria through fostering engagement through the use of reward.

### *Investment*

The application's tutorial stage gets users to workout, set goals and reminders and go through an assessment to receive a customized workout. The time and data investment within this stage is intended to encourage the return of the user to the application. Progress tracking and goal setting is another form of investment in this application. (point 4 of criteria)

### *Other Features*

The informational component within the tutorial addresses points 1 to 3 of the criteria. In this stage users are provided with information on pelvic floor health, anatomy (via 3D model) and exercise technique. Women are reminded to consult a clinician for an assessment, as per point 8 of the criteria.

Statistics that emphasize the benefits of PFMT are shown to the user throughout the application, such as in the tutorial stage or pause dialog. This addresses point 6 of the criteria through increasing perceived benefits.

In the assessment stage women establish a baseline for their exercise regimen. This enables users to adapt their workout to their specific health needs (point 5). These exercises can be updated later if needed.

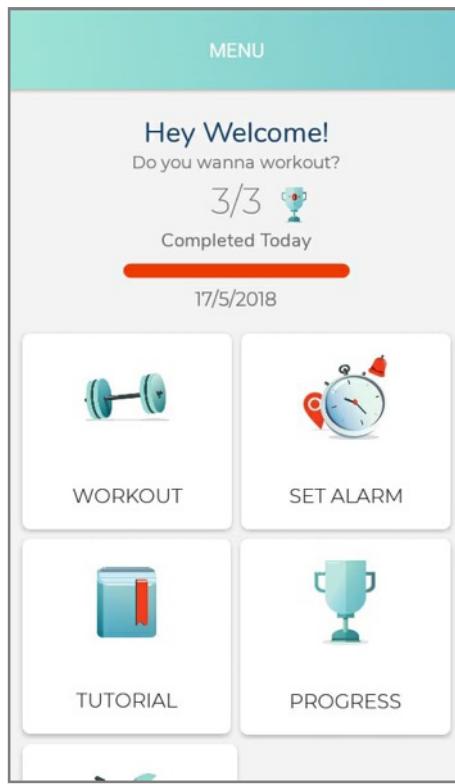


Figure 3: [Application Home Screen]

## Discussion

The designs produced within this study fulfilled the developed design criteria (see Figure 2) to varying degrees of success.

The findings from this study indicate that a mobile application may not be an effective means of educating PFMT technique (criteria point 2). Strategies explored within this study to communicate



technique, such as metaphors and visualizations, aid women's understanding to some extent. However, these strategies are a form of written instruction, which clinicians identified as an ineffective means of guiding PFMT technique.

While the prototyped application may not provide effective instruction for PFMT technique, it has the potential to assist with PFMT through fostering engagement with exercises. The integration of the Hooked model is an example of a strategy to foster habitual engagement. Additionally, the design of the final app integrates features that address each part of the design criteria, and the barriers to adherence as identified in this study. The application can theoretically be used to help foster habitual engagement, but as one facet of treatment which includes consultation with a clinician.

Limitations for this study include the small number of women participating in the survey and user testing. Additionally, the use of engagement strategies is still speculative as the final application has yet to be tested with women.

The next step for this project is to test the efficacy of the prototyped application in improving women's engagement with PFMT.

## Conclusion

This study follows the process of designing an application to assist women with their pelvic floor muscle training. Several significant barriers to engagement were identified including lack of information/guidance, trouble remembering to perform exercises, stigma and lack of perceived benefits/susceptibility. These findings from this study were integrated into a design criteria, and a prototype application was developed based off this criteria. The prototype explored various engagement strategies to fulfil this criteria. This study revealed that a mobile application is likely an ineffective means of teaching women proper PFMT technique. However it still has the potential to be an effective means of fostering habitual engagement with PFMT, through utilising engagement frameworks such as the Hooked model (Eyal 2014).

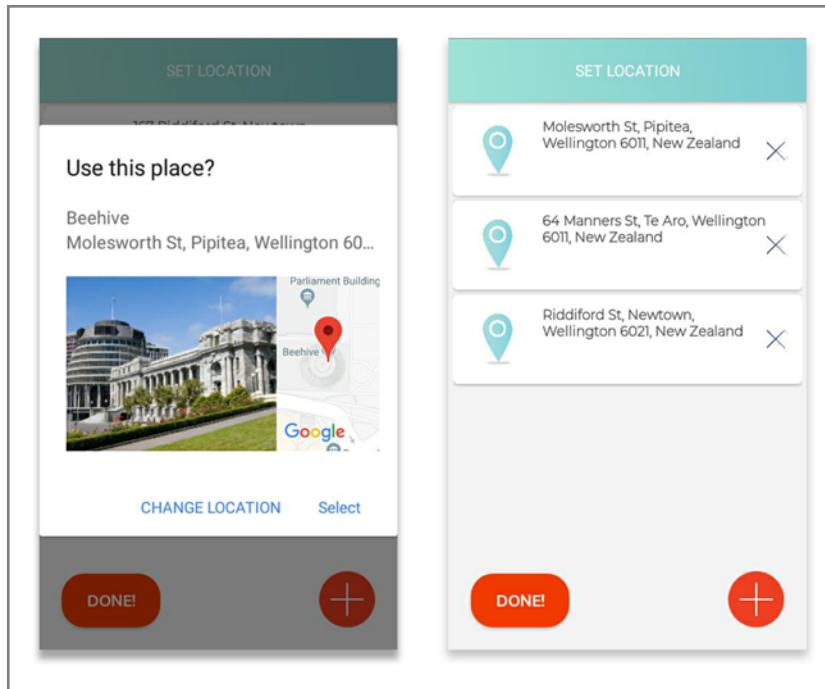


Figure 4: [Application Prototype - Location based notification feature]

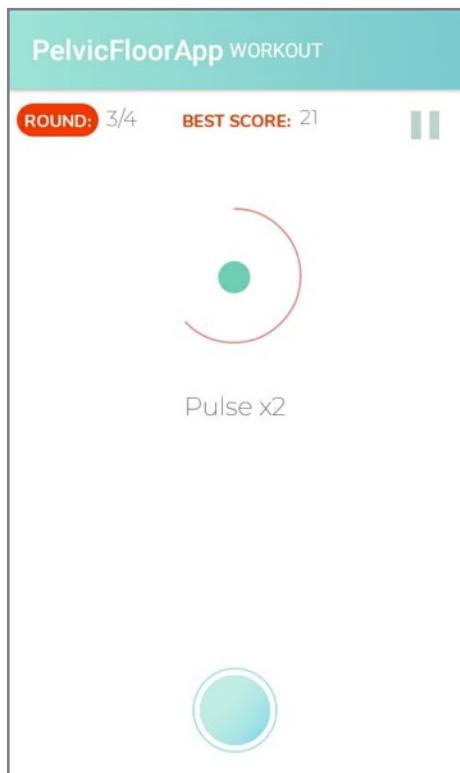


Figure 5: [Application Prototype - Workout]

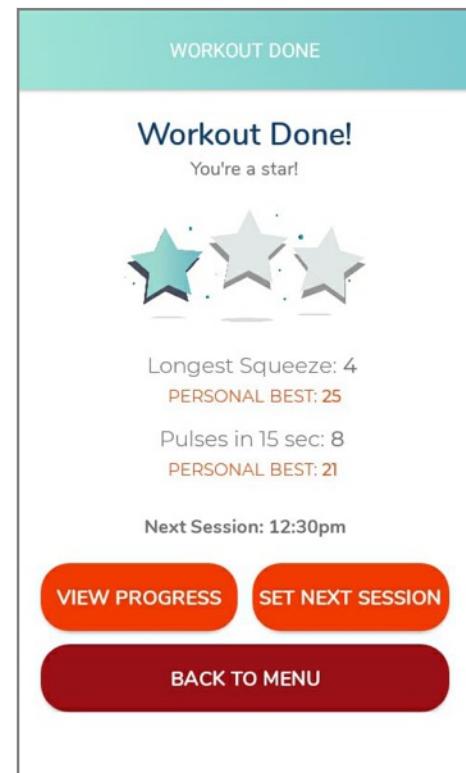


Figure 6: [Application Prototype - End of Workout]



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## A qualitative study of dental hygiene practices of visually impaired people in India

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**ABSTRACT** *Design for change, design for need and design for people are the slogans often employed by design schools to emphasize the purpose of design. However, for a student to comprehend the larger meaning of these slogans, an empathetic approach towards identifying the real-world problems needs to be cultivated.*

*The aim of this study was to foster empathy among students by exposing them to the world of visually impaired people and to discover ground realities beyond the world of sighted people. India has more than 5 million individuals with a visual impairment. The activities that appear simple and routine for sighted people may pose challenges for the visually impaired. One such activity, brushing teeth to maintain dental hygiene, was identified. 16 visually impaired participants of varied socio-economic status across various locations in India were interviewed to understand the obstacles and challenges they face in performing this task. Data was collected by conducting semi-structured interviews in users' environments through one-on-one interaction.*

*The study reveals current practices adopted by visually impaired for maintaining dental hygiene, obstacles faced, ways to cope, how they navigate around these obstacles and the resultant behaviours. It also shares students' experiences of conducting the study and how it enhanced their sensitivities towards perceiving design problems.*

*While addressing the needs of larger population, conscious inclusion of the visually impaired people not only broadens the scope and challenges of the design act, but makes it more inclusive/universal. This study helped students inculcate the true meaning of those slogans in design pedagogy.*

Keywords: Visually impairments, dental hygiene, inclusive design



## Introduction

In 1969, Prof. Nadkarni who studied at 'The HfG Ulm' established the Industrial Design Centre (IDC) at IIT Bombay (Rane 2017). IDC was therefore influenced by the Ulm Model of education. Although the Visual Communication program at IDC began as early as 1984, packaging was never formally introduced. The school consciously alienated itself from communication related to persuasion.

In 2016, the authors introduced an elective course in packaging design at IDC, not limited to persuasion but expanding its concern for populations with special needs (visually impaired and colour blind).

A quick example illustrate this; the authors advocated for design inputs in the packaging industry concerned with identification of vegetarian and non-vegetarian markers on food packets (see Fig.1) (Rane 2017). On August 1st 2011, the FSSAI issued a notice, in which section-2.2.4 stated that all food packets must be marked with either the vegetarian or the non-vegetarian marks (FSSAI n.d.). Fig.1 depicts the two marks in current usage. The red dot inside a square symbolizes non-vegetarian and the green dot vegetarian food. This demonstrates the lack of concern and awareness for the blind and colour blind populations of the country.

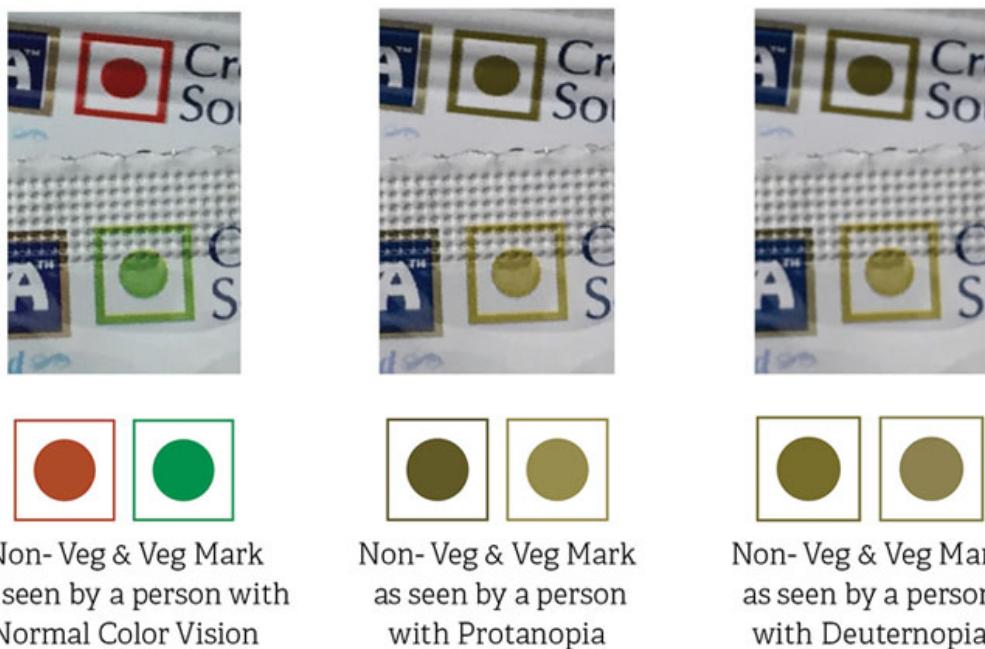


Fig.1: The Food Safety and Standards Authority of India (FSSAI) prescribe the vegetarian/Non-vegetarian mark on all food packaging. Colour being the only difference, it is very difficult for the colour blind to recognize.

The packaging industry being very competitive, Indian brands invest a lot in persuading people to buy products through brand ambassadors and TV commercials. However, our search did not find



many case studies done to simplify day-to-day things and make products accessible to all even though, as per latest census conducted in 2011, India has 5.03 million visually-impaired people (Report 2016).

## Study Design

The study had a two-fold aim:

1. To understand and expand our knowledge of how people with special needs (specifically visual impairments) access and use packaged products.
2. To expose our students to the ground realities of such contexts and sensitize them to identify and discover opportunities to make design more inclusive.

## Methodology

As sensitizing students was one of the aims of the study, the authors preferred user interviews (semi-structured) to collect data. Semi-structured interviews use interview guides but allow flexibility in the order of questions to facilitate a natural flow of interaction and add follow-up questions to get a better understanding of respondent's view. The guides allow information from different interviews to be comparable (Guthrie 2012). Since five different students were conducting interviews in five different cities, it was important to define guidelines in order to achieve comparable data. Interviews also involved few intended re-enactments by the participants.

Participation was voluntary and no monetary compensation was provided. The basic flow of inquiry was in the manner of recounting experiences which followed the structure of nurturing (*warm-up*), energizing (*area of discourse*), body (*core content of the interview*) and closing (*summarizing*) (usabilitynet n.d.). The participants were free to discontinue the interaction at any time or to decline from sharing any information.

## Participants

The interviews were conducted at five locations across India; Kolkata (east); Patna (north); Pune and Mumbai (west); and Kerala (south). 3 female and 13 male participants in the age-range of 24-65 years were interviewed. They were either blind by birth or had lost eyesight due to wrong medication or diseases.

Recruiting participants was done by means of personal contacts, social acquaintances and word-of-mouth, except for two locations, where the interviewees visited a rehabilitation centre for the visually impaired and a hostel for visually impaired scholars. The sample population can be broadly characterized as those belonging to the lower socio-economic strata, mostly aided by benefactors,



well-wishers and family members. Among the data collected from sixteen interviews, we came across subjects disadvantaged doubly by their acquired or congenital visual faculty as well as financial standing due to the same.

### *Interviewers*

Five male students of IDC opted to conduct the interviews of visually impaired participants across various states in the country. All of them had an exposure to methods of contextual enquiry during their academic course of User Studies, wherein they were exposed to design research, ethnography and the idea of field studies.

### *Interviews*

The sequence of probes for participants to share their experiences followed this pattern — the immediate family and surrounding, the cause of their blindness and treatment towards the same, education and upbringing, pattern of daily habits and activities, nature of involvement by immediate fellows, their shopping and dental hygiene behaviour, patterns and attitudes. In the course of the interview, depending upon unfolding of their own narration, participants were asked to re-enact an activity. The most mundane and routine activity of brushing teeth was chosen to make students realise that design opportunities can be identified if one looks at an act empathetically. The act that participants were told to perform involved putting toothpaste from the tube onto the brush, or any method akin to their individual methods of brushing teeth. For this, a tube of toothpaste and a toothbrush was provided and the interviewees responded with their personal take about these two objects. As the choice of the activity was time bound and personal, observation and access to the context in which it occurs was difficult.

The data was collected in form of notes and photographs (*with a prior verbal consent to take photographs*) from interview responses and enactment.

### **Study Findings**

#### *Current Practices/ Obstacles faced - Personal solutions to the act of brushing*

Traditionally people in India chewed *Neem* (*medicinal plant*) twigs or poured coal ash and cow dung cake ash in the middle of the palm and brushed their teeth using the index finger. This was a common practice until, in 1949, Colgate launched toothpowder to capture this market. Only two participants in our study were found using toothpowder and finger for brushing. On probing they mentioned that gauging the quantity of powder on the palm is easier in comparison to toothpaste. Another reason mentioned was of toothpaste falling off the brush leaving participant unaware until he puts the toothbrush in his mouth.



Alternate ways of applying toothpaste on the brush were also noticed. A usual way is to apply paste on the finger and then transfer it directly to mouth or toothbrush (Fig.2).

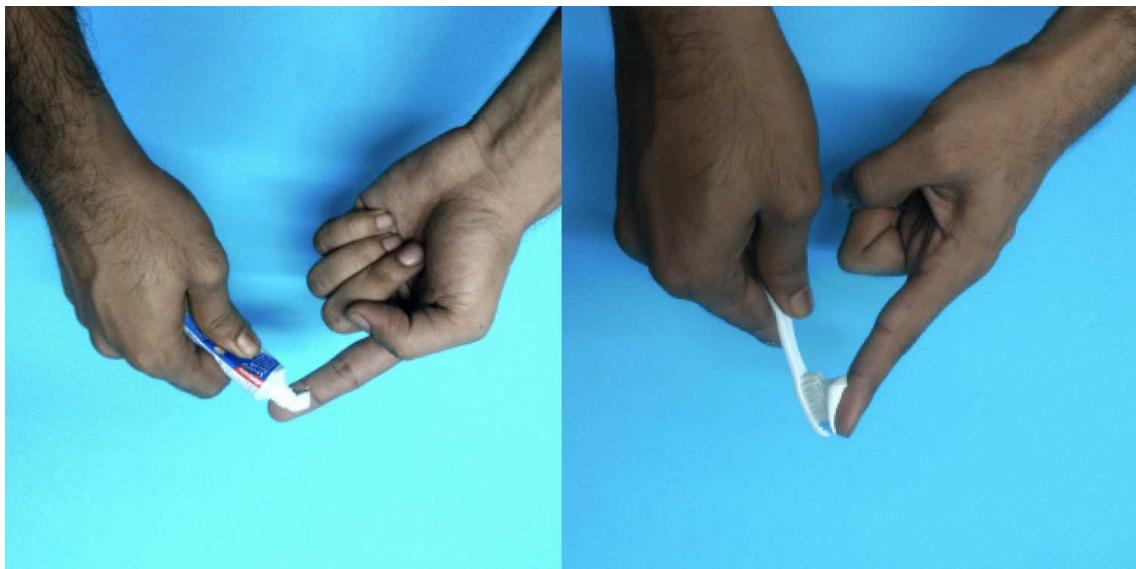


Fig.2: Applying toothpaste on finger (left) and transferring to toothbrush (right)

In order to estimate the amount of paste on the brush one participant keeps his left thumb along the length of the bristles. Then he puts the paste feeling the bristles, transfer the brush to his right hand and starts brushing (Fig.3). He cited accidental spillage of toothpaste on a few occasions but has adapted with it and now it is a seldom event.



Fig.3: Thumb along the bristles as reference



Another method that is taught to the visually impaired (Wikihow n.d.), and is found to be practiced by a few, was holding the bristles between index finger and thumb and applying the paste directly on to the bristles (Fig.4).



Fig.4: Holding bristles between thumb and index finger for reference

The issue of closing the cap of the toothpaste is found to be a problem especially if randomly kept or mistakenly dropped.

It emerged out of the study that cleaning teeth with toothpaste-toothbrush is the most common method (among 14 out of the 16 respondents), in contrast to using toothpowder which involves less wastage. However, problems of simultaneously handling the brush and paste, cleaning it prior to brushing, applying toothpaste, sealing the cap afterwards and other constituent tasks have not been resolved. A single best-suited method of cleaning teeth failed to emerge out of the responses gathered. The respondents accept spillage from tube, inexact quantity of paste expended, difficulty in orienting brush and tip of tube as unavoidable challenges within the task. Squeezing paste from the tube which is about to get exhausted, for example, is one such task which is difficult to negotiate, and affordances of such tasks are absent and an obvious design opportunity.

### *Hygiene practices*

Although all the participants wash their brushes before using it, one participant soaks her brush in a mug of water for 10 minutes every morning and smudges the bristles thoroughly in order to clean it. In contrast, at hostel where accommodation is shared by students, the brushes were kept in unhygienic conditions on a windowsill (Fig.5).



Fig.5: The Toothbrush, toothpaste and tongue cleaner stored on windowsill

Usage of tongue cleaner is not very common, however participants who received training at special schools or living with family members were found to be using them (three participants were using tongue cleaners).

Participants were aware of bristle caps but none were found using them. Bristle caps are usually bought separately at large stores and for toothbrushes which are priced lower are rarely offered as an integrated accessory. However, five participants adopted a makeshift solution of preserving the original packaging of the toothbrush to store it (Fig.6). To keep the toothbrush dry and clean, two participants wipe the toothbrush with cloth before storing it inside the pack. The brush packaging is used for storage as it is considered to be hygienic, compared to leaving the toothbrush in the open.



Fig.6: Toothbrush stored in the original pack

Participants had a sensitive touch to assess the quality of bristles. The need for changing a toothbrush is realised through the tactile feedback of the bristles bending outwards.

Seven out of sixteen participants found it tedious to brush twice a day. All the participants interviewed belong to lower income groups. The primary reason recorded to avoid brushing during night was the inconvenience of washroom/basin to be situated outside the house.

Participants either had to go to a common area outside their hostel room; or in certain residences to the community water tap where availability of water was time bound. Harsh winters in northern India, cold water and scheduled water timings were other few reasons to avoid brushing in the night.

A participant shared that he slides his finger vigorously over his teeth and a faint *chk-chk* sound confirms that the teeth are clean. An older lady was advised at a health check-up camp to get a cavity repaired. She avoided it stating that after her husband's death she cannot afford the treatment.

In summary, the awareness of dental hygiene products is influenced by immediate family and helpful shopkeepers, which gives an indication that their preferences do not change drastically and are largely dominated by what is easily available or used by all the family. Hygiene practices of the visually impaired users were found to be mixed and varied. Devoid of visual clues, a visually impaired person is more concerned about the cleanliness and tries his/her own ways to enforce them. It is largely influenced by their level of awareness about dental hygiene, support from immediate dependencies, cost constraints, personal experiences and perceptions built over time.

### *Need for identifiers/ personalization*

Participants keep their toothbrush separate from other members of the family. In a hostel for the visually impaired, where group of students stay together, creation of tactile marks on the handle of the brush were found. These marks are made with the help of a cutter or a blade (Fig.7).



Fig. 7: The cut mark on toothbrush grip (left) and purposeful bending of the tongue cleaner (right) for personalization

Purposeful bending of metal tongue cleaners near the handle was also found to be way for identification (Fig.7). At another participant's residence nail paint was applied to tongue cleaner handle. Nail paint would act as the visual clue for his wife and daughter as they had their own separate tongue cleaners. In this case, the participant's wife used to handover his toothbrush and tongue cleaner every morning.

The mother of one participant attaches an embroidery flower to his shirt so it can be identified separately from his brother's shirts. One participant bit his sandal to identify and differentiate between left and right foot.

### *Shopping preferences and nuances*

All the participants who shop by themselves prefer to shop from small local shops, where the shopkeeper hands over the items they ask for. They avoid going to shopping malls and supermarkets as they find it confusing and expensive.

One participant shared an incident when he went to supermarket to buy a deodorant but accidentally purchased shaving foam. Later, when he applied it over his shirt, the foam spilled ruined his shirt.

Smaller toothpastes were preferred as the spillage is less and they are easy to carry considering the fact that the washroom or basin may not be in proximity. In a family setting, larger toothpaste tubes, though heavier and difficult to interact with for the visually impaired family member, were generally the preferred choice for economic reasons.

Except for one participant, no other participant had a brand preference for his/her toothbrush. The main criteria for selection of brushes appear to be cost. In our study, we found that personal



preferences for a particular brand is generally not cultivated, and 'one-brand-fits-all' mantra for all members of a family is adhered to.

The pervasive social structure in which the visually impaired are traditionally disadvantaged, their inability to own money and make choices, with little to moderate financial impact, shapes the nature of affordability and want-based purchases. A single brand gets stuck on in imagination not simply due to loyalty, but because to procure it instead of an alternative is less hassle. For participants to make an informed choice requires special efforts with regards to how long their queries can be entertained and length of interaction possible between them and the shopkeeper. For example, explaining their choices to the shopkeeper, comparing cost, and being unable to know expiry dates are some of the pressing concerns.

### *Students learning and experiences: Problems have to be discovered*

One observation of the authors that marks attention was the students' tendency (in the preliminary stages of the interviews) to expect clearly articulated problems from the participants in response to their questions. On the other hand, participants stated to have no problems, as they have managed to perform tasks of daily routine with utmost ease, over time, resulting into habits. Therefore, in the initial stages students were not able to surface any evident problem in tasks performed to conclude for everything to be fine. Only after careful observations and guidance from the authors could students come up with deeper insights. For example, when participants realise their options are limited and governed by the world of sighted people, they attempt quick fixes (*jugaad*) to their daily problems or be dependent on people around them. Students understood that there is a difference in formation of habits through quick fixes in the context of limited choices, versus having access to a multitude of options and making meaningful choices in products of daily use. In summary, the quick fixes currently adopted are a result of lack of options and neglected design interventions which require the designer's attention.

## Conclusion

The authors realised that such empathetic studies give students an opportunity to internalize/ externalize the true meaning of the slogans; design for change/ need / people. Though the study emerged from the context of packaging, students acknowledged that the interviews and observations of such a mundane and routine task of brushing teeth helped them realise how to expand their focus beyond the world of sighted people. In depth studies about needs, preferences, behaviours, habits, constraints and makeshift solutions by people with special needs are fertile ground for design interventions to make products of daily use more inclusive.

The need for identification markers, improved design of toothbrushes and pastes, attention to information related to cultural preferences (veg and non-veg), critical information (expiry dates, price) and providing access to alternate ways of disseminating available information by acknowledging the cost constraints of the people with special needs, will further expand the

narrative of design to make it more insightful and challenging. Outcome of such efforts will lead to increased awareness about the untapped design opportunities in the design of products for people with special needs, further propelling these unvisited territories to become a part of valid concern for the mainstream.

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## Older adults and mobile applications for health

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**ABSTRACT** Aging population is a global issue that affects almost all areas of life. Health is one of the most important issues related to ageing and this leads to a need for innovative health management interventions. Demographic trends combined with the growth of mobile phone usage among the older adult population suggest that mobile health applications can be a promising tool to improve the quality of life for the elderly. Therefore, these applications must be adapted to the needs and preferences of older adults. In order to do that, designers need to understand the way older adults use these products.

This work will present the results of a qualitative research where the use of health applications was observed using verbal protocol analysis. 20 individuals aged between 45-65 who are active smart phone users were selected to participate the study. Results of the study shows that there is a gap between mobile applications and real-life health services. Moreover, there is also a cultural gap, where these applications use a global, mobile, younger language where the users have problems understanding this language. This cultural gap is even deeper, where all the written information is translation. These two gaps prevent users to use these applications efficiently.

Keywords: gerontechnology, older adults, mobile apps

## Introduction

In 2045, the number of older people all over the world is expected to exceed the number of children for the first time (United Nations 2010). First experienced by the more developed countries, this unexampled demographic change is now a global issue. World Population Ageing 1950-2050 Report by United Nations (2002) shows that older population is growing at a much faster rate in the less developed regions. Therefore, developing countries like Turkey will have a shorter time to adapt to the changes associated with population ageing.

Ageing population have effects upon almost all areas of life, from economical to social and political (United Nations 2010). With ageing, there is an increased possibility of having various health problems, which leads to an increasing need for health management interventions.

The demographic trends combined with the growth of mobile phone usage among the older adult population suggest that using mobile phone as a platform for interventions in health may be the solution. Mallenius, Rossi and Tuunainen (2007) revealed that elderly people are interested in using mobile phones and services, but these services need to deliver real value for them. Therefore, mobile applications must be adapted to the needs and preferences of older adults. In order to do that, designers need to understand the way older adults use these products.

Mallenius, Rossi and Tuunainen (2007) also identified a set of issues that need to be taken into account when designing technology and services for older adults by using semi-structured interviews with a number of different stakeholders interested in older people. Their study revealed that one clear reason or benefit for acquiring a mobile phone and using services for older adults is the need to communicate with friends and relatives.

In 2014, Kim and his colleagues reviewed various health-related devices including mobile phones and different ways of using them. According to their study, various methods for integrating healthcare management with mobile phone use are, telemonitoring and tele-coaching, transfer of medical information, scheduling hospital visits and medication compliance, increasing drug compliance and treatment adherence, life-support system for the single-family elderly. Kim and his colleagues also listed the difficulties encountered by elderly people using IT. These difficulties are; physical and cognitive changes in the elderly due to ageing and the difficulties of using mobile phones and a decline in learning capabilities. To solve these problems, they suggested that the applications running on mobile phones need to focus on convenience, use large icons and fonts and clearly distinguishable colors, and have a simple structure and intuitive visual representations for elderly mobile phone users. Moreover, they suggested that the system should initially utilize simple words, with the learning ability of the user taken into consideration and step-by-step services implemented for elderly users.

Currently, there is an expanding number of health-related mobile interventions for elderly. In order to examine the current state of mobile phone use for health-related interventions targeting older adults, Joe and Demiris (2013) searched PubMed and CINAHL for articles using 'older adults'



and 'mobile phones' along with related terms and synonyms between 1965 and June 2012. According to their review, research on health-related mobile phone interventions has ten major clinical domains. They are, activities of daily life, Alzheimer's /dementia care, chemotherapy symptom management, palliative care symptom management, congestive heart failure, chronic obstructive pulmonary disease, diabetes, falls and fall risk, osteoarthritis and dermatology. Joe and Demiris (2013) stated that more investigation is needed to confidently establish whether mobile phone technologies can meaningfully improve an older adult's health and well-being.

Plaza et al. (2011) presented a review of the status of mobile functionalities and applications that can satisfy the requirements and needs of older people and improve their quality of life. Their review showed that elderly people think that mobile phones are more accessible than personal computers and the Internet.

Although there are various health related mobile applications available, three of them have special importance: 'Health' application by Apple, 'Samsung Health' application and 'LG Health' application. All three of these are pre-installed applications in smart phones. Therefore, users automatically have them, when they buy an iPhone or a smart phone by Samsung or LG.

'Health' application offered by Apple consolidates health data from iPhone, Apple Watch, and third-party apps that the user already has, aiming the user to view all his/her progress in one place ([www.apple.com](http://www.apple.com)). The application highlights four categories: Activity, Sleep, Mindfulness, and Nutrition. One of the benefits of the iPhone Health application is allowing users to create an emergency Medical ID card that lets first responders to access their critical medical information from the lock screen, without needing the passcode ([www.apple.com](http://www.apple.com)).

'Samsung Health' aims to help users to maintain a successful diet and lead them to a healthy lifestyle while recording and analysing user's daily activities and habits. The user can add and track the various physical exercises and activities using the various built-in trackers. Samsung Health allows the user to record a variety of information like food, caffeine and water intake details. The application also has a sleep and stress tracker. Just like the users of 'Health' application by Apple, Samsung Health users can also track their heart rate, blood pressure, blood glucose levels, stress and weight using third-party devices. The intuitive charts, helpful tips and physical exercise programs guides users to achieve fitness and diet goals. The App supports all Samsung smartphones starting from Galaxy S3 onwards and includes Non-Samsung Android smartphones as well ([play.google.com](http://play.google.com)). The application allows users to compete with their friends and check their ranking. Moreover, users can check daily health news of their preference with customized news feed and get tips offered by health professionals.

'LG Health' tracks users' activity levels and provides an interface and related content based on that information, so all types of users can customize the app to fit their own activity levels. The application offers users two different levels: At the beginner level, user can see beginner exercise info when exercise is not part of her/his daily routine. The exercise circle shows the progress to user's goal over 24 hours. At the advanced level mode, user can see advanced exercise info when exercise is part of user's daily routine. The exercise circle shows the progress to her/his goal over



24 hours by type and intensity. Users can also add logs manually. Like the 'Samsung Health' application, users can see personalized tips above the exercise circle and tips are shown according to the user's lifestyle and exercise patterns. The application lets the user to manage fitness activities, track her/his weight and monitor her/his diet using LG Smart Watch and Tone Active. The App supports all LG smartphones and includes Non-LG Android smartphones as well.

Mobile phone usage is growing enormously in Turkey. According to Turkish Statistical Institute, 96.9% of households in Turkey have mobile phone (incl. smart phones) in April, 2016. Held on 6 continents attended by 53 thousand 150 people from 33 countries including Turkey, 'Deloitte Global Mobile User Survey 2017' offers significant data about mobile consumers ([www.deloitte.com](http://www.deloitte.com)). 92% of the 1005 people surveyed from Turkey stated that they have smartphone access. According to the survey, the average number of times users look at their smart phones during the day is 78 in Turkey which exceeds 1.5 times the European average which is 48. According to the report, the rate of those who say they have changed their phone in the last 18 months is 64% in Turkey. While the use of smart phones is really high in Turkey, there seems a great potential in integrating them to health care management of the growing number of elderly people.

This paper will present the results of a qualitative research where the use of health applications was observed using verbal protocol analysis. 19 individuals from Turkey who are aged between 45-65 and active smart phone users were selected to participate the study.

## Research Methodology

The research was conducted by the students of a second-year Industrial Design course named 'Human Factors in Design'. Before doing research, students were trained. Then, mobile health applications were reviewed, and the research protocol was planned.

Each student must select two participants who are aged between 45-65 and are active smart phone users. The use of health applications was observed using verbal protocol analysis. Each participant has to follow a certain protocol: opening the application, uncovering different properties of the application, setting a medical ID and view her/his active steps for the day.

19 individuals participated the study, 9 of them were men. 10 of them were iPhone users, where 7 of them are using Samsung and the rest were using LG. All of the participants were close relatives of the students, allowing them to behave naturally during the analysis.

## Results

All participants agreed that mobile health applications are beneficial but none of them was using these applications except the step counting function: Using the step counter turned out to be one of the most beneficial factors of health applications in every interview. Interviewees accept and



enjoy using the step counter, some of them stating how they challenge their selves to increase the steps they have during the day.

However, there emerged two significant gaps between these users and mobile health applications: The first gap is the one between these applications and real-life health services. All of these applications need third-party applications, additional devices and/or the health data to be entered manually. First of all, participants of the study are not sure if the mobile phones are intelligent enough to track their health data or they need additional tools to do this. For example, one participant asked if her phone can track her daily food intake or she needs to enter them manually. Creating a Medical ID or manually entering even the basic information about themselves require a lot of hard work, and they think it is not worth it. Moreover, the hospitals and the medical labs in Turkey are not efficiently connected to mobile services. The gap between mobile health applications and real-life health issues or services prevent users to use these applications efficiently.

The second gap is the cultural one. The visual and verbal language of these applications seem to belong to a different culture: A younger, global, mobile culture. No local clues are present in these applications to help users understand and use them easily. Even if a younger relative is helping them, there happens a lot of mistakes and misunderstandings while trying to use these applications. The participants of the study do not want to be labelled as 'too old to use technology' and they want to cover their mistakes. The information being presented in these applications, warnings and explanations seem to belong to a different culture, that they barely understand. This cultural gap prevents these people using these health applications.

## Conclusion and discussion

This paper presents the pilot study for identifying the factors that determine the usage of mobile health applications by elderly population in Turkey. By using verbal protocol analysis, a range of issues were identified.

A significant amount of research has recently been dedicated to integrating health management with mobile phone use for older adults. However, none of them focused on pre-installed applications in our smart phones. On almost all smart phones, these applications are ready to use without the effort of downloading from the application stores. Considering the number of potential users these applications have, they can help us managing health with mobile phones.

There was a clear consensus among interviewees that mobile health applications are beneficial, especially for step counting. However, the gap between real life health issues and these applications seems to prevent users from benefiting from these applications. Integrating mobile phones into the health management system requires the use of various applications, sensors or products that allow the health status to be checked regularly. Moreover, the visual and verbal language difference between these users and the applications create another gap. These applications use a global, mobile language. Especially for Turkish users, this cultural gap is even



bigger, where all of the written information is translation and there are many sentences that are grammatically incorrect or can cause misunderstanding.

The results of the study showed that there is a great value in studying the needs and behaviours of elderly mobile health service users, especially with a focus on cultural needs.

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## Communication aids for nursing staff, foreign-language patients and their relatives in paediatric care.

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**ABSTRACT** *Clear, comprehensible communication between medical experts and patients in their care is essential. Misunderstandings can cause a sense of insecurity and even incorrect action on the part of the patient. Therefore, foreign-language patients are a special challenge to nursing staff. This situation will become increasingly problematic as immigration rates rise.*

*The aim of the initial project was to define guidelines for the type of communication aids needed by nursing staff in paediatrics. Such guidelines had to encompass the acceptability, comprehension and interpretation of the communication aid with the children.*

*Research questions:*

- *What aids can support communication between nursing staff and foreign-language paediatric patients?*
- *What design parameters have to be considered when developing such aids so that they are accepted, understood and properly interpreted by children from different cultural backgrounds who have little or no understanding of the local language?*

*Patients' needs were determined by means of two focus-group workshops. In workshop 1 (held with nurses), personal experiences were reported and methods and aids were discussed. Extant analog and digital tools were presented, and ideas for new aids were developed. In workshop 2, children with an immigrant background offered their interpretation of the visual depictions along with their preferences, and described procedures in visual terms.*

*The evaluation of workshop 1 allowed conclusions to be made about the type of communication aids required by nursing staff. The results of workshop 2 offered recommendations for the design of such aids. Based on these findings, a follow-up project which is currently taking place, is focused on the development of these corresponding communication aids.*

**Keywords:** communication aids, nursing staff, children, foreign-language patients, health care



## Introduction

Switzerland is a country of immigration. In the 20th century, the proportion of the population with an immigrant background was over 25 % (Federal Office of Public Health [BAG] 2008). There are approximately 700 000 persons (around 9% of the population) living in Switzerland whose main language is not one of the national languages. From this group, there are 200 000 persons who neither understand one of the national languages nor understand English (Swiss Hospitals for Equity 2016). In recent years, the Swiss Federal Office of Public Health has repeatedly launched programmes in order to meet the challenges posed by the increasing diversity of patients in Swiss hospitals. Their declared goal is 'to enable all patients equal access and high-quality treatment – independent of their background, language, socio-economic position and health competence' (BAG 2016). In the face of political developments, especially with the escalating refugee crisis in Europe in recent years, one must assume, that the topic of migration and the challenges it brings to the healthcare system, will continue to increase in the near future.

Clear, comprehensible communication between medical experts and their patients concerning care is essential. Language barriers constrain medical treatment, negatively affect therapeutic success, affect quality and compliance and endanger patient's safety. Misunderstandings can cause too many, too few or incorrect medical treatments, and can lead to unnecessary costs to the healthcare system (Swiss Hospitals for Equity 2016, Bischoff et al. 2006). Appropriate and cost-effective treatment in hospitals calls for successful verbal communication between medical staff and their patients. Consequently, foreign-language patients are a special challenge to medical staff – especially to nurses (Metz 2010). Hitherto, investigations have shown that the most effective method of overcoming these language barriers is to engage a professional interpreter (Flores et al. 2012). However, often there is no budget for translation services in the daily routine of nursing staff. Frequently, patients' family members are utilized for translations, often for reasons of simplicity, even though there are many problems proven to be associated with this supposed solution (Flores et al. 2012). Many nursing staff try and deal with communication barriers through the use of mimicry and gestures, hand-drawn sketches, or more rarely, through the use images downloaded from the Internet. Attempting to explain things using dictionaries or picture books often is not practical due to the pressure of time. This situation will become increasingly problematic as immigration rates rise.

## Aim

This initial project had the goal of defining guidelines for the type of aids required by nursing staff in order to communicate with foreign-language children. Furthermore, recommendations needed to ensure that the communication aids were designed so that the children would accept them, understand them and interpret them correctly.



## Research questions

The overarching research questions to be answered by this study were derived from the above considerations:

- What aids can support communication between nurses and foreign-language paediatric patients?
- What design parameters need to be considered when developing such aids so that they are accepted, understood and properly interpreted by children from different cultural backgrounds who have little or no understanding of the local language?

## Methods

To answer the above-mentioned research questions, the project was developed in the following steps. Firstly, research was carried out to investigate both literature on the topic and the existing communication aids. Secondly, nurses' and childrens' experiences and needs were determined by means of two focus-group workshops. The analysis of the results led to implications and recommendations for practice.

Workshop 1 was held with 9 nurses from different hospitals and home care services. Personal experiences were reported and the nurses' methods in handling language barriers and known communication aids were discussed. Extant analogue and digital tools were presented and reviewed in group discussions. Ideas for new communication aids were developed by creating desired prototypes of such aids.

Workshop 2 was carried out among two primary school classes, with 21 and 16 pupils respectively. The children were 10–14 years old, and 36 out of 37 had a migrant background. The main focus of the workshop was the children's visual competences and preferences regarding the development of a visual aid. Concerning the topic 'nursing staff at the hospital', the children worked through five different workshop stages with tasks such as: recognising images; describing procedures in sequences of images (picture stories); school-based knowledge about the inner workings of one's own body; offering their own preferences for depiction; and drawing the different steps in a process, using images.

## Results

### *Focus-group workshop 1: nurses*

Evaluation of the nurses' workshop allowed conclusions to be made about the type of communication aids required by nursing staff. This was accomplished through transcription of the



recorded group discussion, and extraction of the central points. These key points were next summarized into themes such as 'aids' or 'personal experiences'.<sup>1</sup>

The participating nurses emphasized that it is not just translating different languages that is a major challenge. Overcoming cultural differences is also an important component of their daily work with foreign-language patients. According to the nurses, these cultural differences were due to several factors such as patients' limited health literacy, religious beliefs, diverging cultural and family values along with superstitions. They reported communication difficulties throughout the entire process of providing care: during patient admission, in daily care (when having to explain special examinations or with the administration of medications), or when patients should give informed consent. They attested that on the part of patients, such communication difficulties could cause a lack of understanding, and to some extent even anxiety, anger or refusal to receive treatment. On the part of the nurses, language barriers could lead to feelings of not meeting the requirements of one's job. These findings correlate with the literature (Calza et al. 2016). In the discussion of the extant analogue and digital communication aids, it was revealed that a broad variety of used aids, such as dictionaries, pictorial dictionaries, wall charts, glove puppets, sketches or self-made aids (analogue) and Google Translator, translation apps, pictogram apps or medical apps (digital), were utilized by the nurses. However, many of these apps, are designed for adults and do not meet children's needs, intellectual abilities or preferences. The participating nurses stated that there should be a variety of choices available between different communication aids, depending upon the patient's individual situation. In the last part of the workshop, the participants were instructed to create their ideal communication aid, regardless of costs or realisability. All the results were digital solutions that should be available on a tablet computer and should consist of a combination of different features such as recognition of language, simultaneous translation, explanatory images and movies as well as background information about patients' culture or a direct hotline to a professional translation service (Figure 1).

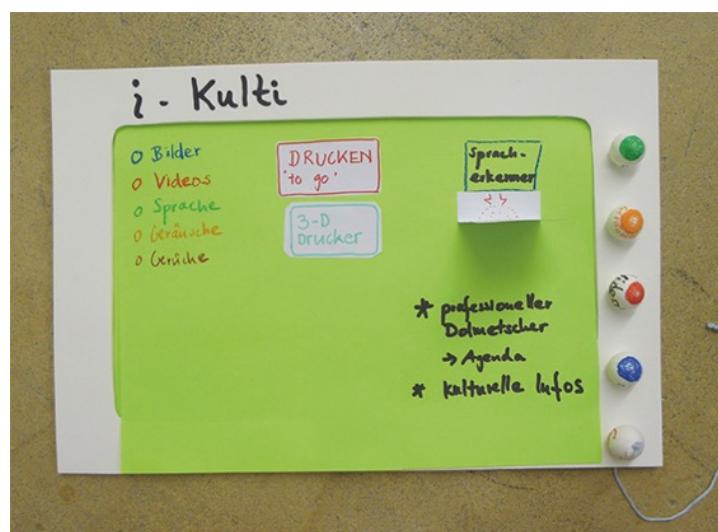


Figure 2: Desired solution for a communication aid as developed by nurses in Workshop 1.



## *Focus-group workshop 2: children with a migrant background*

The main goal of the children's workshop was to detect which kind of images and image sequences children could read and interpret the best, along with which visual preferences they had and what they knew about their bodily functions. The pupils were asked to solve five tasks on the topic 'nursing staff at the hospital'

The workshop's data was interpreted via visual analysis (Hahn et al. 2015). In this process, visual content, formal regularities and characteristics are stated and discussed. Through looking for similarities in the data, the structures and connections in form and content can be revealed. In addition, some tasks were analysed by counting the results (e.g. number of favoured pictures).<sup>9</sup>

The results of the first task revealed that children did recognise strongly naturalistic or photographic depictions most quickly during a rapid search process among pictures with different degrees of abstraction – a finding that is not surprising. At the same time, there were also some abstract images among the best identified objects (doctor's bag, scissors). However, the visual message of these objects was very clear and characteristic. Therefore, we can assume that quick detection of objects through children, mainly depends on the image's clear information and less on the degree of abstraction (Figure 2).



Figure 3: Good identification (left) vs. poor identification (right) – a clear and characteristic representation is most important for recognisability

In task 2 the participants were asked to choose the most beautiful images from their point of view among three series of pictures (ambulances, beds, children). When offered a choice, the children also preferred explicit, naturalistic forms of depiction. Regarding the illustrations favoured by the children, they chose representations with a friendly expression and exaggerated proportions (big head and eyes, small torso and limbs), as known from comics or cartoon movies. Furthermore, the favoured characters refer clearly to the children's own gender (Figure 3).

<sup>9</sup> Detailed results are listed in the project's final report (Drack et al. 2016), which can be obtained directly from the authors.



Figure 4: Selection of children characters considered the most beautiful by the participants.

Task 3 consisted of drawing the inner workings of one's own body into a girl's or boy's silhouette (Figure 4). The completed drawings represented school-based knowledge corresponding to the respective grade. Here it is obvious that the children depicted the mainly 'tangible' body elements, such as bones, the lungs or the stomach. These elements were illustrated mostly in isolation rather than being related to one other in a systemic conception of bodily functions. The choice of the silhouette was also shown to be gender-related.

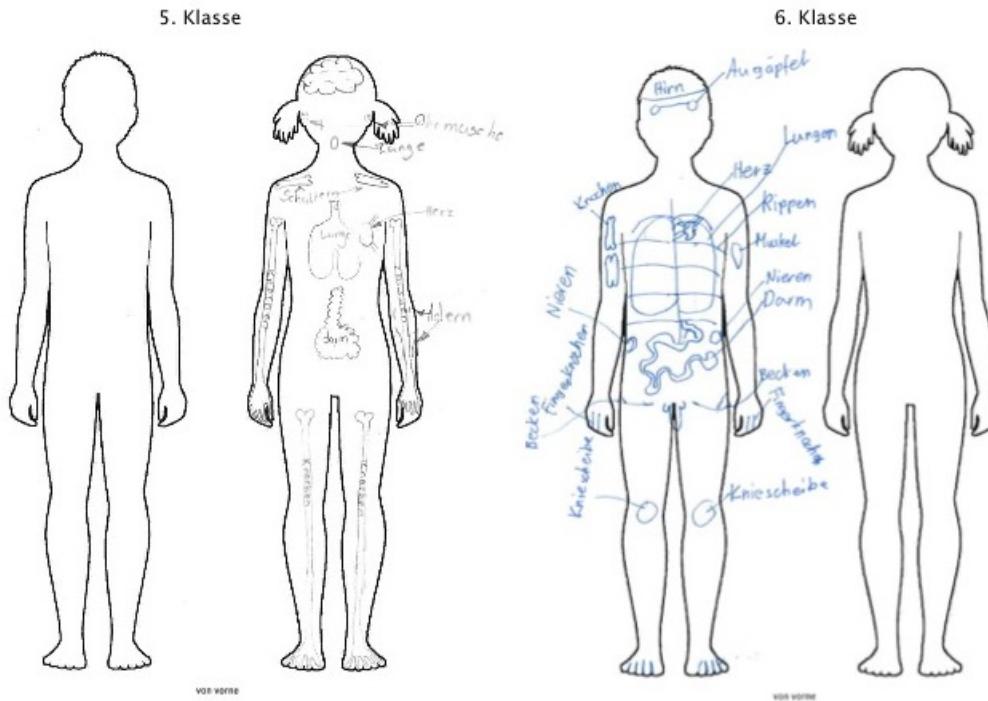


Figure 5: The children have a good school-based knowledge about anatomy.

In task 4, the children were asked to describe a series of six images. Thereby, it was left open if the images were described individually or read as a continuous story. Evaluation of the results demonstrated that most children were able to interpret the single images correctly, but only a few children could read a coherent story. This finding shows that it is important to clearly link the individual pictures to a sequence (e.g. by means of numbers or arrows), so that they are not regarded as single images. In task 5, in which the children were requested to depict a story of an



everyday activity in pictures of themselves (Figure 5). In the majority of the cases, they did so using two or three individual pictures. However, some inserted a relatively large number of pictures (up to 15). The drawings focus on the essence and the story line was often made visible by using elements such as numbers or arrows. Several participants included humorous details or allusions in their pictures, which confirms the findings of Grootens-Wiegers (Grootens-Wiegers et al. 2015), according to which children like humorous content, even in pictorial depictions of medical matters.

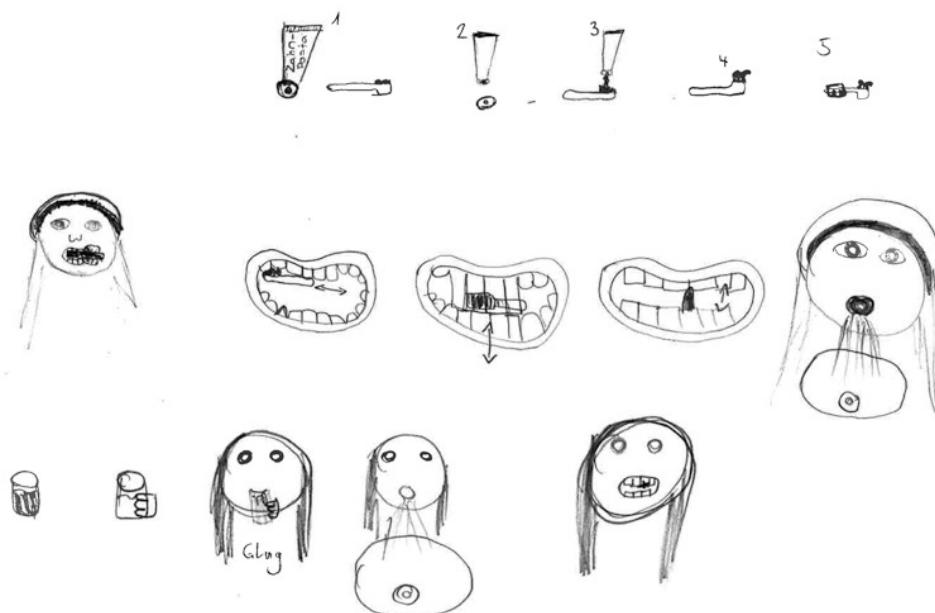


Figure 5: Example of how children draw everyday actions as a picture sequence (here: brushing teeth).

### Limitations

A limiting factor concerning the children's workshop is that the results were mainly focused upon the target group of children in general, as the migrant factor was not clearly evident. This may be due to the fact that most children were well integrated, since they had already been attending school in Switzerland for several years. Another limitation is that the results only refer to the age group of 10- to 14-year-old children. They cannot universally be adapted for other age groups, especially not for younger children.

### Conclusions

In summary, in regard to nurses, language barriers create difficulties in the provision of daily care to their patients. Along with these language barriers and translation difficulties, another big challenge in giving care to migrant patients is the aspect of interculturalism. In regard to communication aids, it is clear that a *one-fits-all* communication aid does not exist, and also that



such an aid is not desired. Instead, the most suitable communication aid should be chosen depending upon the situation. However, the nurses did consider an easy-operating digital solution as being desirable.

Referring to the children's visual competences and preferences, it can be determined that images in a communication aid should be designed as clearly and as unambiguously as possible.

Additionally, children appreciate the inclusion of humorous details. A character with whom the children can identify and that assists them in the use of a communication aid should possibly be designed. It should include gender-specific characteristics and should use cartoon or manga style.

The themes of migration and health, as well as the problem of language barriers in medical practice, are not new and considerable research has already been done in this field. Nevertheless, difficulties surrounding the delivery of professional nursing care to foreign-language patients remain mostly unresolved. The majority of existing communication aids do not assist with these problems, particularly in regard to the cultural differences. Specifically, digital solutions are neither designed for communication with paediatric patients, nor do they cover the specific needs of nursing staff in the Swiss health-care system. Additionally, there are no existing standards ensuring the accuracy of the content of existing apps (e.g. translations, medical visualizations, cultural information).

Based upon the results of these workshops with the nursing staff and the primary school pupils, follow-up projects are being planned to develop corresponding communication aids. The main recommendation derived from the results of this project is to create a 'communication tool box' that contains a range of different communication aids, both analogue and digital (Figure 6). This would give the nurses the option to choose between different aids, depending upon the patient's age and situation.

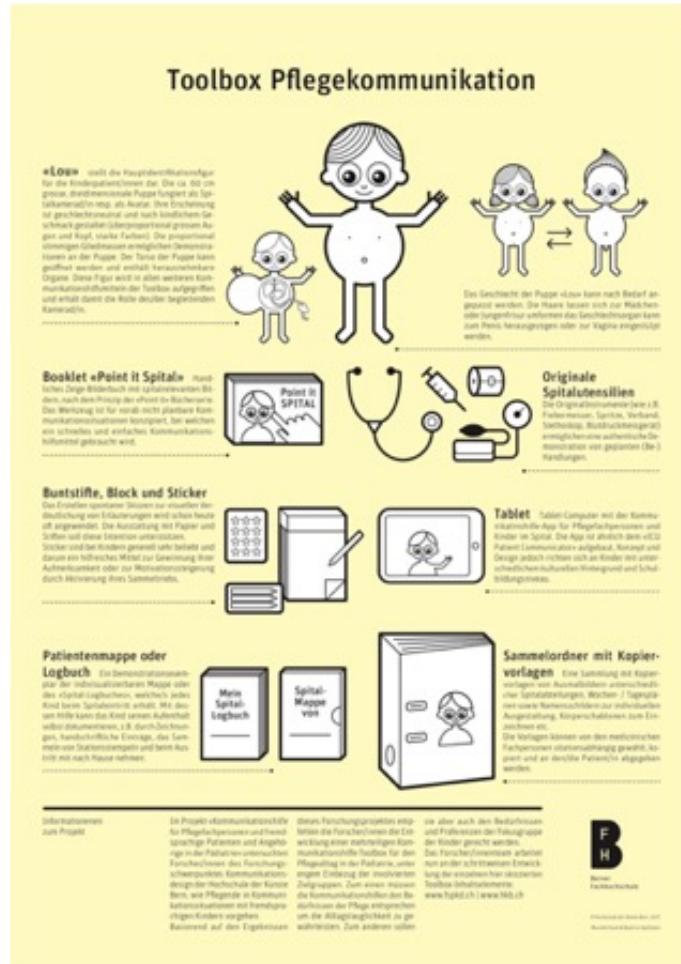


Figure 6: Concept of a communication aid tool box including several digital and analogue aids, such as hand puppets, hospital devices for demonstration, tablet PC or a sketch pad.

As an initial step, a research team of designers and nurses, is carrying out a survey regarding the communication situations of nurses and children in their daily hospital routine utilizing the 'shadowing' method. This ongoing project started in January 2018 and will provide initial information for the development of a communication aid app, to be provided on a tablet PC in the communication aid toolkit. Each tool will be designed taking into consideration the results of the workshop with the primary school pupils, and will entail the further involvement of children with a migrant background.

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## Evaluation or 'anecdote'? Understanding the impact of design

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**ABSTRACT** Designers are increasingly engaging in participatory co-design approaches to understand the needs and wants of the people who will engage with the artefacts produced. These approaches are particularly relevant for design that focuses on social change, work undertaken with vulnerable groups who may not be articulate, and for designers working across disciplines, engaging with, for example, health related issues. While these projects may have clear goals in terms of outputs, often outcomes are not as clearly defined. So, how do we measure, evaluate and understand what has taken place, and reflect and report the findings?

This paper reports on a UK-funded research project designing for people living with advanced dementia using mixed methodology research and evaluation. It explores issues around how designers self-evaluate and report on outputs and outcomes, and how robust evaluation can be undertaken throughout projects that use design research and thinking, or action research approaches. While, informal feedback in design projects can sometimes be dismissed as 'anecdotal', it suggests that unsolicited responses provide rich and valuable data to inform the overall evaluation and findings of a project. While designers may resist evaluation, feel that evaluation is imposed on them, or are not sure how to evaluate their projects, this paper suggests that by evaluating appropriately they can produce evidence to show the value and importance of their work.

Keywords: design for dementia, evaluation, participatory design



## Introduction

As design is reconceptualized as a professional practice, as a growing area of research, is an activity that is 'constitutive of human beings', and increasingly aims to engage meaningfully with users and stakeholders by focusing, for example, on improving quality of life for individuals, changing behaviour, or bringing about social change, so the mechanisms used to assess and evaluate and help us understand how design impacts also need to adapt and change (Krippendorff 2006). In designing for individual benefits or for social impact, design, designers, and design researchers are working across fields and disciplines and are introducing and being introduced to new methods, approaches and procedures. They include new ways to assess, evaluate, measure and understand the impact of design.

Designing in areas such as health is complex and impacts a wide range of stakeholders, that may include, for example, scientific, clinical, and medical professionals and practitioners, nursing and care staff, people receiving care, family members, informal carers, and care organisations and advocacy groups. Design in healthcare may range from the technological to the pharmaceutical, include preventative approaches, or support lifestyle decisions, quality of life, and impact general wellbeing. Therefore, no single approach can be used in design and there is no simple 'one size fits all' approach to the assessment, measurement and evaluation of the impact of design.

This paper will discuss the evaluation processes undertaken in relation to the LAUGH (Ludic Artefacts Using Gesture and Haptic) project. The UK Arts and Humanities Research Council funded project designed objects and activities to promote pleasure and joy, to stimulate sensory engagement and contribute to the quality of life and subjective wellbeing of people living with advanced dementia. As the project's aims extended beyond the development of, and engagement with artefacts, and was intended to have social impact, a range of evaluation methods were used to ensure that the project was thoroughly assessed.

## Background

As design research and projects focus on bringing about behavioural or social change or impacting quality of life through design, it is necessary to understand the needs and wants of people who will potentially engage with the artefacts (objects, products, activities or services) produced, and what impact the artefacts will have. This means not only focusing on the 'users', but also the wide range of stakeholders invested in or impacted by the design process and outcomes. To this end designers are employing co-design methods that enable them to design 'with' rather than 'for', that suit projects which require understandings beyond a single discipline, and that facilitate high degrees of personalisation and customisation. In projects, such as those that aim to contribute to health and wellbeing or work with people living with dementia, participatory approaches need to be adapted to ensure inclusivity for those with specific access needs or compromised communication abilities (Hendriks et al. 2014; Maldonado Branco, Quental , and Ribeiro 2017).



Design research projects using participatory approaches often have clear goals in terms of the artefacts to be produced. However, outcomes—what is the greater goal beyond what the artefact is to achieve in context—are not always made explicit. This can make evaluation difficult. Furthermore, even if the overall outcomes are expressed, they may occur over an extended period of time, and long after the project has been concluded. So, how then do we measure, evaluate, reflect on and effectively report the findings so that we can show the impact of a design research project that aims to bring about change?

Measurement and evaluation used in relation to projects that aim to impact change must account for not only how design artefacts are placed within a context and responded to, but also what change takes place as a result of the overall design process, outputs, and outcomes. It is, therefore, useful to understand measurement and evaluation frameworks developed in other fields and disciplines, to assess programs designed to bring about individual or social change. Program evaluation has an established history in the social sciences, in public policy making, epidemiology, in communication strategies, and in exploring how policy, decisions, and interventions impact people. Many of the approaches used can be applied to co-design projects to create an evaluation framework to enable quantitative and qualitative data to be triangulated and provide robust evidence-based findings (Calidoni-Lundberg 2006).

Confusion can arise in establishing evaluation frameworks because the terms evaluation and measurement are used interchangeably—even though they talk about different things. We might think about measurement as a means of matching an object, process, or response to a preconceived scale where it is processed as *units* (most often numbers), whereas an evaluation is an exploration of values assessed against *criteria* which may be tangible or intangible, and may remain as language<sup>10</sup>. All too often at the borderline of disciplines, for example when design comes up against clinical, medical, economics or business, the robustness and validity of data evaluated and expressed in language is questioned. This can arise because the rich and valuable data of unsolicited feedback, so important to design projects, may not be sufficiently put into context as evidence, and so dismissed as ‘anecdotal’. This paper discusses the use of qualitative interpretive data that aims to provide evidence rather than ‘anecdote’.

## The study

The LAUGH design research project ‘intersected’ with the health and wellbeing of people living with advanced dementia (Vogelpoel and Gattenhof 2012). Stakeholders included people living with dementia, family members, carers, professional care staff, directors, the management of the partner care organisation, designers, and the funding body. The project aims were varied and included participation with stakeholders, enhancing subjective wellbeing, personalisation and the development of hand-held objects that promoted pleasure and enjoyment in the moment. It used

<sup>10</sup> For an example of this see Krippendorff’s comparison between colour expressed in digital form as numbers, and as an individual’s perception expressed in language (2006 pp 20-23).



inclusive **participatory** design approaches in a three-year research study to inform the development of playful artefacts to support the **wellbeing** of those for whom quality of life has been compromised by memory loss, or cognitive and physical impairment. The research investigated ways of **integrating digital technology** into designs to supplement physical and material properties, providing opportunities to **personalize** the experience (for example by including family photographs or favourite music), and making it possible for people living with dementia to interact with the devices either independently or socially. A toolkit for designing playful devices for people living with dementia was produced based on the findings from the research, in order to inform the design community and care professionals working in the sector (Treadaway et al. 2018).

The study used a participatory approach engaging in design research within a compassionate design framework (Treadaway, Taylor, and Fennell 2018) and interpretative qualitative research methods, working within a realist context and paradigm. The project employed summative and formative research and evaluation approaches which included questionnaires; ethnographic methods (real-time and post-event observation); structured and semi-structured interviews; journaling; and recording of designer/researcher reflections and reflexivity. Narrative, thematic, and text analyses of the data were carried out. The findings show the richness of the data collected and provides insights into the variety of experiences of participants in the study and the outcomes for stakeholders.

A wide range of data was collected however it is not possible to discuss it in the context of this paper. It included demographic, social and cultural data about participants living with dementia; attendee data from the workshops; notes from the advisory group and research team; interview and case study data; photographs, and audio and video recordings of the workshops and artefacts in context; real-time observation schedules of the artefacts in context; and questionnaire booklets. Data was analysed in Excel and Nvivo 11 with case study notes transcribed verbatim and all other data transcribed to note form. Audio and video recordings were coded by up to four coders. Qualitative data was subject to thematic analysis and case study data to text analysis.

## Findings and discussion

This paper will focus on two related data sets to show how they inform our understanding of the design research project. Further analysis of other data collected and the findings will be published in due course.

### *Questionnaires*

A questionnaire was prepared as a colourful easy-to-read A5 booklet, to minimize formality and reduce potential impact on participants' mood which may influence research findings. To ensure face validity it was based on the work of Lawton, Van Haitsma, and Klapper (1996), Logsdon et al. (2005) and Kenning (2017b) and was adapted to suit proxy completion and cultural differences



(Kenning 2017b, a). The number of questions, adapted from mood scales, self-esteem questionnaires and quality of life surveys, was reduced to avoid tiring participants and to account for staff workloads. Each questionnaire was completed immediately before people living with advanced dementia were introduced to the design prototypes developed personally for them. But, due to time constraints and shortages of staff, all forms were completed by proxy with the person living with dementia, when possible, in close proximity to answer questions.

The questionnaire began by asking 'How do you [they] feel today?' In the twenty questionnaires completed over four separate visits only one response suggested 'Very unhappy'. The majority of responses were 'Happy' or 'Very Happy' (65%). In response to questions about quality of life, 90% of replies to 'Do you think your memory is ...' were 'Poor' or 'Fair'. Similarly, to 'Do you think your [their] physical health is ...' 80% suggested 'Poor' or 'Fair' and to questions about energy levels 75% said 'Poor' or 'Fair'. However, when asked about mood most suggested that their mood was 'Good' or 'Excellent' (65%) and no one suggested their mood was poor. Responses to the self-esteem questions were divided. Responses to 'I can do things as well as most other people' were overwhelmingly negative with 70% suggesting they disagreed with this statement. However, all responses to 'I take a positive attitude toward myself' and 'I am satisfied with myself' suggested that they 'agree' or 'strongly agree' with the statement.

The care staff completing the questionnaire often provided important insights by offering both verbal and written unsolicited information. For example, suggesting that one person living with dementia '... is currently unwell, would not respond to any questions today'. Care staff often added their own perspective to the few words offered by the person living with dementia — still replying in the first person —by suggesting, for example, that participants had an understanding of their condition; 'I have dementia and need support and encouragement on (sic) times', and 'I have dementia, I sometimes forget things and forget where I am, I need lots of encouragement and reassurance'. Another suggested 'I have dementia but can remember certain (sic) things when I want to - I don't like noise, I make people laugh and I can make them cry', and another; 'I have dementia so have problems completing and understanding some verbal questionnaires. I depend on staff to guide me through this'. Care staff also made observations as shown by the remarks about a particularly well-dressed participant, adorned with jewellery; 'I live on an EMI unit. I have always took (sic) pride in my appearance, my house and my children. I was always a strong character within my family'.

There were limitations in that questionnaires were completed by proxy, and not all in close proximity to the person with dementia; time restrictions meant some people could not be asked the questions directly and not all questionnaires were completed for each person on each visit. However, they provide valuable data by providing glimpses of a social or shared understanding of individuals' quality of life and self-esteem. This was further reinforced when data was cross referenced with data from real-time observation and analysis of the video and audio recordings.

It was also noted that most care staff answered questionnaires generically, comparing abilities across the group, rather than answering inter subjectively for a particular person at a specific date



and time. These generic responses provided insights into group dynamics—including staff interactions—valuable for assessing the observation data.

## *Observation*

Researchers observed the interaction of people living with dementia with the prototypes and artefacts made for them. To record their observation they were given an observation schedule adapted from design research projects carried out in Australia with similar populations of participants (Kenning 2016; Kenning 2017b). The schedule, based on the work of Kinney and Rentz (2005) focussed on the seven domains of wellbeing: interest, sustained attention, pleasure, negative affect, sadness, self-esteem, normalcy. These domains of wellbeing can be observed through bodily responses such as making eye contact; attention to activity for sustained period; verbal or physical expression; closed body language; weeping; expression of pride or satisfaction; or connection or group engagement. To support the observation by researchers, care staff and family members with an intimate knowledge of the participant were asked, prior to the observation, to provide information about person-specific responses. They were provided with suggestions of bodily responses to emotions and asked to indicate how their participant showed, for example, interest, disinterest, or annoyance, and asked to identify any other responses not listed. This provided valuable insights for researchers undertaking the observation who became aware, for example, that when David moved his hand to his abdomen this was a sign of discomfort or pain, and suggested he wanted to withdraw. Researchers were also made aware that Thelma often sat relaxing with her eyes closed, and this was not because of disinterest or because she was sleeping.

Observation notes were made about body or verbal responses to researchers, care staff, and the objects and activities given to each of the participants to engage with. Researchers particularly focused on levels of intensity and frequency of responses, marking the observation schedule accordingly and adding descriptive notes, such as 'reaches out and touches the *Hug*' and 'Thelma said "don't touch him"' as she holds *Hug* tightly.

## *Concluding comments*

It is not possible, in this paper, to discuss the nuanced findings that arise as a result of the triangulation of the range of data available, these details will be published in the near future. However, the examples of data analysed here, show how different types of data can provide different perspectives and robust evidence with regard to what took place in an engagement between people, an interaction with an artefact, individual's embodied or verbal response, and group dynamics. This approach allows for the data to be interpreted and for the findings to be validated and considered trustworthy because of the range of data available that allowed for the same conclusions to be drawn from various sources. Working through the data in this way and



understanding what happened and the types of engagement that occurred produced reliable findings which can inform future research and development, point to new possibilities, and future outcomes. The LAUGH project not only created a series of objects and activities that impacted the wellbeing of people living with advanced dementia, it produced artefacts with the potential to become products, and impacted a wide range of stakeholders in dementia care.

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## The role of micro-interactions in patient use of medication monitoring and control devices and packaging

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**ABSTRACT** Medication nonadherence is a common and increasingly recognised problem in health care delivery that is often linked with groups of people that face difficulties in managing their medication. This research explores the possibility of improving daily living of those people, by analysing their interactions with smart devices and packaging that aim to monitor and control the management of medication (Granger and Bosworth 2011; Naditz 2008) and more specifically by examining the design of micro-interactions that take place when patient users interact in such contexts with medication monitoring and control devices (Saffer 2013). The paper proposes a set of guidelines and design requirements for designing and evaluating such technologies. Finally, we present a case study of designing a smart medication monitoring and control device and outline our findings from the evaluation with actual users.

**Keywords:** Micro-interactions, visually impaired patients, elderly, smart devices, smart packaging, medication adherence, dosage, pills, RFID technology, smart home, connected healthcare



## Introduction

Medication adherence is defined as the extent to which a person's behaviour corresponds to their healthcare goals (Granger and Bosworth 2011). People with cognitive and mental impairments, the elderly, the visually impaired and blind people, or people with other difficulties and physiological characteristics that prohibit them to manage their medication adherence, constitute an important part of our society which experiences such issues on a regular basis (Isaac and Tamblyn 1993; Zullig, Peterson, and Bosworth 2013). The issue of adherence to medication regimens is quite serious because people with the aforementioned profiles run a higher risk of taking the wrong medication (medicine or dose) unintentionally (Checchi et al. 2014; George, Elliott, and Stewart 2008; MacLaughlin et al. 2005; Murray et al. 2004). An average of 50% of patients with chronic diseases do not follow their medication program as prescribed (Checchi et al. 2014; Granger and Bosworth 2011; MacLaughlin et al. 2005). The rate of poor adherence has remained stable for over two decades with 40% of patients failing to follow a prescription and over 50% discontinuing medications within a year (Granger and Bosworth 2011). The responsibility for medication non adherence is shared by doctors, patients, clinicians, caregivers and of course the entire health care system (Granger and Bosworth 2011; Zullig, Peterson, and Bosworth 2013).

The first objective is to help patients understand what medications they take, how, when and why adherence is important for their health. Frequent patient counseling and accountability interventions are critical in reinforcing understanding and ensure sustained improvement. This can be peer-to-peer support, social support and telephone messages or live sessions. Also, self-monitoring is an essential tool that helps inform the health care team about a patient's behaviour and health needs. New technologies such as automatic pill dispensers or smart pill caps are used for that purpose, as well as collecting patients' biological data like blood pressure etc. Following this, patients can be informed by direct feedback and thus become aware if their treatment adherence is successful (Zullig, Peterson, and Bosworth 2013).

To facilitate adherence, the medical costs must be reduced so patients can afford it. This can be achieved by coverage of prescription medications, reduced co-payments, and refill assistance. Regardless of the specific strategy used, increasing access to medication through logistical solutions which aim to reduce prescription costs is one of the most vital components of efficacious interventions to improve medication adherence. The strategy and technology used for every patient must be suited to their individual needs. Some patients require in-person counselling, others may require telephone contact while a large number of them may only need well-timed messages to remind them to take their pills (Zullig, Peterson, and Bosworth 2013). Another way is to direct adherence through health information technology (HIT). This technology can remind patients to take their medication or even warn physicians in the case of a mistaken program (Checchi et al. 2014).



## Related work

Clinical trials of technology-based interventions can be broadly categorised into two groups: automated detection and reminder systems like telephone intervention via messages, and in-person systems with an electronic component like a monitoring device with audiovisual alarm (Checchi et al. 2014; Granger and Bosworth 2011).

A feature common to all EMP (electronic medication packaging) devices is the recording and storage function. Their second most common feature is digital displays and audiovisual reminders. These displays use auditory beeps or flashing lights to inform about the last time the patient used it, for how long it was opened, or even the total number of times they opened it. It seems that when this feedback was combined with short message service text reminders there was a significant improvement (Checchi et al. 2014; Laster, Martin, and Fleming 1996).

People over 65 are the highest users of prescription drugs. It has been proven that visually impaired people over 65 are two to three times more likely to need help in managing their medication (Crews & Campbell 2004; Grindrod et al. 2014; Press et al. 2011). In addition, 1 in 5 adults over 65 also experiences some cognitive dysfunction such as dementia (Graham et al. 1997, Grindrod et al. 2014, Prince et al. 2013). The problems these patients face are risk of getting the wrong medicine, wrong dosage or an expired drug, risk of not taking advantage of the drug, inability to replace an expired drug in time, loss of privacy, lack of full information on the side effects or doses of the medicine, decreased capacity to participate in decisions related to their treatment, high rates of being re-hospitalised, extra costs, increased mental load, inability to understand any possible mistake of the pharmacist (Granger and Bosworth 2011).

## Methodology

This study aims to examine micro-interactions that occur while patients interact with their drugs or medication monitoring devices. The interviews' purpose was to capture how patients move in their physical environments, how they recognise their medication, how they identify different drugs, the way medicine packs are placed, what techniques are used by each patient to differentiate drug packages themselves, how do they remember that she/he took his doses or at least the right drugs and which micro-interactions emerge during the interaction. At first, current micro-interactions had to be studied through interviews in fifteen patients. The participants ranged between 53 and 85 years old, and they were living with at least one other person. Some of them had also been visually impaired for more than 3 years, with 80% or more sight loss and not knowing the Braille alphabet. The process took place in the participants' houses. After observation and explanation of the medication system that every participant uses, the reviewer asked all the above and let patients discuss any problems or other difficulties they face in general. According to our research findings users incorporate a number of empirical methods and custom techniques in order to identify and keep track of their medication schedule. Participants distinguish their medicines according to their names, their packages' colour, and pill shape.



Figure 1: Empirical methods and techniques for identifying and keeping track of their medication schedule:  
Shape of the packaging or the pills, special label or other tangible characteristics, handmade sticker with custom notes.

For visually impaired patients, size and any special sign of the pill cardboard are also important. Some of them have their own bottles for every pill or stack paper letters in every different bottle, to separate them. All participants take their medication according to their daily activities. Patients store their pills mainly in the kitchen room. Some of the visually impaired patients also keep a specific series of the packages. All participants stated that they have consumed a wrong pill or dose or even a pill that has expired. Also, another main problem was that patients cannot be sure if they take their pills or not, common problem for this age-range after a while. Most of them, mainly hypertensive patients, mentioned that they can recognise if they forgot any dose because of their subsequent symptoms, such as a headache. Also, three of them mentioned a specific technique which helps them understand if they took their pills or not, like rotating the bottle upside down after use. On average, they take 3 to 9 pills per day. Most of the users had a pill box to organise their daily medication and all the visually impaired patients had a "talking" handheld device or some other assistive technology. Beside the main problem, there is also the possibility of forgetting a future dose or not taking the pill at the appropriate time, or run out of medicines, which may be long-term but remains a major risk to the patient's health. Concerning the micro-interactions, a basic one is the upside-down placing of the bottle after use. Another similar trick consists in placing different drug pills in separate containers and putting rubber or Velcro on the packaging, cutting and sticking paper letters to containers or placing stickers on them. Yet another is arranging containers based on a particular order.

### *Methodologies for Interaction and micro-interaction design*

Interaction Design is the design discipline that deals with the user activities and systems responses, the most appropriate workflow for achieving user goals, for identifying relevant information for each activity, and the processes of interaction (Goodwin 2009, 35). Micro-interactions are particularly important because they fill the gap between human and computer by



directing all interactions. (Creative Bloq Staff 2014). They provide users with feedback and understanding of process development, making the interface accessible, regardless of the complex logic behind it. Dan Saffer has divided micro-interactions into four key parts: triggers, rules, feedback, loops and modes (Saffer 2013). Concerning this particular target group of patients, there is a special need for proper feedback to the user. The design starts with the lack of visual or hearing user-device communication and therefore the stimuli and feedback mechanisms should automatically trigger the rest of the users' senses in such a way that they do not become disturbing to them.

## Concept

The system should operate autonomously, aiming to remove any cognitive load from the user while reassuring that they are properly following their medication. This case study refers to people aged 50 and older, with chronic health problems and vision or hearing loss. The device must interact with the users and provide adequate information and guidance for medication adherence. It must be usable and accessible for the elderly. Instructions must be in a user-friendly format. It should present the ability to change the alert time, to store up to ten treatment medications and four universal medications, have a digital clock in a prominent place and connect to the network for treatment updates from doctors. It must afford sound recording/playback, proximity triggers, a notch in a suitable size to accommodate drug tabs and to identify the type of tabs.

Micro-interactions must be active or passive in each occasion, activated by a user's action, must have a maximum duration of four seconds and must require the least amount of effort. According to Saffer's guidelines for designing micro-interactions, the design is controlled through rules which create a flow on users' actions. Feedback must be comprehensible from the user and it must not lead to interaction dead ends. Those feedback mechanisms should communicate a "message" to the user, so it has to transfer as much information as possible with minimal messages. Finally, loops must cease after a specific time and can stay open or closed depending on the characteristics of the specific case. Because of the specific cognitive, mental and physical characteristics of our target users the interface should remain minimal with simple steps for completing the different tasks. Moreover, the device must free the patient from the procedure of distinguishing the different drugs, to inform them of medication effect and expiration date, to log the patients' activities and keep doctors informed.

## Prototype analysis

The primary aim is to free patients from the drug management process. The only user intervention is to feed the device with the pill tabs through the acceptor located at the top. Tabs equipped with RFID technology provide all the necessary information including name, effect, expiration, side effects.

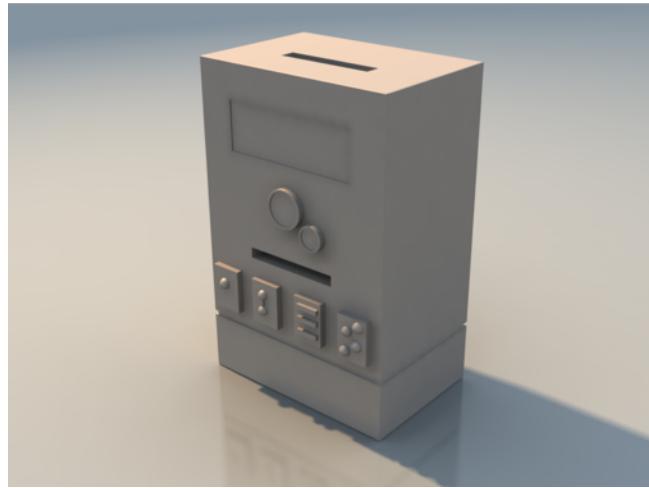


Figure 2: A three-dimensional representation of the low fidelity prototype of the smart device

The RFID reader retrieves appropriate information from the tabs and organises medication in the appropriate compartments. The actual medication schedule is provided by the doctor through the networked functionality and alerts the users on time. As an exception, the users can request pills of frequent use by pressing the four lower buttons with the surface/tangible texture. Finally, users can postpone an automatic dosage notification at a future time if they are unable to take it on time, and also provide feedback for the reason they do not adhere. If a dose is cancelled, the device can also be configured to either inform the health care provider or log the events and feedback from the patients.

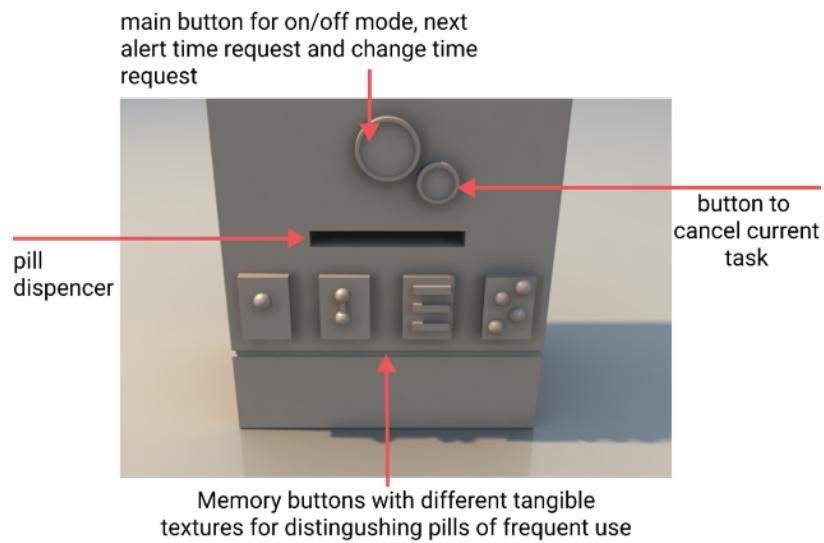


Figure 3: Details and functions of the devices' buttons and other components

The device consists of a part where the tabs are inserted and stored and the second one where the empty tabs are discarded. The device is portable with a rechargeable battery capable of around



48h of usage. The following micro-interactions are afforded: on/off, inserting medication tabs, update for the next dosage, postpone dose time and the request pills of frequent use.

## Evaluation

After interacting with the device, users noted that it is quite effective and easy to learn. Most of our users easily identified the designed micro-interactions. All managed to turn the device on and off and identify the feedback mechanisms. Most users needed some initial assistance to feed the device with tabs, but managed to successfully complete the task in consequent scenarios. All users identified the next dosage alerts and with limited initial assistance managed to postpone a dosage.



Figure 4: Actual users interacting with a low fidelity physical prototype during formative evaluation

People at the early stages of a disease found it particularly helpful and a very important companion, especially in cases where the rest of the family or the person responsible for taking care of them is not present. Three users mentioned pill different sizes should be considered, and one user requested for an alert to feed the device before it gets empty.

## Conclusion and future work

Our evaluation sessions showed that the device considerably improved people's medication adherence. Our current research is focused on a larger study with longer periods of application and testing, necessary to confirm our findings and provide us with valuable information regarding the design of the device, user habits and behaviour and other requirements of the different stakeholders involved including medicine makers, suppliers, pharmacists, caregivers, doctors, family members. We plan to compare our design with other medication adherence devices and low cost solutions (Choudhry et al. 2017).

During the formative evaluation phases, we identified a number of improvements and enhancements that can advance the overall quality of the design. Crucial notifications about expiration date or the current feed state of the device may take place when the user is in close proximity with the device, and pill identification mechanisms should be improved. To conclude, we also identified that patients with a complex medication regimen pose a special case where medication adherence becomes a difficult task, as it requires more information to be captured (history of events), analysed and provide feedback to caregivers, doctors and patients.



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## Service Operations: An Integrative Framework for Agile Service Design, Delivery and Operations

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**ABSTRACT** This paper reports on the discovery phase of an econsultation project, that aimed to deliver a technology enabled service for consultations between healthcare professionals and patients to occur using digital communication tools. The project involved a mixed methods research phase that supported agile service design work. A number of learnings were derived from the project and these are contextualized into high-level framework for agile service design that starts from a Minimum Viable Service through provision of a Minimum Living Service (MLS) through to a Minimum Sustainable Service.

**Keywords:** service design, agile, socio-technical design, consultations



## Introduction

This paper reports on the discovery phase of a digital healthcare project that investigated the introduction of a new e-consultancy service to the National Health Service (NHS). The project sought to define a vision for a new digital service and created a proof of concept that enables face-to-face consultations between patients and General Practitioners (GPs) using a proprietary digital communication platform (Skype for Business). The project was funded and delivered by Accenture and aimed to explore virtual consultations as a way of meeting increasing demand from patients for digital access to health and care services. The resulting prototype was completed in two months and enabled online consultations, appointment management and basic functionality centred on five core use cases:

- Book an appointment
- Cancel an appointment
- Reschedule an appointment
- Edit an appointment
- Take part in a consultation

The future role out of the service would offer many benefits to patients, GPs and health professionals alike. These include increased and improved access to primary care, including hard to reach patients and those with stigmatized conditions including mental and sexual health issues. The service is also anticipated to reduce time and cost in consultancy delivery, streamline operations and provide better and more secure data collection. Patients engaged during the discovery phase, also noted the potential to reduce contagion by not having to travel in person to surgeries. Most importantly, online consultations offer the potential to better quality and timeliness of diagnosis, through broader knowledge sharing and improved, faster ways of triaging. Together, these relatively small incremental improvements contribute to better healthcare in the broadest sense and specifically for:

- Follow up appointments and doctors
- Repeat prescriptions and doctors
- Sexual health advice and test results.
- Mental health advice and check-ups
- Medication reviews for doctors
- Getting advice and results online



Despite the benefits, poor connectivity, unfamiliarity with technology (especially for older patients) were cited as negative aspects of the new service. Further evidence is currently being collected on these issues, as well as further insights into the value and impact of video consultations in healthcare more generally. In addition, work is also continuing in testing the prototype and evaluating options for enhancing functionality and running a broader pilot study.

## Approach

Research was carried out during a short (three week) immersive research phase. This work included in-situ interviews, observation and generative workshops with 8 Doctors, 11 Patients and 6 Admin staff of mixed demographics. Sessions took place in various locations, as well as some conducted remotely using video telephony. A hybrid approach was taken to research and design as the new service related to three different domains. Firstly, the work focused on the development and adoption of a new technology (socio-technical focus) where adoption is critical. Secondly, the outcome is a public service (service design focus) where a holistic approach (e.g. service design) is needed to orchestrate the various actors and activities into an optimal whole. Lastly, this new service comprises screens, buttons and interfaces to a proprietary software product (human-centred design and technology focus) that were to be developed using agile methods.

The hybrid approach was exemplified in using socio-technical methods (e.g. Technology Acceptance Model, TAM Davis, 1989). Insights from TAM assisted and augmented the service design (Shostack 1982) work, specifically uncovering adoption issues and opportunities that would otherwise have been neglected in more traditional user studies. We found that despite doctors and admin staff having a positive attitude towards virtual consultations, the perceived usefulness of the service was comparatively low. We also discovered that despite participants having high self-efficacy, they were anxious about having such a service rolled out. Moreover, staff felt that the value of consultation could be diminished if online consultations are either overused or misused. This may have contributed to being anxious about using it. Lastly, we learnt that staff felt that management support around the service would be limited, but also believed they have the technological equipment required to launch the services as a kind Minimum Viable Product.

## Analysis

The research phase produced abundant data, spanning functional and non-functional requirements, collaboratively produced sketches and interview transcripts. The insights gained were analysed using an Agile Coding and Framework approach, where data was reviewed with a research facilitator and an initial model of the data and framework produced (top down). Themes were explored using this top-down approach as well as a bottom up Framework (Ritchie and Lewis 2003) approach. Together, the data mapped to four themes comprising:

- Access to Technology



- Access to Healthcare
- Quality of Healthcare
- Quality of Experience

As every data point had been classified and counted it was possible to quantify relative weights to the groupings and also the relative strength of constituency (e.g. patients vs. GPs) among all participants. While the data pertained to specific healthcare project, in relating to the design and development of a new, technology enabled healthcare service could be generalisable. In essence, the commonalities with other similar projects centre on the need for a strategic framework for delivering sustainable new services built around unlocking value. The findings suggest that enabling access to healthcare through technology is both 'locked' in terms of being a barrier to adoption by less technically savvy patients and providers. At the same time, it is 'unlocked' as it drives adoption generally and specifically among technical astute users (e.g. younger, geographically dispersed groups etc) who might otherwise be less willing to get treatment. The notion of lock also suggests that digital healthcare services must therefore transition through states of increasing sophistication. This means that adoption needs to be built through incremental service improvement, with each step widening the potential audience for the service, but without risking developing expensive and/or risky functionality.

### *Convenience and efficiency*

A key theme that derived from both patients and clinicians was convenience. Patients viewed this as one of the most important features (especially millennials) and those who were reliant on public transport. Because patients stated that they were more likely to attend online appointments, it would, in turn, result in more patients being treated sooner. For clinicians, the convenience of being able to conduct some home visits virtually would save approximately 30-40 minutes per day in travel time, which again suggests that more patients could be treated. These benefits were operationalized in the prototype through a GP and admin dashboard and appointment form.

### *Consultations*

The rapport between patients and GPs was noted as a possible challenge to virtual consultations. Elderly patients stated that the relationship that they had built up with their doctor over many years might become less personal. GPs in most cases, agreed with this assessment, but reported that everyday face to face consultations would not be replaced entirely and rather that only specific appointments could be served through this channel. For younger patients, the loss of rapport was not an issue, particularly because they did not feel the emotional connection with one particular doctor, and just wanted to be seen quickly.

### *Better patient care*

Better patient care was a key theme across all patient and clinicians. Millennials noted that they were more likely to book an appointment and turn up if it was online, meaning their health concern would be looked at, and if required treated via this channel. For the younger generation,



mental health was a key concern, (also confirmed by GPs) and that most check-ups are already done over the phone. Being able to see the body language of the patient online, was seen as positive attribute of the new service as it would provide a greater insight into the patients' feelings, thus offers the potential to support greater patient care. The elderly were less wedded to the idea that virtual consultations could improve health outcomes. These insights fed directly into the design work through providing a patient waiting room and help and advice content relating to general medical issues.

### *Technology*

From a patient's perspective, internet connectivity was one of the main areas of concern. Most believed that this would be the greatest barrier to this technology performing well. The user's choice of device was also a discussion point. GPs had similar worries on internet connection and felt that this might actually cause delays in their appointments. Most GPs noted that they had the right necessary equipment with just a few gaps requiring an investment webcams or microphones, would be required. All participants agreed that by using technology, access to healthcare could be increased and hard to reach patients would receive more and better healthcare. A WIFI signal check was built into the prototype to help alleviate this issue.

### *Demographics*

From the interviews and particularly from the TAM related data, we found that both patients and doctors had concerns around the social groups that would be able to use virtual consultations. Millennials were the most enthusiastic about such a system. Yet, parents with small children were sceptical and specified that they would rather their children be physically examined. Elderly patients were mixed in their response and were dependent upon their specific device (such as a tablet). Clinicians concurred that virtual consultations would make treating the hard to reach much easier, which in turn, would result in better healthcare.

### **Agile Service Operation Framework**

From the research, the project progressed into design and development. This was carried out using an Agile approach (Beck 2010). While agile has established itself as a tried and tested software development methodology, cases relating to healthcare applications are few and even fewer when wrapped up with a service design approach (e.g. Vink et al. 2017; Lee 2011). Agile manifested itself in developing a 'Minimum Viable Product' (MVP) rather than a fully provisioned end-to-end service. The service also utilized existing technology, that included much of the necessary functions, rather than developing a fully bespoke solution. On the negative side, this means that the resulting product or service is always only capable of providing a subset of the fully functioning end state version.



Agile is also based on regular deliveries of 'working software' delivered in short sprints. This means that releases can be trialled, and feedback gained early and often. In the case of the project, this data-driven approach was further enhanced by providing a patient feedback screen. From an operational perspective, agile's common language of 'user stories' provides an accessible and easy way ensure full and deep stakeholder involvement. For healthcare projects this clearly requires balance and a focus on reducing risk, driving adoption and data driven enhancements.

Service design's affinity with 'digital transformation' in general and public service optimization specifically, makes it a natural partner in healthcare technology. Evidencing services out of seemingly disparate service encounters (whether digital and/or human) would seem to be one a positive differentiator to other approaches. Similarly, designing across multiple, individual actors, interactions and systems sets service design apart from the single interaction focus of user experience design. In addition, co-creation (designing with a broad set of active stakeholders) distinguishes it from more instrumental User-centred Design methodologies. Despite this potential, there are arguably a number of areas in which service design needs rebalancing in order to support technology-based healthcare applications.

Immersive research is ubiquitous within the service design domain. Augmenting 'ethnographism' with more socio-technical methods would make sense given contemporary everyday life is bound within non-visible networks, databases and intelligent automations. A different kind of data that goes beyond observing technology's end users' behaviour is needed for designing viable healthcare services. Naturally service design privileges the kind of data produced through immersive research as inputs into design. The value of such data is unquestionable in its usefulness in ideating new service concepts. However, data pertaining to and generated from the real-time, actual use of service is arguably even more valuable to verifying concepts and optimising the experience for healthcare services.

Emphasizing human activity (at the expense of technological capability) in the here and now (e.g. before service use) naturally follows through into the predisposition for mapping, blueprinting and modelling in service design. Having mapped out an optimal snap shot of human activity for a service, it is relatively easy to layer on where the technological magic happens. This 'design futurism' discounts the nitty gritty nuts and bolts of actual service delivery and optimization which at best is vision setting and at worse misleading. The blueprints also embody an architectural metaphor which lacks relevance to living services where interactions track to fixed paths and 'journeys' that extend over time. The notion of dynamically created and evolving services is, to some extent, counter to Service Design orthodoxy which focuses on mapping extant to future prescribed services. Instead this research and resulting framework suggest that while mapping actors and activities is important to the design of a service another lens is required (that of living service) is required to ensure the sustainability of the service.

The holistic but largely conceptual focus of service design makes sense when projects are design-led, timescales and budgets are generous and project goals are transformational. The lack of health-related cases is perhaps an indication that these conditions are relatively rare and perhaps



more importantly out of step with best practice in delivering positive change through technologically based innovation. Agile is not only a reaction to the failure of delivering large-scale expensive software projects but a potentially valuable counterbalance to the 'blue-sky thinking' that underpins so much of service design cases. Instead, we should augment agile's focus on delivering tangible, working systems but framed within a strategic design approach that delivers incremental as well as long-term value.

The rebalancing of service design is thus partially built on recasting the role of technology. Technology must shift from afterthought to primary importance in the research and design of a service, in order to fully realise the value of the approach. For health, this a critical and relevant focus as healthcare providers' challenge is most often connecting legacy systems into usable services. This does not mean that service design should be constrained by technical constraints or limitations. What is needed is a more nuanced and sophisticated approach to services that recognises the centrality of the materials of their construction and the organic nature of their use and development, beyond design.

As with all of the project's design work, this was carried out in close collaboration with the developers and took account of the platforms limitations and capabilities. Designing for a specific platform is a commonplace approach in commercial design and requires creativity and technical ingenuity to deliver well-crafted living services. Design systems are a natural corollary of designing services to fit platform constraints and enablers. Unlike traditional, 'design a blank sheet of paper', this approach utilizes common components that integrate with the platform well, offer a consistent experience and are consistent to users. At the same time, designers can focus all of their creativity on where elements are lacking.

A structured framework for delivering agile service design, would help sensitize service design for healthcare. This would begin with founding projects on the basis of a Minimum Viable Service (MVS). An MVS focuses on enabling access to a simplified, stripped down version of the service. Such a proposition is by nature basic and supports a few use cases, but is built to ensure it enables core functions and proves the viability of the service. In the case of econsultancy, this means ensuring that the service provides a simple and convenient way of organising consultations for both healthcare professionals and patients. An MVS is, however, more than a conceptual proof of concept. Its adoption and use enables early data collection that can help develop richer features, but more importantly enables mapping service supply and demand data. In this sense, a simple digitalized entry point for healthcare becomes the first manifestation of a Living Service, where data is used to enrich the experience and start to build a critical mass of users. Having established a strong and sustainable user community, the next phase of Minimum Living Service (MLS). This is focused on delivering an optimized experience that can drive broad adoption. Finally, a Minimum Sustainable Service focuses on facilitating value co-creation and operational excellence.

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## The Service Experience Framework

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**ABSTRACT** This paper describes a Service Experience Design Framework. The paper starts by positioning the framework within the corpus of design, with a focus on practice. A rationale for emphasizing practice is given and also how the lens of 'design doing' potentially requires new kinds of knowledge and research outcomes. A case is then introduced relating to the design and delivery of a digital consultation service. As an example of a real-world service design for health, the case illustrates some weaknesses (and opportunities) in the current service design orthodoxy. Weaknesses in ways of working include philosophical predispositions on the relative value of human versus technological agency, as well as issues relating to practice. Enhancements are suggested including shifting focus from largescale, 'blue-sky' project work to smaller, data driven service tweaks that exemplify frugality. These various strands are bought together in the final section of the paper that introduces the framework itself.

**Keywords:** service design, design frameworks, co-design



## Introduction

Donald Schön's 'reflecting in action' (Schön 1983, 54) is a widely accepted description of design as a learning process of doing and reflecting. Buchanan (2006) shows how this recursive process manifests in designers continuously reframing problems. Simon (1996) and Chapman (2005) position this kind of 'Design Thinking' (Lawson 2009) as a utopian endeavour done by 'futurologists'. These various accounts of theory highlight the unique value of design (as a primarily individualistic cognitive activity). Almost without exception, such works lack substantiating data. While theory has currency in a general sense, practice is where designers and researchers realise their own value and their chosen profession.

Then there is the practical end of design. Here, the messy, visceral, complexity of doing (Accounts of Practice) has the veracity of real world design, often providing reflexive and theory building potential for other practitioners and the broader community (e.g. Broadley and Smith 2018). Accounts of Practice understandably tightly focus on contextualizing design thinking through examples of design doing. Beyond cognitive process and studio activities, design work is integrated into the complex production (and consumption) of goods and services. As well as any 'Overarching Context for Design' (artisanal, craft, industrial, commercial etc.), there is also the specific one relating to the work at hand. Today any specific service design context is almost certainly highly collaborative, distributed and tightly coupled with technology<sup>F2</sup>.

Frayling's (1993) research *into, through and for* design is some way distant from accounting for such diversity of practice and the kinds of knowledge that is produced. To do this, a fourth genre is needed (Reflection on Practice) which frames design as a continual process of learning (Reflexive Practice) done either by practitioners themselves or with them by researchers. This would entail revealing reflexivity as a process. From and with the doing there is the externalizing of thoughts, the checking to related (and less related) knowledge and to the continual evolution of practice itself over time. Whether practice is optimizable or in endless dialectical flux is irrelevant. Such 'Reflection Cycle's might enable generalize the specific into broader theoretical insights (Practice based Theory). These will evolve.

This paper provides a reflection on practice. It takes learnings from a project (Knight et al. 2018) involving a small team designing and developing a digital consultation service. Data from this work suggests that health design projects need to account for highly context specific goals of flow<sup>S2</sup>, value and quality. Broader insights were also developed from the case as well as number of other related projects during an eight-month reflection cycle. This reflexive activity suggests the service design orthodoxy is currently highly ritualized and needs specific contextualization for to the realities of health. These factors are operationalized at the end of this paper. Superscript characters denote linkages to framework elements.

## Reflection on Practice – Real World Service Design

This paper reflects on the discovery phase of project for the UK National Health Service (NHS). The project created a proof of concept for digital consultations between patients and healthcare professionals using Skype for Business. To do this, a classic service design approach was taken and combined with agile (Beck et al. 2001) methods. The core team (or pod) consisted of a Business Analyst, a Service Designer and a Skype Developer. The practitioners worked in sprints through a combined backlog<sup>50</sup>, with some direction from a Product Owner and Design Strategist (the author). Patients, General Practitioners (GPs) and operational staff were involved in contextual inquiry, co-design<sup>50</sup> and user testing sessions that were run during sprints. As part of the agile methodology, reusable assets (including design deliverables) were produced for use in future releases and other projects. Less commonplace project activities included applying The Technology Acceptance Model (David 1989) in the research sessions and also conducting a literature review of health consultation research. These had a profound impact on the direction of the work as they surfaced barriers and opportunities to adoption of the new service.

Service design projects are rarely explicit in the technology that underpin them. In this case, a well-known, proprietary communications tool was used to underpin a new service. This technology was not tangential to achieving the project goals. Rather it was central to tangibly improving healthcare and the service experience. In other words, the core service use cases could not have been enabled without the specific technology used in the project. The decision to use Skype was a pragmatic one, where the advantages far outweighed the disadvantages. It is conceivable that this might have affected service experience quality<sup>52</sup>, although this was not reflected in the research. In some ways the opposite happened; the quality of the platform contributed to high levels of usability and user satisfaction. These were measured with standard benchmarking tools such as SUS (Brooke 1996). Adapting an existing platform (rather than building a custom solution) meant that the service could be rapidly deployed at minimal cost and assured high levels of security, data integrity and support. This approach is somewhat contrary to the prevailing 'Blue-sky' thinking in service design.

There are good reasons service design has privileged human agency over technology in the past. With ubiquitous computing, this position is at best misdirected and at worst a break on progress. Harnessing machine agency for good should be the goal of any service design project. Instead, the focus is often abstracting surface-level (e.g. non-technical) signs of a service into 'Blueprints' (Shostack 1982). As static snapshots of activity these undermine the primacy of Living Services. Rather than partial mapping, we should unlock service flow, load and quality<sup>52</sup>. This should be achieved through human-centred innovation within the 'Living Service' using 'Innovation Games'

<sup>50</sup>.

Technology has methodological implications too. Service design artefacts don't integrate well with the needs of service engineers and developers. While blueprints may exemplify design craft they



don't map to service architectures and platforms that are integral to service delivery and operations. Standardized tools to do this exist but generally lack adoption in contemporary service design practice (Sangiorgi 2009 is an exception). A more radical interpretation of this situation is that the gap between design and development is reducing. This could mean defining some hybrid, standardized, systematic notation between design and development. This would both accurately model socio-technical activity, to the level where interactions can be designed, developed and help load and cost estimations to be made at an early point in sprint planning.

The prevalence of 'scrum' (Schwaber 2004) has driven the service design community to adopt agile practices such as sprints. The project used a lightweight agile framework involving sprints, scrums and a story backlog. The growing sophistication of agile tools, increasing reuse of assets (including Design Systems<sup>F2</sup>) and automated production meant that the pod was a fully self-organizing one. As well as digital production tools, the project used epics and stories to communicate requirements. Based on user research data, these 'Service Stories'<sup>F2,S1</sup> were a common language that aided planning and documented current and future releases tasks.

Agile is not just a new addition to the domains burgeoning 'Sticky-note' design toolkit. Rather the nexus of lean and agility is arguably as big a break in modes of production as the factory method of manufacture. In this case, long in-depth 'up-front' research and design was condensed into short sprints where research, design and development worked in parallel. For service design, the implications of agile/lean on the service experience are more profound than changing how the work done. This is because of the unique properties of digital materials used in the production of products and services and the underlying philosophy of lean that takes a socio-technical approach to continuous improvement.

Digital products and services are endlessly mutable. Agile/lean exploits this affordance through iterative releases of increasing quality and personalization. This mutability challenges the fundamentals of service design orthodoxy where blueprinting new services (Green Field Design) wins out against fixing existing ones. Similarly, wholesale design oriented to an (unspecified but distant) time (Design Futurism) in prioritized over the here and now. The case was entirely different. Instead, the need to increase access, enhance the consultation experience, contribute to improving healthcare provision and cost of service through the pragmatic use of technology in the shortest time took precedence.

Speed of deployment and rapid, incremental enhancements make a lean/agile service design approach relevant to any domain. Lean's focus on value, flow and frugality also make it particularly important to service design for health (also see Waring and Bishop 2010). This has repercussions for the service experience and modes of design, production and operation. In the first case, this means running short releases of incremental change that focus on unlocking value<sup>S2</sup> with minimal impact on resources<sup>S2</sup> at all points within the service ecosystem. In the latter case, it means industrializing the process and focusing on reuse. While this was partially achieved in the project, the broader implications of agile/lean service design are described for future development in the framework that follows.



Service design ought to frugally tweak services toward optimal flow, rather than focusing on big ticket projects that disrupt and cause unforeseen adoption issues. That is not just a pragmatic approach to framing any specific context for design, but it is also the embodiment of the ethical design tradition. Use the minimum of resources to extract the maximum of value. The focus on value has two implications. Firstly, frugality ought to inform all our plans, methods, deliverables and interventions. Secondly, a focus on value should not just be the cornerstone of services in general (Vargo and Lusch 2004) but the experience too. While value could be realised through a thoughtfully envisaged future service it could also be more prosaic, increasing throughput of consultations as in the case.

This frugal attitude is in many ways at odds with much of the literature. Here the holistic nature of services rationalises expansive research where everything needs to be known before anything can be done. This knowledge is then abstracted into design deliverables (Kimbell 2009). These complete, complex and appealing ‘Pixel Pushing’ produced ‘maps’, blueprints’ and schemas demonstrate ‘Deliverables Bloat’ rather than leanness. Not only should we focus on minimalistic and lean descriptions, but we should rigorously question how deliverables aid service production. That could mean defining the most expedient deliverables (reused or custom cut-downs) for the case at hand using the Shaping Game<sup>50</sup>. This workshop activity involves team members regularly checking back on project fundamentals through a collaborative question-based game that asks members to reflect on:

1. What resources are available for service design, delivery and operation activities
2. What is the precise agreed problem/opportunity?
3. Is the agreed problem/opportunity, the right one(s)? If not, what is?
4. What are the 6As? –

Agents – people, systems and technology involved in the service ecosystem

Attitudes – Data pertaining to agent insights

Activities and Actions – The atomic and sub-atomic (user stories) service interactions

Artefacts – Tangible manifestations of the services

Axioms – Rules (implicit and explicit) that underpin the living service

5. What is possible/impossible?
6. What is fixed/changeable?
7. What can be reuseddesigned?
8. How might flow, load and quality be improved?
9. What does the minimum viable service, living service and sustainable service look like?
10. Which solutions are likely, possible, desired and best?



There is a deeper question on service design deliverables. Why do we need them at all? If the goal is to improve an existing service (i.e. not Green Field Design), then practitioners should operate 'In Service' rather than separate from it or via any form of abstracted knowledge. This would mean truly participatory design (with service agents) not before production but within it. There is a risk is that short, incremental change may not build to strategic positive service transformation. The project evidenced this danger. The research pointed to the need for a Service Roadmap<sup>F0</sup> that tackled three service adoption thresholds. These started at broadening access. Then the service would need to reach critical mass (and with the necessary features to do that) and then finally, it ought to surpass the quality offered by the non-digital service.

Not only is design work a service production cost but cost to value ought to be a factor in practice. Without this boundary, design becomes not only utopian but disconnected from its real-world context in the here and now. To do this, any agile/lean service operations project should deliver high Sprint Value to low Sprint Cost. Similarly, the impact of a release should be to provide increase Service Utilization and lower Operational Cost. These rather dull factors should be both a spur for designers' creativity and critical be areas to tackle through design thinking. This also means that all design work should be continuously estimated, and outcomes measured in order to maximize value and to steer further sprints. As happens in lean/agile.

## Reflection on Practice – Real World Design Research

Frugality has implications for any necessary design research, rather than starting from scratch, this important foundational work should minimise impact: validating rather than eliciting. One way of achieving this is to use 'Story Card'<sup>F2</sup> approach. This uses cards to describe service agents, insights features, components and interactions. These can then be used as a common set of elements in research and then also translated into service stories that map back to the '6As<sup>F1</sup>.

The mission of any service designer ought to be to evidence the touchpoints of any given service but to identify points at which data<sup>F3</sup> can be continuously collected 'in service'. This service data is likely to pertain to flow, load<sup>S2</sup> and quality levels and would be collected by chaining together data from the living service itself. Not only would this kind of data facilitate design work, but it would also frame any other research activities that might be needed.

This could be derived through observations. However, despite the vogue for ethnographic style studies, 'backstage' service activity is hard to evidence. In reality, such interactions involve socio-technical networks that are partially hidden within machines. Thus, understanding the role of human agents is only part of the story. Immersive research should therefore be more closely coupled with digital anthropology. Here, data could be collected and triangulated approach for qualitative studies, analytics from service usage and service load data (e.g. number of consultations).



## The Service Experience Framework

Resolutions to the theoretical challenges within service design orthodoxy have been discussed in previous sections; these build on practical insights gleaned in the case to form the framework below:

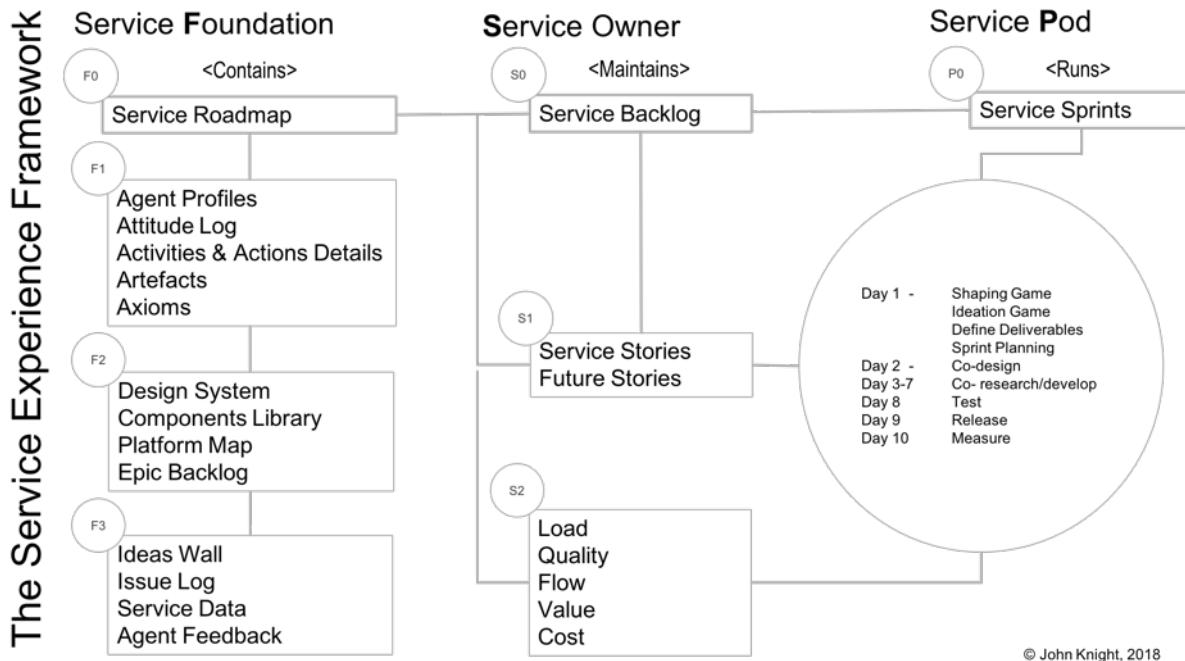


Figure 1 The Service Experience Framework

The practical implications of the case and broader reflections on practice outlined in this paper suggest a fundamental shift in how we design (deliver and potentially operate) services. This shift is predicated on the affordances of digital technology, agile/lean ways of working and the continual evolution of practice. Future work will focus on testing and iterating the framework in this real-world context.

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