



**Proceedings of the 6th Conference on Design4Health**

**Editors:** Kirsty Christer, Claire Craig & Paul Chamberlain

**Volume II**

Proceedings of the 6th International Conference on Design4Health

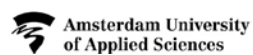
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## Volume 2



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# Foreword

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

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

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

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

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

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

Claire Craig, Kirsty Christer & Paul Chamberlain (Lab4Living)

# Reflections from Sabine Wildevuur – host of Design4Health 2020

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

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

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

Special thanks to the members of the organising committee:

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

# Academic Programme and Review Committee

- Armagan Albayrak (TU Delft)
- Somaya Ben Allouch (*HvA*)
- Remi Bec (Lab4Living)
- Marina Bos-deVos (TU Delft)
- Daniel Bossen (*HvA*)
- Paul Chamberlain (*Lab4Living*)
- Kirsty Christer (Lab4Living)
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- Lex van Velsen (*Roessingh R&D, UT*)
- Peter Weijs (*HvA, VUMC-AMC*)
- Gemma Wheeler (Lab4Living)
- Sabine Wildevuur (*UT*)

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

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

# Themes of the conference

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

The conference sought papers which considered:

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

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

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

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

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# Exploring Digital Sovereignty: Open Questions for Design in Digital Healthcare

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**ABSTRACT** Driven by a culture of ‘data fundamentalism’, datafication is being increasingly introduced in health services, sometimes with little transparency and patient engagement. This paper draws on research from the UK in order to critically reflect on the wider impact of health digitalization and issues of digital rights and data justice, which are sometimes overlooked in this field. The case from the UK deals with the effects of datafication in community health services - and more broadly welfare services - within the field of mental health. People with experience of mental health service using digital health services are in fact made visible, represented and treated differently as a result of their digital activities and records. Theoretically the paper will frame these issues and case studies within the available literature on Digital Sovereignty. The question of digital sovereignty is understood by the authors as central to deal with issues of independence, control and autonomy over the digital self. It raises issues of transparency and accountability on several levels, from the Government’s purchasing of digital tools, to potential impact on health worker and algorithmicization decision making process.

Keywords: data justice, design for the digital self, digital sovereignty

## Introduction: Design in Healthcare

The use of design approaches in healthcare can currently be considered as an established feature in many national health systems across the world. It was in 2005 that the English National Health Service (from now onwards also NHS) started experimenting with design in order to respond to the consistent challenges for improving quality of care, while also delivering more patient-centred and/or patient-led services (Donetto et al. 2015). Initially conceived as a promising approach for healthcare quality improvement, the application of design theory and practice in health has extensively expanded to the new elements of digital healthcare. The digitalization of healthcare service provision has profoundly changed the healthcare system (EU Commission 2019) and this has been happening also as result of the work of designers, employed in higher numbers to develop better digital interfaces, data collection processes and information design. Initially involved in the re-design of the healthcare experience in order to improve its quality within a relational and participatory framework, the design work in digital healthcare seems to have gradually shifted away from the initial focus on the patient experience and turned towards questions of usability, access and interfaces, as designers are involved in the difficult task of mediating between patients' needs, systems' processes and the work of IT engineers and programmers. Dealing with the design of technologies in fact is not something that can be deployed simplistically, as during the technological development phase ethical issues are translated into context specific and actionable practices through design choices (Peters et al. 2020).

## The Digitalization of Mental Healthcare in the UK

We use the term 'digital health' to designate the wider field which involves the use of technologies and digital platforms in healthcare. In this article, we only refer to the use of technologies in the interaction with patients, although we are aware of the impact that digital technologies have on healthcare staff and within the healthcare system more broadly (Djellal and Gallouj 2005).

The case from the UK is in this respect particularly interesting, both for the ambition of the digitalization plan and for its pace. It was 2014 when the NHS England published the *NHS Five Year Forward* plan, including an ambition to 'exploit the information revolution' and already in 2016 the digitalization also expanded to mental health services, as the adoption of information technology in acute, community and mental health services was considered by the NHS to lag behind.

If it is true that healthcare is a quite different sector compared to other public service sectors, for its 'sheer scale, variety and complexity, as well as the (often) fragility, vulnerability and dependency of its clients.' (Robert and Alastair 2017), then we could say that mental health is a different field than many other healthcare fields, on one hand because mental health services cover a huge spectrum of healthcare provision (from wellbeing services to community mental health, up to acute mental health services), and on the other hand because mental health is considered to affect globally 1 in 4 people in society (WHO 2001). If we follow the World Health Organisation statistics, that says that 'One in four people in the world will be affected by mental or neurological disorders at some point in their lives.' (WHO 2001), we also start framing mental health not as a permanent status affecting a limited number of people but as a transient one, which could potentially affect anybody at any specific point in time. In this way, the uniqueness of mental health services, compared to other health services, becomes clearer.

The use of digital technology and artificial intelligence in the field of mental health is currently widespread: from wellbeing and meditation apps, to digital talking therapies and counselling services (the use of which for instance is currently spreading, due to the increased anxiety generated by the Coronavirus pandemic). ‘Digital psychiatry’ is now commonly used to describe technologies that use artificial intelligence ‘to infer, with varying degrees of reliability and validity, whether an individual is suffering from depression, anxiety, autism spectrum disorder, post-traumatic stress disorder, and suicidal ideation.’ (Burr et al. 2020).

Similar to other fields of public service delivery, in healthcare data have acquired a prominent position through what Stevens et al. (2018) call the ‘semantic reality’ built through the dissemination of positive discourses around the AI, always depicted as key to ensure better, faster and more efficient delivery. But critical accounts regarding the use of data also started emerging through the work of scholars mainly coming from Science and Technology Studies. These accounts, acknowledging the complexity of data security and data justice, denounce the potential risks of introducing AI in public services and particularly in healthcare services. As the UK House of Lords Select Committee document on the use of Artificial intelligence reminds us ‘The NHS holds data on nearly everyone in the UK; some of it going back decades.’ (2017). Not much needs to be added to give us an impression of the scale of the risks the system is facing.

Issues with the datafication of mental health service through digital health are varied and all linked to the broader discourses on data justice (Taylor 2017), which highlight the risks of digital tools used in public services, as citizens using these services are made visible, represented and treated differently as a result of their digital activities and records. We could mention the issue of *intelligibility*, as decision-making processes through algorithms can be very opaque (both in the way these are designed and in the way they are actually implemented and they take decisions in practice); but also the question of stigma, as data inform how people with mental health are seen and described through the process of labelling them for the purpose of creating digital categories. The question of stigma and discrimination has been traditionally central in UK mental health services, where *community-based* mental health provision was introduced with the wider ambition and mission – together with providing services in the community – of fighting stigma and discrimination and promoting broader societal change to ensure mental health is viewed, talked and treated differently in the wider society (Sangiorgi et al. 2019). This mission risks not only being *lost in translation* through the digitalization process but being exacerbated if AI and predictive analytics in digital health care are not deployed carefully. Finally, a data-based approach to mental health services risks to undermine the holistic and systemic approach that is very much needed in this area of healthcare (Sangiorgi et al. 2019), as a single app or digital platform becomes the only point of reference to infer from existing data the diagnosis and the possible treatment.

## ‘Practicing’ Digital Sovereignty

Understanding digital sovereignty from a democratic self-determination point of view (according to categorizations by Thiel 2019) means looking at the concept/term as a citizen’s right to be claimed



and a process constantly in the making, as a condition of the ability to critically partake in the digital transformation. The latter requires profound and well-informed public conversations and debates around the main three pillars of digital sovereignty technology, regulation and digital literacy, as they have been proposed by the German Consumer Affairs Council (2017). Hereby, one main field of design practice related to mental healthcare is to foster discussion and negotiation about the ways in which digital technologies reconfigure our daily lives as well as health services – in order to achieve a balanced view of the effects of digitalization in healthcare, as also required by the Expert Panel on effective ways of investing in Health (EU Commission 2019, 8). Especially in line with the systemic approach that is very much needed in the area of mental healthcare, as mentioned above, informed and broader conversations, public negotiations and deliberation processes that include actors beyond those being explicitly involved in the field of mental healthcare are a key factor for democratic self-determination and empowerment within this area. Countering a deterministic technology-driven perspective on digital health, the practice of digital sovereignty as a design practice should take into account the rights as well as skillsets people need to understand and control their data, as a main aspect of their digital literacy. The underlying understanding of this political design practice is deeply rooted in Dewey's political philosophy and his concept of democracy: *'Democracy is a way of personal life controlled not merely by faith in human nature in general but by faith in the capacity of human beings for intelligent judgment and action if proper conditions are furnished'* (Dewey 1939, 2). In order to be understood and lived, according to Dewey democratic values have to be experienced, by individuals and collectives alike. Furthermore, practicing sovereignty relates to the *capability approach* as pioneered by Amartya Sen in the 1980s, where the focus is on what people are effectively able to do, as an expression of their freedom and agency. How we understand and frame freedom and *'the set of valuable functionings that a person has to possess which represents the effective freedom of an individual to choose between different functionings and combinations'* (Saigaran et al. 2015, 191) shape the kinds of policies that are made and the reality in which we live.

Against this backdrop, we understand digital literacy as one that not only stresses competent navigation through the digital world but embraces the dimension of steering and designing processes of digitalization – as a form of critical, socio-political embedded digital literacy, that might also counter the risks and the challenges individuals face when coping with the digital realm. Especially with regard to digital inequalities, a critical digital literacy is needed to adequately address key issues of participation and to address the growing digital divide at all levels, as summarized by Massimo Ragnedda (2018). While the first and second level of digital divide address inequalities in access and use of the Internet, the third level of digital divide (van Deursen and Helsper 2015) refers to the tangible outcomes generated online that are also of social value (Ragnedda 2018, 2366). As a way to analyse the phenomenon of digital divide, Ragnedda correlates digital inequalities to the digital capital and its interrelations with 'social, economic, personal, political and cultural capitals', defining the digital capital as 'the accumulation of digital competencies (information, communication, safety, content-creation and problem-solving), and digital technology' (Ragnedda 2018, 2367). At the basis of this analysis lies the insight that social inequalities influence the increase of digital inequalities (Helsper and Eynon 2013). Ragnedda's analysis shows that skills and knowledge as well as the socio-cultural and socio-political backgrounds determine the way individuals are able to transform their digital experience into social outcome:

‘It is not only knowledge, digital skills and motivation, but also the capacities and possibilities to use the digital capital as a currency to obtain other resources that can improve individual’s life chances. In a digitally-enabled society it becomes crucial to be able not only to physically access, but also to move confidently in the digital arena and get the most out of it.’ (2018, 2373)

In order to improve digital literacies as one of the main pillars of digital sovereignty, broader analyses of the impact of informed and confident usage of ICT within the healthcare sector and the interrelations between the new digital capital and the outcomes for individuals involved in mental care are needed – not only from a data collection and data security perspective, but from a democratic self-determination point of view.

## Open questions for Design in Digital Healthcare

In this paper we wanted to open a series of ethical questions that we believe design should address when it is deployed in the field of digital healthcare. Once we frame the question of digital health as a question of practicing digital sovereignty, as this paper is suggesting, a new role for design emerges which aims to support democratic self-determination and empowerment, whilst countering a deterministic technology-driven perspective. Practicing design as a way of practicing digital sovereignty also means taking into account the skill-sets people need to understand and control their data, as a main aspect of their digital literacy.

As the healthcare sector is characterized by a multiplicity of players with varying interests (from healthcare providers, patients and families, insurers and researchers who are directly involved in clinical practice), designing transparent digital systems that are less vulnerable for discrimination and misuse of data becomes a key concern for designers. On the other hand, ways of designing for digital participation and inclusion are also needed, as digital sovereignty requires a constant deliberative process which involves re-negotiation of rights, assessments of risks, opportunities and capabilities. The value of looking at design in digital healthcare through a digital sovereignty lens therefore includes moving at the forefront of design’s concerns ethical issues of data justice, digital literacy and digital inequalities.

In sharing our open questions on the role of design in digital healthcare, we could not avoid considering some new reflections based on what has been happening in different countries as a result of the Coronavirus pandemic, and the role that data and digital devices have played in this context as we write. These times of emergency have in fact brought many governments in Europe to re-think the use of personal digital data for the purpose of better monitoring and controlling the population, and consequently the spread of the virus. We believe even in these times of emergency, the question should not be posed in dichotomic terms, like citizens had to make a choice between the right to privacy and informational self-determination on one hand, or the efficiency of public health on the other. Both could (and should) in fact be cared for without the need of giving up our digital sovereignty. But of course the COVID19 emergency has affected the debate on digital sovereignty in interesting and profound ways: it has increased the public awareness and participation on this topic; it has moved us to rethink the debate beyond easy ideological standpoints; it has also demonstrated at the same time the fragility and the strategic importance of our digital infrastructures. Finally, as nurses and doctors are celebrated as heroes around the world,

the current emergency has reminded us all of the importance of investing in a strong healthcare system and its analogic components. Digital healthcare developments – like for instance the massive introduction of AI – are high-resources investments, which require funding to be diverted from the State and distributed among private contractors that design and develop the digital infrastructures that the welfare and healthcare system use. In the current times, perhaps a new awareness is taking shape which rethinks and acknowledges the positive role of the state (Mazzucato 2013) as well as the importance of those front-line services and staff, which have proved to be so crucial right now.

Even if it might be too early to advance any conclusion on how issues of digital sovereignty will be affected by the present crisis, what is for sure is that concerns around digital ethics are growing both in the academic and practice field (Peters et al. 2020) and that designers will have to decide what role to play in translating the ethical theory and principles into context specific and ethical digital practices and devices.

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# Are agile design approaches useful in designing for health? A case study

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**ABSTRACT** *When designing interventions for health, multidisciplinary teams increasingly work according to an ‘agile’ process. Potential benefits of this approach are better knowledge transfer, stakeholder inclusion, and removal of barriers to interactions. Unfortunately, the question whether agile approaches are useful in designing health interventions remains as yet unanswered.*

*To contribute to current knowledge, we analysed the process and results of a large multidisciplinary project with an agile approach. Our case study shows such an approach may indeed be a feasible method for the development of health interventions. The process allowed for a high pace, and good stakeholder inclusion. Some limitations also occurred. The agile approach favours speed over rigour, which hinders integration of user research and scientific evidence in the development process. Multidisciplinary cooperation remains difficult because of the limited availability of experts and stakeholders. Finally, the difficulties in documenting the process and results of the agile approach limit its use in scientific projects.*

**Keywords:** intervention development, agile, design methods, case study

## Introduction

The development of (digital) interventions for behaviour change is increasingly a multidisciplinary process, in which design (thinking) plays a significant role (Ferreira et al., 2015; Bazzano et al., 2017). Essential for successful collaboration between creatives (design[research]ers, human-computer interaction specialists), (para)medical and behavioural scientists, health care professionals, and patients, is a shared vision of what constitutes value, expressed in a shared methodology for intervention development (Hermesen, Renes, Mulder, and Van der Lugt, 2016). Unfortunately, medical and behavioural scientists on the one hand, and design and HCI researchers and professionals on the other, more often than not use fundamentally different methodologies (Mann, Kuppim Chokshi, and Kushniruk, 2018). The former generally use linear, theory-driven approaches (e.g. intervention mapping; Bartholomew, Parcel, and Kok, 1998, Behaviour Change Wheel; Michie, Van Straalen, and West, 2011), which rely on well-defined processes, evidence-based tools, rigorous documentation, and pre-set rules and plans. The latter increasingly use *agile* approaches (Beck et al., 2001) such as Kanban, Scrum, Google Design Sprint, Xtreme Programming, etc. Agile approaches favour individuals and interactions over processes and tools, working interventions over comprehensive documentation, stakeholder participation over clear rules, and responsiveness over pre-contemplated plans (ibidem).

Health intervention development could very well benefit from incorporating agile principles (Hekler et al., 2016). Unfortunately, the question whether agile approaches are useful in the development of health interventions remains as yet mostly unanswered; what literature exists from adjacent fields shows potential benefits, but also limitations of agile approaches. Potential advantages are horizontal – rather than hierarchical – knowledge transfer, inclusion of all stakeholders in the development process and removal of barriers to interactions (Beck et al., 2001). Potential disadvantages are problems in integrating user research and scientific theory and evidence in the development process (Ten Klooster, Noordzij and Kelders, 2020, Ploos van Amstel et al., 2017); limitations in reaching shared understanding (Ten Klooster, Noordzij and Kelders, 2020; Ploos van Amstel et al., 2017); no possibilities for testing assumptions because of high pace (Peters, 2019); and a lack of transfer of knowledge through limited documentation (Salah, Paige, and Cairns, 2011).

More knowledge of the efficacy of agile approaches for designing health interventions can help researchers and practitioners from different fields develop a shared methodology and avoid potential pitfalls. Building this knowledge starts with explorative research such as case studies, from which experimental hypotheses can be derived. The current paper provides one such case study; it describes and analyses the process and results of a large project aimed at developing interventions for paediatric physiotherapists (PPTs) to support children with physical disabilities in active play and sports participation. In this case study, we test the hypotheses that 1) an agile approach leads to useful and usable prototypes, based on insights from evidence and user research; 2) the agile approach helps include all stakeholders and fosters good interactions between them; 3) the agile approach benefits multidisciplinary cooperation, and leads to good knowledge transfer between participating disciplines.

## Method

To shed light on whether using agile approaches had a beneficial effect on the development of interventions for PPTs to support children with physical disabilities in active play and sports participation, the authors of this paper collected and analysed the available data from the project: sprint reports, reflective journals (Thorpe, 2004) in which the sprint team collected their experiences and thoughts on the development process, and photos and film clips of sprint activities. All authors took part in a triangulation session with available members of the sprint team, in which we shared our findings and elaborated on them.

## The case study

In this case study, a multidisciplinary team developed a toolkit for paediatric physical therapists (PPTs) to stimulate physical activity in everyday life settings of 6–12yo children with physical disabilities. The team consisted of behavioural scientists, health scientists, paediatric physiotherapists, designers from a design agency, and design researchers, with regular input from parents and children in the design process. The core sprint team contained two PPTs, two behavioural scientists, two designers, a design researcher, and a social worker.

The development process consisted of four one-week periods ('sprints'), following the rules and set-up of the Google Design Sprint (Sari and Tedjasaputra, 2017) approach: a five-day process for answering critical development questions through design, prototyping, and testing ideas with stakeholders. The goal of each sprint was to quickly develop feasible prototypes based on insights from evidence and user testing, with maximum attention to stakeholder participation. In the first two sprints, the team designed practical tools for use in physiotherapeutic practice; in the third and fourth sprint, the team designed a concept for a digital solution that enables PPTs to connect with social workers for sports participation.

Each sprint was preceded by a preparatory phase in which the team collected insights from literature and practice to inform the design sprint. Based on these insights, they prepared a start-up co-creation session. This session took place directly before the sprint and relevant stakeholders such as parents, PPTs and others took part. During the cocreation-sessions, the sprint team evaluated whether insights from literature and previous user research resonated with the available stakeholders: did they agree with the insights? Could they relate these to their own (professional) experience? What wishes, dreams and barriers for potential intervention themes transpired?

Working from these results, the design team then started the sprint week proper. On the first sprint day, the team went through a divergent phase in which they collected and mapped all available knowledge in mapping sessions, user journeys and personas, and reformulated the initial research questions into sub-questions based on the mapped knowledge. If necessary, the team performed further user research on this day, for instance by performing in-depth interviews with experts and stakeholders. The second sprint day focused on converging activities, by selecting emergent themes from the data gathered on day one. On the third sprint day, the team worked on turning these themes into intervention prototypes, by generating ideas using brainstorming techniques, and further elaborating on the ideas using guiding principles and tools to incorporate insights from the behavioural sciences in the design process. On day 4, the designers in the core team developed the



prototypes proposed on day 3. Each sprint finished on day 5, with a demonstration lunch in which the sprint team presented the prototypes to all available stakeholders, and a reflective session in which the core sprint team and other project members evaluated the sprint week. Appendix 1 provides a complete overview of the first sprint week as an example.



Figure 1: Showing connections: start-up activity for a co-creating session at the beginning of a design sprint week

## Results and Discussion

The design team in this case study managed to end each one-week sprint with prototypes that received positive evaluations from stakeholders. This provides a first indication of proof for the hypothesis that agile approaches are useful in designing health interventions: they lead to useful and usable prototypes which can then serve as materials for testing the underlying change mechanisms in experimental or real-life settings.

The high pace and restricted time frame of a one-week sprint leave no room for this testing of assumed change mechanisms, nor of intervention feasibility or intervention efficacy. In this project, therefore, feasibility and efficacy testing took place after finishing the agile project, in a field lab setting which informs further iterations of the prototypes. This combination of agile development and field lab-based testing proved fruitful in maintaining a balance between speed and rigour, one of the known pitfalls of agile approaches. An example is the development of the Photoframe tool (see figure 2), meant as a probe to see what happens when children take a picture of their abilities in



therapy settings and show them to their PE teachers (who are often unwilling to let children with disabilities participate). Positive response led to its addition to the toolkit without further iterations. Pilot testing then showed that this intervention was in fact impractical because of its size and vulnerability. In later versions of the toolkit, a film clapboard will replace the Photoframe – as it is more practical, and it also invites making short films instead of static photos. These later versions of the toolkit will, once again, be tested for efficacy in field lab-settings.



Figure 2: Photoframe prototype. PPTs can use this to inform other physical activity professionals such as PE teachers of children's new skills

The second part of the first hypothesis states that agile approaches are useful in using insights from evidence and user research to build prototypes. In this project, the design team attempted to safeguard the integration of behavioural scientific and systemic insights by having experts from these fields on the team and by using design tools specifically aimed at integrating these insights into design processes. This went well as long as three conditions were fulfilled: the availability of the experts, the availability of well-developed and usable design tools, and (adherence to) a well-defined approach for integrating the insights in the development process. Experts need to be approached long before the sprint starts, but the unpredictable nature of sprints makes it difficult to know when experts are needed. In the case study, this sometimes resulted in experts being available when there were no questions for them to answer, and vice versa. Design tools need to be available and the sprint team needs to familiarize themselves with working with them before the sprint starts (cf. Van Essen et al., 2020 for an evaluation of the use of design tools in this case study). To make the best

use of both experts and tools, a pre-defined structured overview of sprint activities is necessary. The challenge then lies in keeping a balance between adhering to this pre-set schedule and remaining flexible.

Our second hypothesis states that the agile approach helps include all stakeholders and fosters good interactions between them. This case study shows once again that one of agile's strong points is stakeholder inclusion. The co-creation sessions, in which the sprint team tested important insights from literature and user research with stakeholders proved especially powerful in that respect. They delivered rich knowledge to inform the development of the intervention prototypes.

The third hypothesis states that the agile approach benefits multidisciplinary cooperation and leads to good knowledge transfer between participating disciplines. This multidisciplinary cooperation, however, remained an issue throughout the project. Non-academic designers in the team, used to full-time one-week sprints, had difficulty coming to terms with the realities of Dutch academic life and working in the health sector. Neither academics (design researchers, behavioural scientists) nor health professionals (physiotherapists) were available for a full five days at any moment, no matter how careful the planning process. The Dutch practice of working part-time was one of the reasons, and also the immensely busy schedule of many of the researchers and health professionals, which did not allow taking an entire week off other responsibilities. This, combined with the aforementioned unpredictability of the sprint process, forced the team to change from the initial plan of having a multidisciplinary team with all specialities aboard, to a more traditional setup in which a core design team of designers and design researchers worked continuously, bringing in experts when they were needed. But even that proved hard from time to time; the sprint team attempted to solve this by leaving out Mondays and have only the core team designers and design researchers work on Friday. This hindered project continuity and shared understanding, two of the alleged strong points of the agile approach. A solution may lie in slowing down the pace of the sprints.

Finally, the design team found that challenges occurred in documenting the proceedings of the sprints. Even though the sprint team had planned to keep detailed reflective journals, time pressure proved this to be difficult. This lack of documentation threatens transferability of insights in any project but is especially problematic in using agile approaches in scientific research, where rigorous reporting is essential. A solution may lie in appointing a team member with the sole task of collecting data, reporting, and planning ample time for joint reporting and reflection.

## Conclusion

The current paper reports a case study in which a multidisciplinary team used an agile approach to develop a toolkit for paediatric physical therapists (PPTs) to stimulate physical activity in everyday life settings of children with physical disabilities. The study shows that an agile approach is successful in delivering a range of prototypes for interventions. Furthermore, the approach helped in bringing on board all stakeholders.

However, some limitations of the approach transpired. Firstly, it is important to keep in mind that verifying feasibility and efficacy is not possible within the boundaries of the sprints. This may be solved by combining sprints with periods of real-life testing in field labs. Secondly, the case study

showed that it is important to strike a balance between speed and rigour; high pace may especially hinder the integration of user research and scientific evidence in the development process. Thirdly, multidisciplinary cooperation remains difficult because of the limited availability of experts and stakeholders. This hinders both continuity and shared understanding. Finally, if not dealt with, the difficulties in documenting the process and results of the agile approach limit its use in scientific projects.

All in all, this case study gives reason to hypothesise that agile approaches are useful in designing interventions for health, as long as the above-mentioned known limitations are taken into account. This can be done by combining agile (sprint) approaches for development with non-agile experimental or real-life testing of assumptions, feasibility, and efficacy; safeguarding the integration of insights and evidence from science and user testing by including experts on the team, using well-developed and well-known design tools, and adhering to a predefined development process; slowing down the pace of the sprint to generate a workload that fits the schedule of team members from non-design disciplines; and making sure there is ample time for reflection and documenting. Further (experimental) research can test this hypothesis.

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## Appendix 1: Overview of Sprint Week 1

### Day 0 (pre-sprint)

*Co-creation session with PPTs, (behavioural) researchers, designers, parents, education scientists, social workers.*

Central question: how can we support children with physical disabilities and their parents, in that they can take part in daily physical activity in society?

Session was informed by a range of interviews with PPTs, social workers, parents, and children. Participants received a homework assignment: map the opportunities and threats you see from your experience.

During the session, these insights were transformed into main themes for the project. Furthermore the participants developed a range of personas [1]: typical children, parents, social workers, PPTs.

### Day 1 (Tuesday)

*Diverging design activities:* gathering, mapping, and analysing all insights onto a Research Wall [2] in an interpretation session. Then the design team translated the main themes into How Might We-statements [3]: trigger questions that make actionable design ideas possible.

An expert in education then gave a lecture on how to support children in mastering new, insecure tasks whilst taking care of their psychological safety. This session inspired the designers to redefine the main theme for the sprint to 'How might we support the PPT in their therapy, in such a way that they can create a safe insecurity in all stakeholders?'

The design team then decided that they needed further in-depth interviews with two PPTs and a parent, and mapped these new insights onto the Research Wall. All insights were then brought together in a User Journey [4].

### Day 2 (Wednesday)

*Converging design activities:* redefining the How Might We (HMW)-statements from day one so that they reflected the sprint's new main theme around safe insecurity.

The design team then vote on the most relevant How Might We-statements. Selecting the following statements: HMW let children come up with their own solutions, even if they are not perfect? HMW enhance creative solution searching in all stakeholders? HMW involve the social environment? HMW give parents confidence to let their children go more?

Team members then gave short pitches with inspiration from other, similar projects. The design team concluded the day with Crazy 8s [5], a fast sketching exercise that challenges people to sketch eight distinct ideas in eight minutes.

### Day 3 (Thursday)

*From ideation to prototyping: developing and selecting intervention ideas*

The day started with another round of Crazy 8s. The design team then pitched their ideas to one another, and further developed the ideas. They then voted for the most relevant ideas, using guiding principles (fun, equality (between child, parent, PPT), accessibility, support, positivity) and prerequisites (financial feasibility, easy to transport, fitting treatment practice).

The design team then looked which idea answered which HMW, and used the behavioural lenses to further evaluate the ideas. All this led to the selection of four ideas to be developed into prototypes:

- 1) 'A day', a diary tool for children and parents to map helping and overhelping by parents
- 2) 'Fears, Dreams, Actions' card set for PPTs to facilitate conversations
- 3) Dice with tips for children to help them think of their own solutions for challenges
- 4) A plexiglass pane to encourage parents to take an observing role rather than a helping one

### Day 4 (Friday)

*Prototype development* by two designers from the design team

### Day 5 (Tuesday)

*Presenting the prototypes and reflection*

During a lunch meeting, the design team presented the four final prototypes and the design process to all stakeholders who contributed to the sprint week and the preparatory co-design session. Everybody then had the opportunity to give feedback on the prototypes.

In the afternoon, the design team reflected on this feedback, and planned further development of the prototypes for evaluation in field labs. Then, the design team evaluated the sprint week and made a start with formulating HMW statements for the next sprint week.

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# Beyond Science Communication: a service design approach to building mutual stakeholder understanding in the development of novel biotechnologies

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*Traditionally, designers communicated from one knowledge area to another largely through graphics, using conventional linear models where information is provided in a unidirectional flow from the experts (who know) to non-experts (who don't know). This is problematic because the communication is based on experts' assumptions about the 'audience' and does not necessarily understand or address audiences' actual concerns and existing knowledge or enable audiences to interact with the knowledge. Additionally, when we consider the distinct forms of knowledge, such as scientific - explicit codified elements, and tacit - informal processes and experience based on know-how - we need to find ways to reconcile knowledge-sharing between them. To counter this top-down and passive approach to communication, designers have a role in shaping knowledge sharing between the scientific and tacit by involving diverse stakeholders in action-orientated activities that are characterized by social interaction. Drawing on early findings and insights from design researchers working in the public engagement work package of Pharma Factory, an EU H2020 pharmaceutical biotechnology innovation project, this paper argues for a service design approach to healthcare communication, taking into account multiple stakeholder perspectives in knowledge co-creation and interpretation. The value of a more democratic, open and bidirectional approach to healthcare communication and 'public engagement' is considered, along with challenges and limitations.*

Keywords: service design, co-design, biotechnology, mutual understanding, multidisciplinary

## Introduction

Multidisciplinary working has, in recent years, become a desirable feature of science & technology projects funded by the European Commission's Horizon 2020 programme. In particular the inclusion of 'social sciences and humanities' has been cited as being particularly important (FET Advisory Group 2016). This has provided design researchers with the opportunity to work in H2020 projects, such as the Pharma Factory project, where previously their value would not have been considered. While the FET Advisory Group warns against paying 'lip service' to the inclusion of other disciplines, the challenge of describing the value of design research for such projects remains significant. Within biological sciences the traditional role of design might be to support science communication through graphics and exhibition design (Burns et al 2003); with a move towards increasing democratic ways of involving the public in open dialogue around technological developments (Irwin, 2006), design can interactively and collaboratively engage in co-producing knowledge for new technological futures.

Design's role as a process-orientated and facilitatory set of practices is still relatively new and unfamiliar with disciplines such as the biosciences; design, with its naturally human-centred mindset and creative practices, is still often conceived as focused on translating the complexities of codified knowledge into digestible and entertaining forms. In these situations, designers might adopt 'tricky tactics', being invited into the fold on the premise of established ideas of designs' contribution, before prompting, provoking, adapting and reframing that contribution in response to presented situations, adding value beyond what was anticipated (Fisher & Gamman 2018).

Pharma Factory focuses on four novel pharmaceutical technologies being developed using Plant Molecular Farming (PMF), a) an enzyme for treating Lysosomal Storage Disorders (LSDs), b) an edible vaccine for farmed fish, c) a molecule for treating HIV and, d) a diagnostic kit for Sjögren's Syndrome or Rheumatoid Arthritis. Each technologies development sits within a specific work package and is located at different stages of research and development. Two strategic work packages straddle the technologies, focusing on public engagement and regulatory pathways. A team of design researchers from University of the Arts London, collaborating with social scientists from St George's University of London were tasked with the public engagement package. Applying service design principles and co-design methods the team aim to understand opportunities and challenge barriers and for public acceptance of these new pharmaceutical technologies.

Service design is established in healthcare settings in Europe (Springham & Robert 2015, Bailey et al. 2019) and in the global south (Tseklevs et al. 2019), to address public health issues, involving multiple stakeholders in co-design processes to innovate and deliver new and improved services for a range of health and social care contexts. Less common is the application of service design at the very front end of biomedical research such as the Pharma Factory project. The adaptability of co-design tools and methods makes them ideally suited to this challenge, as they seek to avoid assumptions and first understand a person's experience, then to enable that person to co-design an alternative future (Sanders & Stappers 2008).

Whereas service design is most often used to design services (with or without a product focus), this research focuses on adapting these methods to facilitate the co-creation of knowledge, enabling mutual understanding of the value of novel technologies between stakeholders and scientists. In this frame the 'service' element is a co-created shared understanding of the value of that technology at

different points of the stakeholder's current and future experience (Akoglu & Dankl 2019; Sanders & Stappers 2008).

The purpose of this research approach for Pharma Factory is twofold:

1. to understand the value of the technologies afforded by PMF to a range of stakeholders.
2. to understand the perception of genetically modified (GM) plants when used within the context of pharmaceuticals, providing potential narratives and language that could be used to challenge (assumed) barriers to acceptance.

## Beyond science communication

Science communication - or 'the deficit approach' (Bubela et al. 2009) - can be understood as the unidirectional flow of information from scientific knowledge domains to lay audiences to fill apparent gaps in understanding. Often this includes assumptions about what those audiences want or need to know, and what they already know. Science communication has evolved to some extent to include 'audience research' but in doing so there is the additional risk of promising too much in order to engage and entertain those audiences (Bubela et al. 2009). Once an understanding of an audience's values or expectations of emerging biotechnologies has been achieved, there is an ethical responsibility to ensure that the communication 'frame' doesn't obscure the specificities of the science, which can damage trust. These shortfalls have been recognized within the field of biotechnology with authors calling for greater focus on 'dialogue' with lay people (Bubela et al. 2009; Burns et al 2003). While multidisciplinary is seen as essential in contemporary critiques of science communication (Fischhoff 2013), the value of design has not been considered in this context.

A service design approach using co-design tools and methods can help to address these challenges of 'science communication', as it goes beyond 'audience research' to involve the participants in validating co-created artifacts, and in subsequent design of artefacts and events informed by the resulting co-created knowledge (Chamberlain & Partridge 2017). As a methodology distinctly different from the biosciences and social sciences, design research arguably provides something fundamental that science communication has been missing. Being flexible, problem-oriented and empathic, co-design provides designers with the tools to build a bridge between the highly specific, but abstract science with its codified language, and the values of specific stakeholders or wider audiences. By revealing hidden values and providing narratives or 'frames' (Burns et al 2003) it makes the science empathic and relatable to wider audiences. Furthermore, co-design provides the means to build that knowledge through an iterative, guided process. In this way the methods and tools challenge assumptions and reveal deep-seated value systems through participatory research activities.

In Pharma Factory, the research process involves co-designing first with the scientists, then with stakeholder groups, feeding back to the scientists and then communicating with wider audiences (fig. 1). Akoglu & Dankl (2019) argue that mutual learning and understanding are a central outcome of a co-creation design research approach, building empathy amongst stakeholders. This makes co-design well-suited to the challenges of communication in healthcare where new technologies are



highly specific, and their production and use impact particular groups of people with non-standard needs and values.

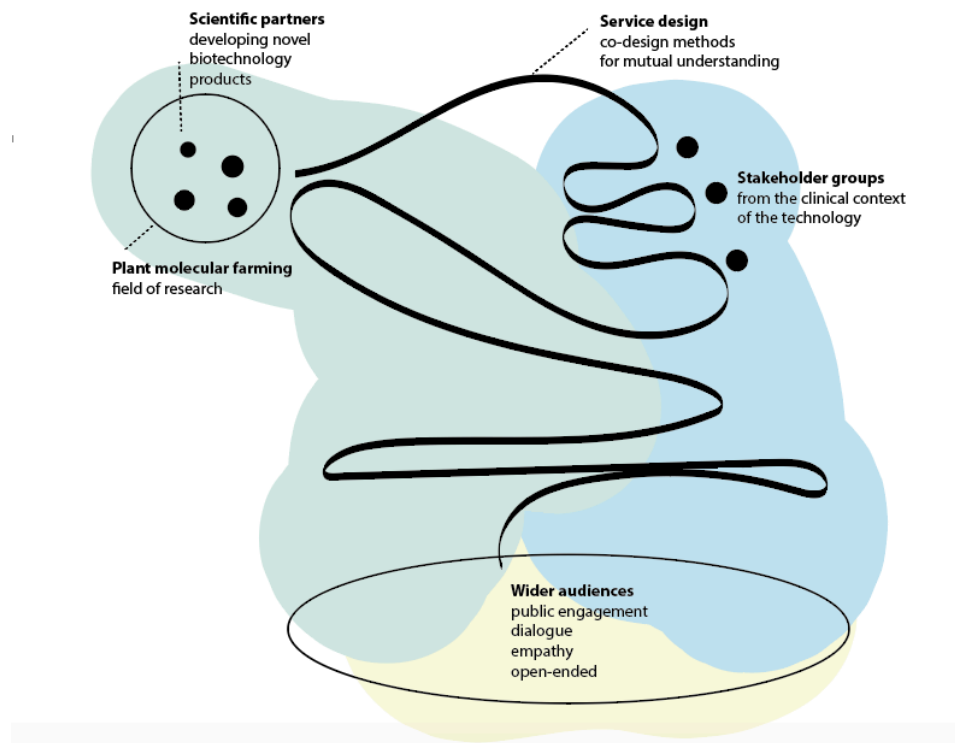


Figure 1: Service design research process pathway in Pharma Factory

## Methodology

This project uses a service design approach with co-design tools and methods - some adapted from standard tools, and others contextually designed (Chamberlain & Partridge 2017). The approach of the design facilitation was in the spirit of emergent practice as described by Aguirre et al (2017) which relates to a 'research by design' methodology: "designers fly in complex patterns—they act as both participants and facilitators. In the latter role, they must foster participant interactions that generate emergent material. Such emergence is "brought into existence by the way a whole [event] is bound together by substance and order through relationships and connections." (Aguirre et al 2017:199). In the current project mutual understanding can be considered the 'emergent material', afforded through revealing hidden values and challenging assumptions, in turn leading to translation and bridge-building between biotechnology, stakeholders and wider audiences, as described earlier.

The design research team first designed and delivered co-design workshops with the scientific partners to identify and understand the stakeholders connected to the novel technologies and to explore scientists' assumptions about the value of their technology to them. After analysis and sensemaking phases, the design researchers sought to engage a range of stakeholders, designing and developing workshops for each group recruited. Currently, the design researchers are recruiting, designing and conducting this 'stakeholder engagement' phase of the research. Early findings presented relate to the first of these stakeholder workshops conducted in February 2020. As described earlier, once complete the findings of the engagement will be reported back to the

scientific partners and the European Commission to inform their ongoing work, as well as providing valuable insights to inform public engagement activities, including interactive exhibitions and pop-up events within the timeframe of the Pharma Factory project.

As the research is ongoing and there are limitations in reporting the full findings at this stage, this paper reflects on one of the four technologies - the production of a molecule to be used in the treatment of Lysosomal Storage Disorders (LSDs) - and the discussions that took place in a workshop with 8 specialist Pharmacists. The aim here is to discuss how a service design approach may have contributed to original insights and understanding of stakeholders' perceptions and values, and how this supports the production of mutual understanding.

## A short case summary

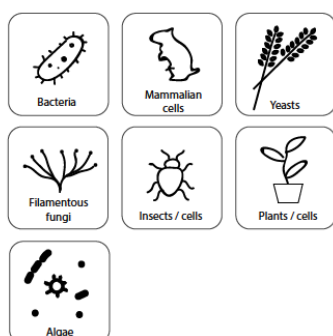
This case summary reflects briefly on the first Stakeholder Workshop conducted within the Pharma Factory project with Pharmacists as described above.

A 'Project Glossary' was co-designed, to enable the translation of some of the codified scientific language and key concepts into narrative tools, so that workshop participants could easily engage with the technology (fig. 2).

### 1. How are medical proteins produced?

Modern medicine increasingly involves using proteins, peptides and other small molecules to treat a variety of medical conditions.

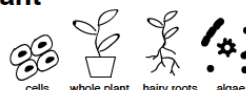
Industrial protein production typically involves engineering cells from an existing organism to produce large quantities of proteins, enzymes and peptides for medical and other biotechnology products. The following organisms, or cells derived from these, have been engineered to express proteins for pharmaceuticals:



Pharma Factory

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 101019719.

### 2. What is Plant Molecular Farming?



Plant Molecular Farming (PMF) is one type of recombinant protein expression system where plant cells are used to produce proteins, peptides and small molecules.

- The process involves introducing recombinant (genetically modified) DNA into a plant to 'tell' the plant to produce a protein of interest, this either temporarily or permanently alters the plant's genome.
- The production typically takes place in a 'contained' manufacturing unit, which prevents accidental release of genetically engineered organisms and also protects the product from external factors.
- Waste plant material is disposed of in an autoclave, using heat and pressure to destroy genetic material.
- The production process is regulated in the same way as other types of pharmaceutical production under a license for Good Manufacturing Practice (GMP).

Pharma Factory

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 101019719.

Figure 2: Biotech concepts and terms were translated into narrative workshop tools

During the first activity in the stakeholder workshop - an ecosystem map - pharmacists revealed an interesting micro-network of stakeholders involved in treatment provision for LSD patients. During the task pharmacists were encouraged to think about who they interact with during their work with these particular patients. Design facilitators were then able to prompt additional questions iteratively, building detail incrementally, supported by worksheets for visual reference. Through this exercise the important roles of 'Prescribing Nurses', 'Specialist Nurses', 'Homecare Coordinator' and

‘Dietician’ were identified, which added detail to the ‘hospital’ as a general stakeholder. This challenges assumptions that pharmacists are the sole operators bridging between prescription (clinician) and treatment (patient) and are in fact part of a more complex network of actors (fig. 3).

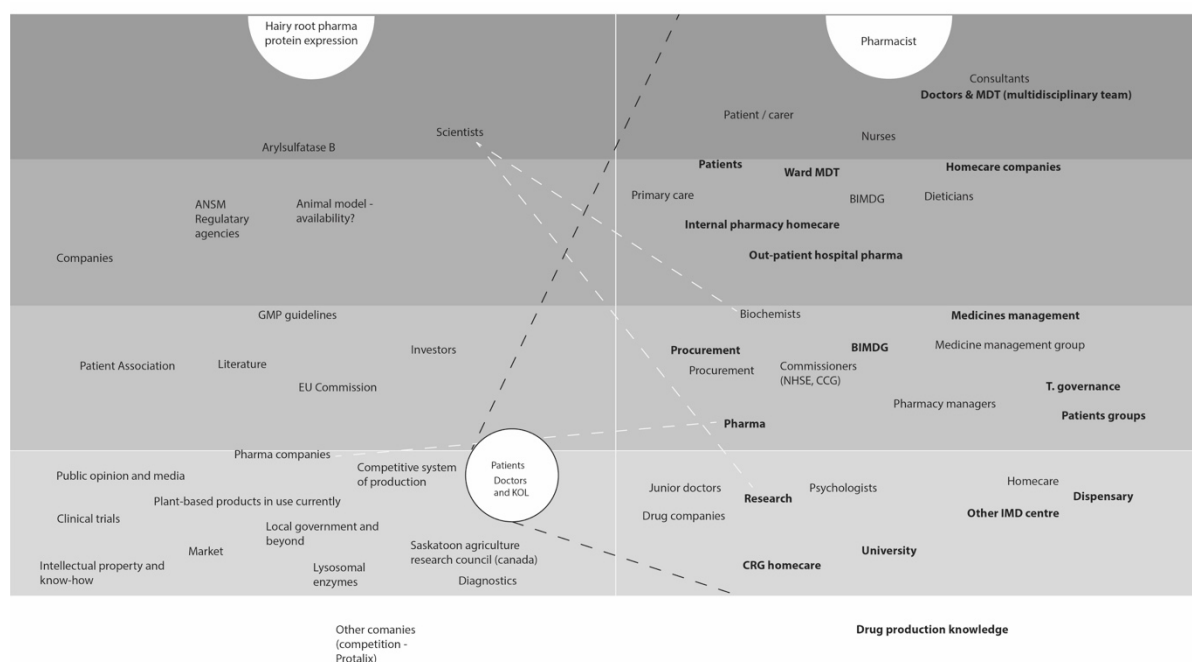


Figure 3: A visual comparison of the scientific partners' ecosystem map with the pharmacists' map, showing the expansion of 'hospital' into a more detailed network of actors.

In a subsequent activity the scientists were fairly accurate in their assessment of the value of their technology to patients and clinicians. They identified 'safety' and 'efficacy' as key values and this was echoed by pharmacists. However, the definition of 'efficacy' was seen as incredibly important to the pharmacists and how this translated into clinical impact. There were additional values that the scientists had overlooked such as 'ease of use' when administering the drug, and 'the novelty value' as patients seek to try new treatments to improve their condition.

The workshop also provided insights around terminology when engaging general audiences. For example, the term 'recombinant' was familiar to the participants and normalized in relation to pharmaceutical production, whereas 'GM' appeared to be rarely used or associated with pharmaceuticals. When participants were given information about PMF and the term 'GM' was introduced for the first time, they immediately switched to a more populist view of the implications, seeing that 'the media' could have both a positive and a negative role in how people perceive the new technology (fig 4). Interestingly, when focusing on the actual medication, whether it was produced by one method or another (for example, recombinant plant or mammalian cell, or chemical) was not a concern to the pharmacists, but as soon as they were encouraged to zoom out and think from the general perspective, they began to think about how the use of GM plants could cause concern to 'the public'. This raises the question of whether those who are not directly benefiting from the products would be more likely be concerned by the use of GM.

Speculative prototyping provided participants with the tools to address this challenge: what would they do to allay peoples' fears of the technology? Using their own experiences, they shared how they would reassure patients about the robustness of treatments, largely through established government-owned information platforms, regulation and standards (fig. 4).



Figure 4: Speculative prototyping: participants explored possible public perceptions of PMF (PNs on left) and discussed how they might allay peoples' fears (PN on right)

## How co-design affords mutual understanding

As discussed previously, service design takes a different approach to the central challenge of PMF - indeed any novel biotechnology - in enabling lay-understanding and acceptance, than conventional methods used by the sciences and social sciences. Central to this approach are co-design tools and methods which can reveal hidden values and enable dialogue between diverse stakeholders.

Although analysis and theory building is ongoing, the case summary provides preliminary evidence for how the approach has already laid foundations of building mutual understanding, by:

- challenging or adding detail to the assumptions of the technology developers, for example in expanding upon the stakeholder ecosystem of ‘the hospital’ and revealing important additional care and coordination roles in pharmaceutical provision;
- revealing the values of the technology to stakeholders which were hidden from the scientific partners prior to the workshop, for example the importance of ‘ease of use’ to the specialist nurses in particular and the ‘novelty’ of trying a new product for patients;
- translating and facilitating, in the workshop preparation - for example, translating the codified technology into understandable narratives around pharmaceutical production, and during the workshop - and by facilitating mindset shifts from the micro frame of the clinical context to the macro context of the populous view.

This paper aimed to demonstrate how design researchers can resist the conventional roles for design in service of ‘science communication’, by facilitating emergent solutions, not simply providing them (Fisher & Gamman 2018:215; Aguirre et al 2017) and creating open-ended co-designed interpretations of stakeholder experiences and values (Mattelmäki, Brandt & Vaajakallio 2011) in relation to novel biotechnologies.

The early results show that stakeholder engagement in healthcare is often challenging, opportunistic and therefore imperfect. However, service designers perhaps more than other fields of research, employ exploratory, sensemaking, co-design methods which can be adapted to the changing situation as it evolves and as the research scenario unfolds.

The value of our approach for the project is not only that we can communicate these insights back to the scientific partners, but also that it provides us with possible mechanisms or narratives for challenging peoples’ fears of the technology.

A shortcoming perhaps of this type of multi-disciplinary project is that there are limitations on design’s role and the subsequent research design. Invited into the fold, we - the design researchers - are not leading the show, we are guests and must tread carefully along the path of expected design roles. This poses challenges for the service design approach, particularly in a project that is organised on a science and technology innovation premise, defined by scientific conventions. However, we can be the ‘tricksters’ (Fisher & Gamman 2019) working with the co-design tools and methods at our disposal to reveal hidden value and meaning both of the technologies and of design’s role.

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# Co-design for wellbeing with mental health participants: from identifying a problem to creating prototypes.

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**ABSTRACT**     *The paper provides an overview of a co-design research project organized in collaboration with a mental health charity. Clients with mental health problems volunteered to help explore how engaging in design activities may impact them. Often adapted to respond promptly to the context, a series of workshops aimed to engage people with mental health problems in exploring matters of concern, defining issues and responding to these through design within a frame of layered participation. For 10 weeks, activities took place once a week for approximately 2 hours, although participants could drop in and out at any time. Four participants engaged quite consistently throughout the process, working with the researcher/facilitator. Under the general notion of co-designing for wellbeing, the project was organized around 5 stages, called 5 I's: Identify, Ideate, Invent, Initiate and Implement. The project concluded with interviews, and an event to showcase the process and design outcomes to others. The paper discusses the challenges and opportunities that emerged in the process and provides a short summary of participants' insights on their experiences. Their accounts variably suggested that the project helped with thinking, coping with loss or grief, reflecting on one's past, or adversely prompting hidden anxieties. The paper ends by discussing how this experience may help inform future projects within mental health and reflects on the potential role of co-design as an activity that promotes recovery in its own right.*

Keywords: mental health, co-design, methods.

## Introduction

This research is framed within the recovery movement which focuses on restoring functioning above and beyond symptom reduction, and recognizes the ability of people with mental health problems to participate in society (Davidson 2016). Mental health represents the highest burden of disease in many high-income Western European countries and comes fourth or fifth in some low-income countries. (Health Organization Regional Office for Europe 2015). Yet, research projects led by designers within mental health are scarce. Notably, Kettley, Sadkowska, and Lucas (2016) formalised a Person-Centred Approach (PCA) to co-design, Nakarada-Kordic et al. (2017) developed methods to engage young people with psychosis in the process of co-designing an app, Renedo-Illarregi (2018) explored the role of uncertainty in design engagements of people with mental health problems, and Renedo-Illarregi, Alexiou, and Zamenopoulos (2019) explored why designing may help people with psychosis. These conditions seem to present a good opportunity to further explore new ways to support recovery.

The main purpose of this project was to improve participant wellbeing by engaging participants in a design process. Based on informal feedback from previous projects, engagement with design seems to be different from art therapies commonly offered in mental health services. Not framing the workshops as a therapeutic intervention avoids skewed expectations and creates opportunities to inform theory directly from their experiences. Participant engagement was thus framed as an opportunity to 'simply design'. The thinking behind this was that any benefits on wellbeing emerged as a side effect of participants efforts to design, and not proposed as an outcome to investing in specific therapy or recovery.

## Method

As this research wanted to observe and better understand the experiences of participants within a relatively nascent subject of research, a case study method was selected. The research design was adapted from previous experiences developing a six-week co-design workshop (see [bidean.co.uk](http://bidean.co.uk)). This co-design project focussed on cooperation in which participants find synergies across their different interests, but work independently on their respective goals (Zamenopoulos and Alexiou, 2018). Still, other forms of co-design emerged and were encouraged when it was considered favourable for participant engagement (e.g. when participants preferred to adopt a supporting role). This research refers to such engagement as layered participation which aligns with the work of Kanstrup and Bertelsen (2018) who point to the designers' obligation to legitimize a mixture of investments in participation, including peripheral and low participation. Design opportunities are layered to encourage a variety of ways to engage.

After obtaining Open University Human Research and Ethics Committee approval (REF 3050), participants were recruited through flyers and posters shared with a mental health charity. Seven participants responded and met the inclusion criteria of having personal, first-hand experience with mental health problems. Information sheets and consent forms were distributed, and semi structured interviews were proposed at the end of the study. Four people participated throughout, three agreed to be interviewed, and one of them was also comfortable with a questionnaire.



The process was designed to accompany participants in exploring their interests and issues creatively, articulating a design challenge, and creating a prototype. They first expressed their challenges anonymously and explored them together as a way to inform design challenges. Next, they were encouraged to each work on design solutions with some degree of cooperation. The intention was to create opportunities for participants to generate design ideas for projects that will help themselves as well as others, thus investigating indirect beneficial effects on their own wellbeing (e.g. sense of giving). The process was guided by 5 I's - Identify, Ideate, Invent, Initiate and Implement. The case below focusses on the 4 I's, as Implementation takes place if resources for further development and production exist.

## Identify

At the beginning of the project, sessions helped participants familiarize with design notions and identify issues, which are often informed by participants' experiences. These are rearticulated as design challenges. Sessions began by familiarising participants with design notions.

In one activity called "Infinite why's ", participants sat in a circle, each wrote out an issue (often informed by personal experience) and placed it in a pot. The pot was stirred, and each person took a note. They read their note aloud, and asked the person next in the circle why?. This person had to invent a reason, then ask why? to the next person. This process is repeated until the circle is completed, then another note is read.

Another activity was the use of metaphors, like the tree (Figure 1). The main issue is written in the trunk with possible causes proposed as the roots, and consequences as the branches. Metaphors were perceived as a playful way to explore the complexity of some of the issues. It also involved an element of making which was used as a strategy to encourage participation from people who may not want to engage in the process via spoken language.

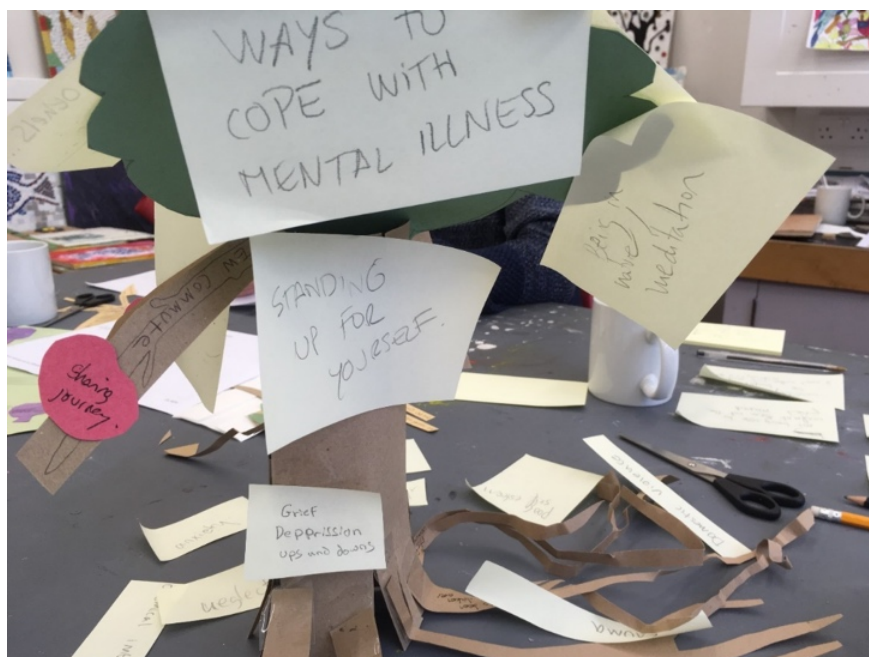


Figure 2. 'Tree' group activity to analyse how problems relate to one another.

Overall, the step Identify aimed to facilitate the externalization of problems anonymously (e.g. Infinite why's activity) and shift the focus from participants' personal experiences to potential users' experiences; or from my problems to ours. This helped participants look at issues from a different perspective and become aware of how problems are often shared with others. According to Williams, Almeida, and Knyahnytska (2015) contributing or giving back to the community appear as a consistent component of recovery. Therefore, creating designs intended for a wider public -whilst informed by own experiences- may support recovery. Identify concluded by participants each selecting a design issue, although some preferred to take supportive roles. In this project, several challenges were chosen, namely (i) How to get help with grief?, (ii) How to feel more calm and relaxed?, (iii) How do we improve (our) understanding to improve inventions?, and (iv) How to feel self love?

## Ideate

In this stage, the focus was to facilitate the generation of ideas, through brainstorming. Different tactics were proposed to encourage participants, namely the use of performance and randomness. Performing can push participants outside their comfort zone, decreasing a judgemental attitude, and help generate more ideas. In one session, an issue was placed in the middle of the table. Using a box, each participant was encouraged to act out an imaginary solution in silence. Others had to express what they thought the person was representing, and each idea was transcribed onto post-it notes (Figure 2).

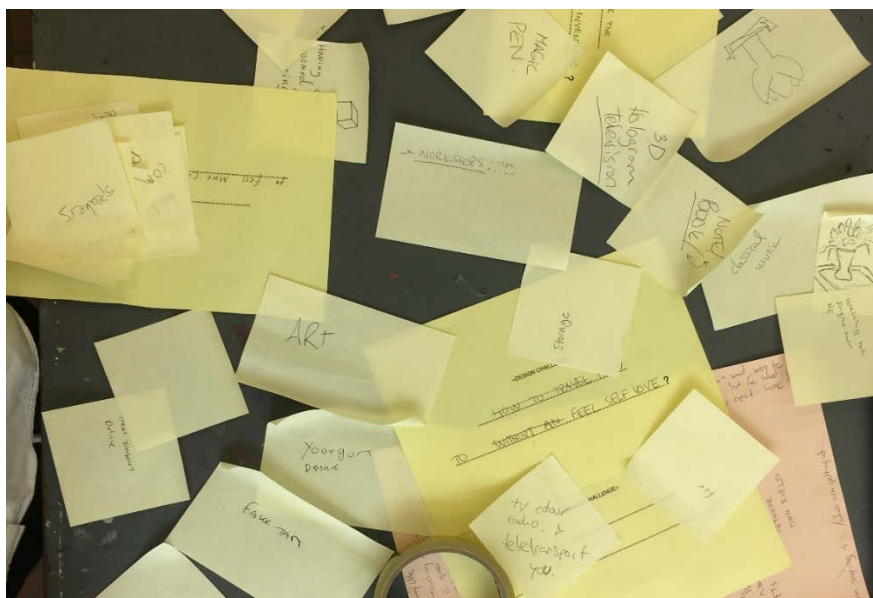


Figure 3. The box, responding to how to feel self love?

Otherwise, the use of random combinations of design elements was also particularly useful to stir imagination. One participant, for instance, did not respond well to generating ideas saying that 'nothing comes to mind'. The facilitator or other participants can help by beginning to generate ideas and randomly combining elements to see what emerges. Figure 3 shows various words which were placed in different pots and combined randomly (e.g. calm, camomile, jewellery, wheel). As a result, participants more readily engaged with idea generation.

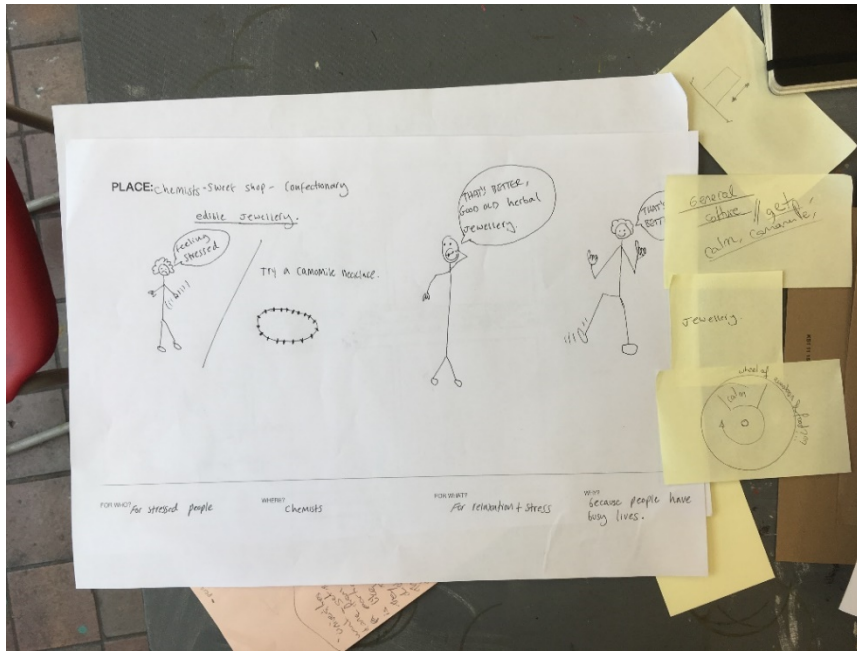


Figure 4. A participant combines camomile with jewellery and wheel of emotion in one concept.

## Invent

Inventing something could be associated generally with parts coming to form a whole. Templates have great potential to guide this process for participants who may lack motivation or find making design decisions challenging. It can also help bring back attention to the concept, and function as a communication tool between participant and facilitator (Figure 4).

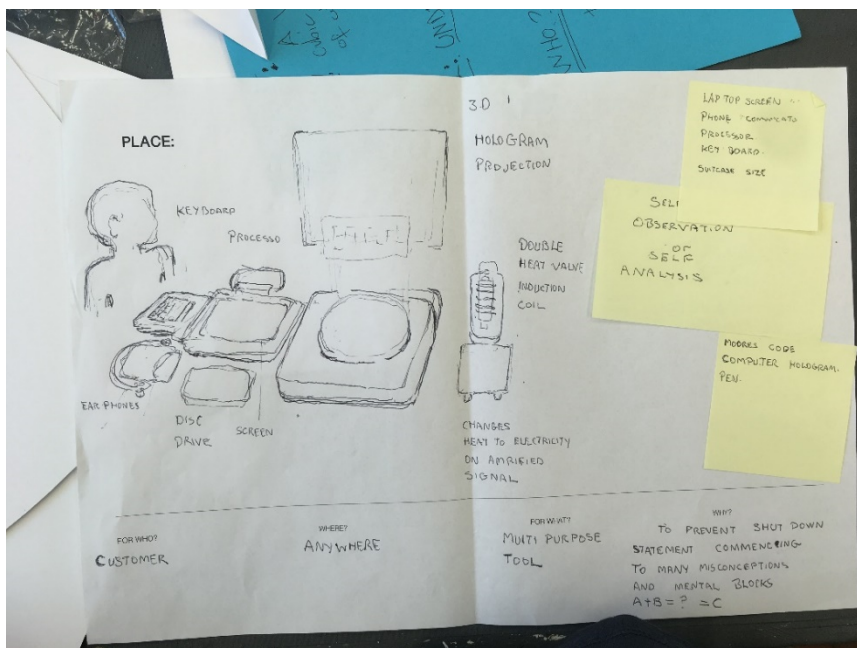


Figure 5. One of the participant's (Raymond) first draft of his concept in a template.

## Initiate

Finally, in Initiate prototypes were built using various mediums. They represented the designs created, culminated their efforts, and helped share the work with others.



Figure 6. Participant prototypes and tests game to help with grief.

## Exhibition

To reflect and celebrate the workshops, an exhibition was organised where photos and descriptions of participants' prototypes were put up on the walls at the mental health charity (Figure 6). The exhibition was open to other clients and staff of the charity and refreshments were served.



Figure 7. The design process and the final concepts were exhibited.



It seemed that the exhibition was a great way to celebrate the group's contributions and facilitate a sense of closure.

## Collecting Insight on the Case

A few days following the exhibition, three participants were interviewed share their experiences in the workshop, the impact it had (if any), and if/how the activities affected their mental health. When prompted about their experience, they all suggested that it was positive. One participant added that he loved making. Another elaborated further, describing that it 'was rewarding in a sense that [...] processes would take place very quickly, and [...] it was just really interesting how people worked together as one'. Another participant added: 'well... I think people managed to look back on things in the past actually I thought it was a reflection'. Regarding their experience, participants were also questioned about their most memorable moments. While one talked about a general impression 'I remember there is a nice flow, there was a nice flow to it all, I thought...', another recalled one particular activity where they worked on a system to stop an egg from breaking when dropped. The third elaborated on the relationship of this moment to their broader situation, how it 'is to do with people's problems basically it is to do with you know the desire I mean still sorting the depression...'.

In reflecting on any impact the project had on them, one participant was unsure: I wouldn't go that far, not really... but maybe... like I said with thinking, it has helped in some way. Maybe when you study design you think in design terms so maybe... I haven't noticed but maybe it does. Another participant said the experience was fun and, when prompted for details replied that it got me smiling. He recognized that his chosen design issue had to do with grief, which he identifies as the cause of his mental health problems. When he was further prompted about whether him developing that design has helped with his own grief, he replied it did a little bit.

Regarding the effect on mental health, one participant shared that 'Yeah, I thought [the design process] is quite healthy; [...] it may help think a bit differently, it must be healthy'. Another suggested that making was important, wherein 'making things relaxes you and it makes you not think bad things'. Finally, the third participant raised concerns: 'erm... well it is interesting but what I am saying is it may be chancing it because the person may have a hidden stress load'. When asked if the project caused that in him, he responded 'no exactly no no no I mean no, I am saying that other people may feel stressed'.

## Reflecting on the Case: Challenges and opportunities

Through a first broad analysis of themes, it seems that the workshop was a positive experience although its impact seemed to vary from participant to participant (e.g. a new frame of thinking or a relaxing activity). Either way, each varying perspective -held within unique insights, skills, health conditions, and preferences- seems to suggest that such co-design activities can support recovery.

Still, it is possible that some activities (e.g. exploring issues) could trigger stress. Although it was not reported in this study, it is believed that having alternative, simpler tasks at hand - such as making tree leaves - could work as contingencies if this was observed.

The approach of layered participation allowed participants to engage in different ways. For instance, one of the participants chose to not engage in an active way with most activities, but to carry out some alternative art activity while in the session. However, they paid attention to what others were saying, and often joined by either helping out other participants, or by adding an opinion on what was being said.

Participants' responses to tasks varied. For instance, while one of the participants tended to strongly respond to any creative activity, another would often respond that 'nothing came to mind'. The facilitator's role in the process becomes very important to help bring attention to the task at hand and to help create collaborative links among participants. Challenging moments may arise when the facilitator is not able to understand a participant's motivations or concepts. When this happened, the effort was to reframe the idea and communicate this back to the participant; but stating one's own limitations is also an important vehicle which can help create a sense of shared ownership and responsibility. Otherwise, allowing participants to leave and return to the room at any time and be in close contact with key staff for support was also important.

Participants were asked to share suggestions to improve the project. Two of the participants said they would not change anything, and the third suggested that he would want a part two. It would be worth exploring how such projects could be sustained long term.

## Summary and discussion

Overall, the project suggests a potential in using co-design with the aim of improving participants mental health and supporting their wellbeing. The approach followed in this study favoured layered participation offering opportunities to work individually and in a group, and was friendly to indirect, peripheral participation. Enabling participants to be in the space while doing another activity (e.g. art) and appreciating their indirect participation helped build trust. The act of making in particular provided a layer for participation which was key for those who did not engage verbally in discussions. Each participant was able to create their own meaning and reported a different impact. Although the small group size may account for this heterogeneity, the flexibility of the process appears to have enabled participants to craft their engagement in ways that respond to their particular recovery journeys. Finally, externalizing the problems and then designing to address these may help participants look at issues from a different perspective and acquire a sense of contributing to society, which according to Williams, Almeida, and Knyahnytska (2015) aids recovery. This swift from a strictly personal focus may differentiate the way in which co-design supports mental health from most therapeutic initiatives, such as art therapies, which tend to focus on art media as a form of personal expression and communication to support people (British Association of Art Therapists. 2020). The use of personal issues to inform collective or societal challenges, and the subsequent focus on designing solutions, may constitute forms of empowerment and contribution specific to co-design, situating it as complementary among other mental health services.

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# A space for personalised sensory experiences: A successful care approach for people living with dementia

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*[ABSTRACT only] Within dementia care, a sensory-enhanced care model has increasingly gained significance for facilitating appropriate engagement and meaningful experiences for people living with dementia, particularly in later stages. In this context, recent interdisciplinary research investigated the role of experience-focused, sensory design benefiting the wellbeing of people with dementia and their carers (Jakob and Collier 2017). From this research a new guide advising on the design of multisensory spaces in residential care was developed (Jakob and Collier 2014). Resulting from the guide book's online publication, a collaboration emerged between the research team and a South London care-home to create a new space in the home's dementia suite dedicated to providing personalised sensory experiences and activities. This partnership offered a unique opportunity for implementing research in practice, and further for evaluating and assessing the design via user feedback and, if necessary, revising the guidelines.*

*During the design and installation process of this new space, a co-creation approach was applied, including participatory start-up workshops based on the guide book and design feedback sessions with care-home staff and family members. Unexpected practical challenges during the set-up had to be conquered and valuable learning and knowledge was gained from this process – informing future activities and development of such environments in a dementia care context. Initial feedback from staff has been very positive in terms of the achieved benefits for the residents. However, gathering and analysing responses from the actual users, the people living with dementia, is essential for drawing final conclusions. The researchers are currently exploring strategies for evaluating the environment's design involving the participation of the residents of the care-home's dementia suite.*

*Based on this example, the authors highlight the value of appropriate sensory design and its impact on the wellbeing of people with dementia and their carers, recommending the sensory care approach.*



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Keywords: dementia, sensory design, multisensory environments, co-design, implementing design research

# Guided by Lights: Stimulating physical activity through an adaptive personal light system

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**ABSTRACT**     *Increasing physical inactivity and its subsequent health concerns have made promoting healthy and active lifestyles an important endeavour for many governing agencies. In this paper we focus on the influence of the environment to encourage people to move more. As a second iteration of an existing ‘Smart Exercise Route’, a 1.8 km walking and running path consisting of LED tiles in a public park, we designed a system that supports runners or walkers to set personal goals and gain intrinsic motivation to be physically active. The design focuses on aspects that positively impact motivation and/or performance: personalization, goalsetting, and feedback mechanisms. An initial evaluation of a prototype placed in three public parks, showed that participants (N=35) appreciated the personalization of the route and its goal-setting opportunities. While one third of participants indicated the prototype as directly motivating, these positively experienced features are expected to indirectly increase motivation to be more active even further.*

Keywords: exercise motivation, physical activity, urban environment

## Introduction

Physical inactivity is a major public health concern for many governments. Amongst interventions at the individual or social level, urban planners and policy makers have started reflecting on the design of active urban environments, supported by technology. To increase physical activity and social cohesion, the *Slimme Beweegroute* (Smart Exercise Route) was installed in Eckart Park in Eindhoven (Netherlands) in 2017. This running and walking route resulted from co-creation sessions with the neighbourhood. It consists of LED tiles on the ground, powered by solar energy. Users can choose one of four preset speeds by stepping on a coloured tile. The LEDs will light up sequentially, matching the selected speed. The system aims to motivate people to keep their pace and exercise frequently.

Interviews with municipality representatives and citizens showed that the route has had technical issues from the start, which led to a bad reputation and low usage rate. The main issue identified when the route was functioning were the fixed speeds, not matching the user's desired pace. Interviewees also indicated the LEDs were hardly visible and some had trouble understanding how the route works, despite the information board.

We thus researched how this route could be improved to stimulate the motivation of people to run or walk in a park, focussing on making the light system adaptive and personalized. This paper provides insights in how an intervention in the environment can influence people's behaviour and stimulate them to be more physically active.

## Related Work

Urban environments have the potential to strongly contribute to physical activity through their design (Sallis et al. 2016), especially with possibilities of evolving and increasingly integrated technology continuously adding new opportunities (Stephanidis et al. 2019). Technology also enables new and enhanced ways for tailored design and personalization, which are typically more impactful in design for motivation and sustained behavioural change than universal designs (op den Akker, Jones and Hermens 2014).

The research presented in this paper explores the value of a more interactive and personalized running experience. There is ample research available on personalization through interactive technology in the Human Computer Interaction (HCI) community (Stephanidis et al. 2019), that argue personalization plays an instrumental role in motivation (Sebire, Standage and Vansteenkiste 2009). Here, we position our work in research that relates specifically to physical activity and running.

Looking into enhancing advanced amateur runner's experience, Knaving et al. (2015) proposed design guidelines for future runner support technology. These include the importance of allowing runners to define personal and social goals to strengthen internal motivation. Regarding feedback, they urge designers to use non-intrusive interfaces that minimize distraction during a run.

Enhancing interest for an activity, goal setting can increase motivation, especially when the motivation is intrinsic (Sebire, Standage and Vansteenkiste 2009). The strategy of goal setting was used by another interactive running route, located in Oosterpark, Amsterdam. Bluetooth beacons

with a connected app tracked a runner's speed and position. Messages via the app suggested exercises, goals, to the users (Dallinga et al. 2016). These goals, however, are set by a system, while autonomously set goals result in better performance (Sebire, Standage and Vansteenkiste 2009).

Reflection on goals creates more awareness, helping to set the right goals and improve skills and motivation (Lee et al. 2015). Additionally, allowing goal progress monitoring promotes behaviour change (Harkin et al. 2016). *GoalLine* and *GoalPost* are research probes used to investigate physical activity motivation using goal setting, rewards, self-monitoring, and sharing (Munson and Consolvo 2012). Using primary and secondary goal setting resulted in increased motivation of participants. However, the reward system and sharing feature relied on extrinsic motivation and did not have the desired effect.

To measure achievements and recognize reached goals, system feedback is important. During a run, haptic and visual feedback by light could motivate people to persist (Wozniak et al. 2015). The interaction can become more effective when varied feedback is used (Arroyo, Bonanni and Valkanova 2012).

Feedback systems for runners should provide simple visual output, being more effective than auditory feedback and requiring little cognitive effort during a run (Wozniak et al. 2015). Providing visual feedback for self-monitoring through an app is effective for increasing physical activity (Murray et al. 2017). However, while smartwatches and smartphones can present large amounts of data, these interfaces are not optimal for in-run feedback (Colley et al. 2018). Exploring other ways of presenting data, they developed a shoe that gives feedback on running pace through light signals. Similarly, the interactive shoe *Pediluma* lights up when walking as immediate positive feedback (Lim et al. 2011). It had a positive effect on the step count, yet users felt uncomfortable with the light at night and preferred a goal-reward system.

For our design, we build on the successes and recommendations of this previous work to create a lighted path that motivates people to be more active.

## The Design

To research the influence of personalization of the designed route, we created a prototype of the new light route, including an improved and brighter light system and a shorter distance between the lights. The system is now tailored to each user; aware of his/her pace and lighting up accordingly. Additionally, this lets users track their progress and set goals.

The prototype-setup is 55 metres long. The user's speed is measured within the first five metres. After another five metres, a LED matrix displays their speed, allowing personal goal setting and progress tracking. The display turns off when the pace reaches the first light. From here, five poles with LEDs are placed every ten metres. These lights guide the journey of the user and provide feedback every ten metres. The lights turn on when the user should be next to it, based on their speed in the measuring section. The LEDs are red, as this colour showed to be most visible in contrast to the green park and was seen the brightest in sunlight.



Figure 1: System Setup

## Method

As inspiration for this research we used the Experiential Design Landscapes approach, where design propositions are placed in people's everyday lives. Using sensors and smart technology, their experiences and behaviours are captured and analysed, identifying patterns and creating new design opportunities (Peeters et al. 2013).

### *Pilot Study*

Eighteen interviews were conducted with park visitors, to understand their mindset regarding exercising and running in this environment. Questions about the current light route were included to investigate people's pre-existing knowledge about the route and if they used it.

## Research Setup

After the pilot interviews, two observation studies of 3.5 hours each took place in Eckart Park and Stadswandelpark. A third experiment took place on the Eindhoven University campus.

The goal of the first observation studies was to observe if park visitors would spontaneously use the system and how they interact with it. Researchers observed from a distance without interacting with participants. Users that adapted their pace (N=2) also filled out subscales of the User Experience Questionnaire (UEQ) (Rauschenberger et al. 2013) related to attractiveness, perspicuity, stimulation and novelty of the system.

The third experiment was focused on motivation for physical activity and the design's appearance. Twelve participants, all students (18-25 years old) and unfamiliar with the smart exercise route, were given information on the original route and the design before filling in part of the Physical Activity and Leisure Motivation Scale (PALMS) questionnaire to measure their motivation for physical activity (Zach et al. 2012). Only the physical and individual subscales were used. Next, participants were asked to use the course at their preferred pace. Observations were made on pace and attention paid to the display and lights. After the test, participants filled out the UEQ subscales. Open questions were added to better understand participants' replies.

## Results

During the first observations 23 people passed the testing area. Eight of them (34%) interacted with the adaptive light route and only two (9%) adapted their pace to the route. Mostly young people (up to ca. 20 years old) interacted with the route. Observation showed that the novelty of the setup at the second location did not significantly influence the results.

The UEQ shows that although the design is not perceived as very novel or innovative (Novelty subscale:  $M = 0.6$ ;  $SD = 1.4$ ), respondents found it attractive ( $M = 1.1$ ;  $SD = 1.2$ ) and somewhat stimulating ( $M = 0.9$ ;  $SD = 1.3$ ). The design scores highest on perspicuity ( $M = 1.4$ ;  $SD = 1.6$ ), meaning it is understandable and easy to use.

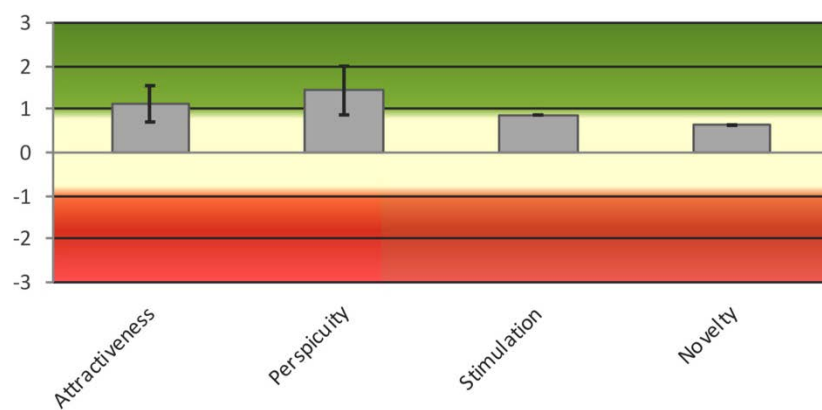


Figure 2: UEQ Scales (Mean and S.D.)

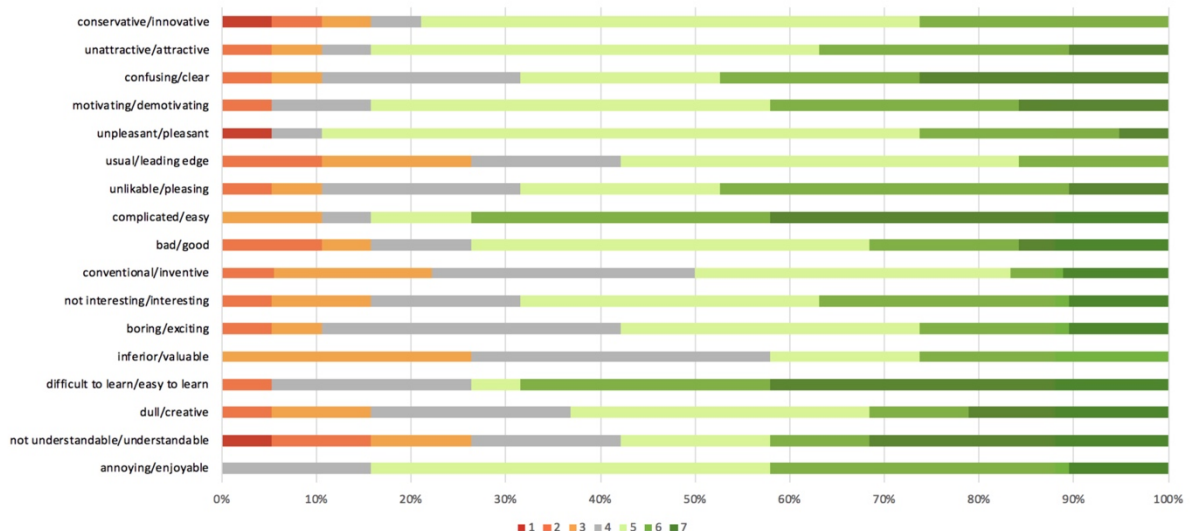


Figure 3: UEQ Answer distribution per item

Regarding motivation, responses to the open questions ( $N = 12$ ) can be sorted into three categories. Two participants did not find the route motivating at all: 'I'm not a running fan, design could be

more innovative or fun' (participant 1). Five participants found it potentially motivating but were not sure based on this test: 'I can imagine the whole route can be motivating. The user test was such a small part that I find it hard to say anything about this' (participant 12). Five others found the route motivating and positively experienced the personalization of speed: 'nice to complete a milestone with each light' (participant 2).

People found the best time to encounter the route would be when walking, running or playing sports, especially in the evening. The most mentioned motivations to use the system were to improve oneself and using the lights for guidance during so there's no need to think about directions. Main points of feedback were the length of the prototype route and the visibility of the lights. Suggestions were given to provide more information at the start of the route, to make the design more remarkable and to further personalize the route with colours; people indicated that controlling the light colour or pattern would make them feel more connected to the system.

## Discussion

Motivating people to become more active is a complex challenge, because motivational factors differ per person. Other influencing factors are uncontrollable, such as the weather. For our design, we focus on personalization, goal setting, visibility and understandability.

### *Personalization*

In line with the literature review, the main reason for the increased motivation was the personalization of the route. However, the 55m of prototype setup was not long enough for all participants to form a clear opinion about the effect of the system on a longer circuit. Observations also showed that five metres are not enough to measure the user's speed. People did not have a constant pace, resulting in many participants not finishing alongside the light indication.

### *Goal setting*

The related work showed that goal setting and appealing to intrinsic motivation, can increase motivation to be active, while not being forced to do so. The new system depends on the user's memory and willingness to improve their speed. Yet, some people indicated they may still need an extra push to exercise.

Because of the small sample size, generalization of this research is less reliable. While being the target users, people living near Eckart Park were already familiar with the original light route. This possibly influenced their opinion or interaction with the design during the first experiment. To get a more objective view on the project, another observation was done at the Stadswandelpark, where the visitors and participants largely represented the target users. All participants in the experiment on university campus were 18-25 years old. Even though these ages are part of the target group, this group does not fully represent the residents of the neighbourhood.

Because of ethical regulations, a sign informed people that anonymous data would be collected if they proceeded along the route. This clearly influenced the results, as people intentionally avoided the area and were less inclined to interact with the design.



While we conclude that personalization creates more motivation for people to run/walk, this does not yet show a direct relation between increased motivation and actually using the route.

### *Visibility*

The design was enhanced to improve visibility of the LEDs and, based on conclusions from related work, also give them more meaning for the user. Observations showed that the new system was noticed more in the park setting and drew the attention of people passing-by. However, they were not always visible in bright sunlight, making the user test inconclusive for some participants.

### *Understandability*

Despite a positive score for the system's understandability on the UEQ, it is not clear from these results to what extent this only lowers the threshold for using the design or actually affects the motivation for physical activity.

## **Conclusion**

To increase people's motivation to run or walk more through design, multiple aspects need to be taken into consideration. The personalization of the route; adjusting to the user's speed, is experienced as more pleasant and creates a connection with the design. It also provides the opportunity to set and check personal goals. Additionally, the Guided by Lights design is more visible than the original system and efforts have been made to make it more self-explanatory and understandable. When designing for behaviour change, this combination of personalization, goal setting, visibility and understandability is essential for any similar system to boost motivation and physical activity.

## **Future Work**

To improve the personalized running route concept, further research needs to show the effects of a longer route and the impact of repeated speed measurements along the track. A next iteration of the design should be longer to test the effect more thoroughly. A longer run-up and speed measuring in multiple places can help staying connected to the user's pace and allow for personal training variations. Brighter lights or colour patterns can increase visibility. Next to that, patterns or a connected app could enable further personalization or a playful element in the route, motivating people to use the lights in a new way. Additional studies can also help to determine in which stage of a run this design is most effective. These iterations would create a better connection to the user, providing new and improved ways to motivate people to walk or run.



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# ‘It somehow worked in the end’: Managing demanding communication situations between nurses and migrant families in the paediatric hospital setting through the use of communication aids

Kaufmann, Helfer, Pedemonte, Simon

**ABSTRACT** *Clear and comprehensible communication is essential in the hospital setting and is crucial for the wellbeing of patients. However, maintaining cost-effective health care systems while ensuring efficient communication is particularly challenging for healthcare staff. This is a relevant issue, especially when migrant patients are involved. Language barriers constrain medical treatment, can endanger patients’ safety and are a notable challenge to hospital staff. To provide appropriate treatment, staff must often rely on communication aids.*

*The aim of this project was to research which criteria were most important in the development of digital communication aids, to improve the care of paediatric patients in the hospital setting. What requirements do nurses have regarding communication aids in the care of migrant paediatric patients and their relatives?*

*This paper is the subsequent part of a previously-conducted study (Kaufmann et al. 2020). The initial study was conducted by the same interdisciplinary team consisting of design and nursing researchers. It utilized Thematic Analysis qualitative research methodology. The following steps of data collection were undertaken: (1) literature research on two topics corresponding to the research questions, (2) a focus group interview with paediatric hospital nurses, (3) observation of the communication between paediatric nurses and children/parents through shadowing, (4) individual interviews with paediatric nurses and (5) a focus group interview with experts.*

*The initial study revealed that a variety of communicative challenges influenced the care of migrant paediatric patients (Kaufmann et al. 2020). The results also highlighted which requirements communication aids should fulfil, in order to increase their acceptability by nurses, paediatric patients and their relatives. Using case examples, this paper focuses on these requirements, for the design of sustainable communication aids.*

**Keywords:** communication aids, nursing staff, children, migrant patients, foreign-language patients

## Introduction

Switzerland, like many other countries, is facing challenges in supporting its migrant population. In comparison to the Swiss population, the health of the migrant population is, in many ways, decreased (Rüefli 2015). The treatment and care they receive is often of lesser quality, due to language barriers (Langer and Wirth 2014). The inability to use language effectively, can lead to feelings of stress, isolation, or depression (Ennis-Cole 2019). Hence, mutual understanding is one of the most important needs for both patients and their relatives, as well as for nursing professionals (Jaeger et al. 2013). The inability to communicate has a direct impact on the daily work of the nursing staff. This is revealed in the literature and also in the previous article, in which this study is based upon (Kaufmann et al. 2020). It has been found that communicative challenges in the care of migrant paediatric patients (MPPs) are manifold, and communication problems in conjunction with their underlying causes, influence one other, and occur at different phases of the hospital stay (Kaufmann et al. 2020).

As described by the authors, utilizing professional interpreters is the most effective way to manage language barriers (Kaufmann et al. 2020; Flores et al. 2012). However, such interpreters are not always available, either due to reasons relating to time or cost (Langer et al. 2013). There are also many situations in which an interpreter is not necessary, but gestures alone are not enough. In such situations, for example, when providing basic care, a digital communication aid designed according to the requirements of the patients and nurses, could provide ideal support (Day and Song 2017; Crowley et al. 2017). Therefore, this paper specifically addresses communication aids used by nurses when dealing with MPPs and their parents. The benefits as well as the disadvantages of four case examples are discussed, along with how design can improve communication in everyday clinical practice.

## Research questions and aim

The presented study examined the communicative challenges that nurses working in hospitals face, when caring for MPPs and their parents. The aim of this study was to define adequate criteria for the future development of digital communication aids in the care of MPPs. Therefore, this paper explores the design aspects of communication aids, in order to demonstrate their feasibility and sustainability.

## Materials and Methods

The initial qualitative study, upon which this paper is based was conducted by an interdisciplinary team of nursing and design researchers (Kaufmann et al. 2020). The following steps were taken for data collection: (1) two systematic literature searches according to the research questions, (2) a focus group interview with five nurses in a paediatric acute care unit, (3) observation of the communication processes and contents between nurses and child patients or their parents by shadowing in everyday hospital life, (4) short interviews with the observed nurses, and (5) a focus group discussion with experts in the fields of nursing, diversity management and communication design. Analysing four case examples, the present paper more closely examines the communication strategies and the requirements for digital communication aids.

## Results

### Applying aids as a communication strategy

Depending on the situation, nursing professionals use different communication strategies when caring for MPPs and their relatives. The communication strategies documented in this study are varied, ranging from nonverbal communication or using plain language, to using interpreters. One important result is that *showing* is an efficient strategy in daily communication. This was often observed during shadowing and was mentioned several times in the interviews, as highlighted in the following quote:

‘With the West African children, my experience is that I put them in the shower because it looks like a latrine and then they pee in the cup. Because a lavatory doesn't mean anything to them.’ (Person 4, focus group interview with nurses)

Concerning important and complex topics, professional interpreters are, however, essential. Due to their time and cost, they are often booked solely for medical consultations. Relatives or hospital staff are often involved in translations, although this is not recommended best-practice (Flores et al. 2012). Alternatively, pictures and sketches can be very effective:

‘With children it is sometimes helpful to draw sketches.’ (nurse 8, short interview)

In many situations, nurses use proven aids which already exist on the unit, or ad-hoc solutions specific to individual situations. See table 1 for the aids, which were utilized by nurses in the study.

Table 1. Overview of communication aids as observed during shadowing or reported in individual and group interviews.

Use of communication aids		
	Proven aids	Ad-hoc solutions
<b>analogue</b>	Pictures, picture dictionaries, picture books Dictionaries Information material (German, or translated) Daily schedule with magnetic pictures Doll (Lucy) for demonstration of procedures Questionnaire in different languages Consolation or discharge booklet	Spontaneous notes/drawings DIY by patients: sheets with translated phrases Custom made insulin scheme and medication plan
<b>digital</b>	Information/educational films Distraction/entertainment on tablet or bedside station	Pictures from Internet Contacting relatives for translation on private phone Entertainment/distraction on smartphone Showing information regarding anamnesis on smartphone Google Translate / Translator app

Regarding these communication aids, it is important to note that digital solutions were used primarily in the case of ad-hoc solutions. However, there were no digital tools available on the unit,

except for two tablets with films for entertainment/distraction. If digital devices were used for communication, they were mostly the patients' private devices, and they were then used frequently.

## Case examples

The following case examples describe different strategies utilized and reveal the potential for improvement through design solutions.

### *Case example 1: Magnetic picture cards*

'The nurse explains to the mother in simplified German, when the blood sugar has to be measured again. She uses the magnetic pictures on the wall to show the daily schedule.' (fieldnote shadowing)

An analogue aid established on the observed unit was the magnetic picture cards (Figure 1), in which the daily schedule for diabetes patients could be individually displayed on the magnetic wall of patients' rooms. These cards were developed by the unit staff. See table 2 regarding the authors' observations of the discussed examples.



*Figure 1: Magnetic picture schedule for diabetes – an effective, image-based communication aid used with children. Note: communication aids are often difficult to access due to the limited space available on the unit (obstructed lockers).*

### *Case example 2: Hospital phrase book*

'As an example, she [the nurse] shows the St. Gallen hospital phrase book. This is only available on the computer (they used to have hard copies of it), and it took a while until she found it. It took a little longer until she discovered a list of food in Tamil. The other nurses present did not know that this dictionary existed.' (fieldnote shadowing)

The 'Spitalwörterbuch', is a hospital dictionary developed and distributed by the St. Gallen Cantonal Hospital, created to suit the needs of Swiss hospitals. The phrase book serves to support communication in daily interactions in 12 languages and includes pronunciation of the words (Figure 2). Nurses on the observed unit could only access it via intranet as a PDF, which was very impractical.

Deutsch	Aussprache	Tamilisch
<b>Wo</b> haben Sie Schmerzen?	engge ungaluku walikradu?	எங்கே உங்களுக்கு வலிக்கிறது?
<b>Wann</b> treten die Schmerzen auf?	opoludu ungaluku walito-dankradu?	எப்பொழுது உங்களுக்கு வலிதொடங்கிறது ?
Ist der Schmerz neu?	inda wali pudida?	இந்த வலி புதிதா ?
<b>Wie</b> sind die Schmerzen?	öpadi walikradu?	எப்படி வலிக்கிறது?

Figure 2: Hospital dictionary with translated standard sentences, including pronunciation in phonetic transcription.

### Case example 3: Hand drawn sketch and pictures from the Internet

'Then the nurse explains to the patient with which foods he has to inject [insulin]. She then draws different foods on a paper towel. She also notes the sugar levels.' (fieldnote shadowing).

A simple ad-hoc solution: using a paper napkin and a pen, the nurse sketched during the conversation at the patient's bedside (Figure 3). The napkin was thrown away after the conversation. Later, the nurse printed out pictures from the Internet with the corresponding foods for clarification, as she did not find any corresponding images in the unit's books.



Figure 3: Ad-hoc communication aid for a diabetes patient: Insulin levels and 'allowed' food hand drawn on a napkin (left), and pictures printed out from the Internet (right).



### Case example 4: Custom-made insulin schedule and medication plan

An individual insulin schedule and a medication plan were designed by the nurses independently (using Google Translate), for a patient who spoke only Arabic (Figure 4). Photos of the medication contained in the medication plan visually provided an overview and were intended to reduce the risk of confusion. However, the plan was only used for one patient.

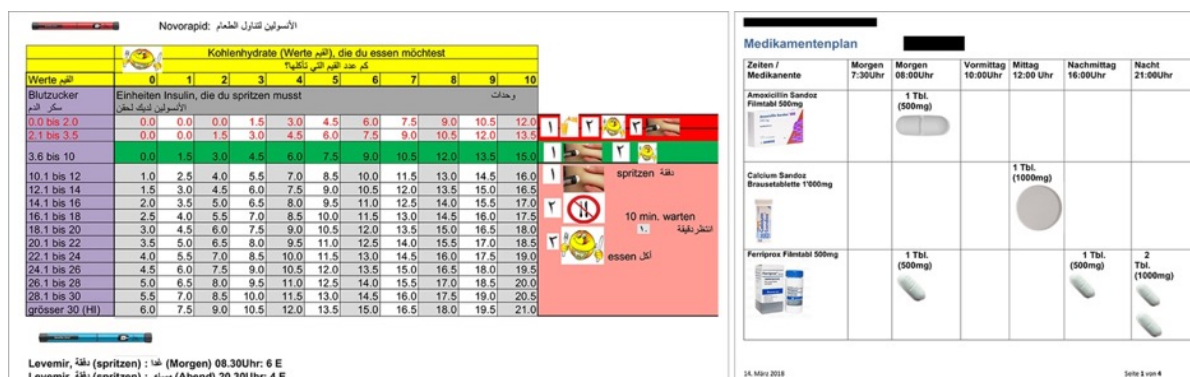


Figure 4: An individual insulin scheme (left) and a medication plan (right) was designed and translated by the personnel.

Table 2. Benefits and disadvantages of the communication aids described in the case examples.

Case examples: benefits and disadvantages		
Case example	Benefits	Disadvantages
1 Magnetic picture cards	<ul style="list-style-type: none"> <li>+ Image-based (no language needed)</li> <li>+ Customizable</li> <li>+ Allows an overview of the day</li> <li>+ Nurses are all aware of it and use it extensively</li> </ul>	<ul style="list-style-type: none"> <li>– Cannot be continued after discharge</li> <li>– Time and insulin dose cannot be displayed in exact numbers</li> <li>– Needs storage space</li> </ul>
2 Hospital phrase book	<ul style="list-style-type: none"> <li>+ Customized for the country-specific situation</li> <li>+ Numerous languages available</li> <li>+ Professional translation</li> <li>+ Medically correct content</li> </ul>	<ul style="list-style-type: none"> <li>– Time-consuming (access, handling)</li> <li>– Cannot be individualized (only for standard situations)</li> <li>– No visual support</li> <li>– Costs (chargeable product)</li> <li>– Updating is difficult</li> <li>– Not known to all the staff</li> </ul>
3 Hand drawn sketch and pictures from the Internet	<ul style="list-style-type: none"> <li>+ Customizable</li> <li>+ Immediate use during conversation</li> <li>+ Visual support</li> </ul>	<ul style="list-style-type: none"> <li>– Time-consuming</li> <li>– One-time use/must be invented ad-hoc</li> <li>– Inconsistent quality of the drawing</li> </ul>
4 Custom-made insulin schedule and medication plan	<ul style="list-style-type: none"> <li>+ Customizable</li> <li>+ Visual support</li> <li>+ Translation: Information in native tongue</li> <li>+ Clear overview</li> </ul>	<ul style="list-style-type: none"> <li>– Time-consuming</li> <li>– One-time use/must be invented ad-hoc</li> <li>– Design by laypersons</li> </ul>

These case examples demonstrated that an advantage of ad-hoc solutions, is that they were practical for specific situations or that they could be applied directly in conversations. However, their creation was time-consuming, especially considering their one-time use. Additionally, their spontaneous design by laypersons, resulted in inconsistent, sometimes poor design quality. They



also revealed, that the use of existing aids was unlikely if they were difficult to access, not familiar to all team members, or not adaptable for individual usage.

## Requirements for digital communication aids

The requirements for digital communication aids, which were mentioned in the focus group and individual interviews were grouped into the following thematic categories: target group, functionality, content, accessibility and challenges/limits (Kaufmann et al. 2020). The requirements that an app should have which were most often mentioned, were that it should be easily accessible, simple, user-friendly and self-explanatory. It was considered especially important that an app contain visual elements (pictures and videos) to support understanding, which is congruent with the literature (Mayer 2001). The desire for speech recognition and correct translation was also frequently expressed. This is likely because the quality of existing translation tools (e.g. 'Google Translate') has often been described as poor, especially regarding medical topics. Nevertheless, they are still utilized, as this quote from the original study reveals (Kaufmann et al, 2020, 267):

'On days when time is short, the nurse often uses Google Translate for translation, even if the translation is bad, as it is better than nothing.' (fieldnote shadowing)

The studies that were included in the literature search revealed that digital aids were well accepted by children and could in certain situations, improve their communication (Crowley et al. 2017; Day and Song 2017). This was supported by the study results:

'Usually, a tablet is very interesting in itself [for children].' (Person 3, focus group interview with nurses)

## Discussion

The aim of this study was to define adequate criteria for the future development of digital communication aids in the care of MPPs. Currently there is little support available for the nurses. According to an expert in the focus group interview, a frequently heard statement by nursing professionals in the context of overcoming language barriers is, 'it somehow worked in the end.' This describes well, that there are no standardized procedures available for dealing with language barriers. Instead, nurses must constantly solve these problems as good as possible, often in an ad-hoc manner. Upon analysing the case examples, it is apparent that the nurses are aware that a clear, image-supported presentation of the contents, increases patients' understanding. They are very creative in developing efficient solutions. However, it is also evident that the individual development of solutions takes time, which is often lacking in the hospital setting. Many ad-hoc communication aids are used only once; therefore, they are inefficient and unsustainable. Any gained know-how is lost and must be reinvented each time. One advantage of ad-hoc solutions is that they are tailored to specific needs, while aids provided by the clinic are sometimes difficult to integrate into workflows. Additionally, despite good content, an outdated form of media can hinder its use (e.g., case example 2). Additionally, the hospital's general rules (no private smartphones for nursing staff, limited access to the Internet due to security regulations, few digital devices on the unit) prevent the coordinated use of digital aids, even though they would, in many situations, offer advantages.

## Implications for the design of communication aids

Concerning the design of communication aids, it is important to find out what kind of aid would be most appropriate. The spider chart is ideal for visualizing and comparing predefined criteria, as in this case, for the different characteristics of communication aids. The authors, therefore, propose the following chart (Figure 5) as a model for the description, comparison and evaluation of communication aids. The individual evaluation criteria were derived from the requirements identified in this study.

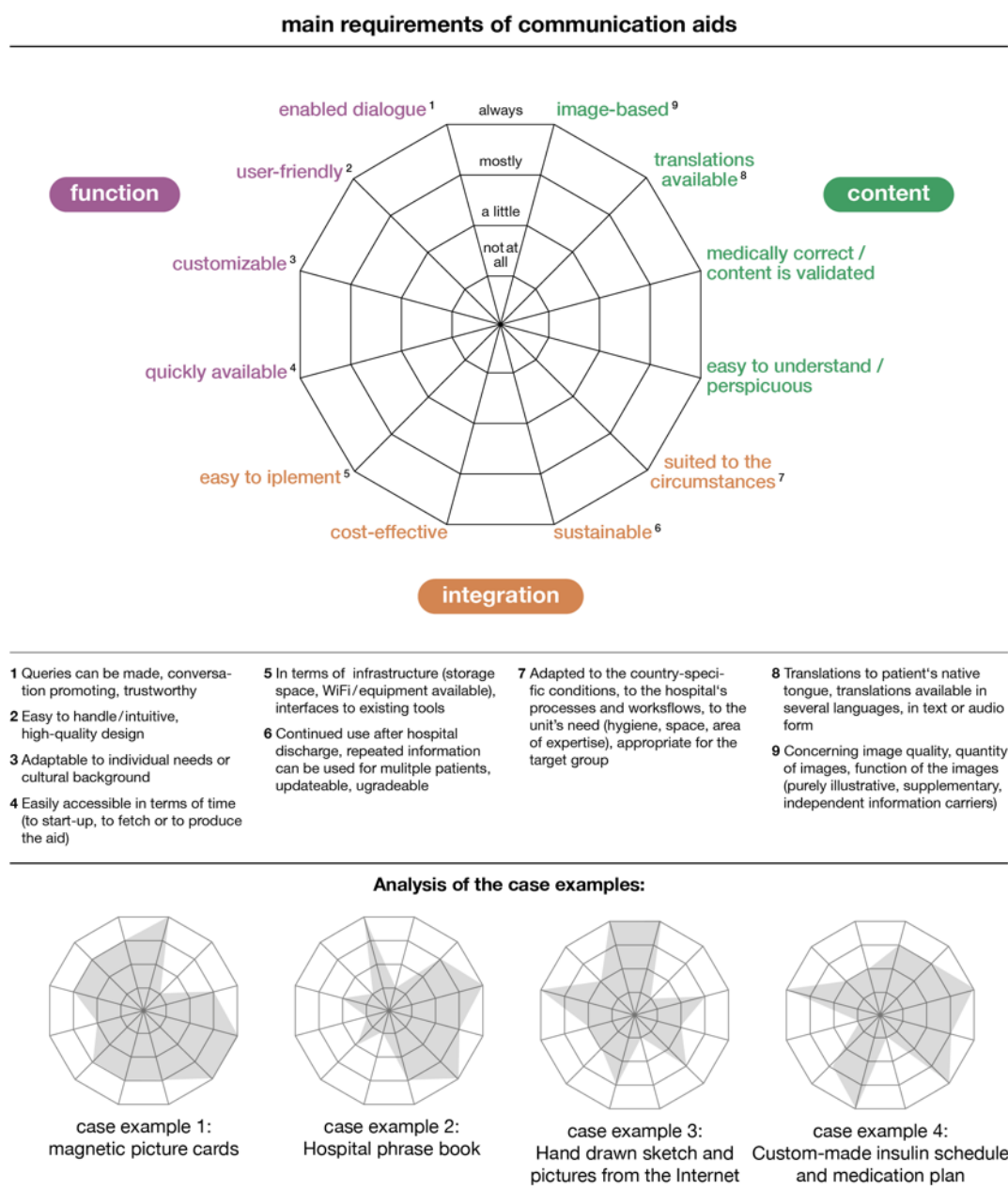


Figure 5: Suggested spider chart to rate and compare existing or planned communication aids.

The design approach must be chosen according to the defined needs. When evaluating or designing a communication aid, the best approach is to involve the users in order to meet the principles of human-centred design (Buchanan 2001). Furthermore, it is important to also consider its integration

into the hospital's workflows and the training of personnel (Jaeger et al. 2013). Otherwise, it is possible that the tool will neither be known nor utilized by the staff.

Communication aids are ideal to bridge the gap between those communication situations that can be easily managed ad-hoc, and those that require a professional interpreter. Topics which are recurring in everyday hospital life (e.g., explanations of interventions, instructions, or medication plans and schedules), are ideal content for communication aids. They could provide additional illustrative material for complex content. Thus, communication aids can be useful tools for all patients (not only MPPs), as they support the general understanding of information.

## The potential of digital aids

In general, the requirements described above apply to all types of communication aids (analogue and digital). Digital transformation is taking place in the health care system, and it is important that communication tools also become part of this transformation. Digital devices are becoming smaller, faster and more economical; therefore, they are increasingly affordable and practical for patients and hospitals. Technology evolves quickly and the users themselves are also becoming more and more accustomed to utilizing digital tools. Generally, young patients are curious and enjoy the digital world (Hølge-Hazelton 2018). Digital devices often serve as an icebreaker for the nursing staff, and they help them in building rapport with their child patients (Jackson and Mixer 2017). They not only support the flow of information, but also offer distraction during painful treatments or boredom, which was observed repeatedly during the shadowing.

It is feasible that digital aids that are used in the hospital, could continue to be used after discharge (e.g. self-management in diabetes). They might be tailored to specific needs and utilized for a longer term, thus avoiding one-time solutions. Inclusion of these aspects could contribute to the development of sustainable solutions. Importantly, critical consideration should be given to the integration into hospital processes and should focus on aspects such as hygiene, workflows and data security.

## Limitations

A possible limitation of this paper is that the initial study did not include any interviews with MPPs or their parents, in order to adhere to ethical regulations. However, interviews with the nurses involved in the study were conducted. Additionally, due to a lack of time and financial resources, the study was limited to one hospital unit. Strengths of the study are its interdisciplinary research team and the variety of data sources utilized.

## Conclusions

This paper outlines the requirements for (digital) communication aids in the hospital setting for MPPs. There is no single solution. Instead, many aspects must be considered in order to develop suitable communication aids. Interdisciplinary cooperation is essential in the development of suitable and sustainable solutions. Additionally, the involvement of users is crucial, to incorporate human-centred design. Digital communication aids could be one cost-effective measure which could assist, for instance, in the provision of everyday care. But communication aids cannot, and should

not, replace verbal communication. Instead, they should support and enhance all forms of communication.

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# ‘I am not old, I am only 83’: Arts engagement to understand community needs

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**ABSTRACT** *The health and wellbeing of older members of the community is of major concern. Government, organizations, and local authorities are increasingly looking to understand who their citizens are, and their want and needs as they transition into old, and advanced old age. There may be 40 years, and deeply different needs and wants, between citizens who may be considered old (60) and those in advanced old age (100). Furthermore, the post-war generation that heralded change, are also demanding change in how old age, ageism and aged care impacts them as they potentially transition into greater dependence.*

*Councils have used approaches such as focus groups, surveys, town hall meetings to gain insights into the needs of the community to inform the development of strategic plans for environmental planning and care services. Increasingly they are recognising the limitations of such approaches, because of survey fatigue or because the most vocal are ‘the usual suspects’ or habitual respondents.*

*This paper will report on a project that used creative workshops to engage with older members of the community, as part of a city-wide arts and mental health festival, to understand the needs and wants of the wide range of older members of the community, and to produce an artwork to be exhibited in the festival. The project shows the art and design project was a means of gaining the trust of the citizens to allow them to express their deep joys and anxieties and formed the basis for ongoing engagement to facilitate longer term research projects*

**Keywords:** art/design engagement, reciprocal design, ageing, co-design

## Introduction

Australian society, like many developed countries is now made up of a greater proportion of older people than at any time in the past. This trend is expected to continue (Australia to 2050 2010, United Nations 2015). This creates challenges and opportunities for individuals, communities and the authorities and organisations providing services to these communities. Many of the social systems, infrastructure, environments and social norms are predicated on populations with a significantly lower mean age.

It is not only the increased number of older people that will impact society, but also their changing needs. Those entering old age now, and future generations, have very different lives from the pre- and World War II generations before them. Their wants and needs differ significantly. So, how do we find out what older people need, to have a good quality of life as they age? Focus groups, surveys, and questionnaires are commonly used to find out people's wants and needs. But these approaches have their limitations. This project used a series of innovative creative workshops with older people to explore their wants, needs, joys and anxieties. The Woollahra Emotion Visualisation Experience (WEVE) *It feels like home!* focused on people's emotional responses to how and where they live. The project reached 'beyond the surface' to find out older people's concerns, to understand their views on ageing and to imagine and design community solutions to support ageing well in Woollahra. The workshop culminated in a visualisation artwork of the experiences of older people taking part in the project, and a series of arts events as part of *The Ageing program* in The Big Anxiety (TBA) a festival of arts and mental health.

Woollahra Municipal Council (WMC) partnered with Researchers from the Ageing Futures Institute (AFI) and fEEL (the ARC Laureate Felt Experience & Empathy Lab) at the University of New South Wales (UNSW) and older members of the community. In addition, artists Laura Jade, Gail Kenning and Warren Coleman produced and presented artworks and events.

## Background

Woollahra Municipal Council (WMC) is in the eastern suburbs of Sydney, Australia. The population is around 52,000 with almost 30% of people over 55, and more than 8% of the population over 75. It is on the land of the Gadigal and Birrabirragal people. WMC frequently engage with the community to understand how council can respond to and support their needs. To extend their understanding of the needs and wants of older people in the community, WMC partnered with AFI, fEEL, UNSW and The Big Anxiety 2019. The Big Anxiety (TBA) is a month-long Sydney festival promoting mental health and wellbeing through arts projects that combine science and creativity. In 2019 TBA launched its first Ageing Program produced by Dr Gail Kenning. It focused on the wellbeing of older members of the community.

## The project

The Woollahra Emotion Visualisation Experience (WEVE): *It feels like home!* project focused on the emotional responses of the community to their home and where they live. The aim was to understand the deeply held views of older members of the community. The project generated qualitative data which was analysed and visualised to reveal how the community feels. The data

revealed a wide range of issues relating to mobility, loneliness, relationships, illness, bereavement, finances and the joy of living in a beautiful environment, having friends, sharing experiences and being able to travel.

The WEVE project began with a brainstorming session to understand how to engage with the community and how to engage them in the project. The project drew on the work of national and international artists and researchers to find an approach that would reach a wide range of people and elicit a wide range of responses (Nold, Aberdeen, Leggat et al. 2010). Outlines were drawn up and the project was allowed to iteratively evolve in response to the needs of the various project partners and the responses of community participants. The project began by focusing on responses to the environment and then gradually began to focus more closely on the theme of *It feels Like Home!*

## Methodology

The project used a range of methodologies to explore the wants and needs of older people in the WMC region. The aim was to employ deep qualitative approaches which would be enjoyable for participants and respondents to engage with while providing deeply held, thoughts and feelings about ageing (Kenning 2018, Kenning 2020 in press). This approach allows for an inclusive, interactive and flexible approach to the collection of reliable data that would form the basis of the public artwork. The project needed to be adapted to take into account the wants and needs of the participants and the wants and needs of the project partners. Therefore, it used a range of ethnographic, participatory approaches (Macdonald 2012). Data was collected in workshops, and through surveys and interviews over a period of six months. The workshop activities were designed to connect with participants and to prompt their thinking and talking about what ageing in their community meant to them. Each of the workshops were audio and video recorded for post-event analysis and to ensure that all comments and non-verbal responses could be captured.

The rationale for this broad approach was to move ‘beyond the surface’ and to gain access to deeply held and felt responses and to allow people to respond and comment however they chose. The aim was to avoid controlling the flow of conversations, and to enable participants to hear what others had to say. This approach sought to broaden discussion beyond the often-rehearsed engagement that can take place between council and the community where, for example, respondents focus on known issues, or ‘pet’ topics (Craig and Tracy 1995, Paulson and Willig 2008, Tashakkori and Teddlie 2010, Mitchell 2011, Macdonald 2012, Neuman 2012, Dervin and Foreman-Wernet 2013, Creswell 2014, Glassman and Erdem 2014, Dick, Sankaran et al. 2015, Leavy 2015).

## Participants

The project worked with a purposive sample, recruiting participants using a snowballing approach. Recruitment for participants began in March 2019 with a series of drop-ins at clubs, meetings and events organised by WMC. People were invited to take part if they identified as a senior, or older member of the community. The criteria also included anyone who lived, worked, or spent a considerable amount of their time in and around the Woollahra Municipal Council region.



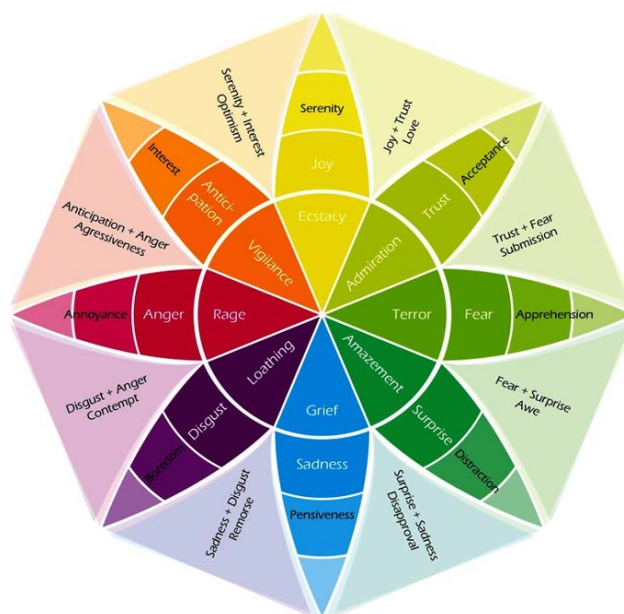
## Ethics

Ethics was considered negligible risk and was approved for the project by the Human Research Ethics Advisory Panel (HREAP) at UNSW. Consent forms were provided to all participants, who consented to video and audio recordings to be made, photographs to be taken and for the data to be used for publication.

## Workshops

A series of six workshops took place. There were on average 8-10 people in each workshop, with some participants attending several. They ran for two-hours and included enjoyable, informative, activities, to find out what are the community's wants, needs, concerns, joys and anxieties. The workshops focused on three topics, emotions, home and community all in the context of ageing and growing older. A series of workbooks were produced to explore *ageing, emotions, home* and *community*. *Take-home* journals and workbooks were available for those who wanted them. There were also online surveys to complete and interviews carried out with a small number of key people.

## Emotions

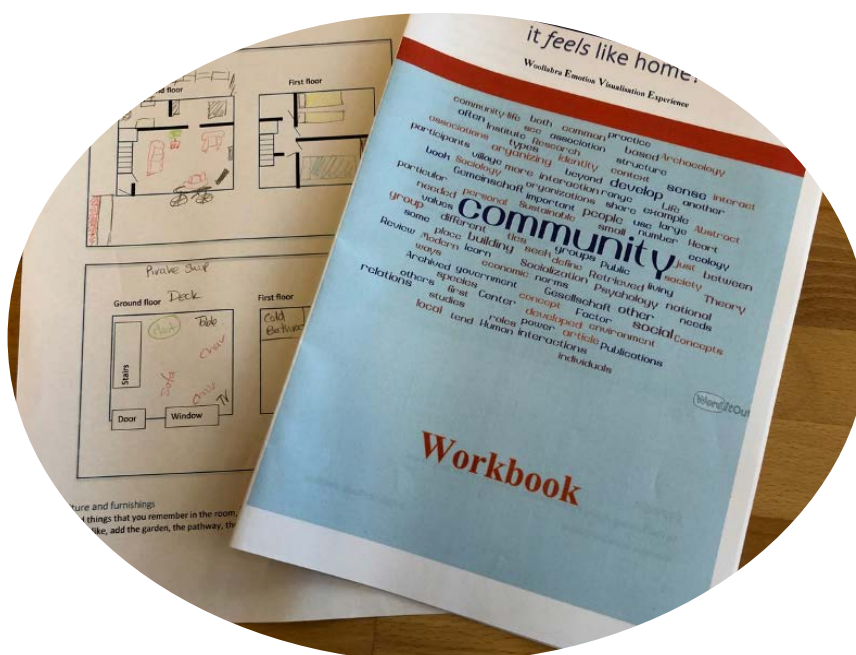


The first workshops introduced the concept of complex emotions, how we feel, why we feel, when we feel, and how we can use this information for our wellbeing. Participants were given an introduction to emotions using psychologist, Robert Plutchik's *Wheel of Emotion* (Plutchik and Kellerman 1980). Participants were asked to think about their own emotions and respond to a series of questions.

## Home

Some workshops focussed on the concept of home. Participants were introduced to the many varied concepts of home. They included Eastern and Western philosophies on home, including for example, house, city, state, country, and ancestors. Participants were also asked to explore the concept of home as place you retreat to or escape from; as a place of stillness and a place to stop; and home sickness. They were also introduced to home as represented philosophically and materially by Gaston Bachelard in *Poetics of Space* (Bachelard and Jolas 1994). Participants were asked to draw a map of the first home they remember on trace paper. They were asked to plot the rooms, the furniture, the spaces and places they were familiar with. They were then asked to overlay this map with a second piece of trace paper and to draw the furniture and belongings that were important to them. Finally, they were asked to take a third piece of trace paper and map their emotions on to the various places and space of the home.

## Community



The third topic area explored in the workshops related to community. The workshops explored definitions of community; understandings of what community is; how community is formed; what creates a sense of belonging in a community; how communities change and adapt and; types of community and motivators for community. In addition, participants were asked to explore aspect of their personal identity using identity wheel mapping and their social identities and how they presented themselves to their communities. Participants were also asked to explore whether they thought that their personal identity and social identity changed as they age.

## Findings

A wealth of data was collected and analysed in a range of ways. It is not possible to provide in depth findings here. However it is useful to show the wide range of themes that arose in the project.

## Themes

The discussion from workshops, interviews, writing, drawings and in spontaneous discussion between researchers and participants was audio and video recorded, and journal notes, debriefings and drawings were made. The recorded data was analysed using Nvivo9, excel, and word applications in relation to discourse, themes, and text.

Activities\Activity - Cards  
Activities\Activity - Celebrate  
Activities\Activity - Choir  
Activities\Activity - Chores  
Activities\Activity - Church  
Activities\Activity - Cinema  
Activities\Activity - Gems  
Activities\Activity - Craft  
Activities\Activity - Drawing  
Activities\Activity - Exercise  
Activities\Activity - Exercising  
Activities\Activity - Fair  
Activities\Activity - Gallery  
Activities\Activity - Games

A theme that was addressed in all workshops, discussion and interviews was 'how old is old'. The age range of participants was 60-93. This meant there was more than 30 years between the youngest and the oldest and they had different understandings of what constituted 'old'. The most frequent response was 'I don't feel old'. This view was also expressed by a 93 year old woman who walked up to 10km a day and an 83 year old who suggested 'but I am only 83'

Activities  
Ageing  
Agency  
Ancestry  
Attitude  
Awareness  
Behaviour  
Belief  
Belongings  
Bureaucracy  
Care  
Communication  
Connect  
Culture  
Death  
Education  
Emotion  
Environment  
Experience  
Feeling  
Finance  
Food  
Gender  
Generations  
Health  
Help  
Home  
Information  
Location  
Memory  
Mobility  
Organising  
Reading & Writing  
Relationships  
Security  
Technology  
Time  
Transport  
Travelling  
Work

Forty primary themes were identified in the data (as shown). Within the 40 themes were a series of sub-themes (480 in total), drilling down to show the concerns of the community. For example, *activities* was a strong theme. People were concerned about 'keeping busy', 'doing things' the importance of being active, and their own mental and physical health and wellbeing. Participants focused on exercise, cultural activities such as writing, singing, book club and, socialising in meetings, social gatherings and events. This was important to all participants and was seen as a way of ensuring that people were not in a situation of having 'nothing to do' it was reinforced in concerns about the need to 'stay active', and was seen as a means of ensuring that people did not let

depression 'get to them'. A sample of the sub themes (40 in total) for *activities* are shown above. Similar sub-themes were created for all primary themes.

## Discussion

Overall the project made some important observations and findings which will be written up in more details in academic journals. While the project had been informed by similar projects in Australia and overseas, it became apparent that the project needed to be flexible and able to adapt to the many partners involved and the different communities of Woollahra. The participants were primarily highly educated women, who were physically and mentally active. Most were financially independent and appeared highly motivated. Many had professional careers and had had jobs with responsibilities, they included radio and TV producers, writers, airline staff, artists, scientists and researchers. It became apparent that the men who had been attracted by the thought of engaging in research were less interested when they understood it would engage 'talking about emotions'.

One of the many findings was the extent to which the people engaged in this project were a valuable resource for councils and local authorities, because 1) they exhibited resilience, they had lived through difficult times and had experience and knowledge 2) they were highly articulate and not only had a sense of self that recognised what they had 'come through' and what their strengths were, but were also able to communicate it 3) they were motivated by being challenged, as shown by their interest in the workbooks that traversed psychology and emotions, philosophies of home, and identity. They were also all eager to continue with the workshops and eager to be challenged with new topics.

The project culminated in a Synchronised multi-screen visualisation of the data, by Gail Kenning and Warren Coleman, which was exhibited as part of the Big Anxiety (Festival of arts and mental health) across Sydney in 2019.

## Conclusions

In setting up the project we had assumed that one of the main drawcards for people taking part in the research project was the culmination of the research in a public artwork to challenge prejudices and stigmatization of older people. However, we found that this was of less interest to the participants (although it was of interest to the viewing public) and they were more interested in being intellectually challenged through the workshops and by further discovering things about themselves and their emotions they did not feel they knew. The workshop environment, workbooks and drawing exercises provided a focus that prompted a level of engagement and depth of discussion that would not be available through focus groups or surveys alone (as observed through clashes of personalities that were observed before and after workshops, but not during).

## Acknowledgements

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# Healthy by Design: Using participatory design methods to develop a healthy lifestyle intervention for vocational students

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**ABSTRACT** *Unhealthy lifestyle behaviours are common among vocational students and increase their risk of non-communicable diseases later in life. Unfortunately, only a limited number of school-based healthy lifestyle interventions have been developed for vocational students. Moreover, there is no evidence that these interventions are effective. They have often been developed by professionals without involving students and therefore may not align with the target group's perceptions and needs. We used a participatory design approach to develop an intervention to promote healthy physical activity and dietary behaviours, in co-creation with vocational students. 'Contextmapping' was used to assess student conscious and subconscious motivation for a healthy lifestyle (n = 27, ages 17-26 years). All sessions and interviews were recorded and transcribed. The transcripts were analysed using framework analysis. Contextual characteristics that influenced student lives were their peers, family and short-term motives like earning money, being cool and looking good. In addition, they often had a passive attitude towards daily life, were unaware of their health illiteracy and being healthy was a goal for the distant future. These findings led to four design concepts that converged in a peer-led healthy lifestyle intervention that includes a social media campaign and activities to demonstrate and practice specific health behaviours among vocational students.*

**Keywords:** participatory design, healthy lifestyle intervention, vocational students

## Introduction

Unhealthy lifestyle behaviours are common among vocational students (Pearson et al. 2009; Bonevski et al. 2013) and increase the risk of non-communicable diseases later in life (Bellou et al. 2018; Lee et al. 2012). Unfortunately, only a limited number of school-based healthy lifestyle interventions have been developed for senior vocational students. Moreover, there is no evidence that these interventions are effective in sustainably changing health behaviours in vocational students. In order to develop interventions that successfully change behaviour, the context of the target population must be understood. The intervention should be based on the meaningful participation of the potential users of the intervention (Bartholomew et al. 2011; Van Sluijs and Kriemler 2016).

Within the field of design research, potential users are increasingly involved in the design process in order to better meet the needs of those served through the design. Apart from evaluating design concepts through usability and prototype testing, users are also involved in earlier stages of the design process to allow them to exert more influence on the new design through idea generation and concept development (Sanders and Stappers 2012). By sharing their routines, desires, needs, dreams and fears, users provide contextual knowledge about what would best serve their needs. This knowledge is a fundamental starting point for the design process (Sleeswijk Visser et al. 2005).

This study applied a participatory design approach to developing a healthy lifestyle intervention that promotes healthy physical activity and dietary behaviours among vocational students. In this paper we describe the outcomes of the contextual user research methods to understand the behaviour of potential intervention users.

## Methods

### Research design

A qualitative and design-driven form of research was conducted to gain insight into the daily life and experiences of vocational students and to develop a healthy lifestyle intervention in two sequential phases. In the first phase, contextmapping was used to gain an understanding of the experiences, desires and needs of vocational students. The basic principle of contextmapping is that users are ‘the experts of their own experiences’ (Sleeswijk Visser et al. 2005), but this expertise lies in deeper levels of knowledge, of which users are not immediately aware. Generative techniques are used to guide users in small steps through the process of accessing and expressing these deeper levels of knowledge. Vocational students were subsequently employed as co-researchers to retrieve in-depth information from fellow students on preliminary design concepts. Co-researchers are potential users who act as researchers in the design process by gathering, sharing and enriching contextual data from the target group. Due to their position between the researcher and target group, co-researchers can gain insight into the lives of the users that would not be accessible to lead researchers (van Doorn, Stappers, and Gielen 2013).



## Contextmapping

Twenty-seven vocational students (16 female and 11 male, ages 17 to 26 years) were involved in the contextmapping phase. The participants were purposefully selected from two vocational educational training programmes in an urban area of the Netherlands. They were all second-year students to ensure that they had sufficient experience with the school system, and all studied at the location where the future intervention would be tested and implemented at a later phase of the project, enabling them to remain involved in the research project.

Data generation consisted of an individual sensitizing period and a generative group session. Participants received a sensitizing booklet with exercises to observe their own daily lives and lifestyles for five days (Figure 1). Participants were reminded to do the exercises by the researchers through WhatsApp messages. The sensitizing period prepared the participants for the next step, a generative session of three hours, led by two moderators. In this session, generative techniques were used to help participants to talk about their daily life and specifically about a healthy lifestyle (Figure 2).



Figure 1 Materials from the sensitizing period and generative sessions



Figure 2 Generative session

## Co-design

After the contextmapping phase, four students (1 female and 3 male, ages 19 to 26 years) were involved in the project in the role of co-researcher. These four co-researchers interviewed 17 peers (8 male and 9 female, ages 17 to 27 years) focusing on exercise and dietary habits and their intrinsic motivations in life. The co-researchers then participated in nine co-creation sessions with a researcher and designer over a period of six months. Together they reflected on the interview outcomes, worked on the creation of user types/personas and scenarios and developed intervention components. Informed consent was obtained from all participants in the contextmapping and co-design phases.

## Data analysis

All materials participants generated during the sensitizing phase, generative sessions and co-research sessions were collected. All sessions were audio and video recorded and transcribed. A framework approach was used to analyze the transcripts and materials (Stappers, Sleeswijk Visser, and Keller 2015). Quotes and artefacts were selected, labelled and clustered to identify topics or issues of interest, recurrent across the data and relevant to the research question. To organize the data these topics were used to construct a framework of main themes and subthemes. Quotes that could serve as an example of the themes in the framework were translated to English.

## Results and discussion

Six main themes were identified. These were: healthy/unhealthy behaviour, motivation, peers, home, passive attitude and practical mind-set (Figure 3). Subthemes that served as link between the main themes were; conscious/unconscious, appearance, being cool, context, short-term focus and knowledge.

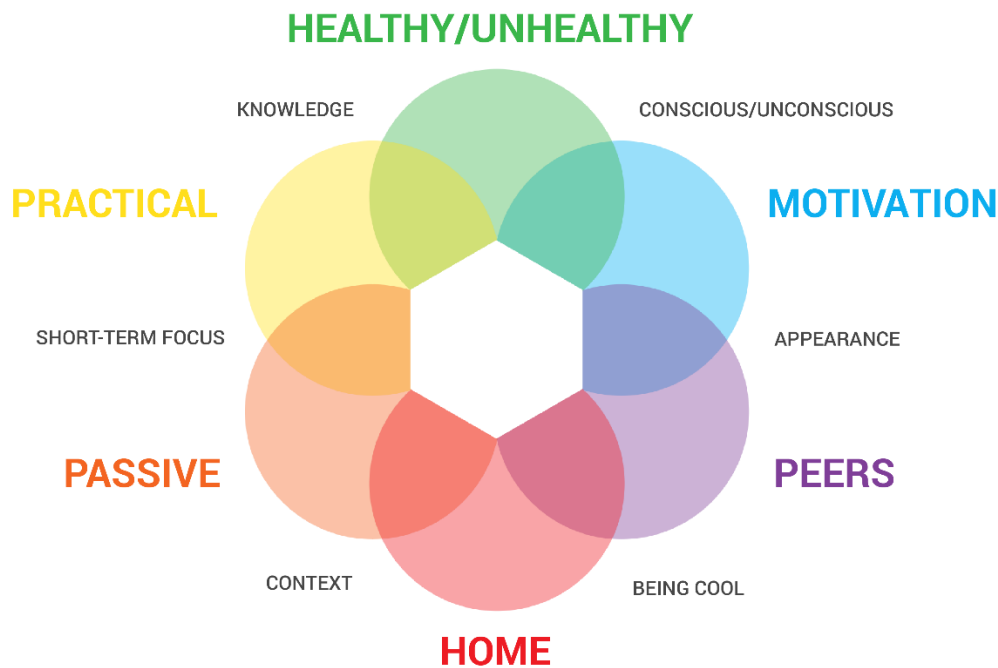


Figure 3 Contextual framework representing vocational student daily life

## Healthy/unhealthy behaviour

Most participants stated that they are not focused on a healthy lifestyle and were therefore less inclined to make a conscious choice in terms of a healthy diet and actions. They often considered their health something to worry about in the (distant) future. Participants stated that their thoughts were along the lines of: 'My body is not that unhealthy now, so why worry?'

It would be another matter altogether if I were fat, but I'm not. So, it doesn't matter.  
(Participant 20)

Even if they wanted to become healthier or more fit, they felt that they often lacked the means and knowledge to make lasting changes to their lifestyle. They also observed that unhealthy food was readily available, either at school or at home.

You intend to eat a small burger, but that usually turns into an entire menu because it is so tempting! (Participant 26)

## Motivation

Participants mentioned that looking good and being similar to peers are very important to them, partly because they think it affects their popularity. Not being overweight seems to be one of the most important factors. When asked, the motives mentioned most often for not exercising or eating

healthily were a lack of time or clearly structured agenda, costs and access to exercise facilities and the fact that eating healthily is not considered 'normal'. Moreover, even if you want to eat healthy, peer pressure often gets in the way. Motives to exercise or eat healthily were belonging to a group/doing this together and the fact that being physically active gave them energy and a way to relieve stress.

## Peers

Most participants try to be among their peers constantly; their phone seems to be an extension of themselves and is part of their social world, as it grants them access to friends even when they are not physically around. Participants said they know they can be influenced by others but, at the same time, observed that they do not act against peer pressure. If one of the group members is tempted to eat something unhealthy, others often join in, even though they might not feel like it at first.

Eating healthy became quite difficult for me because the others sometimes persuade you to go to McDonalds, KFC, etc. (Participant 25)

Eating unhealthily, drinking alcohol and using drugs were perceived as being cool by most of the participants. According to them, it showed that you do not care about later or what others think.

## Home

Most participants lived with their parents and were accustomed to the fact that someone took care of them. However, they often ate alone. Parents were one of the driving factors behind the eating habits of the participants, not only because they usually cooked, but also because parents taught them what 'good' food is. Most participants seemed to think that what their parents cooked for dinner was 'healthy'.

You eat dinner with your mum, right? So it's got to be healthy! (Participant 23)

In many situations, the context seemed to determine how the participants behaved. When at a party, they said it was normal to drink and eat unhealthily and they felt it was uncomfortable to reject cake or drinks. They mentioned two important reasons: not wanting to be different and not wanting to be seen as no fun or not cool.

## Passive attitude

Most of the participants felt as if life was something that happened to them. If something did not go the way they wanted, they often felt it was someone else's fault. Or they said it was just the way things were, not something they could influence. In several examples this caused the participants to give up early on and not even try to solve their problems. Furthermore, most participants thought themselves to be a doer instead of a thinker and therefore did not like to give things much thought in order to understand them.

I knew I was going to end up in a low-level vocational education training programme, so I thought, fine, then I won't make an effort since it won't make a difference anyway. (Participant 21)

## Practical mind-set

Information and classes only seemed of interest to the participants if they understood what they can do with the content in the short term. They mentioned that they prefer practical sessions over theory classes. The same attitude applies to a healthy lifestyle: terms like 'healthy' and 'too much' are too vague to understand. They seem to prefer absolutes such as 'no added sugar' or going to soccer practice on Tuesdays and Thursdays from 7 pm - 8 pm instead of 'exercise for one hour or more twice a week'.

## Relating emergent themes to existing literature

Important contextual characteristics that influenced vocational student lives were their peers, family and short-term motives like being cool and looking good. Furthermore, they often experienced a passive attitude towards daily life, were unaware of their health illiteracy and being healthy was a goal for the distant future.

These contextual characteristics are also described in several studies involving young adults. Young adults are described as having an external locus of control, not thinking about their own actions and being passive or lazy in nature. Furthermore, they show that young adults use incorrect knowledge, believe in myths or do not always understand everything when it comes to health behaviour guidelines. The individual behaviour of young adults seems to be influenced by prevailing social norms which may lead to either healthy or unhealthy behaviours, depending on the norms (Boyd and Braun 2007; Cha et al. 2016; Giles and Brennan 2015).

## Design concepts

All in all, the findings from contextual user research provide a greater degree of depth with regard to existing literature and programme theory (Kremers et al. 2006), enriching the assumptions on the environment-behaviour relationship. We combined these insights into four design concepts:

Firstly, involving senior vocational students as advocates of a healthy lifestyle. Younger students may be influenced by these senior peers to change behaviour.

Secondly, increasing the knowledge of students through social media and posters with simple tips and brief messages focusing on practical information and not directly on changing behaviour.

Thirdly, focusing on the motivation and short-term benefits of their interest, such as earning money, being cool and looking good, and linking this to healthy behaviours. Acting on these motivations may have an indirect effect on health behaviour.

Fourthly, creating a healthy school environment, both with regard to appearance in terms of the available food as well as activities that are already carried out as part of a health-promoting school

approach (Bartelink and Bessems 2019). Students agree that unhealthy foods should not be sold at school.

## Limitations

In qualitative case studies an important indicator of quality is validity, entailing both internal and external components (Bryman 2012). In this study, internal validity is achieved by triangulating the findings using more than one source of data and by involving at least two researchers in every step of the analysis. External validity is promoted by including different groups of vocational students from two different vocational education training programmes in the study. However, the insights acquired through the research are local and primarily serve intervention development and cannot be generalized to other areas without further research.

## Conclusions

The contextual user research methods resulted in rich insight into the experiences, desires, needs and motives for the healthy lifestyle choices of 16 to 27-year-old Dutch vocational students. Based on these insights, the following four design concepts evolved: promoting health as a by-product of activities aimed at student short-term motives, increasing health-related knowledge through social and other media, involving senior students as role models and creating a healthy physical school environment. These concepts converged in a peer-led healthy lifestyle intervention that includes a social media campaign and activities to demonstrate and practice specific health behaviours among vocational students.

## Practical implications

This paper describes the first steps in the process of finding meaningful design directions conducted by a multidisciplinary team that worked iteratively towards the development of a lifestyle intervention targeting vocational students. The team consisted of design and health promotion researchers, each with different expertise and approaches. A combined insight emerged from the rich qualitative contextual user data and existing theoretical frameworks for health behaviour change.

## Acknowledgements

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# Probing the Future of Participatory Healthcare through Speculative Design

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**ABSTRACT** *The aim of this paper is to initiate an interdisciplinary exchange between healthcare and participatory speculative design in order to better understand how patients' self-management may be integrated into future healthcare services. In the paper we introduce a speculative prototype – the Patient Empowerment Kit – that has been co-designed with cancer patients and informed by a number of self-management strategies that these patients have used to cope with their life-threatening disease. In additional ethnographic field studies, Danish health professionals have been invited to use the kit as a way to gain knowledge about patients' self-management and to co-speculate about alternate futures. The contribution of the paper is two-fold: First, we demonstrate how speculative design has a participatory potential to involve health professionals in rehearsing near mundane futures. Secondly, we provide a new frame of analysis that enables design researchers to evaluate empirical material gathered from using speculative prototypes in healthcare.*

**Keywords:** participatory design, speculative design, co-design, design methodology, infra-structuring, design ethnography, oncology, patient-centred care

## Introduction

Cancer patients with limited or non-optional medical cancer treatment often regard self-management and complementary treatment as the only way forward. Interestingly, empirical studies have demonstrated that cancer patients' self-management may have a positive effect on their quality of life and even increase the likelihood of life extension, such as documented in a systematic review of 17 self-management interventions subjected to randomized control studies (McCorkle et al. 2011).

Patient-centred approaches to healthcare have gained much traction in Denmark and other European countries. These approaches are described by a number of interrelated terms such as 'the patient as partner', 'patient-involvement', 'patient empowerment' and 'shared decision making' (Coulter 2011; Castro et. al. 2016). Altogether these terms represent a general aim to let the patients have more influence on the planning and implementation of their own treatment. As such, they seem to align well with the above-mentioned studies documenting a causal link between patients' self-management and well-being. However, some critics have pointed out that often there is a gap between the idea of the patient as partner and its implementation in practice (Riiskjær 2014). In other words, it works in theory, but not in the busy and often stressful environment of hospitals or during doctor-patient consultations under time pressure.

As design researchers we have attempted to understand this dilemma by using participatory design approaches to make inquiries into the hospital's conception of patient democracy as well as detailed inquiry into patient roles and the forming of identity (Knutz et al., 2014; 2017). What we learned is that within public healthcare there is an ambition to move from focusing only on the medical treatment to also include patients' needs, values and wishes. There is indeed a coordinated attempt in Danish healthcare to develop tools for improving health communication and to support doctors and patients in arriving at well-considered medical decisions and evidence-based patient choices. This is reflected in the many shared decision-making tools developed over the years (see e.g. Edwards & Elwyn 2009).

What our fieldwork also shows, however, is that when patients actually assume responsibility and decide, for example, to complement medical treatment with complementary treatment or – more radically – opt out of a hospital's treatment offer to pursue alternative treatment - the positive effects of their self-management strategies are rarely shared with the healthcare system. What patients do on their own, how their self-management improves their life quality is generally not brought up in doctor-patient conversations, and health professionals have difficulties knowing how to handle it. Hence, the potential of patients' self-management remains underexposed.

The purpose of co-designing the Patient Empowerment Kit with cancer patients is precisely to address the difficulty in grasping this potential. The prototype seeks to expand the notion of 'healthcare treatment' to range from care we receive from professionals (formal or informal care) to treatment we can administer to ourselves. The kit can be conceived as a research tool based on empirical insights from cancer patients involved in participatory activities - but at the same time it is speculative, as we have invited health professionals in our fieldwork to use it in rehearsing and researching a possible future based on the following speculative framing:

What if, patients' self-management was an integral part of medical care strategies - enabling healthcare professionals and cancer patients to coordinate medical practice with patients' selfcare, everyday lives and concerns?

In so doing, we move speculative design out of the gallery into the field, addressing the legitimate critique; that the approach lacks interest in providing participatory means to help designers and non-designers to visualise near, mundane futures. Moreover, by using a speculative prototype to capture health professionals' assumptions about patients' self-management, we are able to identify some of the practical, organisational and personal barriers for accommodating self-management in patient-centred care.

The paper has three parts. First, we position our research in the landscape of related work focusing on how speculative design can be combined with participatory approaches and the need to find ways of evaluating insights gained through this mixed methodology. Next we provide details on our case project and our method of inquiry. The summary outlines how we can build a framework of analysis that integrates the methodology ('participatory speculation') and the evaluation. This conceptual model will assist us in understanding how patients' self-management and self-care might integrate into future healthcare services.

## **Related Work: Participatory Speculative Design – Engaging People in Things that are – and in Things to Come**

Speculative design – and related approaches such as critical design and design fiction – have been heralded for allowing designers to step out of the solutionist paradigm and instead using design to query the often unquestioned socio-cultural consequences of emergent technologies, science and innovation (Dunne and Raby 2013; Auger 2013). However, speculative design has also attracted much criticism for being too absorbed with distant techno-centric scenarios, elitist problems of the global north, and speculative prototypes ending up in galleries as conceptual showpieces of the genius auteur-designer (Rosenbak 2018; Strachan 2016).

Counter to this critique, design researchers have, in fact, been interested in how speculation and fiction in design can increase end users' engagement in co-design (Blythe and Wright 2006), or be valuable for making inquiries into people's mundane everyday settings and social life (Hunt, 2017; Wakkary et al. 2015; Markussen, Knutz, and Lenskjold forthcoming). Others have argued for merging speculative design with participatory approaches, for instance, by exploring complex socio-technical issues (Forlano & Matthew 2014) or enabling vulnerable groups such as the elderly, diabetics and children of prisoners to take part in research expressing dilemmas that traditional methods within ethnography have difficulties capturing (see e.g. Knutz, Lenskjold, and Markussen, 2016; Hoang et al. 2018; Tseklevs et al. 2019).

These contributions have demonstrated that speculative design approaches can be fruitfully integrated with participatory design. Typically, participatory speculative design manifests itself in the form of co-design activities where people are invited to engage with speculative prototypes (e.g. through the means of what-if scenarios, diegetic objects, fictional characters, etc.). Thus, the speculative prototype becomes a research artefact that helps generate insights and discussions among researchers and participants through a continuous process of crafting and co-exploring the

speculation. However, a legitimate critique is that much of this work is appreciated simply for succeeding in involving people in early idea generation or spurring critical reflection and debate on a given matter of concern, while the ability of participatory speculative design to effect real change is ignored.

In order to accommodate this critique, we argue that the central challenge for participatory speculative design (PSD) consists in bridging the gap between methodology and evaluation. How do we design an evaluation study that goes beyond merely observing that speculations may enhance people's engagement or appreciating debate and critical reflection as achievements in themselves? What kind of insights can we gain from PSD? How are these insights adopted and used in further research? What can we possibly learn from people engaging with speculative artefacts? Blythe (2014) points out that we need to be critically aware of how we frame and define the purpose of using speculative prototypes in design research.

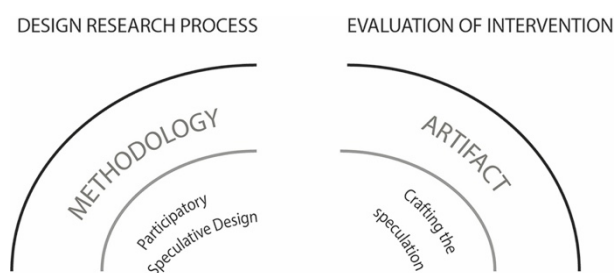


Figure 1: The gap between methodology and evaluation

Various sources offer conceptions of how we may understand the evaluation of speculative artefacts used in participatory design research. One way forward is to conceive of one's evaluation study as a 'design ethnography of the possible' – a way of rehearsing the future through co-exploratory and performative activities (Halse et al. 2010). While, traditionally, in ethnography, observation and interviews are used in fieldwork to understand existing situations and practices, doing design ethnography of the possible allows researchers to delve into speculations of what might be, and the barriers and possibilities for people's shaping and projection of (near) futures (Halse 2013). However, this approach is usually concerned with evocative and 'open-ended' materials that participants can interact with in the 'fuzzy front end' of an explorative design process, offering little understanding of how semi-functional speculative prototypes that have gone through numerous co-design processes can be evaluated in messy everyday settings and practices whether in public or private contexts.

However, such an understanding can be modeled upon recent developments within participatory design, notably the notion of agonistic infra-structuring as introduced by Björgvinsson, Ehn & Hillgren (2010; 2012). 'Agonistic' is a term they borrow from Chantal Mouffe's political philosophy referring to the idea that public spaces (including hospitals) are 'battlegrounds.' (Mouffe 2000). Decisions carried out in these spaces are 'temporary and precarious articulations of contingent practices' (Mouffe 2007) and they never reflect the only 'good' solution. Instead, Mouffe argues that 'Things could always be otherwise and therefore every order is predicated on the exclusion of other possibilities' (Mouffe 2007). From this perspective, public spaces are always political spaces,

structured by hierarchies, dominant groups or views that need to be contested to make different possibilities for the future visible and debatable. The challenge within this conceptual framework is how one can support a multiplicity of voices, while at the same time understand how to transform antagonism (conflict of opposing views) into agonism (acceptance of opposing views). According to Björgvinsson, Ehn and Hillgren this is, however, what infra-structuring is all about.

By using 'infra-structuring' rather than 'infra-structure', the authors underline that participatory design in public spaces should ideally be thought of as an open-ended process (beyond the termination of 'the project'), where designers contest and negotiate multiple, divergent (and sometimes even incompatible) stakeholder interests. From this perspective the prototype is conceived of not as a physical thing but rather as a non-human actor in a network of 'socio-material relations where matters of concerns can be dealt with' (Björgvinsson et al. 2010). Making interventions with prototypes and letting people engage with them becomes a way to express opportunities as well as dilemmas. By continuously making conflicting interests visible, the prototype becomes a thing to think with – and a thing to act with. It is performatively described as a verb 'thinging' rather than a noun 'thing'. By basing our model on this notion of agonistic infra-structuring, we acquire analytic concepts and tools for evaluating how speculative prototypes can be used to probe future practices in complex contexts.

## **Case: A Self-aid Kit for Cancer Patients**

### **Context and design**

The development of The Patient Empowerment Kit (PEK) is part of an EU funded research project (2015-21) which aims at developing concepts that can strengthen cancer patients' sense of well-being and life quality. The prototype has been co-designed with cancer patients that have received conventional, complementary or alternative cancer treatment. It is inspired by a number of self-care strategies that these patients use in their everyday lives to manage or control their life-threatening disease. More specifically, the kit is co-designed to accommodate personal values; provide insight into and an overview of the life one needs to get started 'as a patient' (in a general sense); support and strengthen one's own personal strategy and align one's own strategies with medical treatments (fig.2).

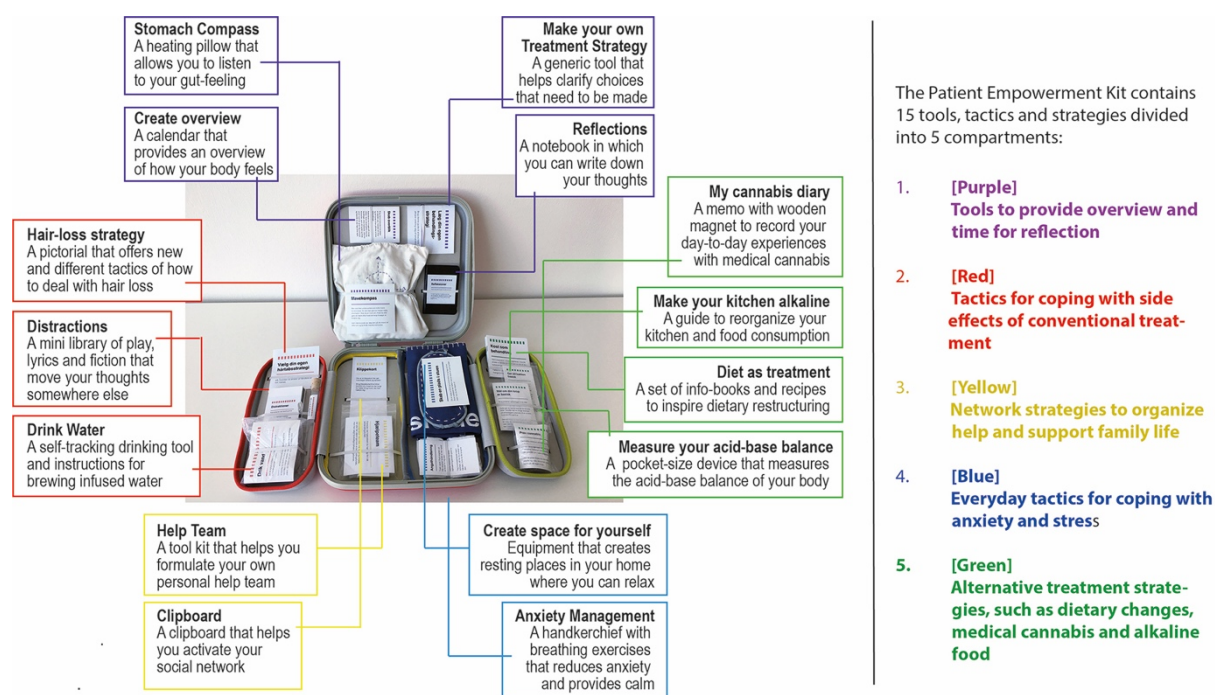


Figure 2: The Patient Empowerment Kit (PEK)

## Protocol for intervention and evaluation study

The intervention and evaluation study aim at understanding how the kit could be integrated into future healthcare services in Denmark and Germany. For that reason, two evaluation protocols have been developed, one for healthcare professionals (working in Denmark and Germany) and one for patients (living in Denmark and Germany). In this article, we focus exclusively on the protocol related to healthcare professionals (fig.3)

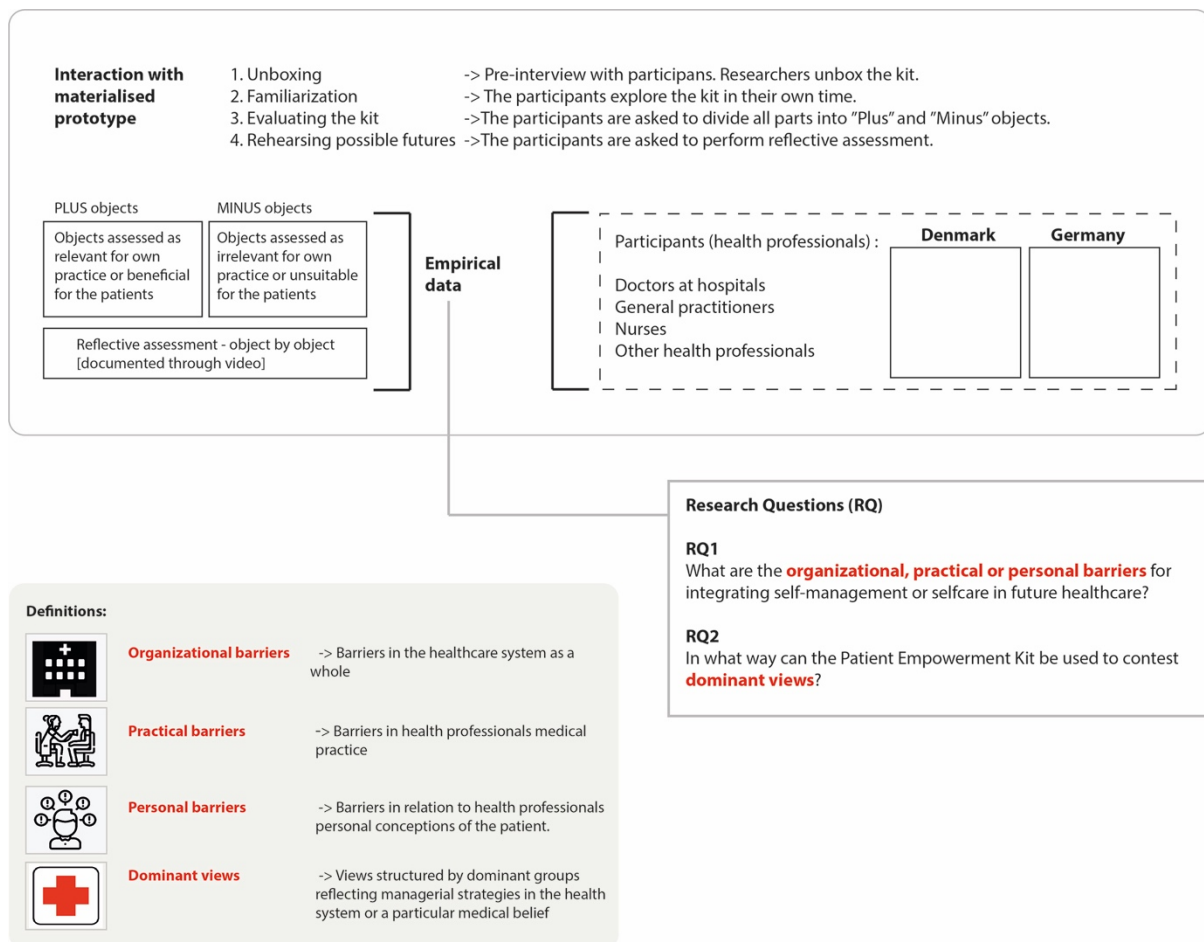


Figure 3: Protocol for health professionals

The intervention starts with a pre-interview to understand the practice of the participants and to 'unbox' the kit. Having familiarized themselves with the content of the PEK, the participants are initially asked to evaluate the content in the kit, based on what they think is beneficial for their own practice or beneficial for the patients (positive need assessment). These are all marked with a 'plus' label.

Secondly, they are asked to evaluate what they consider to be irrelevant for their own practice or unsuitable for the patients (negative need assessment). These are all marked with a 'minus' label.

Finally, they are asked to 'rehearse' a particular future for each object in the kit, in other words, reflect on their 'plus/minus' assessment and explain in more detail – object by object – their specific reason for evaluating a particular object (tool, tactic or strategy). Thus, by continuously aligning partly conflicting interests, we allow the kit to become a thing to think with – and a thing to act with. The latter is recorded on video, as demonstrated in figures 4a and 4b.



## Analysing empirical material

The aim of the analysis is to identify some of the organizational, practical or personal barriers for implementing the PEK in the future and to make different possibilities for the future visible and debatable by contesting dominant views.

The visual analysis below concerns the empirical material from a general practitioner (GP). In the left vertical column, the video footage is organized object by object with the transcripts. In the right vertical column, barriers and dominant views are identified, based on the GP's positioning.



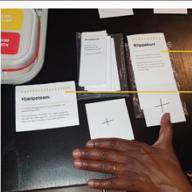
Interaction with prototype "THINGING"	INTERVIEW DATA	Organizational barriers	Practical barriers	Personal barriers	Contesting dominant view
	<p><b>About Stomach Compass:</b> "I believe this [tool] is super positive. Because when the patient is diagnosed with cancer [during the consultation] - they rarely hear what is told afterwards" [...] "It is good when they can take a break... and when they can give themselves time to think about all the information that has been given" [...]"</p> <p>"It is also about taking control and maybe owning one's diagnosis... so that the patient can understand that they are the ones who are at the centre"</p> <p><b>About Make your own Treatment Strategy:</b> "I don't have the impression that patients understand that they can develop their own treatment strategy [...] they understand it as something the doctor says they must do [...] But maybe they will go home and try to understand that they have to participate in the treatment strategy"</p> <p><b>About Create overview:</b> [...] "Overview is often missing throughout the course. Patients don't understand it - perhaps because there are too many involved. That's the way it is organized with cancer treatment in the healthcare system"</p> <p>"There's an incredible number of health professionals involved; from one's own doctor, to a cancer doctor, to various examinations. Often there are several hospitals and departments involved from start to finish"</p>	<p>The healthcare system consists of a network of different specialists and departments, which makes it difficult to maintain the overview</p>	<p>The GP's communication strategy does not seem to work. One cannot listen to additional information while receiving the diagnosis of a life-threatening disease</p> <p>The GP either questions the patients health-literacy or the patients awareness of self-management opportunities</p>	<p>The GP assumes that patients wish to own their diagnosis</p>	<p>How does one take ownership of something, one doesn't want to own?</p> <p>Why is the planning of the patient's treatment strategy not a collaboration between patients and health professionals?</p> <p>How is medical knowledge shared between the patient and the medical stakeholders to ensure continuity and progress?</p>
	<p><b>About Hair-loss Strategy:</b> "There will be a loss of hair. And there is actually being talked a lot about this with the cancer patient - in the health care system. Because people find it difficult. So, I think that this part is taken care of. Perhaps more than all the other stuff ..." [points to all the other stuff in the package]</p>	<p>The healthcare system is more focused on the effect of chemo-therapy than other issues</p>			<p>Why have hospitals decided to focus more on the effect of chemo-therapy than other issues? What managerial decisions and medical beliefs does this reflect?</p>
	<p><b>About Help Team &amp; Clipboard:</b> "This one may require a special personality; to want to have such control over things" [...]"</p> <p>"Here I think the family members could help and be involved... Because relatives feel left out... They don't know what to say and how to help ... and they don't know what the patients are going through. And the cancer patients may also find it difficult ... not having the advantage of talking to their loved ones, their husband and their children"</p>	<p>The family and the relatives are left out the entire treatment strategy</p>		<p>The GP assumes that not all patients are capable of organizing their course of treatment and taking control of their own progress. It requires certain personality.</p>	<p>Why does one need a certain personality to be able to organize and take control of one's own course of treatment? Why isn't it something everyone can learn?</p> <p>Why are relatives not more involved in the patient's treatment strategy?</p>

Figure 4a: Visual analysis (continued in figure 4b)

Interaction with prototype "THINGING"	INTERVIEW DATA	Organizational barriers	Practical barriers	Personal barriers	Contesting dominant view
	<p><b>About Anxiety Handkerchief:</b> "Extremely relevant. Even those patients who are not vulnerable get anxious about not knowing what's coming.... [...] There is often a psychological reaction .... It is good that people know [that it may come] .... and don't become afraid to let go and to tell that they are afraid of dying..."</p>		The GP assumes that many cancer patients are affected by existential anxiety - but it is unclear if this is an integrated part of the doctor-patient communication	GP assumes that patient wants to talk about dying	How is existential communication part of the doctor-patient consultation?  Why does the GP assume that the patient wants to talk about death? Why not talk about survival?
	<p><b>About Diet as Treatment:</b> "[...] Alternative treatment is both plus and minus" "Plus, because one should not take the patient's choices away from them. Everything that helps, you should listen to ... as doctor or as family. And if it helps the patient and if they can cope talking about it ... and if they feel they take control, then it's very positive"</p> <p><b>About Diet as Treatment:</b> "Minus, because I don't want to talk to them as a doctor about this. I'm not trained in this, so it's not something I know anything about" [...] "I do not want to talk to the patient whether they should [go that way] or not. It is also minus because it can take focus away from what can (actually) help the patient"</p>	The GP can't talk about the patient's choices, if these falls outside the conventional treatment and what is offered by the hospital	The GP lacks knowledge of diet as treatment. It is not part of her training	The GP looks at the patient as a person one should listen to - but what is being said one does not need to act on.  The GP does not believe in alternative treatment.	Why is it not possible for the GP to talk about choices that fall outside the conventional treatment?  Who should the patient turn to when the conventional treatments have no effect?  What medical beliefs underlie what is considered to be the "correct" treatment?
	<p><b>About the kit in general:</b> "The whole package is a huge plus [...] Everything is relevant for my practice" "I think it would be super if they [the patients] could get it in the beginning [...] But we have to find out how it's introduced [...] In general practice we only have 15 minutes per [doctor-patient] visit"</p> <p>"When the patients come here and I pass them on because I suspect a cancer diagnosis, this is not the time to introduce the package because the diagnosis needs to be confirmed first. And the vast majority - once their diagnosis is confirmed - I don't see - until they are really far in the process [...] The ones I see [later] are the ones who are terminally ill - where nothing more can be done. Here it might be too late to talk about this package ... some of it of it, at least."</p>	GPs have only 15 minutes per patient   GPs are typically involved in the early onset, before the diagnosis is given, and then late - during the palliative phase			Why are GPs only allowed 15 minutes per patient?  Why can't time be set aside - if more time is needed?  Who defines how much time one patient needs?  Why doesn't the GPs practice assume a more integrated part of the patient's overall treatment?

Figure 4b: Visual analysis (continued from figure 4a)

Through our analysis, we gain insights into the agonistic infra-structuring of patients' self-management (as materialized in the kit), a general practitioner's practice and the underlying organizational structures. Based on this we can summarize our empirical findings in the following frame of analysis:

#### DESIGN RESEARCH PROCESS

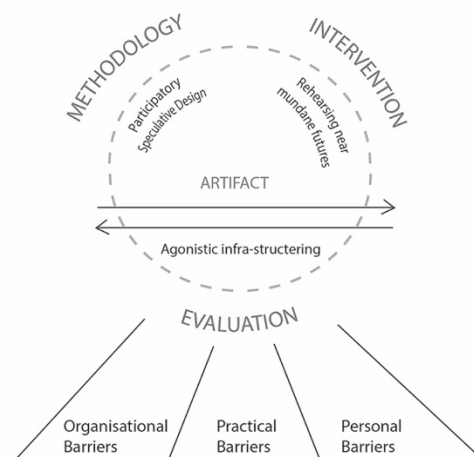


Figure 5: Conceptual model – Bridging methodology and evaluation

Our design research process is depicted as a cyclical, iterative process of agonistic infra-structuring which involves three main research foci of attention: methodology, intervention and evaluation.

The methodology is mixed and focuses on ways in which participatory design and speculative design can be brought together in the process of co-designing the empowerment kit with cancer patients.

In the intervention the focus turns to how the kit can be brought into the design ethnographic study of health professions rehearsing near futures.

Evaluation refers to subjecting empirical data to further analysis and identification of possibilities and barriers (organizational, practical and personal) for integrating patients' self-management into future healthcare practice.

By tying together these three foci of attention, we argue that participatory speculative design can be developed beyond the limitations that the approach has rightly been criticized for and become a bridge between methodology and evaluation.

## Concluding Remarks

In this paper, we have demonstrated that participatory speculative design can be of value for ethnographically oriented studies of future conditions for increasing oncological patient-centred care. More specifically, we have inquired into the possibilities of making patients' self-management an integral part of healthcare practice.

The main purpose of the design and intervention study is to allow conflicting voices to be heard and to provide space for cancer patients' individual and personal strategies, regardless of the type of treatment chosen. In allowing these voices to exist side by side – rather than striving for consensus (about 'good care') – the intervention aims at agonistic infra-structuring rather than a space for 'problem-solution.' We are studying this by letting a co-designed speculative prototype return back into the field – into the hands of healthcare professionals. By analyzing the preliminary results, we provide a new frame of analysis that enables design researchers to evaluate empirical material gathered from using speculative prototypes in healthcare. The model will be applied in our continuous design ethnographic field studies and will inform our further design strategy and attempts to transform antagonism (conflict of opposing views) into agonism (acceptance of opposing views). In addition, it will assist us in understanding how patients' self-management might be integrated into future healthcare services.

## Acknowledgements

We would like to thank all patients and health professionals for sharing their experiences with us. This work was supported by EU's Interreg 5a program [grant number 07-1.0-15].

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# Creating a shared 2030 vision: design for change map for Neonatology Amsterdam UMC

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*[ABSTRACT only] The VU university medical centre (VUMC) and Amsterdam Medical Centre (AMC) are two hospitals that are in a merger to become the Amsterdam University Medical Centres (Amsterdam UMC). Different departments will be located at either one of the two hospitals and one of the first departments to merge and move is Neonatology. Over the next few years the AMC will be renovated. With all this change ahead, there was a need for overview and alignment of a shared vision to reach with the VUMC and AMC Neonatology nurses, care assistants, doctors and management. Research question: What does the merged neonatology department want to reach together in the future?*

*Method: Via a research through design study, a corporate vision and change map were created for the Neonatology department. From design research into trends, developments and stakeholder needs, earlier vision documents, and with an eye on the larger Amsterdam UMC vision, a renewed corporate vision was created. Small creative sessions were held with nurses, care assistants, management and doctors from both the VUMC as AMC location. In these sessions, a desired state was imagined, see figure 1. After defining and validating the shared vision, a change map was created. The already planned change and gaps were mapped in sessions with nurses and management from both hospitals.*



Figure 1: A creative session with nurses at the AMC hospital about a desired future for 2030

The change map was created to show how to reach the corporate vision together with proposed innovations.

Table 1. Sample of participants

Sample	Caretakers	Parents of prematures
Involved in vision phase	42	
Involved in change map phase	38	3

Results: The new vision is: “delivering the best care which is child- and family centred”, see figure 2.

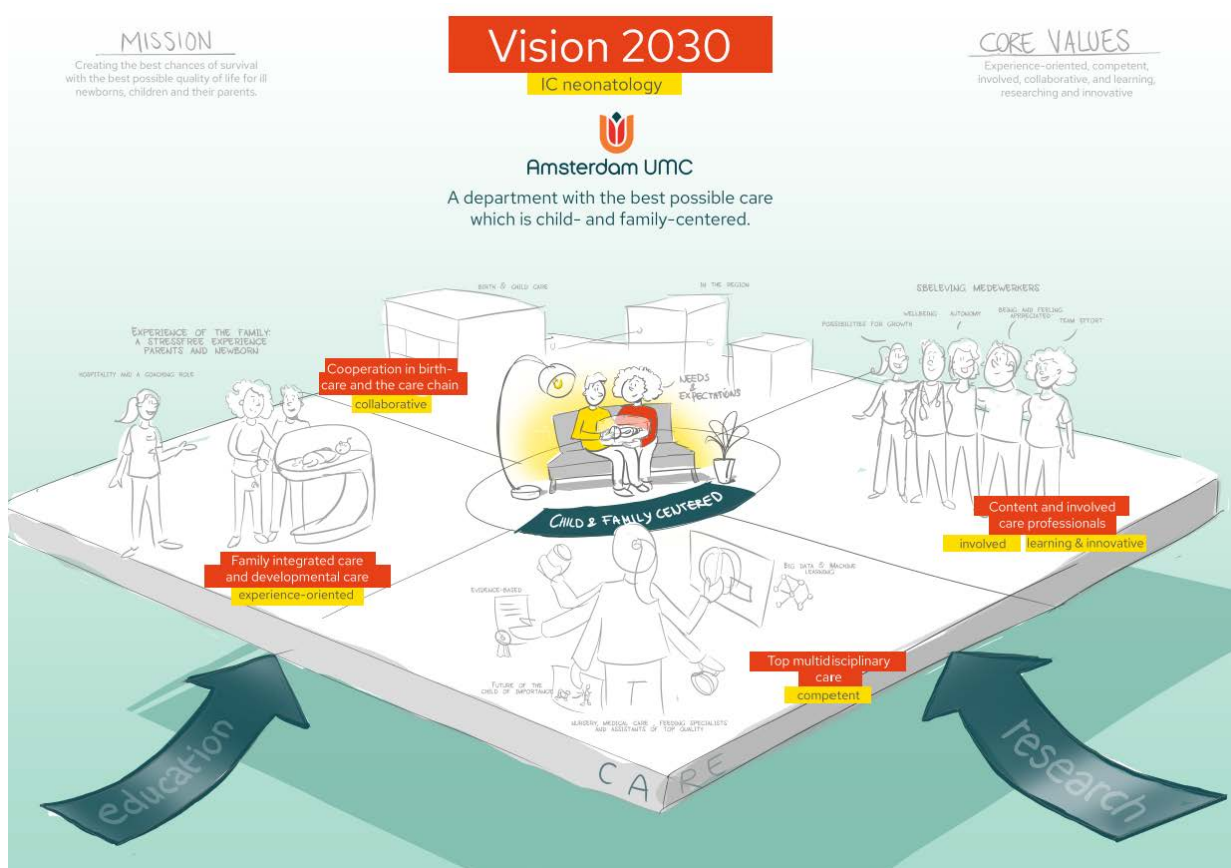


Figure 2: the new shared vision for Amsterdam UMC IC Neonatology



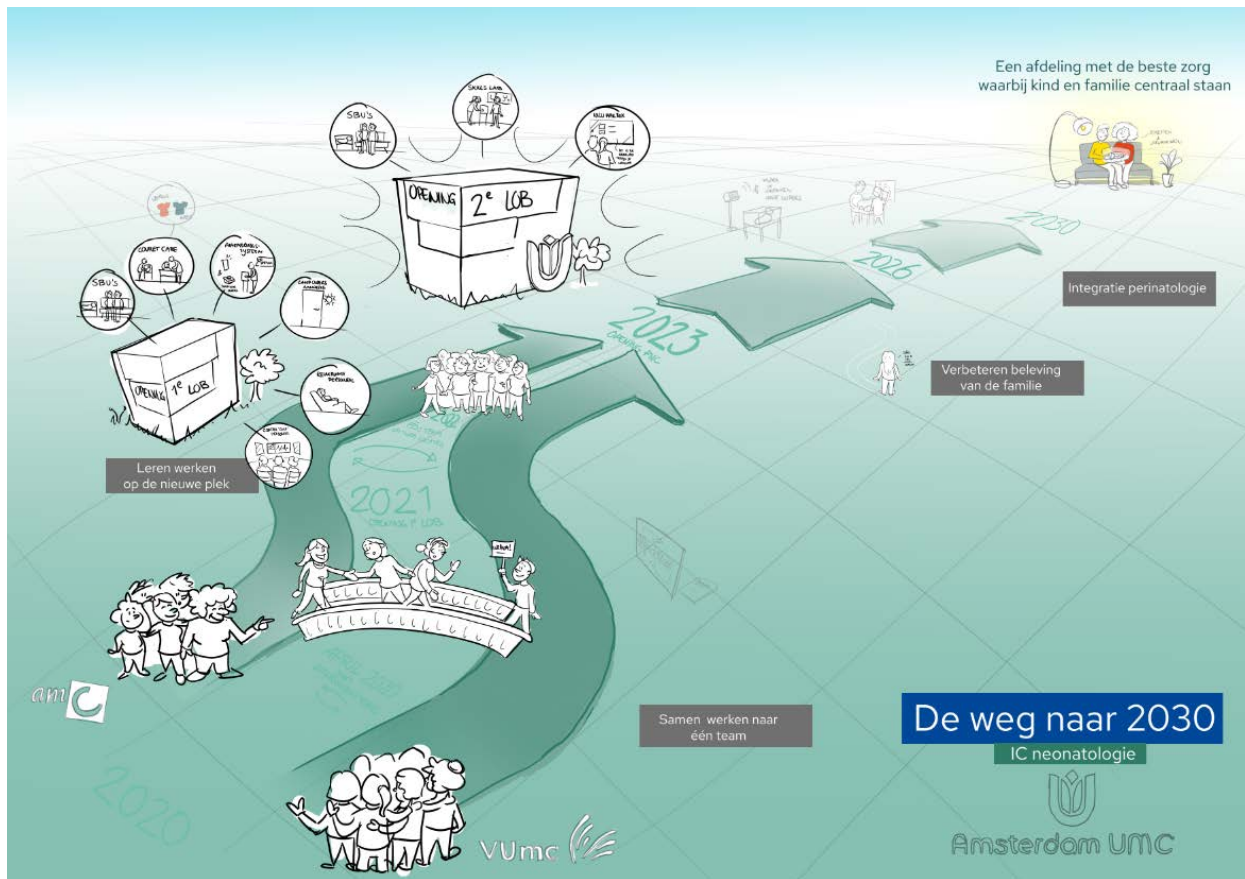


Figure 3: First version of the change map

*As family-centredness is now key in the shared corporate vision, ideas were created to improve employee and family experience in several horizons in an innovation roadmap. These innovations combined with the already planned change together form the change map for the department, see figure 3.*

Keywords: Strategic design, neonatology, design for change, design roadmapping, future vision.

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# Circular Community Concept for Health and Care

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**ABSTRACT** *As the Sustainable Development Goals (SDGs) have become popular in guiding policy and programme planning, we critically examine its role in addressing underlying systemic challenges when it comes to ensuring the health and wellbeing of vulnerable people in conjunction with the social determinants of health framework. In addressing the incongruencies in sustainable development and public health theory with practice, we turn to look at design approaches – in particular, the design of circular systems (circular systems design) in the circular economy – to reconcile the gap in theory and practice through a systems lens. Businesses and the built environment industry have demonstrated a growing interest around circular economy concepts in favour of reducing and reusing resources through designing out waste; we expand this interest to consider circular systems in health community design from the built and physical to socioeconomic environments. The case for circular systems in the social and economic realms to address health, wellbeing, and the healthcare industry has been less studied. Through examining the concepts behind the development of eco-community projects, especially those emphasizing elements of health and care, we consider a new paradigm for a whole system approach in the design of healthcare facilities to health and care services provision.*

**Keywords:** sustainable community development, health and wellbeing, systems design

## Sustainable Development – A Systems Approach

Sustainable development is often associated with ecological-conscious development itself, with issues such as environmental conservation and recycling first coming into mind. However, if we consider the definition of sustainable development as described in the World Commission's Brundtland Report (World Commission on Environment and Development 1987), sustainable development is essentially anthropocentric, noting the goal of development is

to ensure that it meets the needs of the present without compromising the ability of future generations to meet their needs.

The tripartite structure of sustainable development is to consider the environmental, social, the economic realms, and the interactive nature of these systems is emphasized.

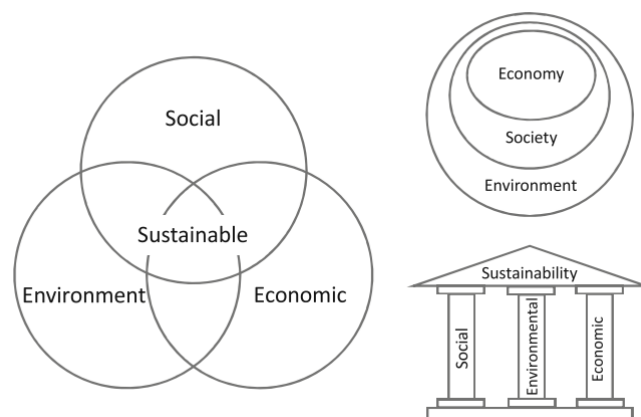


Figure 1: Pillars of sustainable development. Purvis 2019.

While the famous Venn diagram of the three interlocking circles of environment/social/economy have often been used to represent the three pillars of sustainable development, the exact relationship between these three 'pillars' is a perplexing matter, as reflected in the different iterations of the diagram in Figure 1 above. The apparently utopic holistic systems approach has often been critiqued to be vague – without much specific guidance to operationalize each area and how they intersect in practicality (Purvis 2019).

Yet systems thinking plays a crucial part in the evolving area of sustainable development. Boulding (1956) points out the necessity of General Systems Theory to allow for a framework of thinking that is applicable across disciplines, enhancing communication between scientists and scholars of different fields as they have become increasingly organized into 'isolated subcultures' of disciplinary siloes. Sustainability, as it concerns the environmental, social, and economic realms, is no doubt an interdisciplinary project.

Environmental sustainability often takes the spotlight in the sustainability conversation. Social and economic sustainability requires the global issues of exploitation and unequal development to be addressed. A less frequently quoted paragraph in the Brundtland Report (1987) reads:

...sustainable development requires that societies meet human needs both by increasing productive potential and by ensuring equitable opportunities for all.

While the Brundtland Report reads as such, Raco (2005) discusses the dissonance between development agendas that support neoliberal policies and market-driven practices, and the theory in sustainable development literature that calls for social justice, environmental conservation, and democratic empowerment. Although the sustainable development literature employs a holistic systems approach in analyzing the problem, in practice, development activities once again fall back into the established status quo of unidimensional behaviours and responses.

Organizational inertia continues to be a major impediment to greater change in policy and programming that can truly address underlying inequities that affect the most vulnerable people – from infrastructure, energy, construction, to agriculture and healthcare. Swilling and Anneck (2012) write in *Just Transitions*:

These sectors are dominated by large corporates configured as a set of value chains which are designed, specified, financed and managed by people trained to think in ways that reinforce the logic of these value chains, and their personal material interests are tied to tried-and-tested technologies embedded in these systems.

## Social Determinants of Health

The Social Determinants of Health framework to public health has gained traction since the 2000s as a similar systems approach from the sustainable development literature is used to understand and tackle issues in the area of population health.

The WHO currently defines the Social Determinants of Health as ‘the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life. These forces and systems include economic policies and systems, development agendas, social norms, social policies and political systems’ (WHO 2017). In other words, the social determinants look at a large subset of underlying systems, such as economic stability, education, health access, health systems, social context, the built environment, housing, public safety, and the natural environment.

While the field of public health has historically focused on medical interventions and treatment - mostly tackling disease, injury, mortality, and individual behaviours - the social determinants of health approach attempts to drive the field of public health to engage upstream in an extensive multi-sector transdisciplinary project. This is used to begin to address the problems found in the physical, social, service, and economic environments, along with its root causes in social and institutional inequities, as seen in the figure below (Bay Area Regional Health Inequities Initiative 2015).

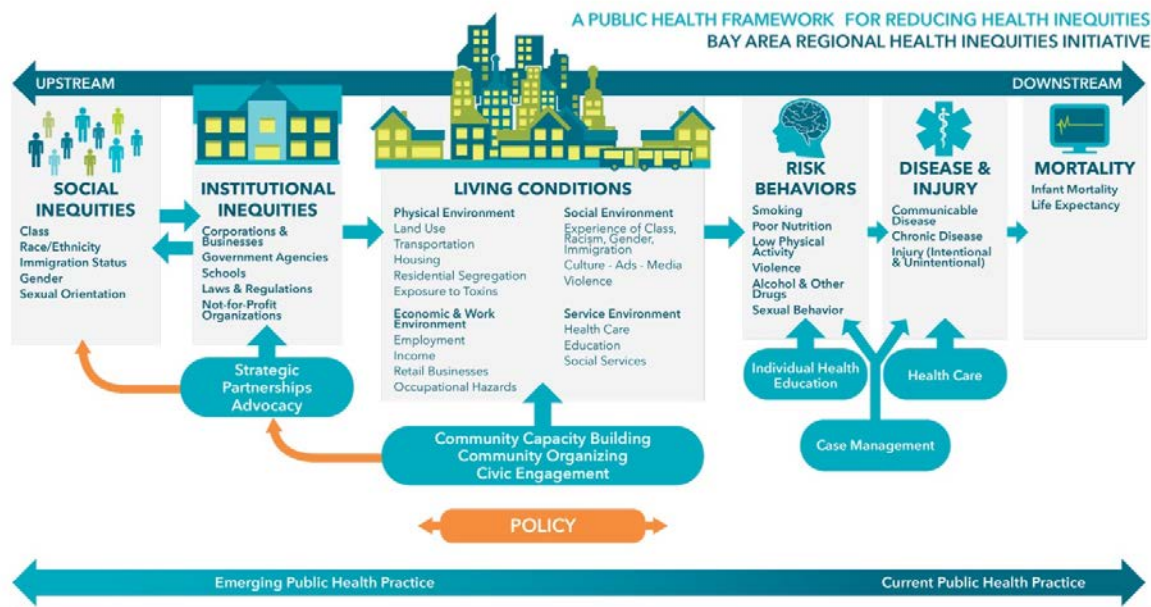


Figure 2: A Public Health Framework for Reducing Health Inequities – Bay Area Regional Health Inequities Initiative. Bay Area Regional Health Inequities Initiative 2015.

As the *Health and Wellbeing* goal in the Sustainable Development Goals (United Nations 2015) aims to address public health issues, the sub-goals all pertain to traditional areas of public health in treatment and prevention of diseases, injuries, and mortalities – with the exception of perhaps the aim to attain universal health coverage and concerns with the effects of pollution and contamination.

Once again, we observe the incongruity between theory and practice in the area of sustainable development and health/healthcare. In a scoping review on the public health sector's role in addressing health inequities, Cohen and Marshall (2017) find that although there is advocacy in the public health sector to address root causes of health inequities via theoretical literature and professional practice guidelines, the review of empirical literature show that public health practices however do not widely address the root causes.

Furthermore, while the sustainable development and social determinants of health literature try to speak to issues of health and wellbeing, less has been said to address the healthcare sector. Nevertheless, the WHO (2017), published *Environmentally sustainable health systems: a strategic document* outlining the following principles:

- overarching action: adopting a national environmental sustainability policy for health systems;
- minimizing and adequately managing waste and hazardous chemicals;
- promoting an efficient management of resources;
- promoting sustainable procurement;
- reducing health systems' emissions of greenhouse gases and air pollutants;
- prioritizing disease prevention, health promotion and public health services;
- engaging the health workforce as an agent of sustainability;

- increasing community resilience and promoting local assets;
- creating incentives for change; and
- promoting innovative models of care.

Most of the principles adhere to creating more environmentally sustainable infrastructure in the healthcare industry. The document proceeds to offer vague suggestions for how each principle can be operationalized by supporting or making minor revisions of existing practices. The following is suggested for ‘promoting innovative models of care’, lacking any sort of systems-oriented re-design:

- changing emphasis and improving coordination between primary, secondary and tertiary levels of care;
- encouraging the use of innovative technologies, including telemedicine, ehealth and mobile health; and
- changing clinical guidelines/standard operating procedures to reflect environmental sustainability.

In the quest to build a better living environment for all – especially for those with vulnerabilities or disabilities who have been historically marginalized, national public health strategies often fail to address the underlying social and economic structures that are the root problems. As national public health policies are drafted by governmental agencies operating under a larger socio-political context, the difficulties for the public health sector to go further upstream are apparent. In a later section, we see how various groups have taken the matter into their own hands in eco-community projects, experimenting with alternative socioeconomic systems to attain better health and wellbeing and caring for all.

## Circular Systems Design

Design methodologies have rarely been utilized to draft public health interventions - including the provision of healthcare services - as public health is often under the scope of top-down policy and programming engines. Circular systems design responds to the complexity of systems, and helps drive comprehensive strategies that respond to interrelated issues across different actors and sectors. While the circular systems design approach is prevalent in circular economy literature and practice has been mainly used to redesign products and businesses, it offers a space to re-imagine the space of healthcare and healthcare services provision.

## Circular Economy

The circular economy concept is rooted in theories of industrial processes and economic systems, aiming to reconfigure the traditional linear economy in which products follow the timeline of ‘produce-use-dispose,’ into a new circular system of production and consumption in which materials and resources are in use for as long as possible through re-use, recycling, repurposing, and other methods. The circular movement of materials illustrated in the circular economy concept mimics the biological metabolism of nature, where no materials are wasted per se, but are fed back into productive organs, thus regenerative.

The foundational principles of the circular economy are cross-derivative of concepts that have been gaining traction since the 1970s such as Sustainable Development, Green Economy, Performance



Economy, Life Cycle Thinking, Cradle-to-cradle thinking, Industrial Ecology, and Ecodesign (World Economic Forum 2018). Current circular economy scholarship and activity focus on analysis in the field of industrial ecology in areas of industrial process planning and implementation, product design, recycling, and waste management, with the overall goal of ecological sustainability (Merli, Preziosi and Acampora 2018).

Medkova and Fifield (2016) write that ‘Design in the circular economy is complex and requires a transformation in thinking, to shift ‘from the current product-centric focus towards a more system-based design approach.’ In the Royal Society for the Encouragement of Arts, Manufactures and Commerce (RSA)’s action research project ‘The Great Recovery,’ the RSA worked closely with businesses and designers examining processes and educational tools to inform broader circular design implementation. The diagram below illustrates the exercises on life cycle and stakeholder mapping, showing the complex interacting elements that play into a product’s entire life cycle. The circular systems design approach responds to the complexity of global supply chains and helps identify actors and processes that require intervention to enhance sustainability and circularity of material flows (RSA 2016). While such design processes have been used for manufacturing within the circular economy context, this can be adopted for the design of healthcare systems and interventions.



Figure 3: Four Design Models. RSA 2016.

Based on a detailed product-level modelling study, the Ellen MacArthur Foundation (2014) estimates a net materials cost savings of up to 19 to 23% of current total input costs if an ‘advanced’ circular economy is implemented. The design of circular material flows can help capture significant cost savings and generate affordability if the benefits are captured by users/consumers. In the areas of health and social care where there is a consistent challenge of decreasing funds (King’s Fund 2018), such cost savings can be significant. As explored in the next section, circular systems in production within eco-communities play an important role in creating a regenerative environment for the community in ecological as well as socioeconomic aspects.

## Eco-communities and Health

Eco-communities are loosely defined as sustainable community projects that span from urban to rural ecovillage, eco-neighborhood to eco-city projects. Eco-community projects vary in their characteristics and governance, the use of automobiles, and technology. For most smaller scale projects such as ecovillages, the heart of eco-communities is the concept of mutual support and living as a community (Barton 2000). Permaculture and the production and consumption of food is also a significant aspect frequently found in eco-communities, as is community managed utilities. The Global Ecovillage Network (GEN) describes the whole systems approach of ecovillages in ensuring social, cultural, economic, and ecological sustainability – reflective of the sustainable development pillars (Global Ecovillage Network n.d.).

In a qualitative comparison of ecovillage approaches, Hall (2015) presents the following twenty elements of ecovillages that contribute to a high level of wellbeing:

- Pooled Economy
- Limited Hierarchy
- Inclusive Decision Making
- Conflict Resolution
- Inclusiveness
- Celebration
- Self-development Practices
- Deeper Personal Relationships & Openness
- Ecologically Responsible Behaviours (ERBs)
- Proximity to Nature
- Shared Work
- Work-Life Balance
- Emphasis on Arts & Culture
- Child-centered Perspective
- Healthy Food
- Physical Activity
- Physical Contact
- Dimensioned Communal Group
- New Values & Common Worldview
- Environmental Activism

Hall further explains that the efficacy of ecovillages in providing wellbeing lies in the combination of built, human, social, and natural capital. The built and natural environment provides benefits associated with residents’ working/living, infrastructure and mobility needs, and the access to nature and natural land-based resources. Human and social capital centric practices highlight community building, education, self-development, mutual aid, and work-life autonomy.

The following are two examples of eco-community projects which also provide health/care services – in this case for people with developmental disabilities:

## Solheimar Ecovillage, Iceland

Solheimar Ecovillage was founded in 1930 by Sesselja H. Sigmundsdottir and is considered to be one of the oldest ecovillages in the world. While Solheimar was first founded as an orphanage, it has since evolved into a village of about 100 residents in total, with about 45 residents with developmental disabilities living permanently in the village (semi-funded by the Icelandic authorities), supported by social workers and care assistants onsite. There are also a number of arts workshops (pottery, crafts, candle-making, herbal workshop) onsite co-funded by the authorities and the village. Every year the village has a steady influx of volunteers from around the world to participate in various activities in the village, with the most popular being food production at Sunna greenhouse, one of the first places to practice biodynamic farming in the Nordic countries. The greenhouse sells its produce at one of Iceland's major supermarket chains as well as the village's local shop Vala - which also sells the products made in the arts workshops. Located at the heart of the village is Graena Kannan Café, where many local and international tourists like to visit alongside the village's guesthouses – the village estimates 35,000 visitors annually (Miller 2018). Long-term and seasonal workers along with volunteers assist with the day-to-day operations of the village in the workshops to its various enterprises.

## Camphill Communities

The first Camphill Community was founded in Scotland at Camphill House in 1940, with the goal to provide education and homes for children with developmental disabilities, following Rudolph Steiner's philosophy emphasizing self-expression. There are now about 100 Camphill Communities worldwide, all with their independent governance systems and different characteristics. Most communities have various arts workshops and permaculture gardens to provide therapy and food. Camphill Communities rely on the work of volunteers and co-workers (providing free boarding and a small living stipend) to support residents with special needs – they are sometimes supported by paid staff that are specialized in therapies and round the clock care for residents. Co-workers live long-term in the community, and many participate in the governance of the communities (Camphill 2020).

## The New Way Forward: Integrating Sustainable Health and Care with the Physical Environment

Reflecting on the work and structure of eco-communities such as in Solheimar Ecovillage and the Camphill Communities, we propose the outline of a circular community – community care model:

The conventional medical-oriented user-provider services provision model as seen in the diagram below relies on service providers in supplying medical and care services. The consumer approach is a uni-directional linear model (as opposed to circular), where the user/consumer only has the role of receiving care, services, and products. Considering the medical/social spectrum where the 'social' operates in the realm of the community as opposed to institutional medical services, the day activities and personal care of an individual that has additional needs effectively becomes part of a medical/care services repertoire.

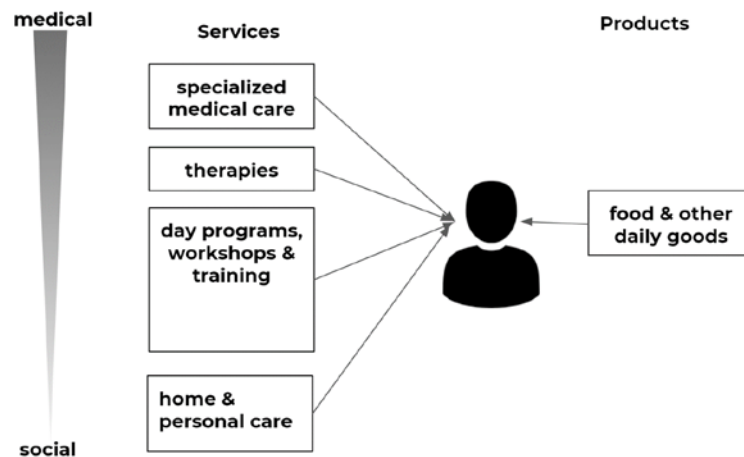


Figure 4: A conventional linear model of user-provider healthcare.

In contrast, we propose a circular community model that integrates the provision of care (services) with land-based assets. As illustrated in the right-hand portion of the diagram below, renewable community energy systems that channel into food and other modes of micro-scale production in the community are part of a loop to generate value and assets for the entire community. The activities of these sustainable industries are regenerative and contribute to creating a better physical environment for the community. On the other hand, therapies, day programmes / training / education, are integrated with the productive value-generating activity of the enterprises – individuals with special needs that are traditionally only receiver of services are embedded to become part of an interactive system. Carers are not merely compensated service providers, but are crucial in the community, also engaging in other activities. The circularity of services and a community production system work hand-in-hand to support an autonomous community that is able to provide for its own needs. The paradigm shift nudges care services toward the community / social realm in favour of the normalization of individuals with special needs.

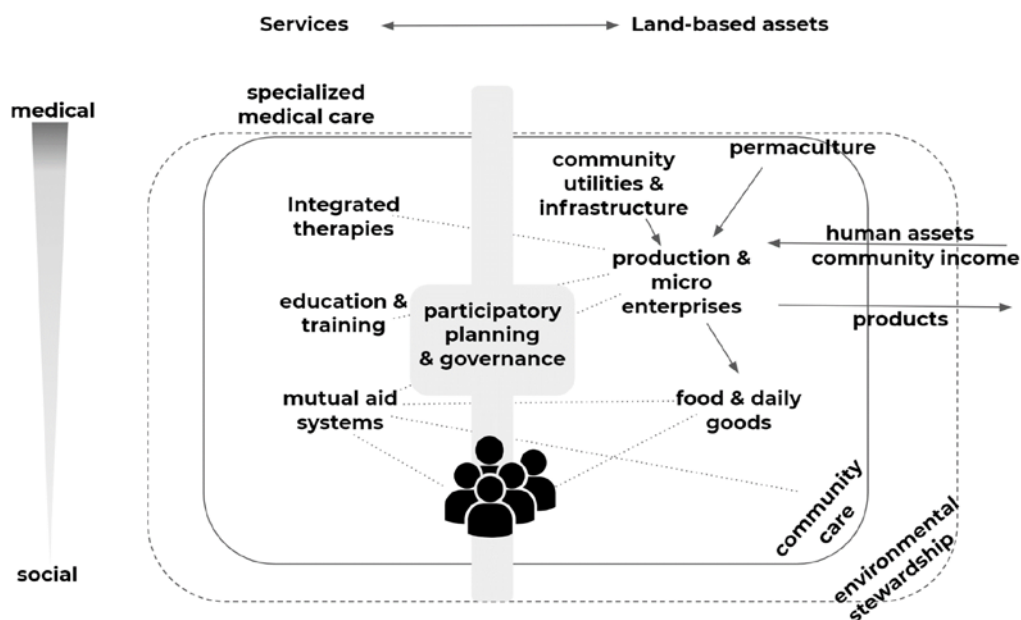


Figure 5: The proposed circular community model for health and care.

## Further Research

As we have presented some of the justifications in using a systems design approach to rethink sustainable communities to provide health and care services, the outline of our design of what circular communities for health and care can look like serves as a scoping effort and is just a beginning. Moving forward, we aim to collect more data and map the relationships of concurrent healthcare service provision models to re-imagine the realm of sustainable health and care services to more detail. We plan to conduct comprehensive participatory action-oriented research with healthcare organizations as well as service users to explore the work in regenerative systems change.

## Acknowledgements

Thanks to Solheimar Ecovillage for the inspiration and opportunity to participate and understand the village.

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# Starworks: Politics, power and expertise in co-producing a research, patient, practice and industry partnership for child prosthetics

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**ABSTRACT**      *Significant advances have been made in the field of adult prosthetic limbs. Conversely, paediatric prosthetic limbs suffer from a ‘market failure’ situation; market forces are inadequate to stimulate product innovation. Children are left with inadequate limb provision at best aiming to minimize pain and discomfort rather than enable independence and quality of life.*

*In 2017, the UK Exchequer announced £1.5M one-off investment in child prosthetics, as a result of lobbying by charities and a small number of parents of children with lower limb loss. Half this investment was dedicated to the provision of ‘activity limbs’ (eg. running blades) for children, and half dedicated to research and innovation over a period of two years. The authors took a lead in the latter, with the aim to re-structure the market forces, catalysing innovation for more appropriate paediatric prosthetics.*

*NIHR Devices for Dignity MedTech Co-operative (D4D), supported by Lab4Living, established a network of key stakeholders based on principles of co-production (Greenhalgh et al. 2016). Details of the process, outputs and impact can be found elsewhere (Mills et al. 2019). This paper focuses on the politics, power and distinctive contributions defined by differing expertise, by which this collaboration was established, operated and sustained. We discuss the co-design methods that helped to achieve this and draw on evidence from the stakeholders and project outputs to demonstrate success of these methods.*

*We conclude by suggesting meaningful co-production isn’t necessarily about including everyone in all decisions, provide some tips for managing political relationships and power differences, and highlight the importance of valuing stakeholders for their (unique) expertise.*

**Keywords:** Co-production, prosthetics, paediatric, innovation.



## Introduction

There are an estimated 60000 people in the UK with an amputation or congenital limb deficiency attending specialist rehabilitation services across 35 centres. NHS England spends about £60 million/year on these services (NHS England 2015). Of these, only a small fraction are children; 2000 as a best estimate (Sky News 2020). Numbers are uncertain due to lack of a central database of UK amputees and prosthetics users.

By 2016/17, a succession of events (2012 Paralympics, 2014 inaugural Invictus Games, on-going Afgan war and increasing prevalence of Type 2 Diabetes) had increased population awareness of prosthetic limbs and limb difference. Prosthetic limbs had changed from plastic legs attempting to look 'normal' to robotic limbs with complex articulating joints, a wider range of functionality supporting a wider range of activities; both daily activities, sporting or lifestyle adventure activities.

In comparison, prosthetic limb provision for children was limited. The numbers of children requiring prosthetic limbs (compared to adults) is very small. Rapid changes in body size and shape mean limb redundancy and turnover is higher; related to growth not just wear and tear. This ruled out costly limb options on NHS procurement, focusing provision more narrowly to functional requirements. For very young children, this is often simply biomechanical stability, ensuring the weight and presence of limbs support the balanced development and alignment of the whole body. Often a practical constraint of size and space limitations between the floor and residual limb only allows a single rigid structure with zero degrees of freedom.

The circumstances described above constructed a market situation stifling innovation and development in children's prosthetics. The extent of technological advancement in prostheses for children was making cosmetic 'sleeves' or smaller adult versions which work for limited situations. However, children should not simply be viewed as smaller adults; their lives and needs are very different. Moreover, the cost of smaller adult prostheses was prohibitively expensive due to limited production numbers at the smaller sizes.

The Exchequer's announcement in March 2017, resulted from sustained lobbying by a small group of parents of children with lower limb prostheses, supported by a few charities (eg Limbpower) for children with limb difference, and was originally dedicated to the provision of activity limbs. Whilst this funding would provide some children with a greater choice of prostheses, the numbers of children who could benefit and duration of availability was limited. To have a sustainable affect, something structural needed to change. A case was made for a more strategic view, diverting half the funding to research that restructured the market so limb provision and innovation of those limbs could be more sustainable.

The authors took a lead in this research, but knew that they didn't have all the answers and would need to adopt a co-production model. However, many of the stakeholders vital to the work were those lobbying for and supporting the funding of activity limbs, and did not necessarily have a 'stake' in the more abstract benefits of research (system changes of benefit to the next generation).

## Background

Co-production (or co-design) literature is diverse yet as far as we could determine there is nothing referring to co-production to tackle 'market failure'. There is broad agreement across this literature about key success principles which include:

...taking a systems perspective (assuming emergence, local adaption and nonlinearity), framing the endeavor as a creative enterprise with human experience at its core and an emphasis on process (framing of the program, the nature of relationships, governance and facilitation)....

(Greenhalgh et al. 2016)

Various authors (Bevir et al. 2019; Oliver et al. 2019; Flinders et al. 2016) outline risks associated with co-production; namely identifying appropriate stakeholders, competing interests and motivations, time, ethical complexity, emotional demands, inherent instability, vulnerability to external shocks, subject to competing demands and challenges to many disciplinary norms. These authors emphasised the importance of practical processes, methods of facilitation and the need to continuously (re)clarify outcomes or expectations.

Nicholas et al. (2019) developed a Critical Systems Heuristics' framework for co-productive initiatives, posing queries about Motivation, Power, Expertise or Knowledge and Legitimacy. Farr (2018) suggests using constant critical reflective practice and dialogue to 'check' levels of equity or power balances.

The authors' previous co-production experiences reflected these issues (Langley et al. 2019; Sheard et al. 2019; Goodwin et al. 2017). Of interest to this case, the authors had support of funders and Department of Health, but needed to 'win over' key opinion leaders from parents and clinicians; those who had campaigned to secure the funding. Some may have preferred all the funding to have facilitated activity limb provision, and/or some felt a co-production process would not identify new issues or solutions.

This account of Starworks, is followed by a discussion drawing on the above literature, exploring our methods of co-design facilitation in terms of levelling power and the concept of expertise, suggesting stakeholders do not have to be included or involved in all stages and all decisions for it to be defined as co-production. It is more important to recognise genuine expertise stakeholders bring and collaborate with them at relevant points/activities in the process. Applied in this way, we suggest change is more likely to happen; in our case change for the sector (addressing market failure) and for CYP with prosthetics limbs.

## Approach

### Phase One: Establishing the network

It is to be recognised that four key stakeholder groups have been central throughout the Starworks project; clinicians, academics, industry experts, and (most importantly) children and families. The

Starworks team engaged with relevant clinical, academic (eg. health research, prosthetics technologists, materials engineers) and industry networks to attract the best talent, ideas and collaborations that have expertise in child prosthetics. For this, the Starworks team undertook primary research to gather knowledge on key personnel, groups, academic and industry opinion leaders. This included face to face meetings and interviews to gain opinions and understanding of issues around child prosthetics from the range of stakeholders' perspectives. Alongside this, we worked with charities and created open social media channels to engage with children and families. This early engagement was successful in gaining trust and understanding from the children and families.

Given the diversity of participants involved, several issues were identified as being problematic in encouraging collaboration. These included giving equal voice to all participants, potentially conflicting perspectives, eliciting issues occurring in everyday life, and engaging children in a fun and relevant way. These issues were anticipated in the methods used in Phase Two (engaging workstreams separately in context-specific ways) and in Phase Three (in the considered workshop structure).

## Phase Two: Multi-stakeholder needs assessment

Consideration of the multiple perspectives of children's prosthesis development and provision has been at the heart of Starworks from inception. The aim of this was to understand the current status of development and provision, identify opportunities for further research (summarised in table 1), to in turn inform Phase Three.

Table 1. table of stakeholder groups, methods of needs assessment data collection and response rates

Workstream	Lead Institution for delivery	Methods	How many people were contacted?	Response rate
Children and Families	NIHR Devices for Dignity HTC & Sheffield Hallam University	Surveys	Approx. 1000 surveys were sent to 500 families (2 per family) at 5 sites across the UK	10 Children, 4 Young Adults and 16 Parents
		Phone calls, individual contact with stakeholders and hospital visits.	2 Children, 6 Parents and 16 Clinical Professionals	
		Workshop activities engaged children and parents in reflecting on their wider lives with prosthetics, identifying challenges and creatively generating ideas to address them.	18 Families	
Clinicians	The NIHR Health Technology Cooperative in Brain Injury in conjunction with Dr. Stephen Kirker	Clinical Audit to establish demand for prosthetics services and activity limbs	34 limb centres	11 limb centres
		Surveys to establish unmet needs within the prosthetic service, managers and medical rehabilitation specialists and a smaller survey circulated to the rehabilitation engineering community and allied health professionals	Approx. 4600 healthcare professionals	67 full and partial responses
Academia	NIHR Trauma Management HTC, Birmingham UK	Review of publicly-funded research projects in the UK, using database searches of funding bodies.	Databases included Research Council UK Gateway, The Wellcome Trust, i4i and SBRI.	94 projects deemed in scope
Industry	TRUSTECH	Desk-based research and Social Media		
		Online survey	Contacted 10 key companies, publicised through Trustech Twitter account (1,392 followers), LinkedIn account (69 followers) and website.	38 full and partial responses
		Telephone interviews with key players	13 interviews	

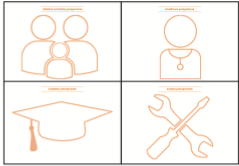



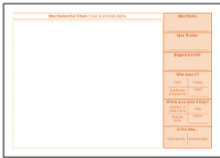

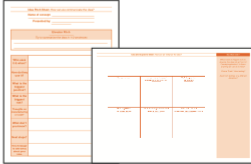
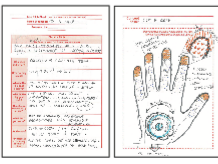
## Phase three: Sandpit events

The core co-production effort in this work focused on bringing representatives of these four stakeholder groups together through four sandpit events exploring challenge areas emerging from phase two. These challenge areas, nominated by the authors from information gathered through Phase two, were *'Socket Interface'*, *'Upper/Lower Limb Personalisation and Adaption'* and *'Service Journeys'*. Although based on input from all stakeholders, these areas were chosen by the authors to identify key, recurring issues, whilst remaining broad enough for interpretation by Sandpit delegates.

To facilitate the participation of as many different delegates as possible, the Sandpits were hosted across the country. They were attended by 90 delegates, including:

- 6 young people who use a prosthesis aged from 2 to 15 years old
- 9 family members of young people who use a prosthesis
- 18 delegates from healthcare
- 30 delegates from academia
- 13 delegates from industry

The 72 professional delegates (comprising of 61 individuals) represented 33 institutions. The structure, rationale, content and outputs of the workshops are illustrated in figure 1.

Activity	Tool	Description	Tool in use	Outputs over four workshops
<b>Problem Definition</b>		Discuss the workshop theme from the perspectives of children, families, clinicians, academics & industry experts.		Approx. 15 new challenge areas elicited
<b>Inspiration</b>		Showcase a range of inspirational materials, projects and research related to child prostheses, as well as analogous materials to inspire creative thinking.		Participants viewed 4 exhibitions, plus talks and/or demonstrations from 7 professional groups and 2 families
<b>Ideation</b>		To collaboratively generate as many ideas as possible in multi-disciplinary teams, supported by a design facilitator. Wild ideas were encouraged from every attendee, then the whole group voted for their top 5 ideas over lunch.		234 ideas mapped onto 59 problem areas
<b>Develop &amp; Pitch</b>		Once participants self-select which of the winning ideas they want to work on, the teams develop the idea further (also highlighting what they don't know at this point). The concept is condensed into an 'elevator pitch' and presented to the group.		18 pitched ideas, 23 applications to proof of concept funding

As shown above, the Sandpits elicited a range of new challenge domains, the majority relating to children living their lives rather than clinical concerns.

## **Phase four: Proof-of-concept funding**

A national call for applications for ‘Proof of Concept’ funding to address key challenges within Child Prosthetics technology and provision was launched in September 2017. Applicants were required to adopt a co-design, multi-stakeholder collaboration, which was evidenced within the 23, high-quality applications. These were subject to external peer review. Those defined as fundable were developed further between the Starworks and project teams to refine methods or partnership agreements. Ten projects were funded and monitoring and support appointed for each. Intellectual Property rights were assigned to the project partners in each case.

## **Phase five: Maintaining and growing the network**

This phase focused on increasing the individual and organisational engagement with Starworks from all stakeholder groups. An ‘expert network’ has been established, including 3 charities representing children and families, 12 clinical organisations, 7 industrial organisations and 15 academic organisations. A ‘Starworks Ambassador’ network has been joined by over 25 children with limb difference and siblings to date.

Additional funding (£427,000. NIHR.) was secured to further explore other areas of research identified by the group, such as developing outcome measures meaningful to children and families as well as clinicians, academics and industry.

## **Limitations**

No detailed, formal, summative evaluation of Starworks has been undertaken to date. Rather, we have used less formal, formative approaches to ongoing evaluation – using feedback from each event or from PoC projects to continually adapt our approaches to the needs of the network. We will offer some of these in the discussion section.

## **Discussion**

There is much to discuss about the Starworks project. In this paper we focus on the challenges in establishing the network, the importance of knowing the stakeholders (and letting them know you), methods of facilitation and the central notion of expertise – all of which address the overarching issue of power between stakeholders.

The early resource invested in finding out ‘who’ the key opinion leaders were across the four stakeholder areas were significant. Publicly available channels of publications, websites and social media were explored and cross referenced. Private channels using email, telephone calls, meetings, word-of-mouth etc were used to further identify individuals. This work took on several phases;

- 1) identifying key opinion leaders
- 2) pitching a case and inviting or requesting them to contribute to the initiative

- 3) determining roles in terms of a Project Reference Group (PRG) or active project participation
- 4) writing the proposal with them and using this proposal as a tool to determine and clarify motivations, expectations and outcomes for each person/organisation involved

This work took several months before funding was secured but was foundational. Point 3 is a hugely political judgement. Some are only able to, or only want to, contribute in specific roles and these wishes must be respected. Others can greatly influence the progression (positively or negatively) in specific roles. Trying to create a balance of critical reflection in the PRG and practical action in the project team is key and some delicate framing of role is sometimes required. The NIHR mandated some funding was spent with the other seven Healthcare Technology Co-operatives, meaning their expertise was sought in areas that added value to the project.

This 'groundwork' came to fruition in the sandpit events. The pitch and tone of the subject matter was suitably 'lay' to enable all stakeholders to understand and engage. The content resonated with all stakeholders due to the background needs assessment. Visual methods were used to represent needs in these areas and highlight how they may differ according to stakeholders' distinctive perspectives, with time to develop these understandings at the events themselves (see the 'problem definition' and 'inspiration' sections of fig. 1). This had a powerful impact on all stakeholders present as an introductory frame for the sandpits, immediately creating an open mindset. It helped to build trust with families, who could see they were being 'listened to' – their voices and needs could not be ignored as their input became a physical presence in the room.

A crucial aspect of our approach was focusing on, and presenting the 'expertise' of each stakeholder. Groups of stakeholders had distinct, explicit and tacit knowledge – our design-based methods helped participants to reflect, share and learn from each other towards mutual understanding and shared problem-solving (see 'Ideation' and 'Develop' fig. 1). The vast number of new unmet needs and ideas identified through these collaborative sandpits is testament to the value of these methods.

The approaches we applied in the sandpits influenced the proof-of-concept projects, where we witnessed and guided academic partners to work collaboratively with other stakeholders. This suggests a longer-term, 'ripple' effect of creating large-scale co-production events such as the sandpits.

The greater legacy of the methods we adopted is in the decision to 'spin out' the network from NIHR funding into a collaborative Social Enterprise founded on representation of the four stakeholder groups. The equity between the stakeholder groups is being embedded as a core value in the draft Social Enterprise structure and governance. The work is ongoing and we look forward to continuing the collaboration through this structure.

## Conclusions

Our experiences with Starworks have shown the importance of investing in getting to know people and building relations with organisations and individuals before setting up a co-production initiative. We cannot always choose our project partners, and some are easier to work with than others. Finding the right roles for people and organisations is crucial. The PRG acted as a point of critical



reflection, voicing concerns, objections and suggestions. Our approach to these wasn't simply to acquiesce, and whilst we will never adopt a 'we know it all' attitude, we do have some faith in our expertise in co-production. Experience has taught us to listen to all comments, to adapt our approach to some of the issues raised (often relating to content), and to ask for trust in our approach with others (often relating to process). This is a difficult line to take in terms of keeping ourselves 'honest' and constantly learning, improving and evolving our approach. However, using this frame of expertise helps us to justify these responses.

This frame of valuing 'expertise' is one we carry through our approach to every stakeholder, not just ourselves. People should be involved because of the expertise, knowledge and evidence they bring. Our approaches seek to draw out of stakeholders and participants what others don't know, and enable them to share these in ways that others can comprehend. The shared understanding is crucial but limited; some of that expert knowledge from one stakeholder can be assimilated by others, yet our approach also seeks to embed an appreciation that there is more expert knowledge (i.e. tacit knowledge) that is embodied by the stakeholder, affirming the need for on-going collaboration.

The methodological approach used in delivering this Starworks project, pending formal evaluation, proved successful. This does not depend on involving all relevant stakeholders in all decisions (for example, the choice of themes for the Sandpits was informed by all stakeholders, but ultimately decided by the authors). Aiming for constant consensus, we believe, is a fragile, reductive gesture at involvement that masks a lack of appreciation and understanding about *why* it is important to involve non-researchers in these co-produced research endeavours. Co-production in health contexts is complex, and meaningful involvement can be supported by design-led facilitation that supports multiple, often conflicting perspectives in a productive, respectful way. Such facilitation requires the acknowledgement of design facilitators' expertise in the *process*, equally to the acknowledgement of stakeholders' expertise in the *content*. To date this research has delivered the national Starworks network, national database of children with prosthetic limbs and ten proof-of-concept innovation projects.

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# ‘Playing’ with Evidence: combining creative co-design methods with realist evidence synthesis

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**ABSTRACT** *Breaking the cycle of declining physical function and physical activity can improve health and independence for people with long-term conditions. Services within primary care are well placed to empower individuals and communities to achieve this. However, the best approach is uncertain, and must consider needs of people with long-term conditions and complexities of service delivery. This study aimed to understand how to reduce decline in physical function and physical activity in people with long-term conditions. We used realist methods integrated with co-design to provide an explanatory account of what works (or does not), for whom and in what circumstances, to generate ideas about service innovation, and provide recommendations for primary care.*

*A key aspect was tracking evidence from different sources, presenting it creatively by converting it into physical games, enabling stakeholders to ‘play with’ and make-sense of it, to inform co-design work, enabling them to draw upon their own experiences and a wider understanding.*

*In this article, we focus on the game activities, adding to the co-design games’ literature and suggest that this expands participants’ knowledge base beyond their experiences, empowering them to contribute more to the process and creating a strong link between the realist and co-design methods.*

**Keywords:** co-design, co-design games, realist synthesis, participation, evidence informed co-design

## Introduction

Challenges of getting research into practice are well documented (Davies and Powel 2015) and there is growing consensus that co-produced research may be a mechanism to address this (Greenhalgh et al. 2016). Successful implementation of evidence and research findings requires additional forms of knowledge and evidence about service users, service delivery and the varying contexts in which services exist (Rycroft-Malone et al. 2004) and new ways of considering how evidence is applied in practice. Co-produced research combines these different forms of evidence to create knowledge that is sensitive to real world requirements of users, professionals, services and organisations in their different contexts. Co-design is one approach to co-producing research, where stakeholders participate as experts of their own experience and are guided through a collective design process, that supports the synthesis of evidence into tangible forms and mobilises knowledge (Langley et al. 2018; Langley. 2015).

The authors engaged in a co-produced research project to deliver physical activity based interventions in primary care for people with long-term conditions, to maintain their physical function. It was found that combining realist and co-design approaches through the use of co-design games, empowered participants to fully engage and contribute not just as experts of their own experiences, but also with a greater understanding of the experiences of other stakeholders and an appreciation of wider academic research evidence. Within the project, this arguably led to richer insights and more context-appropriate interventions. More widely, this raises interesting questions for how stakeholders are positioned within co-design, the contributions they can make to the design process and to each other.

## Background

In England, long-term conditions affect over 15 million people (NHS Digital 2016). The prevalence of long-term conditions rises with age (Barnett et al. 2012), and as they accumulate, worsening physical function reduces health and independence (Zubritsky et al. 2013). Long-term conditions contribute the biggest burden to the NHS, involving over 50% of GP consultations, 65% of out-patient visits, and 70% of in-patient bed days (Department of Health 2012). The benefits of physical activity in the management of long-term conditions are clear, particularly for improving physical function (e.g. Puts et al. 2017), but physical activity promotion is poorly done in practice (Williams & Law 2018).

## Combining co-design and realist methods

Enabling people to be active and sustain function is complex. It depends upon local environments, resources, and the beliefs and values of people; those with long-term conditions and healthcare professionals. Realist approaches are well-suited to evaluate complex contexts, providing explanatory accounts of ‘what it is about a programme (or intervention) that works for whom, in what circumstances, in what respects, over which duration’ (Pawson 2013). A realist programme theory specifies what mechanisms (M) will generate the outcomes (O) and what features of the context (C) will affect whether or not those mechanisms operate. In realist language, ‘context’ is more than ‘where’ something happens. It refers to distinctive features of the individual, local, environmental situation that may influence the mechanism (e.g. the local geography and resources

available, including a person's inner resources or individual circumstances). Context, Mechanism, Outcome (CMO) statements are the distinctive product of realist methods.

Co-design also addresses difficult problems (Buchanan 1992), and has many similarities with realist methods. Both methods accept complexity, are iterative, participatory and draw upon multiple evidence sources. However, realist methods traditionally focus on 'what is'; whilst co-design methods focus on 'what ought to be'. In line with this, we applied realist methods to interrogate existing evidence to understand what had been tried before, what had worked, for whom and in what context in a realist synthesis of evidence. Often, the insights from this academic research would be used to define the parameters of a subsequent, separate, co-design process, using stakeholder's lived experiences to solve these pre-selected problems. However, in this project we wanted to blur these boundaries; between research and co-design, between understanding the problem and developing solutions, and between researchers and co-design participants, to build stronger links between 'what is' and 'what could be.' We aimed to empower co-design participants to have a broader appreciation of the evidence (more in line with co-design's democratic principles) so that all participants (health services researchers, service users, primary care professionals and physical activity providers) had equal agency in the creation of the final product. This allowed evidence from the realist synthesis to blend with experiential, organisational and contextual evidence to create a novel prototype intervention.

This is in contrast with the prevailing position within healthcare (Kidd & Carel 2014) and healthcare research (Rose & Kalathil 2019), where participants are (at best) confined to sharing their own experience and knowledge, not credited with the ability to make sense of other forms of evidence. Key to our co-design, was recognising that enabling a wider appreciation of evidence (experiential, contextual and research) required not just 'traditional' information sharing, but a mode that enabled 'sense-making'. This is where we drew on co-design research of 'games' and 'play' to facilitate reflection and mutual learning between diverse stakeholders.

## Co-design games

Design games are not novel. Vaajakallio (2012) describes them as:

...tools for co-design that purposefully emphasise play-qualities such as playful mindset and structure, which are supported by tangible game materials and rules. Instead of being a well-defined method, it is an expression that highlights the exploratory, imaginative, dialogical and empathic aspects of codesign. {...} The means for reaching these objectives are drawn from design practice (e.g., **tangible mock-ups** and **user representations**) and from the world of games (e.g., **role-playing**, **turn-taking**, **make-believe**) to deliberately trigger participants' imaginations as a source of design ideas...

(Bold emphasis added by authors)

Vaajakallio and Mattelmäki (2014) list other articles, expanding on co-design games. They outline that event-driven applications of co-design (similar to ours), bring co-design participants together with

...predetermined structure, tasks and facilitation... [they] don't produce final design solutions but co-construct [shared] understandings about context, people's experiences, potential designs and dreams....

Supported by Standers and Stappers (2014), they suggest this requires games spanning three time frames; now, the near future and the speculative future. Importantly, for these authors the first time frame (now) is based purely on the experiences of the co-design participants, and not any wider body of knowledge describing this world. Therefore, their games draw out descriptions of personal experience rather than feed in wider evidence.

We expanded this use of co-design games to bring in a wider range of evidence beyond the experiential capacity of the co-design partners. For these forms of evidence, the co-design games take on additional roles of reflecting on, sorting and sense-making, giving the participants the opportunity and structures to rationalise the wider evidence of 'what is' in the context of their own experiences, before using it to inform their ideas about 'what could be.'

Our application of co-design games aligns with the principles of co-produced research (Greenhalgh et al. 2016) by taking a systems perspective through a creative approach focused on improving human experience, while tackling issues of power and hierarchies present in all co-design activity, particularly health research.

This article reports these activities and discusses reflections and learning to aid others in future work. This way of thinking may help to provide stronger links between realist research and co-design, harness greater creative potential of research and co-design participants and support translation from theory to practise.

## Approach

The full method is described in our protocol paper (Law et al. 2020), summarised below in Figure 1. Here we describe two specific elements; the initial theory building workshops and the first (of four) co-design workshops. Preliminary CMO statements preceded the co-design of the resources. However the refinement of the CMOs and the co-design of the resources proceeded iteratively, both informing each other.

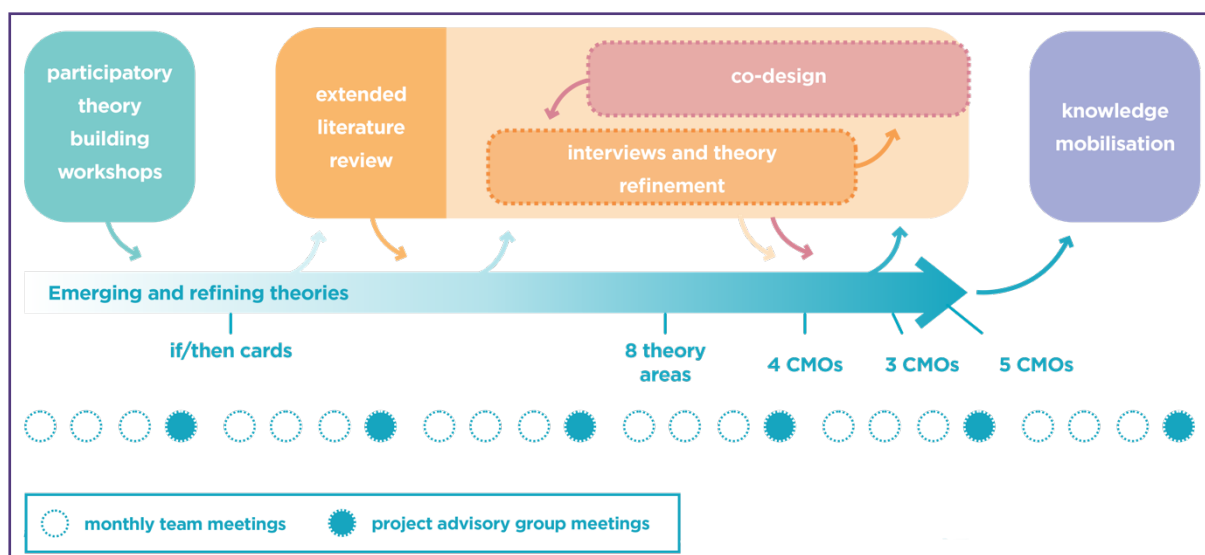


Figure 1: Summary of the full method.

## Theory building workshops

Two participatory theory-building workshops were the first activities in the project. The workshop was repeated in different locations in the UK with similar stakeholder numbers and representation at each (Table 1).

Stakeholder representation	Theory-building workshop 1 (N = 11)	Theory-building workshop 2 (N = 14)
Health services researcher, joint PI of project	n = 1	n = 1
Academic GP, joint PI of project	n = 1	n = 1
Public contributor, long-term condition	n = 5	n = 6
GP	n = 1	n = 1
Leisure centre manager	n = 1	-
Sport and outdoor recreation division of local council	n = 1	-
Health and social care public representation group	n = 1	-
Practice manager	-	n = 1
Researcher, social care	-	n = 1
Occupational therapist	-	n = 1
Third sector organisation	n = 1*	n = 1
Physiotherapist	-	n = 1
Engagement officer	-	n = 1

Table 1. Table of participants at two theory building workshops \* = also had long-term condition

We used LEGO® SERIOUS PLAY® as a participatory method for these workshops, enabling expression and creativity through building models and sharing. This method embodies the key elements defining co-design games (tangible mock-ups, user representations, role-playing, turn taking and make-believe). Each individual created and described models in response to these questions: ‘What does physical function mean to you?’ and ‘What are your experiences of maintaining physical function?’ This gave participants an opportunity to share their experiences, and appreciate and make sense of others. Within the workshops, the participants were led through a process of building individual models, then combining their models to create a shared understanding. The aim was not to reach consensus, but to represent discordant views and experiences equally in the final, shared model.

This shared model produced nascent theories about what worked (and did not) for different people in varied circumstances. This helped to inform key topic areas in the subsequent realist review of literature for wider evidence to support, challenge and explain these working theories.

These early emergent theories from both workshops and realist review were accumulated and developed into thirty ‘*if... then...*’ statements and further categorised into levels (Table 2). These statements were converted into two decks of cards; ‘**If..**’ and ‘**...then**’ cards.

Table 2. Examples of ‘if...then’ statements derived from Lego Serious Play workshops and early realist review



<b>Level: Individual patients</b>	
<i>Physical</i>	
If physical activity advice is tailored to patients' own priorities for functioning...	...then they are more likely to start and continue physical activities
If a functional approach is adopted to the management of long-term conditions...	...then interventions will be more relevant and tailored towards functional limitations that are meaningful to the individual
<i>Psychological</i>	
If being physical activity is linked to freedom, well-being and joy associated with having physical function...	...then people with long term conditions will better identify with the reasoning for being physically active and be more likely to continue
If people have built and engrained physical activity 'identify' through previous experiences...	...then they will be more likely to be motivated to pursue physical activity opportunities
<i>Social</i>	
If people feel supported by family and friends...	...then they are more likely to start and continue physical activity
If people with long term conditions are labelled/stereotyped less...	...then perceived and actual restrictions will reduce, encouraging improvements in physical activity and physical function
<b>Level: Local engagement outside of practice</b>	
If people have access to a variety of physical activity opportunities...	...then they will be more likely to pursue opportunities to be more physically active
If there are sufficient place on exercise referral schemes and physiotherapy clinics...	...then people will receive timely interventions to improve physical function
<b>Level: Whole practice</b>	
If there is a culture of physical literacy in the practice...	...then patients are more likely to receive interventions that promote physical activity
If there are relevant features and cues within the built environment...	...then physical activity and physical function will improve
<b>Level: Health professional consultations with people with long-term conditions</b>	
If self-efficacy and goal-setting are promoted as part of routine care...	...then physical activity interventions will be more meaningful to patients and uptake and adherence will increase
If pacing is used in physical activity promotion, incorporating periods of rest and recuperation...	...then patients with low energy levels and low fitness levels are more likely to persist with physical activity interventions

Through the realist synthesis, these 'if...then' statements were emerging into candidate Context, Mechanism, Outcome (CMO) statements.

## Co-design workshop one

The co-design process began during the realist synthesis. 11 participants attended workshop one, including research team members, professionals from primary care, physical activity providers and people with long term conditions representing services users. An illustrated story board presenting the work to-date was printed at large scale and wall mounted for all to view.

After welcoming and introductory activities, participants divided into three groups. We started with card games followed by reflective discussions in the smaller groups. It was communicated to participants that the statements displayed on the cards represented early working theories arising from the project activity and would be continuously refined by both co-design work and on-going realist review. The groups started with two decks; 'if' and 'then' cards. Participants took turns drawing a card from each deck, sharing the statements and discussing whether they matched. Some clearly matched or mis-matched. Others were less clear, creating discussion as individuals drew on their own experiences and wider knowledge to argue for or against the statements.

In the second activity the smaller groups laid out all cards in both decks to identify matching pairs. These were shared and compared with the other smaller groups, expanding the discussion.

These two activities were repeated with three decks of 'C', 'M' and 'O' cards. The resulting combinations of 'if...then' cards and 'CMO' cards were recorded and discussions noted on flip charts.

Following this workshop, the illustrated storyboard was updated, giving a visual summary of card pairs and the group discussions. This illustrated storyboard was continually updated and brought back to subsequent co-design events (Figures 2 and 3), acting as gentle, constant, visual prompt of our shared knowledge evolution; the collective sense-making process.

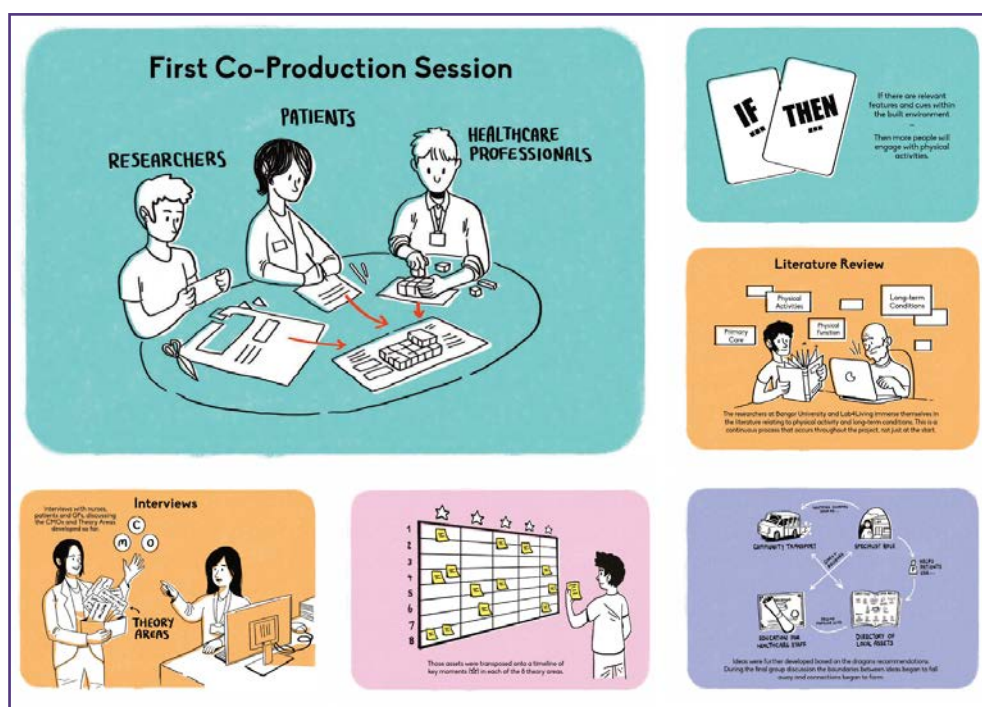


Figure 2: Extracts from the illustrated project process.

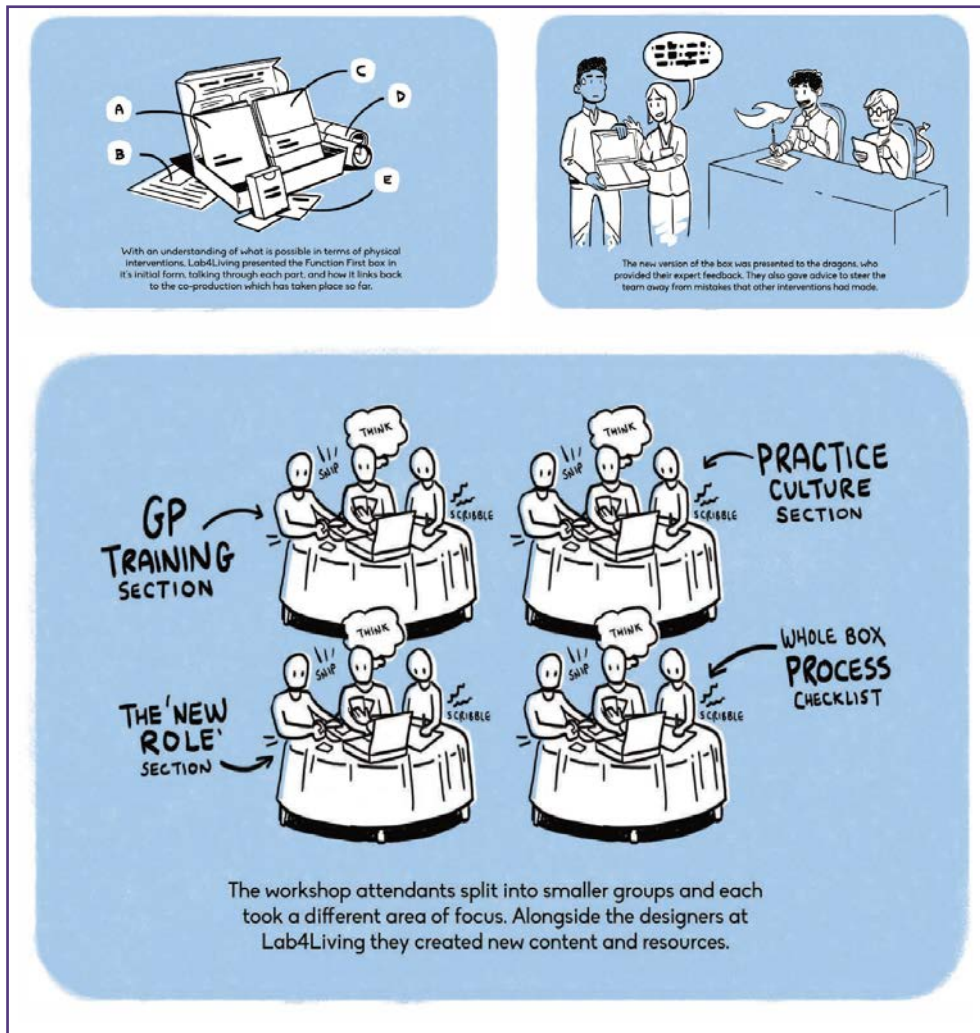


Figure 3: Further extracts from the illustrated project process

## Outcomes to date

Five CMO statements, underpinned by evidence from participatory theory building, realist synthesis, interviews and co-design, were developed (Figure 3).



## f (Context, Mechanism) = Outcome

### CMO 1 changing practice culture through alignment

(C) primary care settings are characterised by competing demands, and improving physical activity and physical function is often not prioritised in a busy practice

(M) however, if the practice team culture can be aligned to promote and support the elements of physical literacy, then

(O) physical activity promotion will become more routine and embedded in usual care.

### CMO 3 Individual advice

(C) people with long-term conditions have varying levels of physical function and physical activity, different attitudes to physical activity and varying access to varying types and amount of local resources, that enable physical activity

(M) if physical activity promotion is adapted to individual needs, priorities and preferences, and considers local resource availability, then

(O) this will facilitate a sustained improvement in physical activity

### CMO 2 providing resources

(C) physical activity promotion in primary care is inconsistent and uncoordinated

(M) if specific resources are allocated to physical activity promotion (in combination with a practice culture which is supportive), then

(O) this will improve opportunities to change behaviour.

### CMO 4 improving capability of practice workforce

(C) many primary care practice staff have a lack of knowledge and confidence to promote physical activity

(M) if staff develop an improved sense of capability through education and training, then

(O) they will increase their engagement in physical activity promotion

### CMO 5 programme credibility

(C) if a programme is credible

(M) then trust and confidence in the programme will develop and

(O) more patients and professionals engage with the programme

Figure 3: The five CMOs derived from the project

The co-design process led to a set of physical and digital resources (Figures 4 and 5) that embody these five CMOs. Physical features of the resources can be specifically identified as representing each CMO statement.

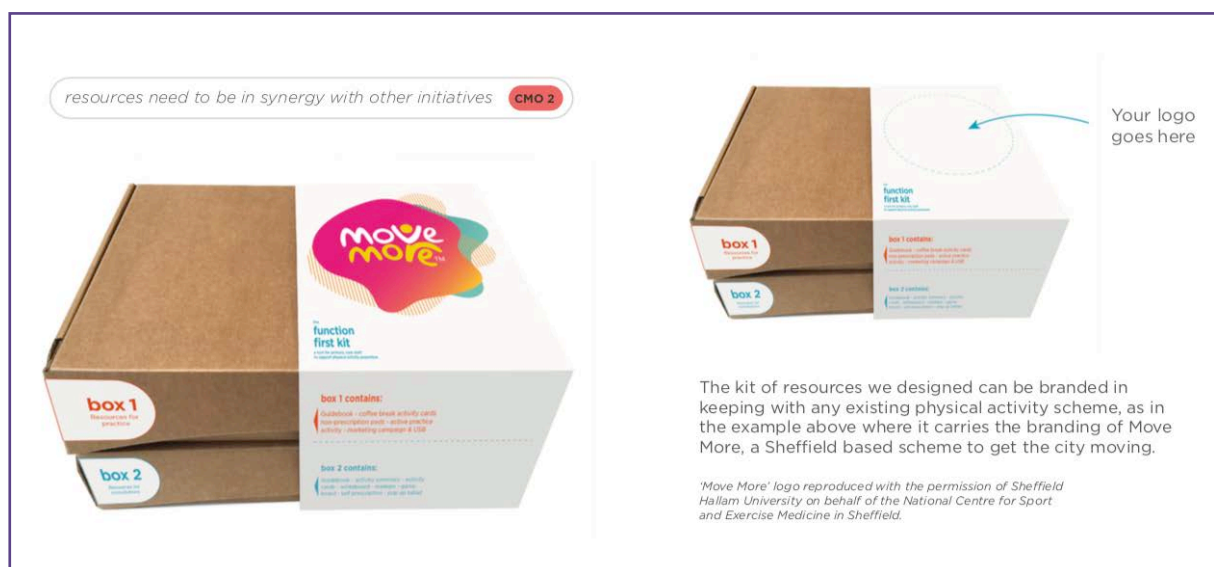


Figure 4: Illustration of the two primary physical components of the intervention

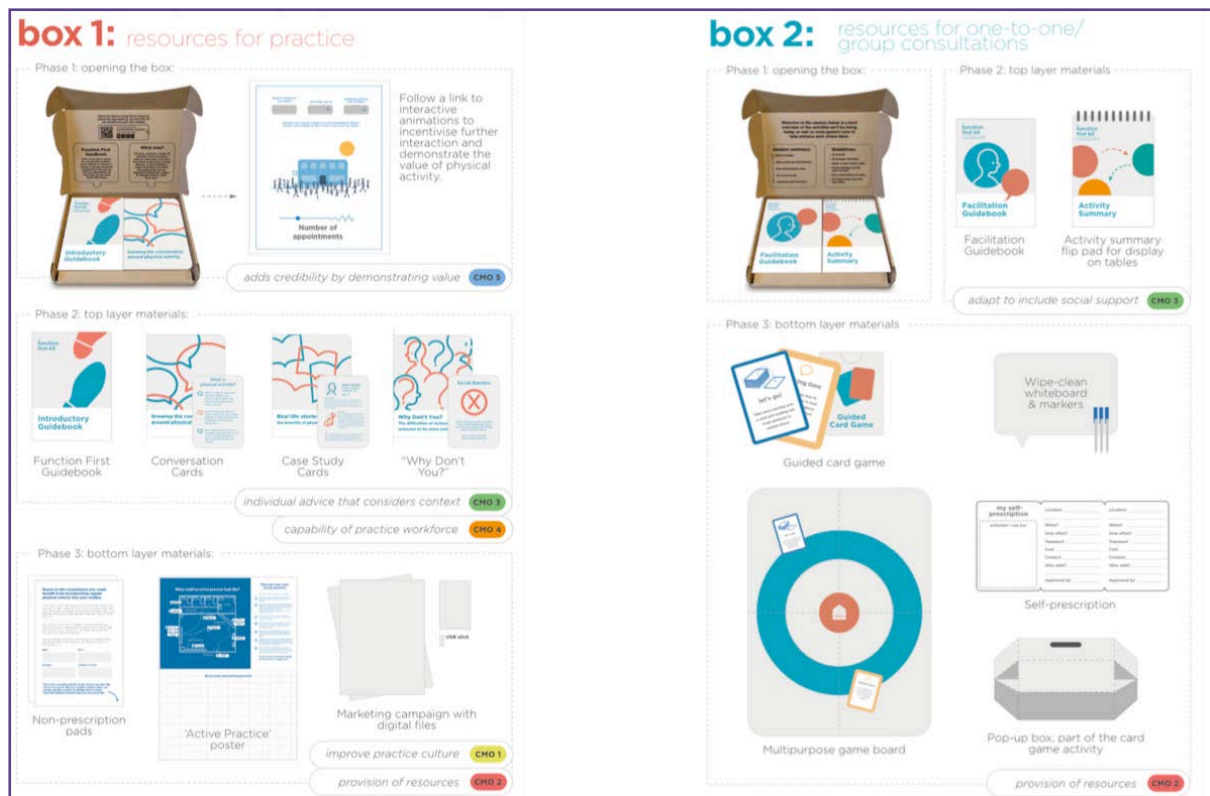


Figure 5: Illustration of the intervention contents (note; attribution of CMOs to specific features)

## Discussion

The development of the Function First prototype intervention was underpinned by a variety of forms of evidence, derived through rigorous research processes, and synthesised into material and digital forms through a co-design process. We identify specific features of these forms and describe the underpinning evidence from academic sources, service users and professionals. The components require further development, small scale piloting and refinement before the final intervention is ready for effectiveness testing. The intervention is intended to be used across a range of general medical practices, for individual patients with differing needs and capabilities.

Co-design games (Lego® Serious Play®) were used to draw out, share and collectively make sense of experiential evidence from service users and professionals working in primary care. Card games were used to give all co-design participants a wider appreciation of the formal and informal evidence derived from the realist review. These game formats allowed evidence to be shared across all participants, encouraged debate, and facilitated critical reflection until the findings made collective sense to all participants. This collective understanding enabled co-design participants to contribute more than just their own experience and knowledge to the co-design process, releasing greater creative potential yet also a deeper appreciation of real world constraints.

Participatory research and co-design have concentrated on involving a range of participants so their differing experiences and perspectives can be captured as a rich source of knowledge and evidence. However, the descriptions of these processes rarely discuss entrusting or empowering participants (often with varying prior experience of research or design) to make sense of the wider evidence

base, and to use this greater informed position to contribute more to the process. This may be a form of epistemic injustice (Fricker 2007) and simultaneously lost potential. The wider involvement of participants in this project was facilitated by gaming formats, design practices that made tangible products for consideration and the continuously present, evolving visual summary of the evidence journey at all the co-design events.

## Conclusions

This research increased our understanding of how to support physical activity for people with long-term conditions managed in primary care. It also developed a prototype intervention, which needs further refinement. These contributions are reported elsewhere (Law et al. under review). In this article, the contributions we wish to highlight are:

1. The links between co-design and realist methods, and how they can address the research to practice gap, by converting theoretical knowledge and evidence into practical, usable forms.
2. The benefit of giving co-design and research participants a wider role in the interpretation of evidence.
3. The value of applying co-design games as a way of sharing wide bodies of knowledge and evidence; enabling participants to understand its relevance.

Beginning any participatory research or design endeavour with gamified, sharing and sense making activities for all participants may reduce epistemic injustices, level power inequalities and reward these endeavours with greater creative potential.

## Acknowledgements

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# Designing an Integrated Wearable System for Biosensing and Self-reporting of Stress

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**ABSTRACT**      *Stress is an important aspect of mental health which impacts on wellbeing. Wearable devices are increasingly used to help people deal with stress in daily life. However, most of the current applications focus on detecting and representing physiological data. In this paper we report on the design of an integrated wearable system composed of physiological sensors and a self-reporting interface. Through an iterative design process, we developed two prototypes and evaluated their technical performance in a laboratory condition. We elaborate on the issues we have encountered and addressed in the design iterations. We discuss how these lessons might contribute to the design of integrated sensing systems in real life. We end this paper by reviewing limitations of the study and directions for future work.*

Keywords: smart wearables, stress management, design for mental health

## Introduction

Dealing with stress on a daily basis is a significant aspect of mental health. Long-term stress affects people's quality of life and could cause cardiovascular diseases (Vale 2005). This issue is urgent especially for people with chronic mental illness, such as depression and posttraumatic stress disorder (PTSD). A variety of wearable technologies have been used to sense daily stress. Most of them rely on physiological signals, such as heart rate, electrodermal activity and respiration (Choi et al. 2012). Other applications include self-reports through smartphones in forms of labels or scales, and prediction algorithms through access to the person's digital life, such as personal schedules, emails, locations and daily activities (Garcia-Ceja et al. 2018). However, these methods are mostly applied in sporadic manners and not compatible with each other. There is a need to design wearables that integrate physiological sensors and subjective reports as sources of sensing stress.

In this paper we aim to design an integrated wearable system composed of physiological sensors and a self-reporting interface. Through two design iterations, we developed two prototypes and tested them in an experimental setting. Only male university students ( $n=12$ ) were recruited for the experiment due to limitation of recruitment methods. We hope the lessons gained from this study will be beneficial for a more diverse group of people which we will include in future studies.

## Design Iteration 1

### *Selection of physiological sensors*

We selected physiological sensors based on literature study and individual tests. We chose three types of sensors targeting the biomarkers of heart rate variability (PPG heart pulse sensor), electrical conductance of the skin (Grove GSR sensor) and skin temperature (Thermistor – 3950 NTC). These biomarkers are most commonly used for measuring mental stress (Choi et al. 2012) and the relevant sensors are easily available on the market. We chose a data acquisition device (DAQ6009) and a desktop software (LabVIEW) to collect and present the data on the computer screen.

### *Developing an intuitive self-reporting tool*

We explored body movements and gestures that are related to stress expression. We chose the gesture of squeeze from those introverted gestures that are associated with expression of internal stress (Neff et al. 2010; Lefter et al. 2015). Accordingly, we developed a self-reporting tool (Figure 1) which is made of a standard force sensor (Grove – FSR402) and two pieces of foam. The sensor is connected to the computer through an Arduino board. The harder the user squeezes the tool, the higher level of stress is reported.

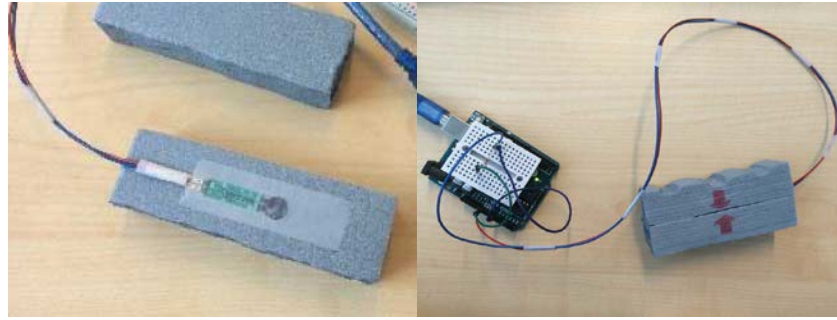


Figure 1: The self-reporting tool for Prototype 1

### *Placement of the sensors*

We chose a vest made of a light and stretchy textile to attach the sensors closely to the skin. All the sensors were located on the left side of the chest to minimise the effects caused by body movements (as shown in Figure 2). Although these sensors have their recommended locations, their performance remains at similar levels according to our test. We covered the sensors and wires in between two layers and only the sensor heads that require contact with the skin were exposed.



Figure 2: Connection of electronics and placement of sensors of Prototype 1

## Evaluation

We introduced this prototype to 11 male university students (aged between 24 to 30) who wore it while being exposed to three simulated stressors. The participants were recruited through posters and personal networks of the experimenter (the third author). The experiment was conducted in a quiet room. The participant was asked to put on the prototype in advance and sit in front of a computer with a pair of headphones on. The experimenter sat beside him and observed the data generated on another computer connected to the prototype. The three stressors were adapted from those commonly used to induce stress in laboratory settings (Plarre et al. 2011; Choi et al. 2012):

*Stressor 1: Fast reading* The participant was asked to read a complicated article in 5 minutes. Meanwhile, an increasingly loud music was played through the headphones to form a slight disturbance. Mild stress reactions were expected.

*Stressor 2: Mental arithmetic* The participant was asked to continuously add up three-digit numbers without the help of any tool. The sound of a timer was played to increase the sense of time pressure. We assumed this would induce a middle level of stress.

*Stressor 3: Sudden appearance of a scary image* A clip of a video game was shown to the participant with a scary image placed at the end. Although the participant was briefed that there was an intense stimulus in this video clip, what and when it would show up were not revealed to them. The image was selected from a horror movie and intended to evoke immediate hypertension of the participant (Bosse et al. 2014). This stressor was discussed within the research team and reviewed by the ethical community of the university.

These three stressors were arranged in order with a 5-minute break in between each other. Before the experiment, we played a peaceful video to help the participant reach a baseline of stress. The same technique was used during each break to help him recover from the previous stressor. In the debriefing session, the participant was asked to rate the three stressors on a 5-point Likert scale, and share his experience of wearing and interacting with the prototype. An informed consent form was signed by the participant before the experiment. The proposal of the experiment was approved by the ethical community of the university before recruitment of the participants.

## Outcomes

The raw data of the 11 participants show varied quality and is not suitable for correlation analysis. Instead, we took an individual approach to analyse the data of Participant 6 (P6), as shown in Figure 3. By doing so, we demonstrate the performance of Prototype 1 in correlation to the stressors and, with comparison to the observation of the experimenter, provide some insights on such changes of data. However, the results might be compromised by individual differences and require further research to develop into generalized knowledge. As can be seen in Figure 3, P6's heart rate data shows no clear correlation to the occurrence of the stressors. There were obvious downtrends in his skin conductivity since the beginning of Stressor 2 and by the end of Stressor 3 (where the scary image showed up). We see two sudden offsets before and after Stressor 3. This could be caused by body movements of the participant according to the experimenter's observation. The overall decrease of his skin conductivity indicates an accumulating effect of stress. This could be due to the fact that the participant was exposed to three types of stressors in a relatively short time. As for his skin temperature, the data shows no clear indication of immediate stress but a general uptrend with a short peak after Stressor 3. In contrast, his self-reported data captures the stressful moments more precisely. His self-reported data in real time and scores given to the stressors afterwards (via the Likert scale) show the same ranking order. We also notice a short delay after he was exposed to the scary image in Stressor 3, which corresponded to the observation that he froze for a few seconds before he squeezed the tool.

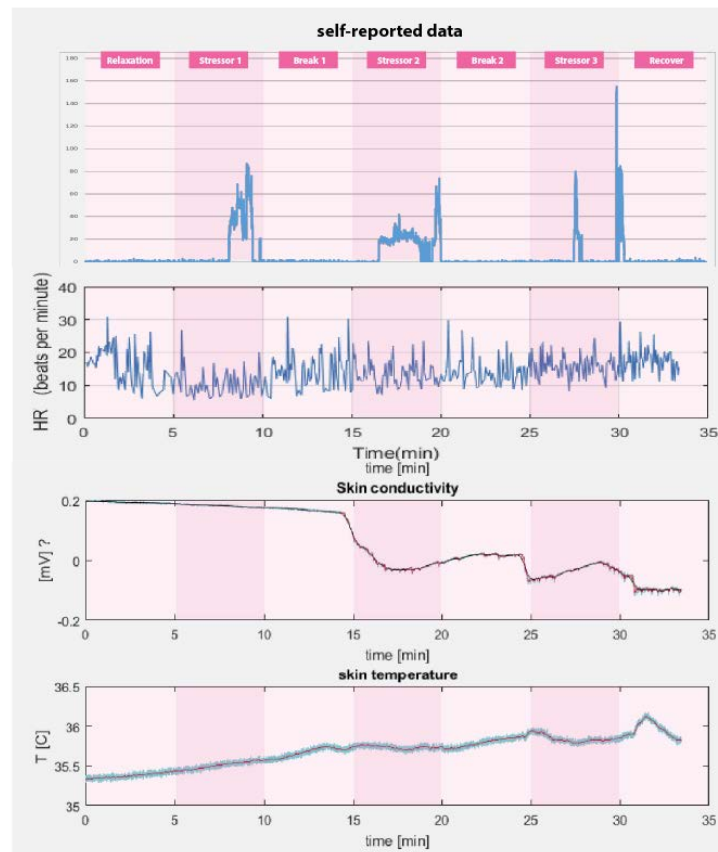


Figure 3: An overview of the bio-sensed and self-reported data of P6

From the debriefing interview, we had some feedback from participants (n=11) regarding wearability of the prototype and the self-reporting tool. Some participants (P1, P2 and P4) mentioned that Prototype 1 was too tight for their sizes. P3 and P5 wished for a more masculine design. As for the self-reporting tool, P1 mentioned that it was not well integrated with the vest. P2, P3 and P5 commented that using the tool could be distracting for the task at hand, and even made them more stressed. P3 and P9 mentioned it was difficult to report their stress when it happened to them unconsciously. P2 and P9 were uncertain about the force they should apply to the self-reporting tool and wished for immediate feedback of stress they just reported. We adopted some of the comments in the next design iteration.

## Design Iteration 2

### *Style study and fashion design*

At this step, we explored possible forms of the design. We came up with 5 concepts and made them into mock-ups using stretchy fabrics (Figure 4). We showed these mock-ups to the 11 participants and asked their opinions in terms of appeal and comfortability. Based on their feedback, we decided to combine the styles of Mock-up 2 and 5.



Figure 4: Conceptual mock-ups of Prototype 2

### *Update of electronics and the self-reporting interface*

We updated the electronics and integrated the self-reporting interface with the garment. We added an accelerometer (MPU-6050) to detect movements of the main body. We changed the self-reporting tool into a 'touch point' (using the same pressure sensor) embedded on the left shoulder. The gesture of touching shoulders is considered as another natural way of expressing stress. We added a Bluetooth module (HC-05 Bluetooth) through which the garment could communicate signals to an alternative device (e.g. smartphones). We chose a small-sized Arduino board (Arduino Nano) and reprogrammed the code in a Python environment. A Battery (Lithium Ion) was used to support functioning of the prototype for at most 3 hours. We designed and 3D-printed a case using PLA material to accommodate the electronics and the battery. See Figure 5 for the design of the case and placement of the sensors on the garment.

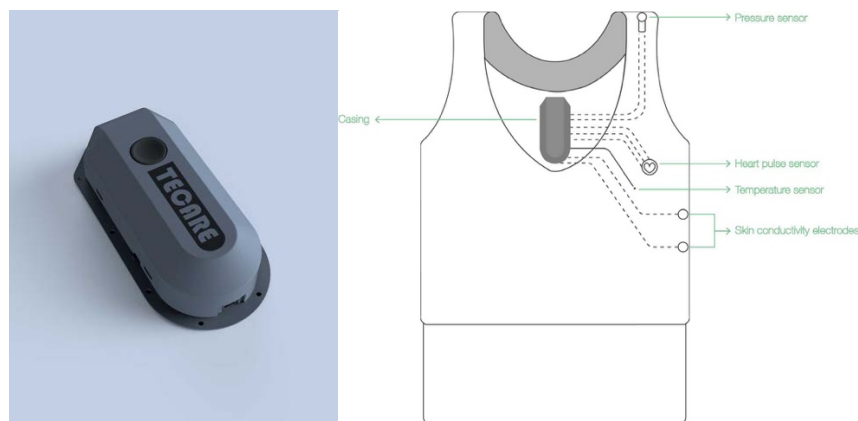


Figure 5: 3D modelling of the case and placement of electronics of Prototype 2

### *Integration of the electronics in the garment*

We embedded the electronics in the garment accordingly. The prototype is made of two layers. The inner layer was adjusted from an elastic fitness shirt with all the sensors embedded (as shown in Figure 5). We used non-intrusive conductive threads on this layer to connect the sensors. The case was then added to the garment. Next to this, we added the outside layer to cover all the sensors, conductive threads and wires. We added elastic trips on the back and Velcro bands around the waist so that the user can adjust the size as needed. Figure 6 shows the final result of the development.

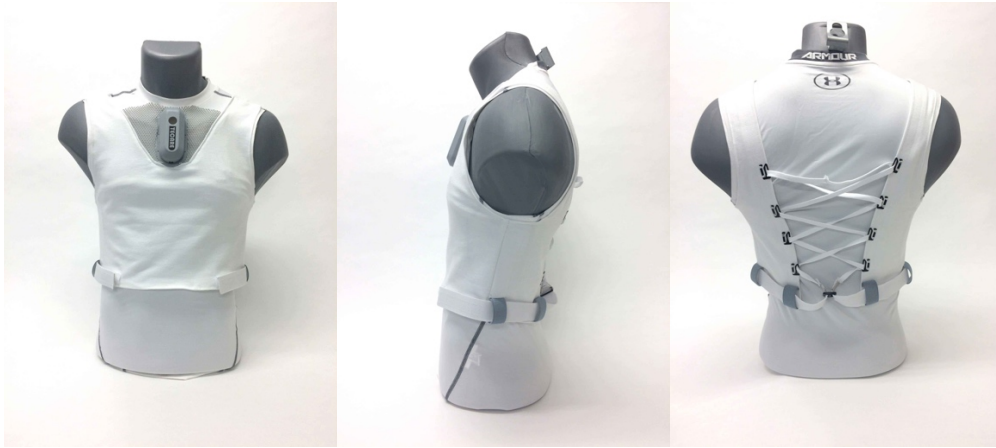


Figure 6: Finalization of Prototype 2

## *Evaluation 2*

We conducted the evaluation of Prototype 2 following the same procedure as Design Iteration 1. Only one participant (P12) was recruited for a preliminary test. Instead of collecting and showing the raw data on the computer screen, the data was logged on the SD card and extracted for analysis afterwards.

## *Outcomes*

Figure 9 shows the overview of P12's raw data. Similar to P6, it is difficult to indicate occurrence of the stressors based on his heart rate. Differently, his skin conductivity was unstable at the beginning and then showed an uptrend with slight drops after the second and third stressor. This indicates that the participant took some time to adapt to the experiment, and recovered from the stressors in a short time. His skin temperature shows a similar uptrend as P6, but no correlation to the stressors. The data collected by the accelerometer proves the disturbance of body movements to the physiological data. We recognize irregular fluctuations in heart rate and skin conductivity when there were sudden moves of the body. As for his self-reported data, he rated Stressor 2 and 3 as the most stressful ones via the self-reporting tool, while he gave the second stressor the lowest score on the Likert scale. This indicates the inconsistency between his real-time perception and recollection of stress. We should also note that his self-reported stress appeared as short pulses shortly after the stress events, rather than constant waves as shown by P6 (Figure 3). This indicates the difference of reporting behaviours between touching the shoulder and squeezing the hand.



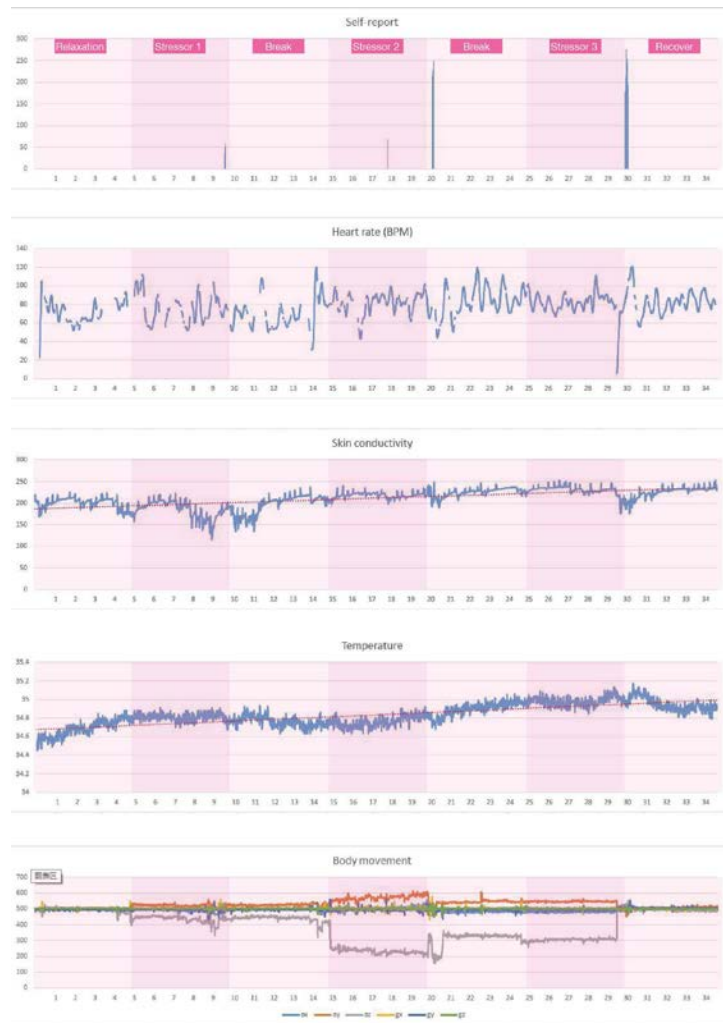


Figure 7: Bio-sensed and self-reported data of P12

In the debriefing interview, P12 appreciated this new way of reporting stress which reminded him of massaging the muscles. But he pointed out that 'it was difficult to find the right position of the pressing point'. He also commented that touching his shoulder required extra movement of his arm and thus difficult to do constantly, which was reflected in his self-reported data.

## Discussion

### *Designing integrated systems for sensing stress*

The bio-sensed and self-reported data show different characteristics in relation to stress which require specific analytic strategies and design considerations. The raw data of heart rate was easily disturbed and difficult to read directly. Skin conductivity appears to be sensitive to immediate stress, but the quality of data could be disturbed by body movements. The additional accelerometer proves to be useful to detect such disturbance. Some filtering algorithms can be used to address this issue by combining these sources of data. The skin temperature was relatively stable, but only showed general trends and vague relevance to stress.

In contrast, the self-reported data show potential to capture stress in the moment. Analysis of self-reported stress depends on the type of the sensor, location, and the behaviour required to use it. The self-reporting tool used in Prototype 1 shows advantage to report stress continuously, but it is inconvenient to use when the hand is occupied. A form of immediate feedback is needed for the users to be aware of their reported stress. Its modality also needs to be redesigned to be better accepted. A direction is to integrate it with existing wearable products, such as gloves and sleeves. The 'touch point' of Prototype 2 serves as an integrated interface on the garment. Compared with squeeze, the gesture of touching shoulders requires extra movement of the arm and might compromise the frequency of using it. Besides, we learn the importance of designing self-reporting interfaces to reduce overthinking of stress. Some participants (P2, P3, and P5) mentioned that checking stress could make them even more stressed. Inspired by P12, we can combine the self-reporting behaviours with relaxation exercises, for example, massaging shoulders. Finally, we acknowledge that it is difficult to design a one-fits-for-all self-reporting interface. We assume there should be an adaptive process before the conflict between mindfully reporting stress and paying extra attention to it decreases.

### *Limitations and future studies*

There are some limitations of this study which inform us of directions for future studies. First, participants of this study are only male and aged between 24 and 30. Future work should include people of different gender, age and professions to promote our learnings from this study. Second, sensors applied in this study are limited due to their availability on the market, which are typically used for low-cost projects and not tailored for wearable products. More advanced sensors are needed to achieve better quality of data. Finally, we took an individual perspective to analyse the raw data generated by the prototypes. More thorough and quantitative methods are needed to investigate performance of the design with a bigger group of participants.

## **Conclusion**

Dealing with stress on a daily basis is a complex issue that involves not only physiological changes, but also subjective feelings of the individual. In this paper we presented the process of designing integrated wearable systems that are capable of sensing both physiological and self-perceived stress. Results show that self-reporting interfaces are potential to capture immediate stress and complement an integrated understanding of stress. We reflected on the lessons of designing such integrated sensing systems and strategies to analyse the data collected. This paper serves as the first step towards designing smart wearables for daily stress, and is helpful for designers who are working on relevant topics.

## **Acknowledgements**

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# Interconnectivity of Health Futures.

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## ABSTRACT

*With a significant growth in cost, and the growing demand of our healthcare systems as a result of populations living longer, there is growing recognition that a healthcare system based on deficit focused models and the treatment of symptoms is inadequate. Whilst health research is continually focussed on the cure of conditions and the management of health, and rightly so, there is also a move to target environment, cultural and economic factors in population health and wellbeing (Hanlon and Carlise 2012).*

*Exploring the Interconnectivity of health to other systems, we used the Manoa Method (Schulz 2015) in a workshop delivered at the Design + Health Symposium at Auckland University of Technology, New Zealand in September 2019, to map out the future of healthcare as a system connected to social, political, economic, science/technology and environmental factors. Participants included designers, healthcare practitioners and technologists from across New Zealand, Australia and Canada. Considering a landscape 20-30 years from now, the groups worked to identify and state a future scenario or trend (for example 'earning healthcare by points') related to each factor, and brainstormed 5-7 primary impacts, related to their chosen scenario. They then explored further associated impacts and mapped the overall connectivity.*

*This paper summarises the themes of each factor and discusses the future scenarios envisioned by the groups and their associated impacts to health. The paper also includes the mapping diagrams developed by participants, provoking questions, conversations and possible actions, such as 'how would your organisation or community change to thrive in each scenario?'*

Keywords: design + health, interconnectivity, systems theory, scenario building, emergence

## Introduction

Healthcare systems throughout the world are facing challenges and pressures. In the UK, some of the key challenges faced by the National Health Service (NHS) are an ageing population, increasing healthcare demands due to chronic diseases such as obesity and diabetes, advancement in technology which leads to more accessible diagnosis and ways to treat ill health, increased costs, closure of local services and the centralisation of specific services, and in NHS (England) the issue of moving to privatised services (Nuffield Trust 2014). Similarly, in other developed countries, for example, Australia and New Zealand, they too are facing pressures as a result of an older and growing population, people with multiple chronic conditions, longer waiting times, availability for hospital beds and limited funding (Ministry of Health - Manatū Hauorangi 2018, Australian Medical Association 2019).

Developing countries have their own healthcare issues to deal with as well. Failing to invest enough resources in healthcare systems and infrastructure, combined with external threats which we may not have control over, such as environmental disasters, can bring damage to social and economic development. The World Health Organisation (WHO) in January 2020 released a list of 13 urgent global health challenges that, if not addressed, have far reaching consequences for society as a whole. These challenges range from stopping infectious disease, to keeping health care clean (water, sanitation and hygiene).

These challenges are wider health system challenges that will not be solved just by focussing on the cure or treatment of diseases. In order to decrease demand and create a sustainable healthcare system, a new vision is required. Relying on current strategies of focusing on increasing efficiency and productivity, consolidating services, reducing staff costs by leaving positions unfilled or reducing administration staff, shifting costs or incentives, introducing charges or eligibility criteria, among other strategies not mentioned to manage supply and demand, have drawbacks and consequences with increasing diminishing returns on improvements (Hannah 2014).

The changing pattern of disease and the rise of conditions, particularly chronic ones, is recognised as being more than the physiology of an individual, but the result of complex social factors. Compounded by a growing realisation that improvements in medications, interventions and diagnostics is not enough to deliver healthcare that is sustainable, a systems approach to healthcare has been advocated as the answer to current healthcare challenges (WHO 2000).

A systems approach has been defined by the International Council on Systems Engineering (INCOSEUK) as being 'a framework for seeing interrelationships rather than things, for seeing patterns rather than static snapshots - it is a set of general principles spanning fields as diverse as physical and social sciences, engineering, and management.' A systems thinking approach 'enables you to grasp and manage situations of complexity and uncertainty in which there are no simple answers. It's a way of learning your way to effective action by looking at connected wholes rather than separate parts. It is sometimes called practical holism.' (INCOSEUK 2010). Burns et. al (2006) defines systems thinking as 'an ability to consider an issue holistically rather than reductively, understand relationships as well as components, and to synthesize complex sets of information and constraints in order to frame the problem.' A systems design approach to healthcare improvement is appealing, however Komashie et. al. (2019) revealed that there is still uncertainty about how to

realise this approach in healthcare. Their paper also claimed that a limited set of 'systems approach' techniques is used and they are mostly from industrial operations management (e.g. lean, root cause analysis, process re-engineering) while other domains such as design thinking and human factors have not kept pace.

Several methods exist such as storytelling or scenario building (Moggridge 1993) and 'Three Horizons' (Sharpe, 2013) can be used to envisage different future systems. These methods have their advantages and disadvantages. In scenario building, strengths include the ability to open up unimaginable possibilities and challenge long held beliefs of an organisation, the ability to include disruptive events into long term planning, the sharing of aims, risks, opportunities and strategies and support in coordination and implementation of actions between participants. Disadvantages of scenarios are that they are extremely time consuming and nuances could be ignored, with scenarios ending up being 'black and white' or utopian in their endeavour.

As we write this paper, we did not expect to be sitting in isolation due to Coronavirus and the COVID 19 pandemic, which has brought global economies to its knees, leaving healthcare systems struggling to cope. What is starkly obvious is the interconnectivity of systems that has brought us to this point. A food market in Wuhan, China, is thought to be the source of Coronavirus and it is suggested that it may have come from bats (Marshall 2020). This food system has had an impact on global economies, communities and health systems around the world.

The interconnectivity of our systems means that we need to view health as a system connected to other systems. To enable such a debate we require a holistic vision of a future that can understand the way in which health is connected to the social, political, economic, science/technology and environmental factors, in order to find a way to shape a future scenario, where our healthcare systems heal in different ways. We currently view our healthcare system as curing conditions, using research to be innovative, and responding to a health crisis. However, this paper, using scenario building, will explore the vision to shape a future where healthcare can prevent conditions such as diabetes, obesity and pandemics, by understanding the way in which other systems create the conditions that impact on the health and wellbeing of communities around the world.

## Methodology

Using the Manoa Method (Schultz 2015), we designed a workshop for the Design For Health Symposium, held in Auckland, New Zealand in September 2019. The intention of the workshop was to explore the interconnectivity of health in relation to other systems that impact our communities.

The Manoa method was the result of Schultz engaging with future forecasters and expert systems research. It uses a process where triangulation is used to connect differences at the beginning and to bring about or maximise resulting impacts. To start, participants are asked to identify three emerging issues of change and state them as mature conditions 20-30 years later. These changes or issues need to belong to at least one of the STEEP (Social, Technological, Environmental, Economics and Political) categories and they should not repeat (i.e. two changes from the same category). An example of change could be "Personalised anti cancer vaccines (Technology/science)".

Taking one issue/change at a time, participants are asked to brainstorm five to seven primary impacts. For each primary impact, there should be an additional three secondary impacts identified.

Impacts should be pushed to the extreme logical conclusion, assuming that for the issue/change to have occurred, there is 20-30 years of development.

Next involved the information being posted on a wall for all participants to see impacts that were of interest are clustered and impacts that are interrelated with those from the other issues/changes are connected. Questions to ask within the group includes 'what changes might amplify or accelerate other changes', 'what changes might balance or constrain other changes' and 'what causal loops emerge as a result'. A cross-impact matrix (Figure 1) can also be used to support thinking through the impacts.

## Cross-impact Exploration Matrix

	Personalised anti-cancer vaccines	Soaring economic inequity and polarisation	Hot, dry climate now common across many temperate zones.
Personalised anti-cancer vaccines	OUTPUT OF FUTURES WHEEL	Longer Life > More Wealth hoarding > longer life	???
Soaring economic inequity and polarisation	Vaccines only for wealthy via private pharma	OUTPUT OF FUTURES WHEEL	Luxury biosphere and terraforming projects
Hot, dry climate now common across many temperate zones.	Widespread famine prioritises basic medicine	Water wars: rich have A/C poor live underground	OUTPUT OF FUTURES WHEEL

Figure 1: Manoa Method: Cross-impact Exploration Matrix

A list is then used to see if other impacts ranging from family structure, vices and crimes, transportation to religion and myths have been considered.

The next step involves scenario building through narrative. Two or three headlines that summed up 'the tenor of its time' are identified, and participants imagine if this is a film or documentary, what would its title be. The next step is to narrate from the present time and use the impacts (and the changes such as innovations, politics etc. that need to happen) that were written down as guides to describe how the future issue/change occurs through a span of 20-30 years. Contradictions are allowed and it is recommended that using 'a day in the life of a character' would be the easiest way to stimulate the narrative.

Participants are then asked to deepen the degree of change imagined by questioning if they have exaggerated the possible impacts and challenged current assumptions about present conditions



continuing. Finally, they shape a call to action with a set of questions to connect the future to the needs of the participants.

An hour was allocated by the symposium for the workshop and there were 24 participants from various backgrounds (designers, researchers, academics, civil servants and health practitioners), working in different organisations who signed up for it. We adapted the Manoa method to fit within the one hour duration of the workshop (Table 1).

Table 1. Our process using the Manoa Method

- Step 1:** Hand out one theme card to each group: Social; Science/Technological; Political; Environmental; Economic, Spiritual
- Step 2:** On a hexagonal post it, write your scenario as a future condition 20-30 years from now
- Step 3:** Brainstorm 5-7 primary impacts
- Step 4:** For each primary impact identify an additional 3 impacts.
- Step 5:** Consider any emerging tertiary impacts.
- Step 6:** Consider links between impacts identified
- Step 7:** Bring all themes together and discuss how they all link together
- Step 8:** Discuss emerging themes across all groups
- Step 9:** Identify emerging future health scenarios

## Findings

Participants worked in five teams exploring emerging issues in the areas of Economics, Environmental, Social, Science/Technology and Politics. The results presented in this section are based on a summary of what participants wrote on their sheets and not a full qualitative analysis.

### Economics

The group focussing on economic change envisioned a future where there is 'no cash' (Figure 2). One possible impact was that everyone's finances (bank statements) are open to scrutiny and salaries are made public. This suggests that the 'tragedy of the commons is solved' and with Google's assets becoming a 'common-pool resource', it uses its data and analytics expertise for medical diagnostics and treatment. This produces an impact where healthcare is earned by points, for example having a certain fitness level and volunteering (e.g care support), allows people to earn points. They also discussed the gamification of technology. The impact is people should be 'rich in health and happiness' and 'wealth is not measured by monetary value'. Economically, universal wages should complement this points system. When asked to take another STEEP category, the group chose Technology as a topic to discuss. They discussed the option of Google moving into healthcare, and

where 3D printed organs could be a resultant impact from the use of personalised data. This could lead to a proliferation of 'self generating' devices. Overall, observing the theme, the group identified that money would no longer be the only trade commodity.

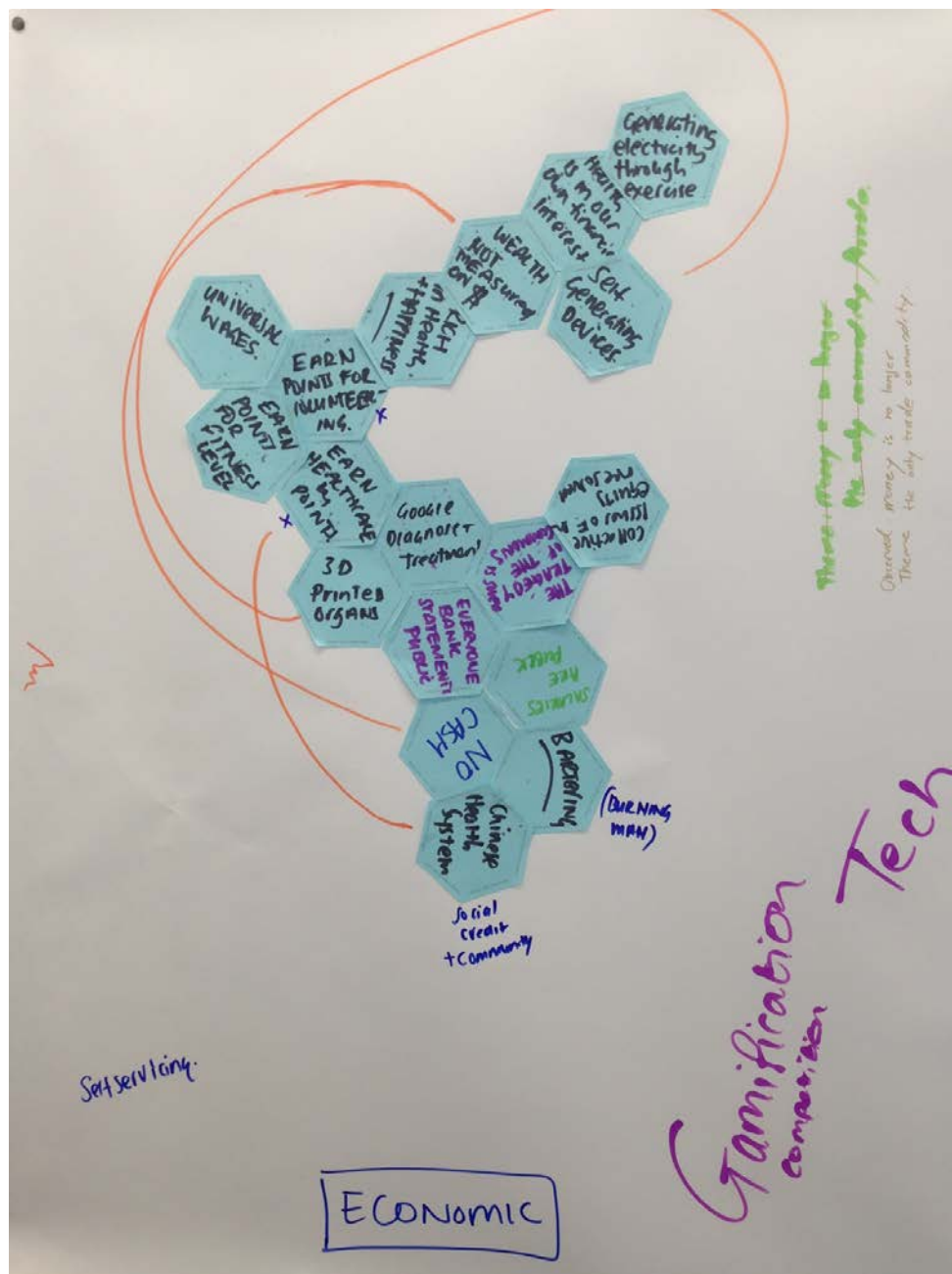


Figure 2: Emerging economics system in relation to health

## Environmental

Within the environmental category, 'the environment is healthier than it is today' scenario was identified as a mature condition. Primary impacts were 1) sustainable agriculture and industry, 2) efficient, zero emission and long range transport, 3) circular economies (no wastage), 4) sustainable

consumer behaviour, 5) hyper advance education systems and 6) all humans have access to clean water. Three broad themes emerged from the primary impacts and they were 1) Choices, 2) New Economy, and 3) Equality (in relation to ecosystem and resources). These 3 themes are interdependent, and central to these themes was 'value' (Figure 3). The choices we make (e.g. eating habits, what we buy) determined how we used resources. What is significant with regards to this concept is for a healthier environment to be a reality, we have to prioritise the choices we make and this might mean restricting choices. Education plays a vital role here. A new economy would be needed to achieve agricultural industries that are sustainable, economically and environmentally. Equality as a human value, in terms of, access to clean water, is important here. Access to water sources are increasingly under threat from contamination, poor governance, over extraction, and climate change impacts, not only on the health of populations, but also on the economic, environmental and social development of communities and nations.

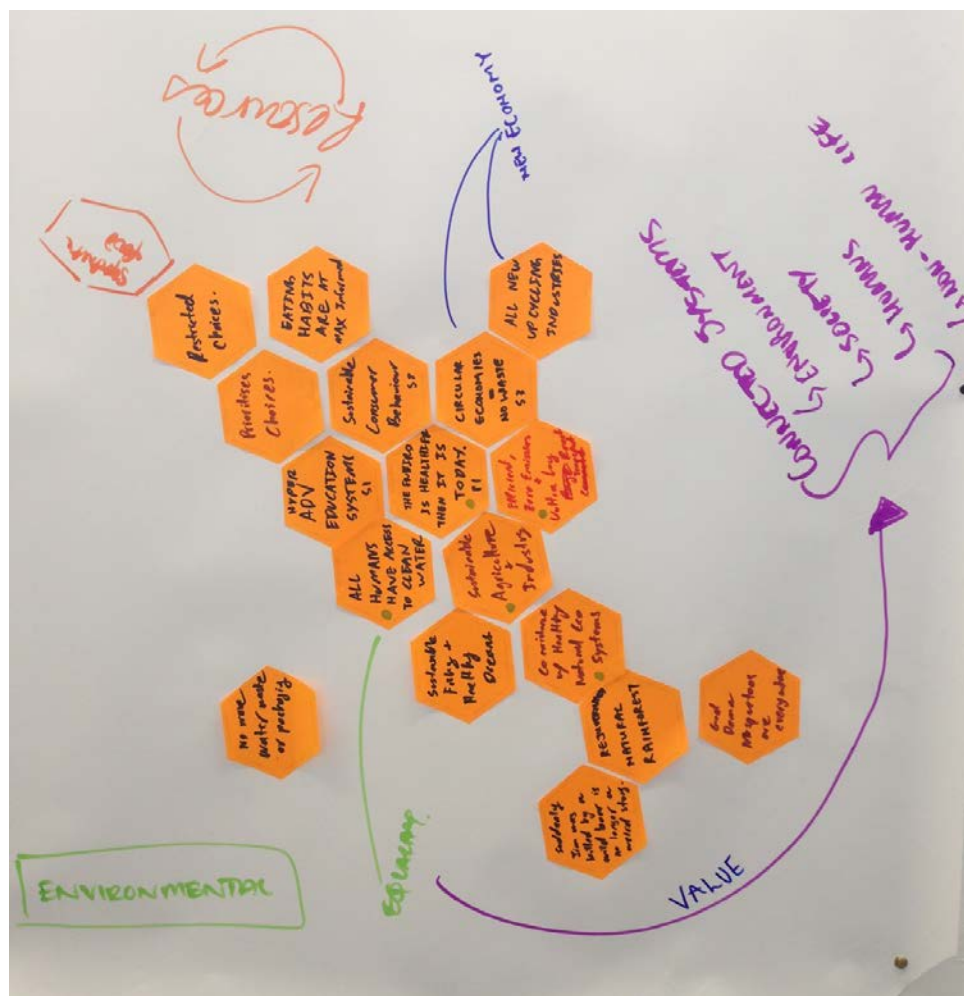


Figure 3: An interconnected environmental system

What are the impacts on a society when 'social media is the key global language'? This group took a more dystopia view of society, observed through the increased role and use of social media, integrated with other technologies. Primary impacts included body objectification, impaired relationship skills, lack of physical contacts, increasing physical challenges, more human-machine interactions and the embedding of microchips into the body. The society that this group imagined was one where technology, such as Artificial Intelligence and data, have a detrimental effect on privacy and one's perceptions of reality. The lack of physical contact, or meetings with others, together with the way social media works, simulates a feeling of closeness and intimacy that does not exist. The group discussed the positive benefits social media brings, but also cited research that reported that spending too much time engaging with social media can actually make you feel more lonely and isolated and exacerbate mental health problems, such as anxiety and depression. This impact effects the sense of self and identity and all issues cascade into mental health conditions (Figure 4).



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## Science/Technology

Human-Robot intimacy was envisioned as a change we would see in 20 years time. 'Loneliness', 'autonomous robots', 'always available', 'predictive emotional modelling', and 'creativity', are impacts this group brainstormed and discussed (Figure 5). Robots were seen to provide social care and disability support, with them becoming prevalent in other industries. One of the tertiary impacts would be that people may have more time for altruism. The coupling of human and robot relationships raised impacts of loneliness. Exploring the negative implications, issues such as 'mental/emotional emptiness' and 'mental health' were discussed, and the ensuing questions around identity and what it means to be human.



Figure 5: Science/Technology change diagram where Human - Robot intimacy is the mature condition explored.

## Political

'Dissolved Nationhood' was the change explored by this group of participants, where they considered 'think global; not local', 'global and local communities', 'digital communication increasing involvement of citizens', 'harder to make decisions - what are the new systems' and 'people feeling a loss of their national identity' were identified as impacts. Questions were raised during the activity



around healthcare, for example ‘who protects health data’ and ‘how do we run and fund healthcare’. Further to local communities being empowered to act, of which context specific solutions could be offered and being involved as a community encouraged a sense of belonging, this in turn was associated with wellbeing and mental health, and the question relating to ‘who coordinat[ed] these activities’ was a concern (Figure 6).

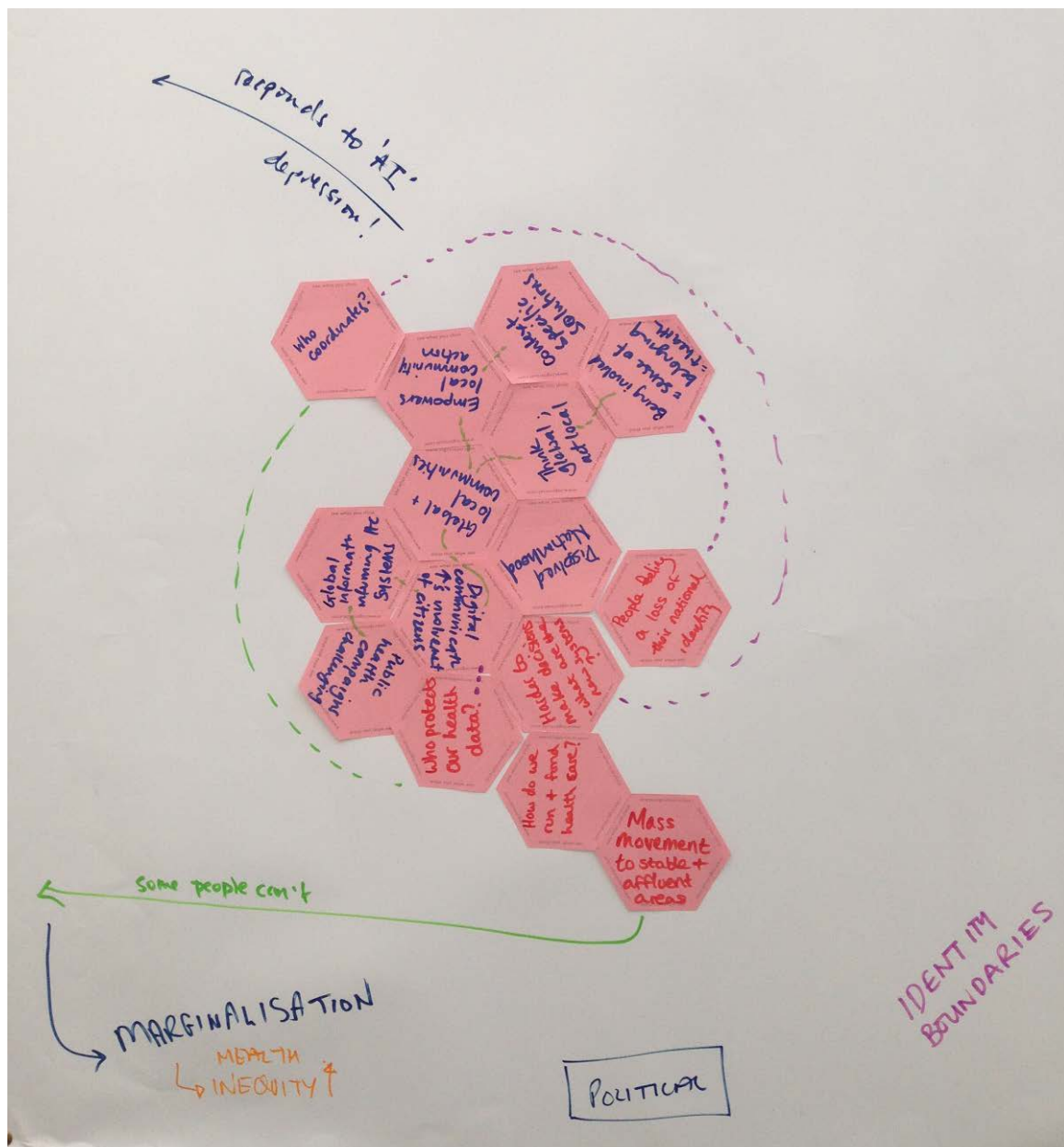


Figure 6: Exploration of “Dissolved Nationhood” as a political change.

## Discussion

Understanding the interconnectivity of health to other systems, and where it can be impacted by them, is crucial, if we are to envision a future where the health and wellbeing of communities, is approached holistically. We can see from the findings of the workshop, that envisioning different

scenarios, gave way to emerging impacts that would affect a future healthcare system. We therefore need to consider how we can begin to explore the complexity of a systems approach to healthcare.

The United Nations developed 17 Sustainable Development Goals (SDGs) to promote ‘a better and more sustainable future for all’ (2015). Good Health and Wellbeing is goal three, but what is crucial about the SDGs is not to look at any goal in isolation of the other goals, but instead consider how one goal will be affected by other goals.



Figure 7: United Nations Sustainable Development Goals

Hannah (2014) suggests that ‘health is a product of healthy relationships, a quality of life held in common and that nobody can be healthy alone’. Viewing our healthcare system as a system within other systems and being impacted by the wider environment, can begin to help us facilitate a conversation that calls on health professionals to look to future scenarios that have the capability to destroy the world as we know it.

This is evident in the way in which global communities are struggling to cope with COVID 19, and with a death toll that rises daily to significant figures, we have yet to fully understand the impact this will have on world economies and the existence and preservation of communities around the world. We are already considering what our world will look like once we emerge from lockdown and what is certain is that we cannot go back to our capitalist frameworks that have driven society up to this point. David Orr (2004) refers to E F Schumacher (1973) who was discussing ‘intelligence’ and he suggested a person ‘loses the power of seeing things as they really are ... in their roundness and wholeness’. Orr (2004) goes on to suggest that ‘whole civilisations can be simultaneously clever and



stupid’ by which he means that they can ‘perform amazing technological feats while being unable to solve their most basic problems’.

To solve the future health of our communities, and create a healthcare system that can provide a holistic approach to health and well being, we need to use future scenarios to begin to understand what the complexity of future problems might be. It is not useful to consider ‘life on land’ (goal 15), without understanding, poverty (goal 1), access to clean water and sanitation (goal 6), hunger (goal 15), inequalities (goal 10) and of course good health and wellbeing (goal 3).

The Design and Health Symposium workshop (2019), allowed us to reframe a future healthcare system and explore impacts that emerged from specific scenarios. Whilst we can innovate new ‘technological feats’ to solve some of our healthcare problems, we suggest that a new health future takes cognisance of wider environmental scenarios to begin to build healthy communities.

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# Rehabilitation environments for stroke survivors: A mixed-methods multiple case study

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*[ABSTRACT only] Many stroke survivors require inpatient rehabilitation to re-learn skills or abilities. The majority of healthcare design evidence derives from research in acute healthcare settings. Inpatient rehabilitation facilities are often located in refurbished acute medical wards or have been designed following a model that promotes inactivity and isolation – behaviours which hinder patient autonomy, practice and learning, and patient-centred care. The aim of this research was to explore how the built environment may qualitatively influence and best support emotional well-being and behaviour in inpatient stroke rehabilitation. A multiple-case study was conducted of two inpatient rehabilitation facilities in Victoria, Australia. Using a patient-centred approach, qualitative and quantitative data were collected on the design of the buildings; safety; patients' location throughout the day; patients' physical, cognitive, and social activity; and their mood, boredom, and motivation. Patients also participated in "walk-through" semi-structured interviews to investigate their experience of the physical environment. Data were synthesised using convergent mixed-methods to produce a multiple-case report. Twenty patients participated at site one (mean age 74 years, 40% female) and 16 at site two (mean age 67 years, 37% female). Overarching themes included entrapment and escape, navigating an institutional environment, the ward as a shared space, and patient-centred legibility and function. Patients spent the majority of their day in their bedroom (>70% of the day at both sites). A substantial proportion of their social, cognitive, and physical activity was conducted in hallways, communal areas, and therapy areas. Important elements for building design were identified, including access to spaces outside the ward, privacy versus isolation, opportunities to personalise the space, communal spaces, and wayfinding and orientation. Using patient-centred methods for investigating the unique relationship between the physical environment and stroke care, the study contributes new evidence to optimise inpatient healthcare environment design for people with stroke.*

Keywords: stroke rehabilitation, mixed-methods, healthcare design, case study; person-centred; emotional well-being; physical activity

# Using novel visualisation methods to combat infection risk during clinical practices

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*[ABSTRACT only]      CONTEXT: Effective infection prevention and control (IPC) is essential for tackling anti-microbial resistance (AMR). The update of appropriate IPC is heavily influenced by human risk perception and consequently how humans interact within a healthcare environment. A referral veterinary practice provided the site for the development of an IPC training intervention. AIM: To provide an appreciation of infection risk in the veterinary surgical environment by designing and piloting a novel training intervention supported by a 3D digital simulation tool which ‘makes the invisible, visible’. The ultimate goal is to motivate changes in perception and ultimately behaviour needed to reduce risk of infection. METHOD: A mixed-methods approach was informed by: video data to determine workflow actions and interactions between people, animals and the practice environment; evaluation of risky procedures and behaviours associated with infection transmission; iterative prototyping of the 3D tool allowing normally invisible bacteria to be ‘seen’ as they spread via contact between actors in the environment; four co-development workshops; and deployment in a UK veterinary school. DEVELOPMENT: The 3-D digital tool comprised a surgical preparation area with avatars (3 clinical staff, 1 canine patient) [figure 1], enabling users’ attention to focus on visual cues showing contamination sources, their spread, and IPC. The grey-based monochrome model enabled enhanced visibility of IPC and contamination information. A red-shaded ‘contamination’ layer was added, showing the potential transfer of microbes during the sequence of procedures in the preparation stage [figure 2], and which interacted with the green-shaded IPC elements showing barriers and sanitised equipment typically used in good veterinary practice [figure 3]. These layers could be switched on and off as required during delivery of the intervention. OUTCOME: At deployment, a total of 51 practice staff participated in 9 separate sessions, experienced and evaluated the intervention.*

Keywords: infection prevention and control, co-design, digital modelling, visual software, veterinary practice training

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Figure 1: Layer 1 showing the pre-surgical procedure with in-built risky behaviours.



Figure 2: Layer 2 'switched on' to show transfer of 'invisible contamination between animal, veterinary staff, surfaces and equipment during a pre-surgical procedure if proper infection control methods are not being properly observed.

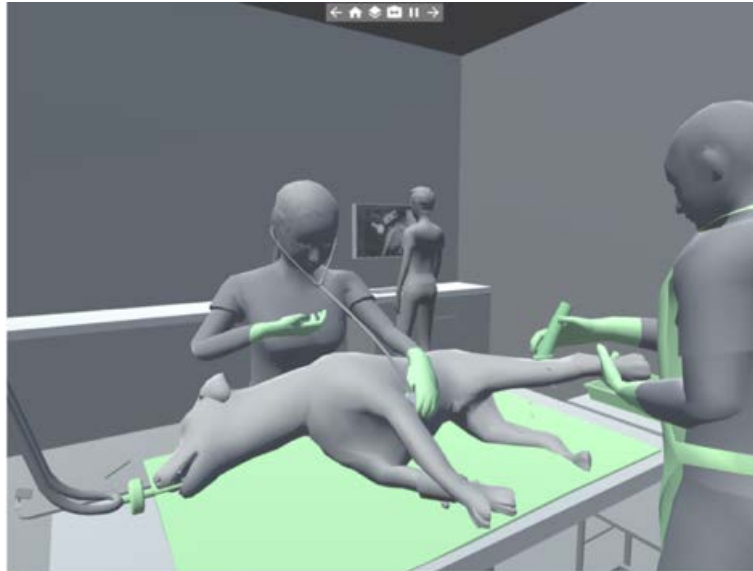


Figure 3: Layer 3 'switched on' showing infection prevention and control (IPC) measures in place.

# Chronic Design: Toward an Ethics of the Unsolvable

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**ABSTRACT** *If the disciplines of medicine and design each seek to improve situations, designers have much in common with doctors. In creating prostheses, wearables, and assistive technologies, designers intervene in bodies to improve function and alleviate discomfort. The ethics of this, however, are contested, as scholars critique how ongoing design interventions can problematize minds and bodies as requiring perpetual repair. With this in mind, how can designers alleviate suffering while ethically engaging with chronicity? I suggest that deriving the concept of 'chronic' from the medical field for use in the design field may ignite new approaches to long-term human-object relationships. While acute (short-term) contexts are amenable to clean-cut solutions, chronic (long-term) contexts often involve problems that can only be managed, never solved. Thus, living with a long-term design intervention or object is like a chronic condition in itself, one with deep implications for agency and personhood. The idea of 'chronic design' is an ethical provocation that considers chronic conditions not simply as problems to be solved, but as sites of experience, identity, and imagination.*

Keywords: design ethics, chronic illness, disability, time, chronicity



## Introduction

If design is a process of, as Simon puts it, turning existing situations into preferred ones (1969), then medical practitioners are much like designers. While doctors deal exclusively in the maintenance and repair of human bodies, designers intervene extensively across media, environments, and even the processes of life itself. Walter Dorwin Teague, founding figure of 20th century industrial design, once claimed that products that had not undergone the industrial design process were ‘sick,’ and that industrial designers were like physicians that treated and cured defective objects (Cogdell 2004).

When designers intervene in bodies, however, the lines between doctorly and designerly intervention become blurry. To navigate these relationships, design for health requires a strong ethical grounding. How should designers (who, in most cases, are not doctors) intervene in medical settings, effectively offering ‘treatments’ to users? This paper addresses one small area of these emerging ethics: design interventions in chronic health conditions. Chronic conditions are ongoing, and in most cases, cannot be fully resolved back to a templated ‘healthy’ or ‘normal’ state. This intractability poses a challenge to design, which is a solution-oriented discipline. When the possibility of a solution is foreclosed, what else can design be?

Here, I explore the interplay between design and chronicity, asking how different conceptualizations of ‘chronic’ provoke different ethical approaches to long-term design interventions in bodies. I distinguish between two perspectives toward the chronic in design. The first, *design for chronic*, approaches a chronic condition from a problem-solution framework, breaking the condition down into its constituent parts, and remedying what it can. The second, *chronic design*, derives the concept of ‘chronic’ from the health field and applies it directly to the design object. Here, the design intervention *itself* is chronic — a state that affords new ways of being. I suggest that this perspective may provoke new ways of thinking about design in chronic health contexts, foregrounding issues of personhood over problems alone.

## Two Perspectives: Design for Chronic & Chronic Design

‘Chronic,’ in the simplest sense, describes something that occurs continuously or repeatedly over long periods of time. Chronic health conditions are long-term health problems, in contrast to ‘acute’ problems that can be resolved with appropriate treatment. While the acute-chronic distinction is familiar in modern medicine, there is relatively little consensus on what ‘chronic’ means. According to Bernell and Howard (2016), definitions of ‘chronic’ vary by country, field, and organization. Some entities classify certain diseases as chronic, while others focus broadly on factors such as duration of illness and the presence of functional impairments. Bernell and Howard advocate for a simplified approach that centers *Merriam Webster’s* definition of chronic: ‘continuing or occurring again and again for a long time.’ This definition neatly excludes acute conditions (like sprains) while accommodating a wide range of other ongoing conditions (like migraines) that can slip through the cracks of conventional disease discourse.

Even so, medical anthropologists have challenged the acute-chronic binary altogether. Manderson and Smith-Morris argue that life-extending treatments and sociopolitical circumstance have blurred the line between the curable and incurable, and that such a dichotomy ‘inaccurately captures the lived experiences of illness over time and in different settings’ (2010, 3). The authors suggest that

focusing on chronicity within the context of individual lives more accurately reveals the implications of health interventions.

For purposes of this paper, I adopt a simplified definition of chronic: continuing or occurring over a long period of time. This non-prescriptive definition accommodates individual experience and social critique, while also emphasizing ‘ongoingness’ as a fundamental part of the chronic experience. I also acknowledge that while ‘chronic’ typically refers to disease, the distinction between disease and disability is blurry — many diseases impact function whether or not they result in a physical disability. Therefore, I use the phrase ‘chronic health condition’ loosely to refer to any type of health ‘problem’ that lasts for a very long time and is resistant to a ‘cure’ or other resolution to a ‘normal’ state.

### *The Design for Chronic Perspective*

In many ways, the design discipline already considers the implications of time. Planned obsolescence — the purposeful design of something to fall apart, break down, or become un-useful after a certain amount of time — has long preoccupied the industrial design field. While often maligned in the context of consumer culture, this obsolescence is key in health settings. The development of medical adhesives, dissolving sutures, and unobtrusive splints are examples of ‘acute’ designs for health — existing only long enough to bring a medical condition to a resolved state.

Alternatively, the creation of prostheses, implants, and long-term assistive technologies represent design for chronic health conditions. Even wearables like eyeglasses fall into this category, as they tend to integrate into individual lives indefinitely. Such objects might come to impact or even characterize an individual’s self-concept. In all of these scenarios, the design object represents a type of ‘solution’ (even if partial) to an ongoing ‘problem’ of discomfort, ability, or mobility. If the “problem” is expected to last a long time, designers create an object that is comfortable, durable, and perhaps equipped with additional features to meet the individual’s needs. The chronic ‘problem’ is the framework against which a solution is constructed: the object is carefully designed *for* a chronic condition.

### *The Chronic Design Perspective*

In contrast, one might also consider the resulting design object *itself* as chronic. I suggest that concept derivation — the transfer of a concept from one discipline to another (Walker and Avant 2019) — may result in a notion of *chronic design* that provokes more open-ended possibilities for interventions in chronic conditions. While typically used in theory-building, I employ the concept derivation method here as an imaginative provocation. In adapting Walker and Avant’s three-step method, I argue that borrowing ‘chronic’ from the medical field can conceptually (and playfully) instigate new ethical priorities in the design field for bodies with chronic conditions.

Table 1: the three steps of concept derivation

Step 1: identify	Step 2: transpose	Step 3: redefine
<p>Concept 1: chronic health condition</p> <p>Field 1: medicine</p>	<p>Concept 1: chronic health condition</p> <p>Field 2: design</p>	<p>Concept 2: <i>chronic design</i></p> <p>Field 2: design</p>

Step one represents the original concept in its original field: a chronic health condition in the context of medicine. Here, ‘chronic’ refers to a long-term condition that doesn’t go away and deeply impacts the individual’s experience of life.

Step two represents the original concept transposed into its new field: a chronic health condition ‘treated’ through objects made by designers. This framing is similar to the *design for chronic* perspective explained above — design is engaging with chronic conditions as long-term problems that do not go away and impact the individual’s experience of life.

In step three, however, the concept of ‘chronic’ is redefined in the design field. Now, instead of just being an object to ‘treat’ a chronic condition, the design object represents a chronic condition in itself — one that interfaces with the wearer or user in a rich, ongoing relationship. This *chronic design*, like a chronic health problem, is a long-term condition that doesn’t go away. Here, a *chronic design* becomes its own sort of chronic condition that impacts the user’s lifestyle, leads to new types of interactions with people, and opens up different ways of experiencing the world. In *A Cyborg Manifesto*, Haraway (1991, 154) explores novel possibilities of human and nonhuman assemblages, a world of ‘joint kinships’ with machines that provoke new meanings and forms of power and pleasure. A *chronic design*, therefore, can be seen as an ongoing relationship between human and object that ultimately transcends the bounds of the initial ‘problem’ to be ‘solved.’ By foregrounding this human-object relationship, and the embodied possibilities therein, *chronic design* objects can certainly still ameliorate the felt negative impacts of a chronic condition. However, they may do this less by making up for what is ‘wrong,’ than by moving toward what is possible.

## Discussion

I have distinguished between a *design for chronic* perspective (primarily oriented around problems and solutions) and a *chronic design* perspective (primarily oriented around the possibilities of human-object relationships). I do not suggest that these approaches are mutually exclusive, nor that they represent any sort of binary. However, I suggest that they are useful points of departure in discussing design ethics in health. While they address chronicity through objects, *design for chronic* foregrounds problems while *chronic design* foregrounds personhood. In practice, this cognitive shift can lead to different ethical framings of design interventions.

## Design for Chronic: Ethical Implications

In chronic settings — where impacts are lasting and identities are at stake — a fixation on solutions can problematize the body and mind as in need of perpetual repair. Conventional understandings of health interventions and assistive technologies tend to imply a certain standard for what a body should be and do, implicitly enforcing standards that McRuer calls ‘compulsory able-bodiedness’ (2006, 8). While perfect health is an impossibility, the underlying idea that a body should have nothing wrong with it pervades both social consciousness and the design discipline. Throughout history, delineations between health and illness have long been used to uphold social standards, legitimize acceptable bodies, and police deviant bodies. Citing Foucault’s extensive histories of health, mental illness, and medicine, Berlant argues that ‘living increasingly becomes a scene of the administration, discipline, and recalibration of what constitutes health’ (2011, 97).

These recalibrations of the ‘chronic’ (and what to do about it) have shaped how we conceive of chronic diseases. In an anthropological analysis of pharmaceutical testing and marketing, Dumit (2012) argues that the prevention of chronic illness has, in fact, become a kind of chronic illness itself — a state that must be monitored and managed with increasing amounts of medication and medical intervention. As a result, he says, we find ourselves in a new health paradigm of chronicity — trained to see asymptomatic risk factors as signs of illness and justification for treatment. This dynamic has conspicuously seeped into the design field as well, as evidenced by a recent boom in wearable medical tech, fitness-trackers, and home-testing kits. These technologies allow everyday users to measure health, assess risks, and at times, even self-diagnose. Because of this, even the practice of maintaining ‘good’ health is a chronic project, and it is clear that medicine and the design industry stand to gain from bodies that are perpetually in need of intervention. In short, designing for chronicity can make even the ordinary precarious.

Since problems defined by medicine can be subjective, malleable, and problematic, designers should take care when engaging in ‘solutions’ to undo them. In worst-case scenarios, uncritical design work on medicine’s behalf treats identities as maladies. Blume’s (1997, 39) account of the dialogues surrounding cochlear implantation in the 1970s represent one instance of this. Counter to expectations, some members of the Deaf community organized against the budding technology, arguing that subjecting children to implantation would deny them the benefits of belonging to the signing Deaf community. In the words of Blume, ‘it had simply been taken for granted that deaf people viewed their deafness in the same terms as medical and audiological professionals: as a loss of hearing.’ Medical specialists had failed to account for how deafness intersects with identity and community, two things drastically undermined by the universal adoption of new hearing technologies. This example underscores how design objects interface with problematic norms, elastic identities, and notions of solvability in general.

## Chronic Design: Ethical Implications

As an alternative, foregrounding the long-term human-object relationship through a *chronic design* lens may have a number of positive implications for designers working in the health setting. Jönsson et al. (2005, 1-2) indicate the importance of ‘situated ethics’ in the design field. Rather than providing a concrete list of ethical guidelines, situated ethics address the most important needs of ‘real people in actual situations.’ The authors cite a case study of a young child, Hanna, with a

mobility-restricting nerve-muscle disease. While a wheeled chair would have provided mobility, the child's caregivers noticed that Hanna seemed to enjoy moving around in an upright position. Because of this, her family provided her with a motorized standing support device, and Hanna continued to use such devices into adulthood. Jönsson et al. question the assumptions behind prescribing certain technologies (like wheelchairs) as default mobility solutions and ask about the ethics of not providing options, arguing that objects do more than fulfil a function, but 'also reshape the person's existence and existential terms' (2005, 2). By considering these existential terms, *chronic design* emphasizes the needs and priorities of the individual. In the case described above, this approach led to an intentional choice of design intervention that supported the particular way that Hanna wanted to move.

A *chronic design* approach can also serve individuals beyond the design of functional objects. Engaging with chronic conditions through critical and epistemological modalities allows design to become an attentive, exploratory process, rather than a purely reparative one. The creative practice of 'cripping' — creating provocative objects that challenge the assumption that disability, or difference, is negative (Williamson 2019, 189) — is one example. Williamson cites many examples of 'cripping design,' from brightly painted wheelchair ramps that lead to nowhere, to prostheses designed for beauty rather than functionality, to attention-grabbing assistive technologies that implicate disability in cultural dialogues of desire and self-expression. These works spark imagination and reconsideration, especially in situations where comprehensive health "solutions" are foreclosed. In the words of Dunne and Raby, 'many of the challenges we face today are unfixable... ..the only way to overcome them is by changing our values, beliefs, attitudes, and behavior' (2013, 2). By absorbing these critical and speculative possibilities, *chronic design* can also help rehash social narratives, unseat paradigms of ableism, and provoke new imaginaries of chronicity. This approach makes space for 'recovering' the everyday experiences of chronic conditions, a 'recovery' that 'may involve an act much like the process of healing' (Morris 1998, 273).

## Conclusion

Problems without end, when 'solved,' become solutions without end. While many have sought to better understand the long-term effects of living with chronic health conditions, this paper attempts to draw attention to the long-term effects of living with chronic health *interventions*. This is not to negate the importance of such interventions, like the development of better prostheses, safer implants, and more convenient modes of dispensing medication. However, these projects would also benefit from absorbing critical approaches to design, chronicity, and identity. The *chronic design* perspective unfurls a world of opportunity for designers to engage with chronic conditions not only physically, but along emotional, social, and imaginative axes as well.

A *chronic design* practice accepts chronic conditions as valid states of being, knowing, and imagining. It provokes conversation and rethinking of norms. Ultimately, it nudges the design discipline away from solving and toward serving. In that sense, *chronic design* may have wider applications than in health alone. By moving beyond rigid paradigms of 'solutions' or even 'betterment,' design becomes free to explore new personal, experiential, and palliative modalities in an increasingly unsolvable world. As real solutions drift farther and farther from the realm of possibility, *chronic design*, in the end, may be all we can hope for.

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# Essentials for wellbeing: Expanding the symbolic value of healthcare design

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*ABSTRACT The relationship between design and medicine is not new. The discipline of design has impacted the medical practice in meaningful ways, from the development of spaces and devices to the optimization of healthcare services and strategies. Earlier approaches have focused primarily on solving or improving specific needs such as designing more hygienic spaces, creating more powerful tools, or increasing medical record efficiency. Function and usability were primary goals. However, as the field of design began to evolve, so did the concept of Medesign. From a utilitarian perspective to a user-centric model, healthcare designers began to explore other dimensions related to experiential comfort, emotions, and motivations from practitioners and patients. The purpose of this study is to expand those user-centered dimensions and to start discussing elements related to the symbolic value and reflective aspects of medicine. A two by two matrix was created to explore the actual universe of healthcare, from a functional approach to an experiential one, to expose opportunities in which design can influence practitioners' and patients' well-being. The practitioner-patient axis determines who benefits from the design intervention. The functional-experiential axis determines the level of problem-solving compared to opportunity-driven approaches. Five cases were analyzed according to this matrix to emphasize and define aspects essential to design for well-being and future healthcare. We expect to identify new action fields that expand the interactions between design and medicine. We discuss five directions for applying design for health and well-being that can broaden the spectrum of design interventions, including the use of metaphors, tangible models, and the level of interaction, among others. These directions can create more alternatives for designers who want to promote a more human slant in medicine, creating awareness, understanding, and the involvement of patients, practitioners, and caregivers.*

Keywords: Healthcare design, symbolic value, design for wellbeing.



## Introduction

Evidence-based approaches became a must for medicine, during the 19th century. Practitioners have turned into experts in data collection to guide their decision-making to cover specific aspects of a patient's condition. Without doubt, this practice has improved the evolution of medicine during the past century, successfully curing many untreatable diseases. However, is that all? Have practitioners reduced patients' illnesses to a set of data? What about the patient as a person? What about human relationships?

Medical procedures have become more efficient by using technology and digital tools. The health system is focused on optimizing resources and processes, while appropriate care requirements particular to a patient's social, cultural, and emotional context are often not considered. Physicians have either limited time or no interest in further exploring the human aspects; patients become mere bodies in a system and not persons with a particular condition.

Nevertheless, evidence-based medicine (EBM) was not only about data. Sackett (1997, 2005), a pioneer in EBM, defined that a good doctor was one that was able to navigate between the data and the patient's needs. A good doctor is one that can understand medicine beyond efficiency and efficacy, one that considers medicine an art. In a study by Rankin (2013), the author highlighted that patients that received humanistic support from their doctors, had a much faster and better recovery than those whose doctors strictly followed only test results.

Design has a significant impact on the epigenetics of our body and, therefore, great responsibility in this respect. This discipline possesses the tools and knowledge to intervene in specific environments and contexts to promote healing processes and integral well-being, and it can help to strengthen conventional treatments by incorporating emotional, experiential, and mental aspects. Design can trigger relaxation responses in patients' bodies and stimulate epigenetic modifications in their physiology through positive products, services, and strategies, making all traditional procedures easier and more effective.

## Methodology

### Functional medicine vs. Experiential medicine

To establish an analysis framework in this article, we define two approaches related to the healthcare context: 1) A functional approach where the study of symptoms is used to find the root of specific diseases. This is based on the collection of measurable evidence, accompanied by data analysis techniques that reduce uncertainty in the identification of types of diseases; 2) An experiential approach that gives rise to a broader vision in the practice of medicine, where context plays a fundamental role in patient well-being. The functional approach generates results, while the experiential approach explores the activation of healing processes specific to the body. The purpose of this article is not to define which approach is better, but rather to broaden the vision of what we call experiential medicine, through suggestions and guidelines for designing medical products and services.

To better illustrate our position, we propose a 2x2 matrix where we place the approach to medicine on the horizontal axis and the type of actor with whom it interacts on the vertical axis (Figure 1). Insofar as the actors, we put doctors on one side and patients on the other, understanding that many of the interventions benefit one or the other. The goal of the matrix is to allow us to visualize different examples through which to propose strategies that contribute to the well-being of the various actors.

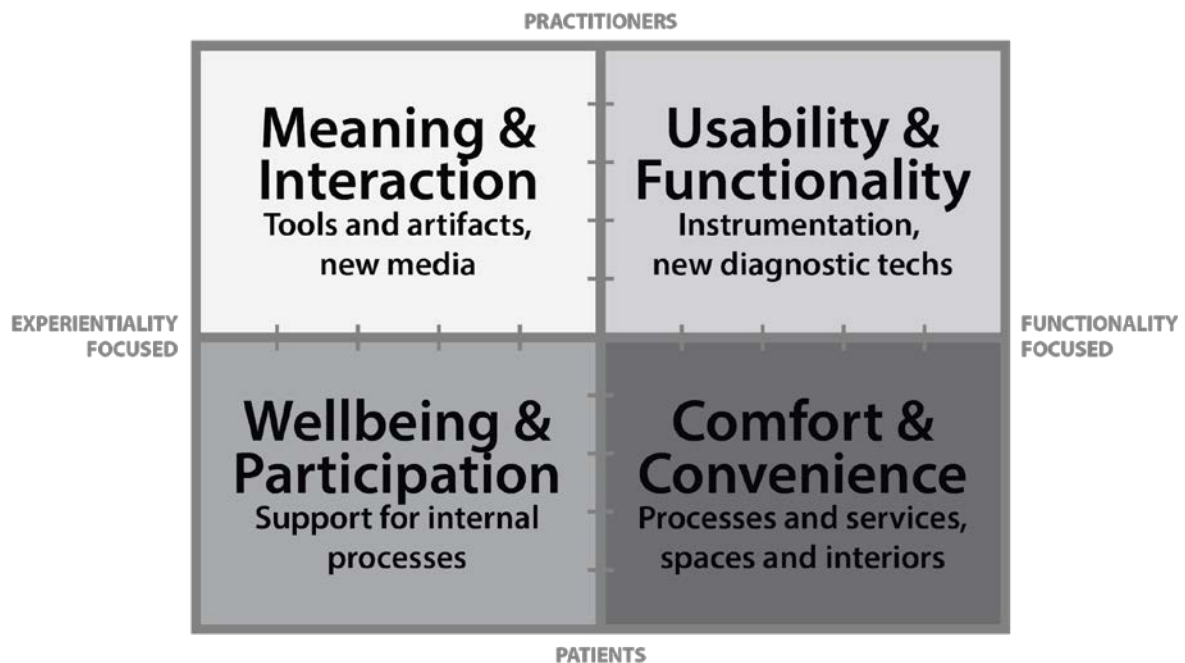


Figure 1: 2x2 matrix to categorize healthcare solutions based on the approach to medicine (horizontal axis) and the type of actor with whom it interacts (vertical axis).

The matrix includes four quadrants with the following characteristics: Functionality-focused on physicians, Functionality-focused on patients, Experientiality-focused on physicians, and Experientiality-focused on patients (Figure 1). The article will emphasize the part of the matrix that focuses on the experiential side and to understand why, we will explain a number of concepts that we extrapolate from the design focusing on emotions.

## Why does pleasure matter?

Medical science has devoted much of its work to relieving pain. The absence of pain, however, is not necessarily understood as the experience of pleasure. Tiger (2017) mentions different dimensions of pleasure, where he transcends the idea that pleasure is directly related to physical satisfaction. Alternatively, Jordan (2002) proposes a pyramid that defines functionality, usability, and pleasure as aspects to encounter when designing a product. Although Jordan and Tiger examine different dimensions of pleasure, this article will focus on pleasure as one of the pillars that constitute the positive design model (Desmet and Pohlmeier, 2013).

## Sometimes good design is not good enough

Design has focused on understanding people's desires. People are overexposed to many products, but few catch their attention. Different authors have developed tools that help designers transcend the boundaries of tangibility and enter the field of meaning. Casais, Mugge, and Desmet (2015) speak of meaning as the differentiating element of a product. People no longer consume a product only for functionality, but rather because of what the product represents in terms of making them belong. Exploring meaning reinforces that design no longer has to be recognized as a result, but as a vehicle that allows the user to travel through an experience (De Francisco Vela and Casais, 2018).

Inspired by these views, we defined five factors that can help to develop products or services within the healthcare context. These are analogies, users involvement, communication, representations, and evidence of building a process. We propose strategies that help designers and other professionals focus on medical situations to create better experiences that promote patient and physician well-being.

## Results

To illustrate the proposed factors, we chose five projects developed within a medical context that are aimed at expanding other aspects of the healthcare experience. These projects are not necessarily designed to cure patients directly, but rather to extend the range of tools to improve factors related to well-being, communication, or interactions among actors. The projects are Homeostasis sanatoris; Konnekt Play; Doplor; CareTunes, and PARO, the Seal Robot (See Table 1).

Table 1. Comparative chart of factors and projects.

	Homeostasis sanatoris	Konnekt play	Doplor	CareTunes	PARO
Analogies and Metaphors	Balance and equilibrium. The analogy is used to emulate the process through the object to find that balance.	N/A	Weather. The representation of the weather emulated the health level of the patient.	Music. The musical instruments symphony emulate the patient's vital signs.	N/A
User involvement	The patient and the practitioner have to interact with the object.	Children engage in playful social dynamics.	Helps visualize the status of the patient.	Helps interpret the patient's vital signs.	The patient looks after the robot.
Type of Communication	Reflection of the patient's	Dialogue in terms of	Visualization of 4	Dialogue about the	Dialogue between

	situation and dialogue between the practitioner and the patient.	playful social dynamics.	different status.	harmony of the vital signs.	the patient and the robot.
Representation or manifestation	An object that gives instant feedback.	Ambiguously -shaped, buildable foam parts.	Interactive art paint.	Sound of musical instruments.	Seal.
Process vs outcomes	The process to identify the stages and barriers of the situation.	The process to engage in social activities framed within building games.	The outcome of precise alerts.	Process of monitoring the vital signs.	Process of looking after a pet.

### Project 1: Homeostasis sanatoris. A therapeutic product that stimulates physiological healing process.

Every disease process comes with changes and challenges, both physical and emotional. Most of the time, people can identify the physical alterations as symptoms, discomfort, and pain, while the emotional aspects of the disease are difficult to identify. Henríquez Martínez and De Francisco Vela (2019) created Homeostasis sanatoris as a water filter placed on a pulley system designed to stimulate patient reflection on the disease and to allow them to make their emotions visible through the elements contained in the product (Figure 2).



Figure 2: Once patients define the water filter, they have to find balance by using the weights. This activity is aimed at triggering conversations about changes in the patients' routines.

The product explores the concept of integral balance and illustrates the diseases as a process. The patient builds a water filter, adding different elements such as stones, cotton, sand, etc. Each item represents an emotion, a situation, or a feeling the patient is experiencing through his/her process. Under the physician's guidance, the patient interacts with these elements materializing his/her intangible sensations, leading to an active dialogue between the patient, the disease, the product, and the physician. Once the filter has been completed, the patient waters the plant to balance in the pulley system. The water crosses obstacles (stones, sand, cotton) to purify itself, just as we overcome symptoms to recover the balance that our body needs and to learn something new (Henríquez Martínez & De Francisco Vela, 2019).

This purpose of this project is to identify and understand a patient's flow of emotions during the disease. Homeostasis sanatoris enhances well-being and supports healing processes based on emotional and mental fields.

## **Project 2: Konnekt play. A set of shapes that allow children isolated in hospitals to play with their peers.**

Child cancer patients have to be isolated in hospitals while undergoing treatment. Jansweijer (2013) developed Konnekt as a means to support the social development of these children by allowing them to play with other children in the hospital. The designer believes that children never stop being children, so he used the dynamics of games as a foundation to create Konnekt.



Figure 3: Interaction between two children using Konnekt.

It works with amorphous foam figures that are attached to the windows of the isolation areas using magnets and suckers, allowing interaction between children. This interaction allows a co-created dialogue that allows children to play despite the physical barriers (Figure 3). The amorphous pieces allow children to create meaning by assembling them as storytelling building blocks. Konnekt becomes a means to stimulate social development rather than producing an outcome as such. The success of the product is in the fact that it promotes new forms of communication.

Konnekt does not cure cancer patients, but it broadens the spectrum in terms of improving their experience during their stay in the hospital.

### **Project 3: Doplor. An interactive art piece that improves auditory experiences for nurses in intensive care units.**

Much goes on in intensive care units; nurses run around looking after patients, family members visit their loved ones, and lots of machines make all sorts of different noises. Redert (2018) proposes a visualization system that shows patients' status without overwhelming them with the sounds of the vital sign monitoring machines.





Figure 4: Doplor's prototype set up in a validation session.

The system is an interactive painting with four representations that show the patient's status using the analogy of sea weather. When a nurse approaches, she can access the information through a description of the situation and visualization (Figure 4). The metaphor makes it easier to understand the patient's situation by using a picture of a calm tide or a storm to represent it. With the information portrayed as a piece of art, the monitoring tool is a more relatable object for practitioners, caregivers, and family.

Doplor supports different means of communicating patient status, using novel forms that do not interrupt intensive care unit activities. It broadens the design spectrum of medical communication elements.

#### **Project 4: CareTunes. A monitoring tool that uses musical streaming to display patients' vital signals.**

Continuing with ICUs, CareTunes proposes an approach based on musicality as a means to understanding a patient's vital signs (Boges, Koen. 2018).





Figure 5: Display of CareTunes controllers.

It uses musical instruments as analogy to represent the patient's vital signs (Figure 5). You don't need to be a musician to know when a guitar is out of tune, or when a percussion instrument is out of rhythm. The device redefines monitoring indicators, representing a patient's health status as a kind of symphony. Although the representation is not physical, it is made tangible through the music.

Tools like this, allow patients to be more attentive to their health conditions, without feeling annoyed by the noise of the monitoring tools.

### **Project 5: PARO - A robot seal for mental health care.**

Caregiver deficits for the elderly increase over time, leading to many negative mental and emotional conditions. Older adults experience depression, loss of family and friends, a change in their social role, and sometimes other mental diseases such as dementia or Alzheimer's. All these conditions decrease quality of life for both caregivers and the elderly. Shibata and Wada (2011) developed a therapeutic medical seal robot, PARO, to promote non-pharmacological therapy in geriatric care (Figure 6).



Figure 6: Using PARO for the elderly.

PARO is an FDA certified medical device that looks like a baby seal. The robot simulates an animal through the mix of sensors, artificial fur, microphones, and artificial intelligence. PARO encourages interaction and communication with users and between them. The use of PARO in clinical trials for anxiety, stress, pain, and depression has shown positive results (Yu et al., 2015; Pu et al., 2020). It stimulates social abilities, reduces aggression, and builds emotional links in the specific context. PARO has been used with children with autism, people with developmental and cognitive disorders, as well as cancer patients.

PARO contributes to the patient's quality of life and helps to alleviate emotional and mental conditions as well as increase communication between caregivers and patients, making the interaction between them and their relationship flow more naturally.

## Discussion

There is a fine line between medicine as an exact science and medicine as an art. It is impossible to say which has a more significant impact on a patient's health and, more importantly, on their well-being. In theory, both approaches should feed off and complement each other, but in practice, quantifiable information is almost always more relevant. There is evidence to support that methods that place a greater emphasis on contextual characteristics, have a positive impact on a patient's health (Montgomery, 1993; McCormick, Dewing, and Mccance, 2011; Guess, 2013; Swift, Cobb, and Todd, 2016). Such methods include, for instance, improving the behavior of the members of the health team to support the healing process. Many authors have called this type of practice the placebo effect (Kaptchuk, 2002; Wampold et al., 2005; Miller and Brody, 2011; Kaptchuk and Miller, 2015), in which the characteristics of the context are such that they are capable of triggering the body's healing processes. It is not easy to determine the input that gives rise to these changes in the

body, but in many cases, we tend to mention characteristics such as information asymmetry, or the patient's level of involvement in his/her process.

By using the above examples, we explained how the five factors can influence design decisions. The first factor has to do with information asymmetry and the complexity of medical language. The use of metaphors or analogies as part of the design will allow us to generate closer connection and understanding of the patient's current situation. Using literal or abstract analogies is fine, as long as it allows users to interact naturally. The second factor is related to the patient's level of involvement. Analogies are important because without clear understanding, we cannot ensure that interaction between the users and the designed object will actually work. A higher level of involvement can generate empowerment in the healing process. The third factor is the type of message carried by the object. The designed object does not cure the disease, but it can promote processes of reflection or dialogue related to them, both internally in the patient and by facilitating communication between users. The fourth factor is the representation of the design proposal. Almost all cases have tangible objects; this reinforces involvement and communication. It is not necessary to opt for tangibilization, but rather for representation through one or more senses, as in the case of Doplor and CareTunes. The fifth factor is related to understanding the healthcare process and using the object as that means, rather than expecting it to yield a result. Making this change is interconnected with the type of communication, which supports the intended messages.

## Conclusions

Throughout the paper, we discussed a couple of projects that explore different approaches to improving patient and practitioner experiences. Most of these experiences are not necessarily expected to improve patients' health, but rather their well-being (Figure 7). Fostering spaces for social dynamics, or allowing patients to express themselves through an object, builds new levels of interaction, which, from a scientific perspective, does not add to the patients' recovery. It is not easy to measure the impacts of these interventions.

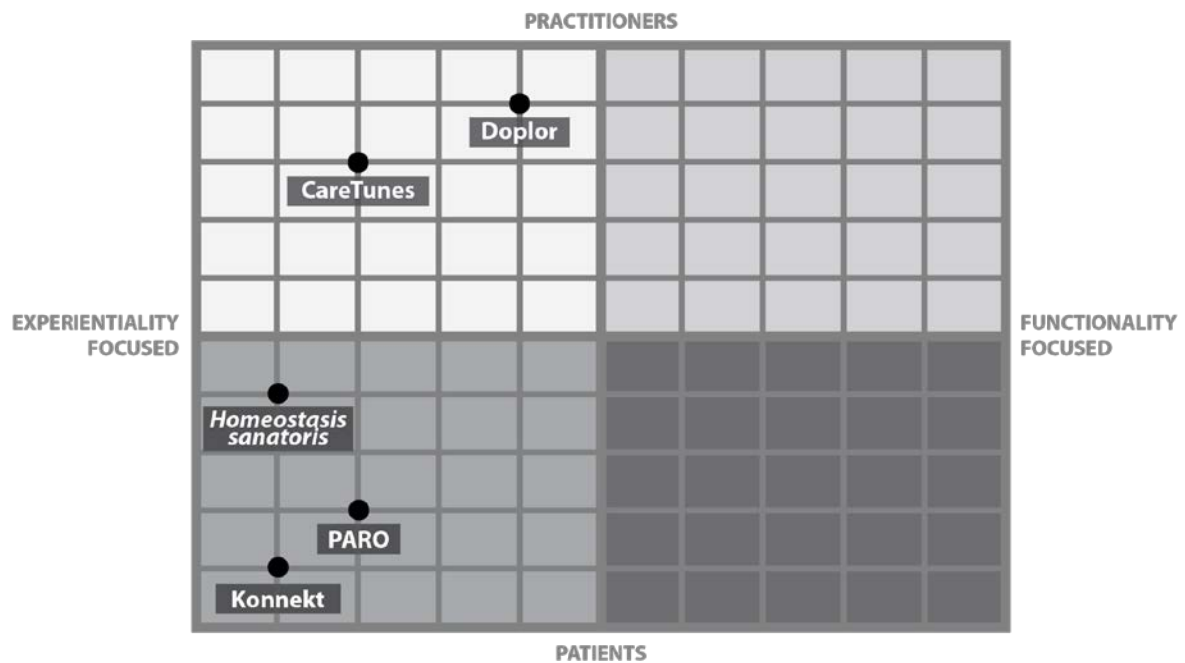


Figure 7: Five healthcare projects geared towards the experiential quadrant of the matrix.

The purpose of the instruments described here is to determine other dimensions, such as the idea that patients remain human, despite their illness. Providing more interactions that resemble human behaviors can help avoid the alienation suffered during pathological processes, and we consider that through design, we can support such approaches by focusing design research on how to create opportunities to enrich such experiences.

Perceiving a patient as a human and not just a body has the potential to change many of the interactions and dynamics in the current healthcare system. The five factors proposed above present a new framework based on which to including emotional and experiential aspects in design. They are not intended to be applied all at once, but using them can contribute to creating solutions for health care contexts. Such contributions can be applied to balance all the physiological systems involved in psychoneuroimmunology and epigenetics modulations to generate positive changes in the body, the mind, and in patient interactions. We suggest a close and coordinated effort that includes all the disciplines involved in a disease process to potentiate the experience of the stakeholders and contribute to their well-being. Design and medicine can mix their knowledge to create powerful methodologies through which to deal with disease holistically.

One of the aspects considered in this process towards improvement is the consideration of other users such as caregivers or family. The matrix only explores solutions for patients and practitioners, but there is immense potential in working with the patient's own support network. We hope that this paper will motivate designers and other researchers to apply different strategies in order to design more meaningful objects and interactions in the healthcare context.

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# VRinMind: Knowledge co-creation in designing immersive virtual reality experiences to support mindfulness practice

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**ABSTRACT** *The benefits of virtual reality (VR) in managing pain are increasingly recognised in the health and design communities. It may also enhance mindfulness practice, a successful therapy for managing chronic pain particularly for those wishing to self-care at home. However, current VR research tends to focus on specific applications related to meditation and relaxation which are different to mindfulness. Moreover, the hardware and software in VR systems are advancing rapidly making more immersive 3D environments and experiences possible. The VRinMind project seeks to co-create a VR application for mindfulness practice to aid the management of chronic pain. It is exploring how users experience different types of VR equipment and immersive applications.*

*A rapid review of the literature to consider the benefits and limitations of VR to manage chronic pain and practice aspects of mindfulness was undertaken. The findings helped craft a co-creation workshop where mindfulness practitioners explored different VR equipment and environments that could be used for mindfulness practice. Participants also engaged in a creative enterprise using textiles, images, and paper to reimagine VR settings where mindfulness practice could be further enhanced. Users' insights revealed features of VR environments such as colours, sounds and avatars that may support or hinder mindfulness practice. The participatory design approach also led to personalised visual environments that could be used in time to design a VR mindfulness application.*

**Keywords:** virtual reality, mindfulness, co-creation, co-design



## Introduction

Mindfulness involves a practice or state in which attentional focus is centred on the moment and intentionally acknowledges thoughts and feelings as they arise (Hilton et al. 2017). It can be a successful therapy, but traditional face-to-face programmes are limited by cost, poor accessibility and lack of availability. Those delivered online or through mobile applications may help address these problems and provide convenience and privacy (Flett et al. 2019). However, they can use poor visualisations and provide limited feedback which may lead to low adherence. Therefore, the mode of delivery and design of a mindfulness programme is important to ensure people remain engaged to improve pain management. The VRinMind project aims to explore the potential VR may have to improve wellbeing through mindfulness practice. It has engaged participants to reflect on features of VR environments which may either support or be a barrier to maintaining a mindfulness practice and begin to co-design settings which have the potential to enhance the self-management of chronic pain.

## Background

Virtual Reality (VR) is a synthetic world in which a user is entirely immersed in computer generated representations of an environment that provide multisensory experiences (Zhao 2009). On the other hand, Augmented Reality (AR) superimposes virtual information over a real world view blending the two environments (Bekele et al 2018). Some literature on VR to aid mindfulness practice exists. Studies have discussed the ways VR may help sustain mindfulness practice through gamification, such as being rewarded points to unlock additional content including new settings or a more interactive environment (Choo and May 2014). This is often framed as a helpful tool enabling participants to sustain mindfulness practice as an adjunct to other therapies and reduce the fallout rate of digital health programmes (Botella et al. 2013).

Work by Tarrant, Viczko, and Cope (2018) suggests that VR enhanced mindfulness practice has the potential to improve anxiety management, with electrophysical markers recording significant change in brain activity. Similarly, Navarro-Haro et al. (2016) and Navarro-Haro et al. (2017) published linked studies suggesting VR can enhance the effectiveness and longevity of impact from other behavioural therapies, most notably in participants with difficulty regulating their emotional state. They posit the immersive experiences of VR, accompanied by mindfulness audio guidance, may improve adherence to a therapeutic programme over time. It is also important to acknowledge the complexities of managing VR software and practicalities of large format hardware: The restrictions of tethered, heavy or uncomfortable headsets and issues with overheating or poor battery life were also common findings in a number of studies, including Chandrasiri et al. (2020).

The design of locations in immersive, VR mindfulness applications tends to assume benefits in natural, open settings. These may be imagined or naturalistic 'real' environments including beach or seascapes (Botella et al. 2013, Chandrasiri et al. 2020), landscapes with spiritual significance such as Angkor Wat or Stonehenge (Choo and May 2014), static positions on mountain tops (Tarrant, Viczko, and Cope 2018) or gentle travelling movement such as floating down a river (Navarro-Haro et al. 2017, Navarro-Haro et al. 2016). Hence, the design of the setting may be a factor in participants' engagement with mindfulness practice.

However, it is in the work of Costa et al. (2018) and Costa et al. (2019) where the specific role of Design and participatory methods is highlighted. In these partner studies, the authors question how virtual environments may be designed to optimise its potential as an engaging space to support the practice of mindfulness, which is immersive, restorative and provides a strong sense of ‘being there’. They highlight the usefulness of participatory design with users to create VR spaces which can enhance sustained engagement in mindfulness practices and suggest further work is needed to explore this further.

## VRinMind Project

The VRinMind project is a collaboration between nursing informaticians and design researchers (The University of Edinburgh, 2019). It aims to explore how users respond to existing VR environments and provide a space in which to imagine their optimal immersive experiences. This will aid in the co-creation of a virtual reality based mindfulness application to help improve pain management. This paper focuses on initial outcomes (having been constrained by the implications of COVID-19) and what has been learnt from employing a participatory design methodology.

### Methodology

The approach builds on a paradigm of interpretive, qualitative research which focuses on participant narratives. In particular, it draws on Tracy’s (2010) descriptions of meaningful research which is relevant and timely, multi-vocal, prioritises reflexivity in both researchers and participants, holds resonance in evoking experience and has the potential to offer practical and methodological contributions. To this end, a range of participatory, sensory and visual engagements were designed for participants, to elicit reflections on their embodied experiences or mindfulness as mediated through the digital technologies of Virtual Reality and Augmented Reality. Whilst two workshops were planned – one for mindfulness practitioners and one for participants who manage chronic pain conditions - measures for mitigating the impact of Covid19 meant that only the first has been carried out to date.

Over the course of one day, 8 volunteers (F:7; M:1) took part in a participatory workshop. They were a purposive sample drawn from professional networks at the University of Edinburgh. Facilitated by an interdisciplinary team of nursing and design researchers, participants rotated in pairs around four ‘stations’ to use and observe one another’s responses to a range of VR and AR hardware and application combinations (see Table 1).

Table 1. Interactive stations for VR / AR immersive experiences

Station 1	Station 2	Station 3	Station 4
Oculus Quest™ untethered headset and dual controllers c. £600	Oculus Go™ untethered headset and single controller c. £190	Google Cardboard VR and Merge™ durable foam mask with smartphone insert c. £10 and c. £45	Magic Leap One™ wearable spatial computer c. £2000
Preloaded with Nature Treks Meditation® VR application –	Preloaded Guided Meditation® VR application - participants	Smartphone operated Hôm® downloaded VR application –	Preloaded Tónandi® - AR application – participants responded

participants selected from settings such as seascape, forest and winter landscape, with ambient sound	selected from settings such as beach or mountaintop, with a choice of silence, music or guided meditation audio	participants viewed a single animated forest setting, observing a butterfly, with guided meditation audio	to and controlled animations and soundscape based on their immediate environment, with Sigur Ros audio
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Figure 1. (Luo, 2020) Participants experiencing Oculus Quest™ and Oculus Go™ VR

Elements of the Toronto Mindfulness Scale™ (TMS) (Lau et al. 2006), which includes thirteen points related to being open to one's experiences, awareness of thoughts and feelings and being receptive to observing changes in mood was used in a questionnaire. Following a focus group discussion, reflections using the TMS and a break, participants returned to the workshop to engage with four refreshed 'stations' to facilitate a creative, reflective response to constructing an ideal VR or AR experience for mindfulness practice. Participants used a range of materials to create a collage, leading to individual accounts and discussion around the creative responses and implications for the technologies (see Table 2).

Table 2. Interactive stations for creative, participatory making

Station 1	Station 2	Station 3	Station 4
Varied paper, brush pens and variety of coloured markers	Photo elicitation selection using 150 postcards of landscapes, close ups and populated scenes	Origami paper in various colours and designs with instructions for constructing a 'thinking tool'	Textile selection - wool, silk, tencel and bamboo fibre in a variety of natural and dyed colours

## Analysis and interpretation

Data were captured in field notes, audio recordings and photographs, then thematically coded using an iterative process. The researchers employed an 'holistic, interpretive lens, guided by intuitive enquiry' (Saldaña 2015: 57) to generate language-based data which could accompany participant-developed visual data (Rose 2016) co-examined with workshop participants during creation and supported by discussion and reflection.

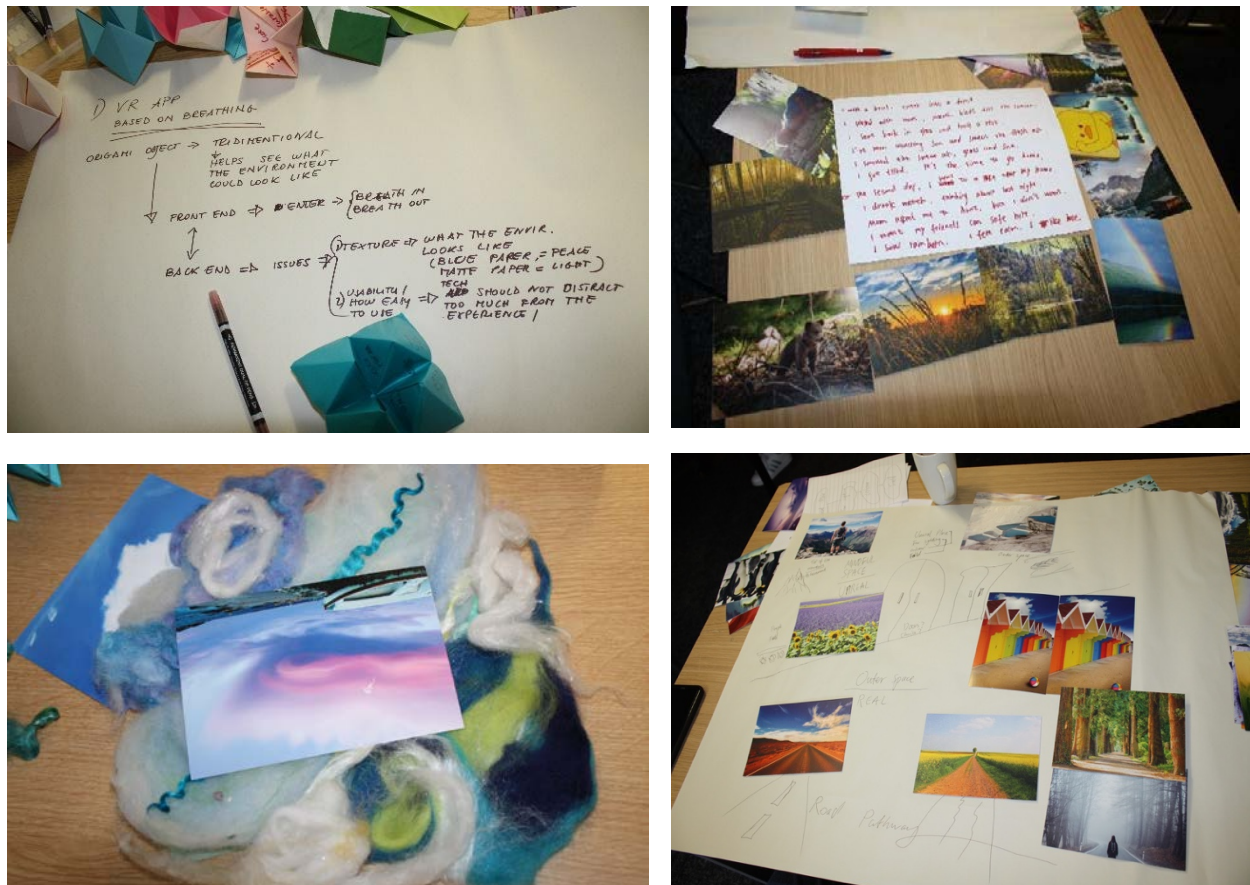


Figure 2. (Mayne, 2020) Examples of outputs from the creative, participatory making at the VRinMind workshop

## Findings

Rich data were gathered from the questionnaires, reflective discussions and presentation of personalised immersive environments through creative collage. What is presented here is a necessarily limited review of participants' responses, with a more expansive exploration to be published elsewhere. Nevertheless, there are insights to be drawn here about the significance of immersive environment design and accompanying audio guidance, the ways that participants found agency in their use of the different applications and hardware, technology as an obstacle in mindfulness practice and views on the connection and centredness afforded by VR and most notably, AR.

## Sight and sound in immersive design environments

Almost exclusively, participants disliked the expansive, open natural settings in the immersive VR mindfulness applications in the workshop. For (9), this was couched as a query – whether the natural worlds of oceans, mountains or forests were too familiar and whether unfamiliar, abstract settings might be helpful in freeing the user from distraction. Others found these settings actively distressing, describing the ‘terrible ... visual onslaught’ (1) of a barren setting or disturbed by the artificiality of, for example, not being able to ‘see’ one’s feet in a landscape where it appears impossible to stand (5).

## Agency and action

Some participants resented the lack of agency offered in some of their VR experiences: This was often about guided mindfulness audio, where the tone of voice or word choices had a negative impact which participants found ‘distracting and unsettling’ (9) or oppressive. Some participants rejected the idea of being given a task to do rather than finding one’s own way or asked to obey an instruction that meant little to them: For example, Participant 5 was irritated at the repeated instruction to self-affirm in the HÔM app as ‘I already love myself’. Subverting or rejecting the imperatives and instructions of audio guidance within applications was sometimes the only way of exercising agency in the VR mindfulness experience.

## ‘You can’t forget the tech’

Participants had much to say about the obstacles that the technologies of both VR hardware and software placed in the way of their mindfulness practice. This varied from anxieties in learning to control and move within the VR setting to challenges in managing the discrepancies between one’s location and emotion (2) or between existing mindfulness practice and instructions in the applications – for example in closing one’s eyes within one application, in order to focus on the breath, negates the point of wearing a visually immersive headset (7). The complex controller functions made the VR hardware feel ‘oppressive’ for Participant 4, who also describes their discomfort in application instructions which directed ‘pressing buttons to whizz me through the environment’. The practical restrictions of using VR resulted in several participants feeling significantly disconnected, working with the floor space restrictions of infrared sensors (1), the graphic representation of hands within the application - where in actuality the external objects are controllers, held within the users physical grasp (2; 7) and common concerns about poor battery life (4) or sliding, heavy headsets (7).

## Connection and being present

Nevertheless, some participants did identify ways that using VR for mindfulness helped them in ‘being grounded and connected, very bodily present’ (6). Almost exclusively, this was felt most strongly with the Magic Leap technology and Tónandi® AR application: The AR experience here was described as ‘joyful’ (6) and provided opportunity for ‘stillness’ and ‘natural movement in the space’ (7). Participant 9 described how the AR interface enhanced their mindfulness practice because they still felt connected to their body and surroundings, rather than being isolated from them in an unfamiliar, visually enclosed, albeit ‘natural’ setting.

## Discussion and Conclusion

This research has only just begun to gather participant views on their experiences of mindfulness through immersive VR and AR technologies currently available and inviting them to construct narratives about how this may be optimised for mindfulness practice. However, these early indicators suggest that assumptions about how to use VR and AR as effective tools to enhance and sustain mindfulness practice may need to be rethought. Participants have suggested that spectacular natural settings may be distracting or oppressive, and that clumsy or restrictive technologies may lead to anxiety, physical tension and disconnection rather than its mindful opposite. The creative collages presented by participants indicate that more abstract spaces which reflect calming colour, light and texture may be effective in enhancing mindfulness practices. This goes alongside a desire to improve users' sense of agency, comfort and reassurance of safety.

Although this study was limited by small participant numbers and the postponement of follow-on co-creation workshops, VRinMind has facilitated users' insights into the features of immersive environments which may either support or be a barrier to maintaining mindfulness practice. Further research in this space is warranted to uncover more insights into how VR and AR technologies could be better designed to facilitate mindfulness practices, especially where this enables participants to self-manage chronic pain. It may also be valuable to expand this research by incorporating hardware and applications which incorporate body monitoring and bio feedback technologies, providing insight into factors such as user's breath or heart rate. In this way, participants could reflect on how VR experiences, combined with personal data tracking, could enhance their understanding and practice of mindfulness, through making the body and mind visible in new ways.

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# The Changing Role of the Designer in the Domain of Design for Health and Wellbeing Exemplified by Educational Case Studies

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**ABSTRACT** *Designers have worked in the healthcare domain mostly designing products in specialist fields such as textiles, devices or spaces. The change from designing products to the emerging focus on designing for a purpose is shifting design competencies away from the traditional compartmentalised disciplinary boundaries. This paper analyses health and wellbeing related educational projects in three distinct design curricula in three different universities. The paper contributes a vision of the skills needed for designers working in health and wellbeing via a systematic analysis of a rich body of design cases realised in collaboration with external care institutions in the context of design education.*

**Keywords:** design for health, design education, design skills

## Designers' Changing Expertise

Design's object-oriented approach is increasingly being questioned and a potential transformation is seen in focusing on relational knowledge and experience in a holistic sense (Ockerse 2012) and on 'designing for a purpose' (Sanders and Stappers 2012). Ockerse (2012) sees this as reflecting 'the paradigm shift from the mechanistic Cartesian worldview (the world as a collection of objects) to a holistic, ecological view of reality as a shift in consciousness from objects to relationships.' The shift from formats of 'designing products' to emerging fields of 'designing for purposes' is ongoing and impacting the design field immensely. Sanders and Stappers have been developing a model comparing traditional and emerging design domains in several research papers (e.g. 2008, 2012, 2017). According to their model, in traditional domains, which are centred around a product or a technology, designers gain 'the skills needed to expertly conceive of and give shape to products such as brand identities, interior spaces, buildings, consumer products, etc.' The emerging domains – namely design for experience, for service, for innovation, for transformation and for sustainability – centre around people's needs or societal needs, and these require a different approach where designers need to take longer views and address a larger scope of inquiry (Sanders & Stappers 2008).

Among other design fields, this shift is evident in design for health and wellbeing (H&WB) where these new approaches have brought designers closer to health institutions and led to a mutual interest in exploring new ways of collaborating. However, what kinds of design skills support such a transformation? This paper contributes a model of purposes in design for H&WB which is drawn from a systematic analysis of collaborative cases involving design students from three different universities and care institutions. The model offers exemplified insights for developing design education programmes and continuous professional development.

## Educational Design Cases

This paper analyses educational design cases from three distinct design curricula in three different universities, which are all carried out in collaboration with health care institutions. The next section gives a very short overview of each case, the methodology used, and outcomes and stakeholder relationships.

### Design Case 1 (DS1): Design for Nonverbal Communication Between People with Various Alertness Sensitivities

A course focusing on real-life clients working in the sphere of cognitive development has already been taking place at the Estonian Academy of Arts (EKA) Textile Design department for a decade. In this paper we look at projects from three consecutive years, when students collaborated with: 1) Tallinn Children's Hospital Mental Health Centre to create educational tools for the therapists working with children with various spectra of alertness sensitivities in 2017 (Kuusk et al., 2018); 2) Juks support centre to create interactive artefacts for people with different cognitive abilities in 2018 (Kuusk et al., 2019a); and 3) Porkuni boarding school for children with special needs, to create items for children to develop and enjoy during breaks between their educational classes in 2019 (Kuusk et al., 2020).

Generally, the project ran all three years based on a similar structure. First, the students were informed about the context of their design challenge and pointed towards reading materials by their academic tutor. Subsequently, the students visited the facilities of the partner institution where specialist teachers and therapists shared insights from their professional experience. The students had a tour of the facilities and observed the clients of the institutions. Several design sessions at the academy followed. In the middle of the course, there was a feedback-critique session with the partner institution to help the students choose and refine their initial ideas. Another making process and critique followed. After final refinements, the items were handed over to the partner institution where the clients use them.

## **Design Case 2 (DS2): Co-Designing Healthcare to Empower Patients**

Design and Technology Futures is a master's degree curriculum jointly run by Tallinn University of Technology and EKA. It combines design, engineering, future thinking and entrepreneurship to tackle complex contemporary issues from the fuzzy front end (Melioranski, 2019b). In 2019, the programme partnered with the North-Estonian Regional Medical Centre throughout two courses: Service System Design and Design Studio: The students were asked to question the ideology of the mass-production of health services. The modernisation of healthcare has changed the way health is perceived; it has become a product that can be bought, ordered or repaired. The aim of the project was to find ways to reverse the objectification of patients and reinstate them as actors in the process by giving them voice and responsibility.

Five student teams with various backgrounds started the design research by mapping the patients' journeys and the service systems in the hospital. These maps clearly showed how fragmented the services were for patients, how easily they got lost and how complicated it was for them to get the relevant information. The concept development, which included several feedback loops with clinicians, resulted in providing proposals for new technology-based product-service systems for stroke patients, palliative care, emergency services, the outpatient clinic and day surgery.

## **Design Case 3 (DS3): Applying Design Thinking and Co-Design in Public Healthcare Context**

Design Case 3 includes two different courses with the aim of focusing on public healthcare service design. Both were run by the University of Lapland. The first course had three minor cases, which were part of the public service design course and lasted four weeks. The main aim was to follow a design process formulated by each team and utilizing design methods they had learnt from previous service design courses. The course started with an introductory theory lecture and then the groups started with their own case studies: multi-service platform for children, pre-employment process for nurses, and HR-service for doctors. The course offered service design cases, where the students could practice their design skills and design thinking.

The second course, co-designing healthcare design sprint (DS3.4), was organised during spring 2019. This intensive, 5-day design sprint followed day the Google design sprint process. The aim of the course was to investigate and develop a care and treatment reservation centre at Lapland Central Hospital by employing design thinking and co-design methods. Two groups of three participants developed two different concepts for the care and treatment reservation centre.

## Design for Purpose in the H&WB Context

All three design cases emerge from different specialist fields and methodological backgrounds, and involve technologies in the concepts in various ways. Twenty educational design cases from interactive textile prototypes to experiential smart services emerged. Each design case consists of the authors' own field notes and student reports. First, the authors discussed the design cases and created a detailed comparison table. Second, the design cases were inserted into the 'Design for purpose' map where three levels were analysed: 1. Emerging purposes of design for H&WB; 2. Key and new skills needed; and 3. Related cases. This helped the authors systematically discuss the skills of designing for H&WB and areas of 'design for'. All the design cases were visually mapped on the Miro online collaborative whiteboard to facilitate joint reflection on the purpose of the designs and the skills involved.

By comparing the 20 design projects from three distinct courses, we identified six specific purposes of design for H&WB: design for learning, design for play, design for shared understanding, design for adaptation, design for engagement and design for empowerment. The six identified purposes overlap with each other to a certain extent, as learning might happen through play, learning might evoke empowerment or design for empowerment needs and design for engagement creates shared understanding. This is visible through the web of relations illustrated on the Landscape of Design for H&WB (Figure 1). In the next paragraphs, each purpose is explained through the educational design examples.



Figure 1. Landscape of Design for H&WB

## Design for Learning

The aim of design for learning is to initiate and support users, participants and designers in gaining abilities and knowledge. Learning processes might happen during the design process and/or while using the design outcome. The main emphasis of design for learning in health related cases is on learning through action, which includes multidimensional approaches to produce learning (processual, contextual, individual etc).

For example, Design Case 1 developed artefacts *Kuvamu* (DS1.10), *UUDU* (DS1.2), *Move Colour* (DS1.1), *3Room* (DS1.11) and *Hello, Uku* (DS1.3) for users with various cognitive abilities to engage with the tactile world through various surfaces and materials as well as cognitive elements. The design case of pre-employment service (DS3.2) focused on clarifying the pre-employment service for nurses, so they can become familiar with the new service environment and hospital processes faster.

## Design for Play

Play is an essential part of people's physical, social as well as cognitive development (Shackell et al., 2008). Designing for play looks at the fun and open-ended aspects of improving one's wellbeing. For example, working in the context of people with various spectra of cognitive abilities, Design Case 1 included the artefacts *Move Colour* (DS1.1), *UUDU* (DS1.2), *Hello, Uku* (DS1.3), *TELK* (DS1.5), *TEKK* (DS1.6), *Nest of Emotions* (DS1.7), *Moodi* (DS1.8), *Kuvamu* (DS1.10) and *3Room* (DS1.11) offering users an opportunity to be challenged and take risks while playing. The objects are colourful and allow different predetermined as well as spontaneous creative experiences. Design Case 3 developed a multi-service platform for hospitalised children to help them learn more from their caring processes and be in better contact with their school (DS3.1).

## Design for Shared Understanding

Design is often used for creating a shared understanding of a particular context (Gomes and Tzortzopoulos 2018). Design for shared understanding, however, creates a space for users to communicate in a mutually meaningful way. For example, in Design Case 1, the shared understanding space is created between the therapists and caregivers and the clients in the projects *Moodi* (DS1.8), *Nest of Emotions* (DS1.7) and *Hello, Uku* (DS1.3) via exploring and understanding emotions. Alternative paths of communication become inevitable when dealing with people with various cognitive abilities. *MedGate* (DS2.5) is a personal digital tool that guides and supports people throughout their journey acquiring medical help by making the medical and the hospital system more transparent so that people can regain control over the situation and their lives.

## Design for Engagement

Design for engagement influences people during and after the design experiment. Engagement can be seen as community engagement, when, for example, a team in an organisation learns to understand each other or they implement design for engagement methods in their everyday work life. Engagement can be a new way to deal with upcoming challenges or develop communication in the community. The hospital representatives that participated in the design sprints (DS3.4) learnt to use design methods and saw the value of visual tools in their everyday communication in the work community. Engagement can also be linked to learning to cope with the world, learning to understand and express emotions, learning to be fully engaged, learning to deal with different people in the context of Design Case 1 projects such as *Move Colour* (DS1.1), *UUDU* (DS1.2), *TEKK* (DS1.6), *Nest of Emotions* (DS 1.7) and *Kuvamu* (DS1.10).

## Design for Adaptation

Inevitably, there are certain points in all our lives, where it is no longer possible to improve our health. This means that we need to cope with the worsening circumstances and through design both mental and physical adaptation can be supported. For example, *SEMU* (DS2.1), a digital platform for stroke survivors, provides a holistic and integrated service pathway with the aim of guiding their recovery to a meaningful life. Another example from Design Case 2 is *Stellar* (DS2.2), which is an end of life device for writing and defining the legacy of patients in palliative care. It is an AI assistant that



helps to record memories, organise and combine them into a coherent chronicle of the patient's past. In Design Case 1, some students focused on helping people with various spectra of alertness sensitivities to adapt to the world around them; for example, using puppets (*Hello, Uku* (DS1.3)), pillows (*TEKK* (DS1.6)) to play and learn with their emotions (*Moodi* (DS1.8)), and using objects to touch, sense and through which to learn to communicate. *Friendly scarf* (DS1.4) comforts the wearer with gentle vibrations, *OFF LINE* (DS1.9) provides small objects for patients to fiddle with when nervous, *TELK* (DS1.5) provides a space for patients to calm themselves and playfully interact with an envisioned underwater world.

## Design for Empowerment

The main aim of design for empowerment is the democratisation of healthcare through the re-conceptualisation of the existing power relations. This is an emancipatory approach to give patients voice, control and responsibility of their own health and lives. By enabling all participants to define and shape the 'project' and its goals empowers patients, communities, nurses and other clinicians. This process is not an optimisation of the workload of doctors, but instead it is for the patients and nurses, who need enabling solutions so they can participate in conscious decision-making. For example, *Medilumen* (DS2.3) is a system that empowers patients by informing them of their own health, by facilitating the relationships between doctors and patients, by helping patients to prepare and by aligning the expectations between the two parties. Another example from Design Case 2 is a service concept called *Amicus* (DS2.4), which combines personal interaction and system automation to support a holistic treatment journey and management of the hospital schedule. With *Amicus*, patients have an assigned nurse as a single contact person, and can follow and access information on the go and be actively involved in every step of their treatment journey. In Design Case 1, the project *Nest of Emotions* (DS1.7) allows children to find comfortable shelter in a created nest as well as teaching them to manage and communicate their emotions.

## Design Skills in the H&WB Context

All three design cases with a total of 20 projects were analysed from the perspective of skills. The analysis concentrated on specific abilities related to the design cases, and therefore more general skills (such as communicating, creative or critical thinking) were considered to be inherent skills for all designers and these were not the focus. The skills that were identified were analysed according to the design purposes in Landscape of Design for H&WB. The collection of skills, currently taught in related H&WB courses in three universities, is presented in Figure 2 'Landscape of Skills in Design for H&WB'. Several of these identified abilities are highly traditional and part of the core nature of design, which according to Ockerse (2012), is a process that expresses itself in many ways for making and forming, for opening and understanding, for interpreting and expressing, and for the relational weaving of experiences, interests, needs and actions. The study showed that the skills are not only closely intervened with each other, but this set of skills applies to the full Landscape of Design for H&WB. For example, gamification is directly linked with design for play, but it has been used in design for learning and design for adaptation cases. This landscape of skills shows the shift from object- and material-based form-giving to setting new purposes for design and understanding what designed objects and processes enable the users to do. The shared experience of all the cases is that



dealing with the mindset of designers is primary, as this lays the basis for working in the H&WB context.

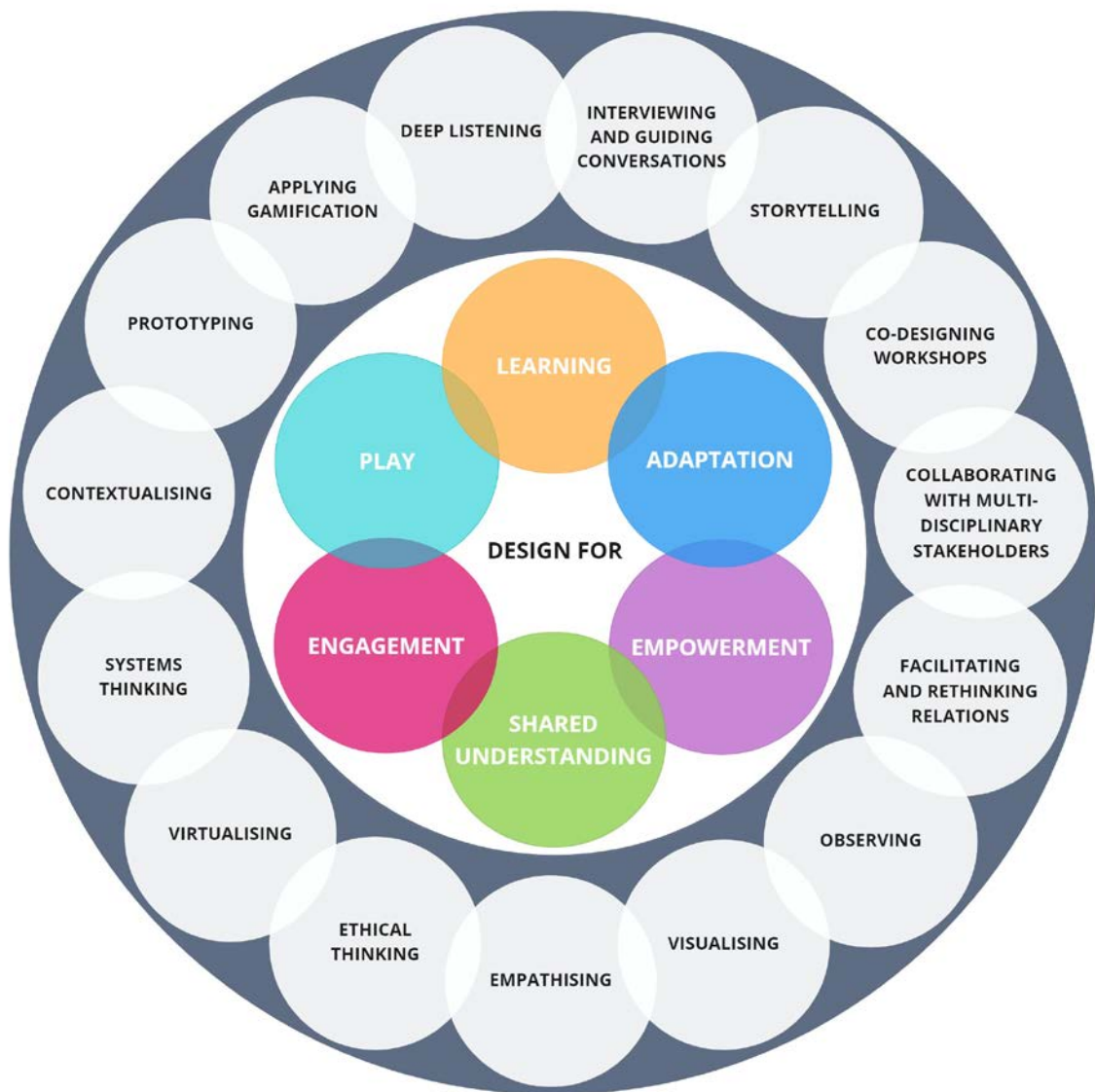


Figure 2. Landscape of Skills in Design for H&WB

## Towards the New Landscape of Design for H&WB

Looking at the Landscape models of Design for H&WB and Skills in Design for H&WB together, we see an interesting story to be told. First of all, the skills and purposes form a web of design skills and experiences. As Ockerse (2012) states, 'design cannot remain as limited, specialised knowledge and skills, but reflects more a process of a gathered, collective effort of expertise.' This processual collective effort is clearly visible in 'democratising' design within H&WB, as interests, purposes and expertise are shared and mutually developed with patients, community members and experts from different fields. The 'Landscape of Design for H&WB' model shows a web of links between design cases and design purposes; meaning that each case had a multitude of purposes. This harmonises with Ockerse's (2012) view of multi-centredness and the need to avoid limiting our perspectives to

the specifics in isolation and look at the purposes and skill-sets as a whole. Multi-centredness should open the dynamics of relational patterns active in this network of relationships between expertise in different fields. An awareness of multiple purposes enables us to perceive the contexts as relational and forces us to keep an open mind and act responsibly toward the whole of attributing factors. This relationality could be illustrated through the contexts of design for empowerment and engagement, which both require shared understanding as a pre-requisite or part of the design process.

Secondly, 'traditional' design skills and professions are not disappearing, but designers are advancing their skills and expertise. As Design Case 1 shows, the students are exposed to much more in addition to their traditional specialist lens through the full learning process. They gain a valuable experience working in a delicate setting with people that have different abilities from themselves. They balance on the line between how outcomes should look and how to make these better to support the client in terms of functionality and ease of use. The study confirms the claim by Sanders and Stappers (2008) that expertise within their area remains important even as new design practices are emerging. 'The Landscape of skills in Design for H&WB' shows this by indicating that a set of core abilities is required for each of these purposes. New forms and experiences of designing are opening new avenues for how to shape and make sense of the future (Sanders 2017). This study showed the ongoing merging of these old and new abilities.

This study is reasoned upon three different design cases, which contained a rich body of examples, but only a short overview of the analysis is provided here due to the format of the paper. Although international, the study was limited by cultural and temporal contexts. Therefore, these models require further discussion and this paper is a starting point for raising the topic in the community. We look forward to consulting the results with peers near and far, and analysing this further as new projects offer the opportunity to explore in greater depth. The authors would like to acknowledge each of the course students, course leaders, colleagues and partner institutions who worked for and contributed to cases studied in this paper.

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

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

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

## Introduction

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

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

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

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

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

## Theoretical Background

### The Quadruple Aim

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

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

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

## Open innovation in healthcare

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

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

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

## Method

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

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

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

Table 1. List of interviewees

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



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

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

## Findings

Our data highlight how the Quadruple Aim (improving the health of the population, improving the work-life of care providers, enhancing patients' experience, and reducing health costs) is used by

actors of open innovation initiatives to make the transition towards a sustainable healthcare system. Four observations regarding the implementation of the Quadruple Aim are presented below.

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

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

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

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

### **2) Not all initiatives are considering all four aims**

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

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

(Chief Business Officer, Biotech space)

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

### **3) Solutions to one aim can cause new problems**

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

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

(PhD, Innovation Lab)

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

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

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

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

(Innovation manager, Collaborative network)

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

### **Conclusion**

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

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

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