Developing Data-enabled Design in the Field of Digital Health

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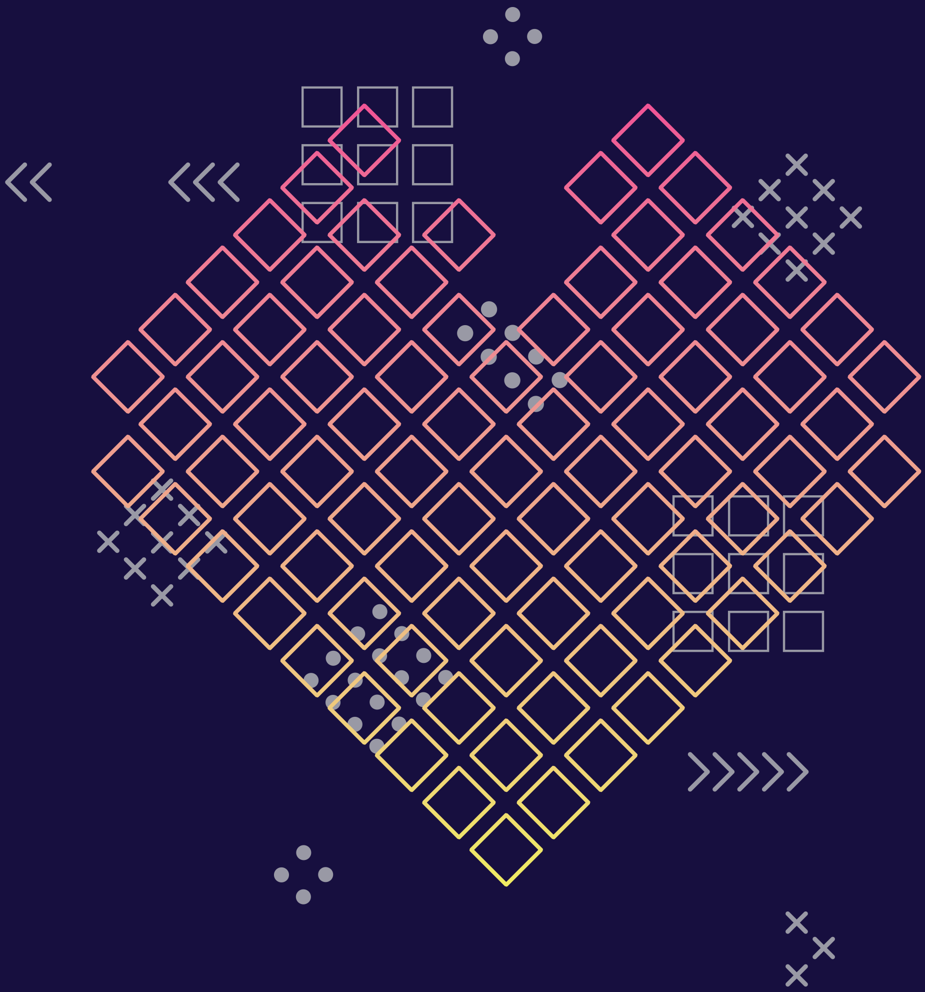

Jiwon Jung

DEVELOPING DATA-ENABLED DESIGN IN THE FIELD OF DIGITAL HEALTH

Jiwon Jung

Developing data-enabled design in the field of digital health

Dissertation

for the purpose of obtaining the degree of doctor
at Delft University of Technology
by the authority of the Rector Magnificus prof.dr.ir. T.H.J.J. van der Hagen
chair of the Board for Doctorates to be defended publicly on
Thursday 11 May 2023 at 15:00 o'clock

by

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To all designers who
contribute to the future of digital health

Contents

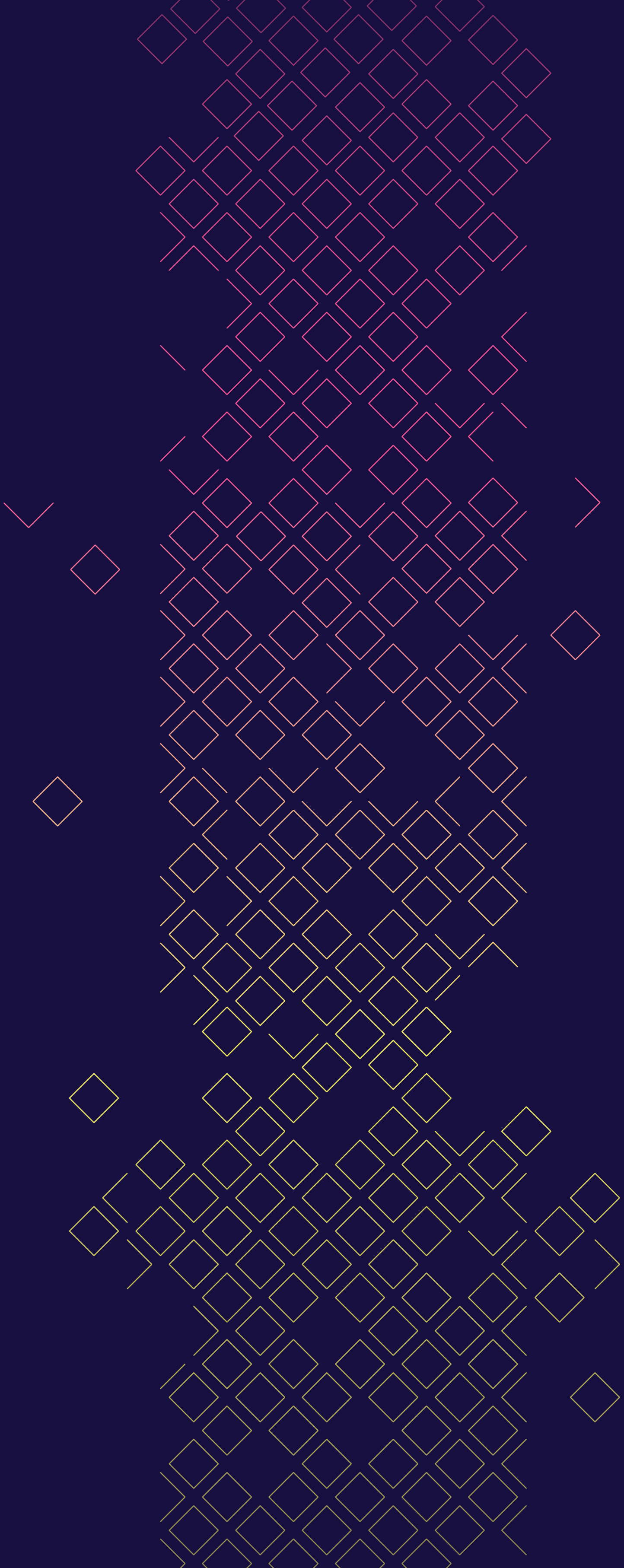
Preface

This doctoral thesis is written with the design methodological concerns of how design activities evolve towards societal challenges along with technological advancement.

As design tasks expand to complex societal challenges such as developing digital healthcare, design tools to tackle them also need to be advanced by integrating the benefits of both humans and advanced technologies. Digital healthcare is a complex societal challenge that cannot be tackled by one-sided efforts. As a result, my research asserts the need of developing complementary efforts of doing design, using both designers' creative skills and advanced data collection and analysis technologies in the digital healthcare development process.

Further, my research is rooted in the need to advance design methods and tools to recognise the collective wisdom of society as a whole to tackle societal challenges. Societal challenges are often beyond the individual context, that is, the expertise of conventional design tools. Furthermore, data and digital technology advancement including machine learning and artificial intelligence are opening up such opportunities to explore society as a whole and delve into collective wisdom. As a result, my research explores the use of tens of thousands of online patient stories and natural language processing (machine learning) to include collective patients' perspectives in a digital health design process.

I reflect on these transitional design methodological concerns through my doctoral thesis. The thesis consists of three levels of knowledge: a design vision (Chapter 1), a knowledge-generating approach (Chapter 2), and a design tool (Chapter 3). I have built a design vision around the transition in design activities due to the advancement of modern computing. The vision establishes the research context for why and how such exploration of design methodological transition is necessary. I further explored a design approach of generating knowledge to realise some central tenets of the vision in the domain of health intervention development. Finally, my research continued by developing a design tool — Patient Community Journey Mapping — to realise the approach in design practices.



CHAPTER

0.

Introduction

In this chapter, I explain the context and my research background at the start of this PhD research trajectory. This thesis began with a quite intuitive, albeit strong conviction, in future design contributions to healthcare through technological advancement— particularly being more prevalent and accessible in data collection and analysis technologies. Two contextual research backgrounds feed into this conviction. The first background is the research experience that I gained during my master's at a world-leading design research institute, KAIST (Korea Advanced Institute of Science and Technology). It made me aware of the transition in the ways that designers conduct research due to the technological advancement in people (user)'s behavioural and experience data collection and analysis: moving from usability testing labs towards using society as a lab. The second background is the research environment at CardioLab (Delft Design Labs, n.d.), a Delft Design Lab at the Delft University of Technology (TU Delft), where I executed my doctoral research. CardioLab enabled me to continue my research on future design research transitions that happened through such advancements in data collection and analysis technologies. The extensive knowledge of design theories and processes that were available and accessible at the CardioLab of TU Delft has added to my research experience. Furthermore, CardioLab provided a field of healthcare as a research context to explore design's contribution to healthcare. Therefore, I wrote this doctoral thesis with a nascent albeit strong conviction in future design contributions to healthcare through technological advancement and prevalence in data collection and analysis.

0.1 Personal design research experience at KAIST

My design research experience at KAIST drives the first element of initiating this doctoral thesis. I became aware of the transition in the ways of design research conducted under the influence of technological advancement. To elaborate, I have been trained as a design researcher since 2011 (starting at Korea University, where half of the design professors trained at KAIST) and have worked at the department of industrial design at KAIST since 2015. The department of industrial design had a very well-facilitated usability testing room (called the UT room) with one-way mirror glass and a complete recording system. The Human-Centred Interaction Design Lab (HCIDL), which I belonged to as a student in a design research master's programme, initially built the room. The HCIDL has more than 30 years of design research history and has generated many user-test-based design research papers and user-centred design researchers (Staff, 2011). However, when I was working there as a master's student in 2015, the facilities of the usability testing room were rarely in use, and the room was entirely removed in July 2021. This was because the design researchers at HCIDL often went directly to the user's environment and context to conduct user studies. The researchers could observe users directly in the users' living context through technological advancements in user data collection and analysis. Later I discovered that this development was not unique to KAIST but was a common practice at various leading design research institutes, including TU Delft.

More precisely, one of many design projects I was involved in at KAIST was with a Korean electronics company that has a subscription-based smart home air purifier as its main product. This company requested that HCIDL designs an Internet of Things (IoT) strategy for their company. Cho, Lee, & Lee (2019) explain the details of this research process and outcome. To design the IoT strategy, design researchers at HCIDL, including me, explored the user behaviour of the smart air purifiers by using the data technologies in the users' daily living environment instead of demonstrating some experiments with the users at the UT room. The collected user behaviour data included qualitative reports on air quality and quantitative reports on indoor gas and CO_2 levels from the purifier's application, users' group diaries with photos using social media, and their other home appliances and furniture (e.g. window and vacuum cleaner) usage log data collected using motion sensors developed by Sen.se Mother. By using these new data technologies, we could conduct user behaviour studies within a natural user living context (without the presence of a researcher in the user context) and for an extended period (one month).

Figure 0-1 summarises my observations of changes in how design research was conducted. Designers often moved from the usability room to the user's living environment to build deeper empathy with the users and record their natural behaviour in their actual living context using small recording devices. Furthermore, they even evolved to track the user's natural behaviour by using advanced data collection technologies such as sensing, processing and storage computing. It made users behave more naturally, and it recorded data for a longer time because designers did not have to be physically present in the user context.

During this period, the industrial design department at KAIST closely worked with information and social computing scientists at the Knowledge Service Engineering department. I also took their department's course. During the course, I observed that information and social computing scientists could investigate user behaviour using already collected online user data from the natural usage of the online platforms (rather than purposely collected research data as in design research). I also collaborated with social computing scientists and compared the user behaviour between two platforms (i.e. Airbnb and Couchsurfing) by analysing 60 user profiles and house descriptions for host behaviour and 180 reviews for guest user behaviour (for the users registered in New York City) from each platform (Jung et al., 2016). We could collect that data using data scraping machine learning techniques. We further separated the collected text data into a sentence-by-sentence format. We conducted a qualitative text analysis of the topic of each sentence and the affinity diagrammed around it. From this study, I could identify the distinctive user participation motivations of the two platforms. However, to further contextualise the motivation (reasons for showing such motivation and behaviour), I needed to conduct in-depth interviews based on the findings (Jung & Lee, 2017).

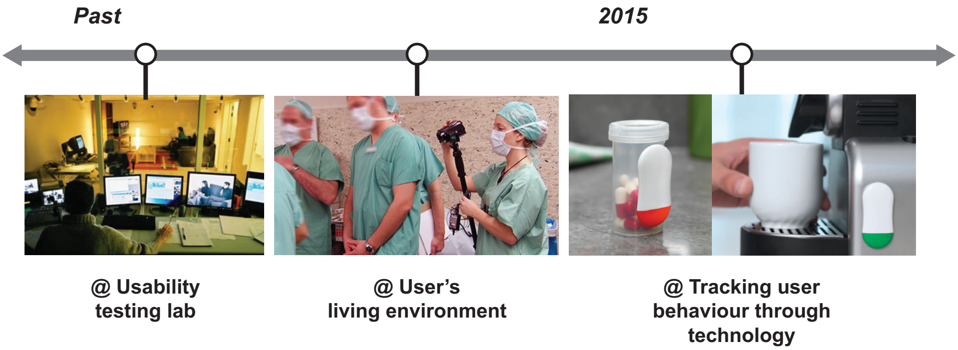


Figure 0-1. Design research transition from my research experience

Through my research experience before my PhD research, I witnessed new possibilities for conducting user studies along with the rise of data collection and analysis technology accessibility. Therefore, my doctoral research is based on my experience with the shifts in design research due to the rise of data technologies to collect and analyse large sets of user data. However, to clarify my experience, I am still aware of the value of conventional forms of conducting design research, such as user studies at usability labs. All conventional methods have distinctive values with different advantages.

0.2 The onset of CardioLab as a PhD research environment

My pre-PhD research experience with the shifts in the ways of conducting design research due to technological advancement led me to conduct PhD research at CardioLab in the Faculty of Industrial Design, TU Delft. This is because TU Delft is a leading design research institute with a strong history of exploring and understanding design theories and methodologies and their transition. Thus, it was the appropriate place to learn and explore my experience in future design transitions through technological advancement based on design theories and methodological histories. Particularly, CardioLab announced its concerns about the changes in design competencies (including methodologies, tools, and capabilities) due to new technologies such as smart systems and big data generated from them. Thus, it advertised a PhD position vacancy to meet the needs of new design competency exploration with the rise of technologies (which includes both smart systems and data generated from them). CardioLab described the given PhD project description as follows:

> ‘Designers have little experience with the design of smart systems and the (big) data generated by smart systems, for example. Moreover, it is unknown how big data could complement more qualitative use data that designers normally use during design processes. The PhD project aims to solve these challenges by developing new design competencies - based on new capabilities, tools, and methods - that support design activities for smart, integrated solutions’. – from the job posting for CardioLab PhD position

To explain further, CardioLab is a research collaboration with Philips Experience Design and TU Delft. The two professors of the CardioLab, respectively, have more than 20 and 30 years of experiential knowledge about design methodologies and transitions in design at the design faculty of TU Delft, where many design theories, methodologies, and histories have been developed over the last 50 years. They had a common interest in exploring the new design competencies brought by the rise of new data technology, particularly in healthcare. Before I joined, CardioLab had several master’s graduation projects focused on the products and technologies supporting cardiology.

I joined CardioLab because we all shared the same concern about changes in design brought on by technological advancement in user data collection and analysis. As data collection and analysis technologies develop and be accessible, designers’ opportunities to obtain user behaviour and experiential data have increased, and the types of data collected have varied. As my previous section describes, I also used smart sensors and machine learning to understand user behaviours, such as the usage and experiential behaviour of home appliances and platform services. Several issues arose during my experience collecting and analysing user behaviour data through such data collection and analysis technologies. The collected data could provide explicit user behaviours, such as frequency of use or which family member is using the product. Still, it could not discover implicit user data, such as a motivation or purpose for showing such behaviour data trends. I had to conduct another follow-up study, an in-depth interview, to complete the user studies. Therefore, I felt the need to explore further how prevalent and more accessible data collection and analysis technologies could and should be used in design as part of its practice and research, as CardioLab wrote in their PhD vacancy post.

However, neither CardioLab nor I knew exactly or in-depth enough how future design (such as competencies, methodologies, or tools) could or should resemble the rise of such technologies. Thus, the research agenda to further develop such a research problem has kicked off with two PhD positions at CardioLab: one was my position, and the other was Valeria Pannunzio's, who had a background in service and interaction design in healthcare.

Philips Experience Design, the collaboration partner of CardioLab, is a front-runner in the design methodology for health technology. It is a major multinational health technology company with over 400 design employees. Within the company, there was a design methodology innovation team called 'Data-enabled Design' with two ongoing PhDs, which was a collaboration with Eindhoven University of Technology (TU Eindhoven). The outcome of the PhD and details of the Data-enabled Design team are reported in Van Kollenburg & Bogers (2019). CardioLab took the Data-enabled Design as the reference for a new design methodology driven by the rise of data collection and analysis technologies. It is a design process where the design studio receives continuous data from the user's context through advanced digital technologies. Simultaneously, the design studio iteratively provides real-time design action based on the user data analysis results. Figure 0-2 describes the process visually, and depicts that it is an open and endless process to design solutions, and problems constantly evolve through a working product placed in the user context. Data-enabled Design is implemented through working products (communication interface and design prototypes) and a virtual design space called 'canvas'. The working products are the system that constantly collects qualitative (i.e. conversational data through chatbots) and quantitative data (i.e. log data from the device-embedded sensors) and reflect the design actions accordingly. The canvas is a software system that directly connects the design studio to the users they are designing for. It visualises the continuous data stream collected from the user context to show what is happening in the user context. It also includes functions for making real-time design decisions on the working products in the user context.

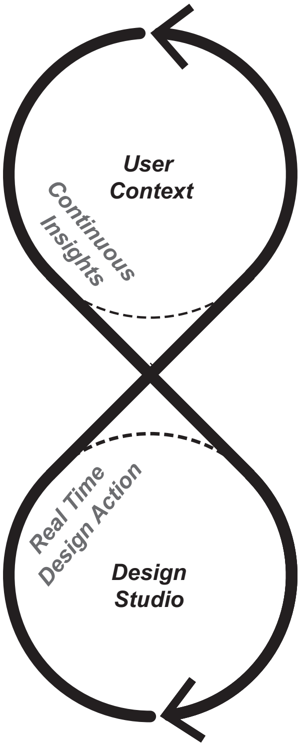


Figure 0-2. Data-enabled design, retrieved from (Van Kollenburg & Bogers, 2019)

CardioLab focused on cardiovascular disease as the context of exploring such new design competencies driven by upcoming prevalent and accessible data collection and analysis technologies. This was because both professors and Philips Experience Design had a significant interest in the context of healthcare for new design transition from technologies. Thus, we tried to build a strong research collaboration with Dutch Heart Foundations (Nederlandse Hartstichting) at the beginning of my PhD research. However, communicating with Dutch Heart Foundations about the hope for future design contributions to healthcare using such technological advancement proved to be extremely challenging. Further, at that moment, CardioLab and I did not have any strong collaboration in the healthcare community where we could work together (particularly in the first year). The healthcare field could not build the same faith as me when I only had very abstract and designerly arguments based primarily on my experience. Thus, I started my PhD thesis with the frustration that I could not communicate the future design contribution through the advancement in data collection and analysis technologies to the healthcare field. However, the changes in healthcare are a transdisciplinary project that requires not only design but also various related fields to work together to make the change.

Thus, on the other than, I also started with a strong motivation and desperate need for further structured knowledge development to communicate my faith for future designers to contribute to the healthcare domain with their new competencies and new methods of conducting research related to the prevalent data collection and analysis technologies.

Currently, both CardioLab and I have built strong networks with various healthcare organisations: such as patient communities, hospitals, as well as Dutch and international healthcare research communities (elaborated more in detail in chapter 4.2), with various positive societal impacts. CardioLab and I hope to achieve societal impacts through this PhD research trajectory: a future design contribution to healthcare using data collection and analysis technologies. I firmly believe this frustration turned into a far-reaching positive societal impact because we conducted strong research on the ways design can contribute to healthcare, given the rise of technologies. Thus, CardioLab now aims to explore new design methodologies based on new digital technologies for data collection, analysis, transfer, and feedback to capture new user and contextual data within various healthcare domains (*CardioLab*). In my doctoral thesis, I share the research trajectory of my conviction becoming reality and the enormous impacts on healthcare that design can realise through research.

0.3 Structure

This section describes how I explored these contextual research backgrounds in an objective and solidly research-driven manner in my doctoral thesis; this is a transitional chapter from personal experience to research-driven. Figure 0-3 illustrates the overview of my doctoral thesis and the relationship between the chapters in the thesis. The thesis consists of three levels of knowledge: design vision (Chapter 1), knowledge-generating approach (Chapter 2), and design tool (Chapter 3). Chapter 1 first builds a fundamental vision around the research question; the transition in design activities due to the advancement of modern computing—which heavily influences the technological advancement of data collection and analysis. The vision establishes the research context for why and how such exploration of design transition is necessary. Chapter 2 further continues by exploring a knowledge-generating approach to realise some central tenets of the vision in the domain of health intervention development. The knowledge-generating approach is to generate a widely adopted and accepted design approach in the broad health research audience. Finally, Chapter 3 carries on by developing a design tool for realising the knowledge-generating approach in design practices.

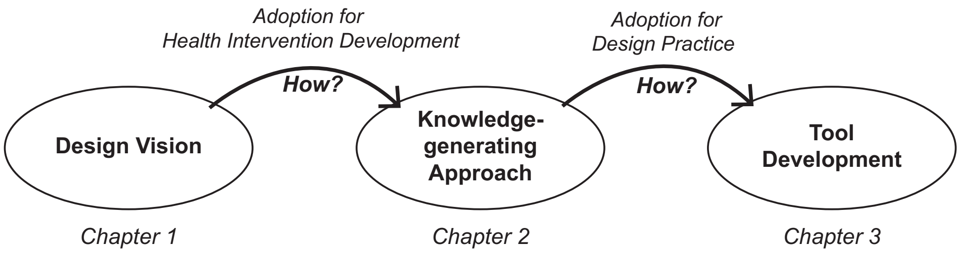


Figure 0-3. Description of the relationships between chapters of this doctoral thesis

The main research question of this doctoral thesis is explorative, as it is driven by two contextual research background elements described in the sections above. The question is as follows:

- **What can be the future impact of design (activities) in digital health, given the rise of data collection and analysis technologies?**

I asked this research question on three knowledge levels: design vision, knowledge-generating approach, and design tool.

In detail, in Chapter 1, I envision design activities for collective computing compared to the previous modern computing eras of personal and ubiquitous computing. Collective computing is the modern computing development that the advancement in data collection and analysis is a part of. I focused on modern computing development because of the strong relationship between the evolution of the design field and developments in computing. Collective computing is an era of complex systems of massive social interaction through various connected computing devices. This chapter presents two research questions:

(1) How do design activities change due to the development of modern computing?
(2) How can designers adapt to the changes in design activity?

To explore these questions, I first conducted a literature review, which resulted in an initial vision of new design tasks, design processes, and the designer's role. I further improved and enriched the initial vision by exploring potential guidance that designers need for dealing with the changes by interviewing 24 informants with expertise in design in relation to computing. The findings from this chapter (Figure 0-4)

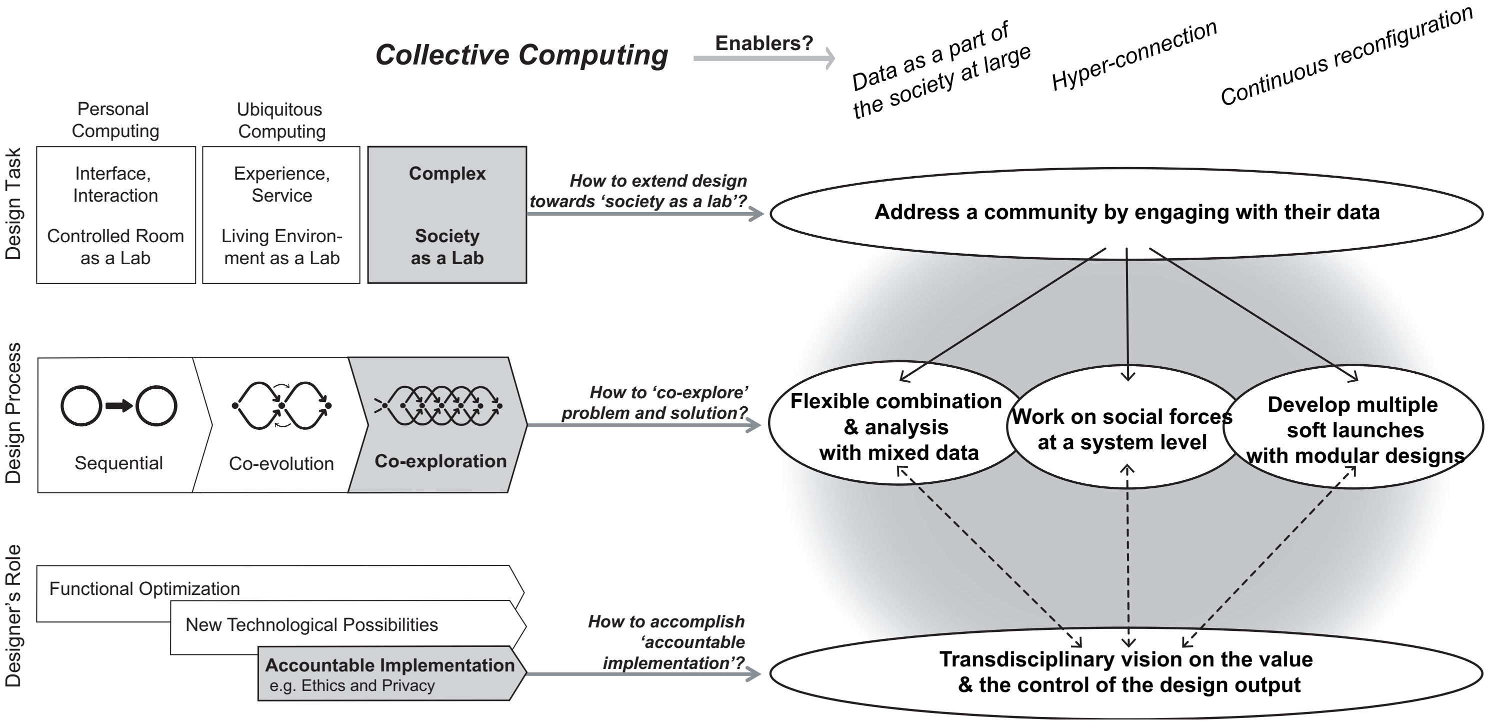


Figure 0-4. Outcome of Chapter 1, a vision for design in the collective computing era (Jung et al., 2022)

are a vision for design in the collective computing era, with actionable guidance for designers regarding a coherent set of new design activities proposed in relation to advances in computing. In the envisioned design activities, I argue that designers have a ‘complex system(s)’ and ‘society as a lab’s design tasks’ and deal with them by engaging with the data of the community they are addressing. Moreover, the design process is the ‘co-exploration’ of design problems and solutions almost simultaneously by considering the flexible combination and analysis of mixed data, working on social forces at a system level, and developing multiple soft launches with a modular design. Finally, the designer’s role is to conduct an ‘accountable implementation’ by incorporating a transdisciplinary vision of the value and control of the design output. This chapter has been published in the Journal of Engineering Design, with the title of ‘*A vision for design in the era of collective computing*.’

In Chapter 2, I study a knowledge-generating approach to realise some central learnings (i.e. developing complex systems by addressing a community) from the design vision developed in the previous chapter in the domain of health intervention development. The approach aims to gain increased acceptability of design research from health-related disciplines. This research is conducted by identifying the core strengths of the frameworks from the British Design Council and the British Medical Research Council, both describing a preferred mode for developing interventions in complex systems. This chapter asks the following research question:

(1) How can designers adopt (public) health research’s core strength of developing complex interventions while maintaining their own core strength?

The study shows that the core strength of design lies in generating knowledge iteratively, by using in-situ experience data at the individual level to creatively explore and test both problem and solution areas. In health-related research, the core strength lies in generating knowledge from the past in a given problem area and by using existing scientific behavioural data at the population level. Based on this interpretation, this doctoral thesis proposes a novel design knowledge-generating approach required in the domain of health intervention development. The approach integrates the core strengths of both frameworks by using existing (already-collected) people’s experience data of the community level (midscale between individual and population levels). The data share the characteristics of design research data which focuses on people’s experiences and health research data which focuses on comprehensive behavioural trends, as Figure 0-5 illustrates. The chapter further elaborates on two design projects adopting the design approach in health intervention development using existing people’s experience data of the community level, and explains the result of societal impacts that the two projects made. This chapter is under review process in a peer-review design journal under the title of ‘*Integrating public health knowledge to design activities for developing complex interventions.*’

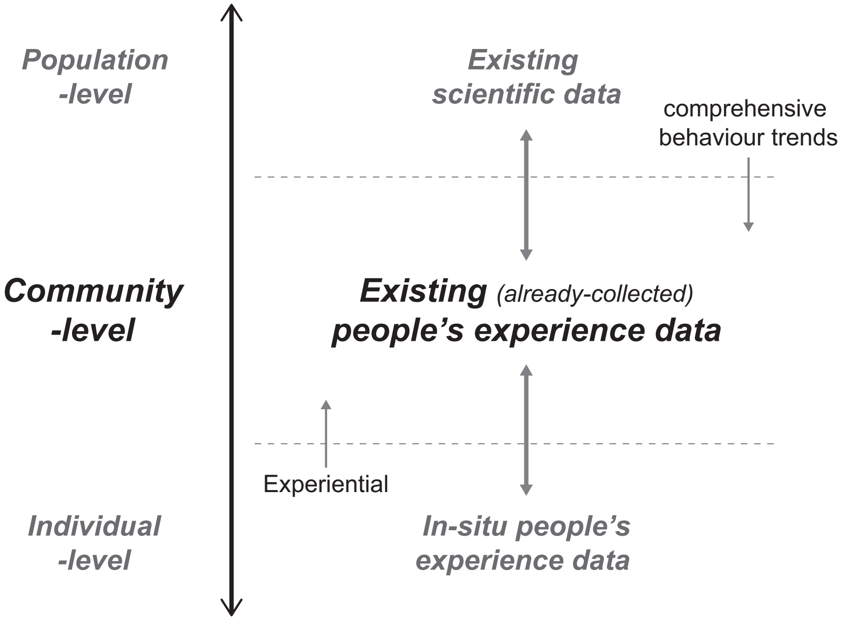
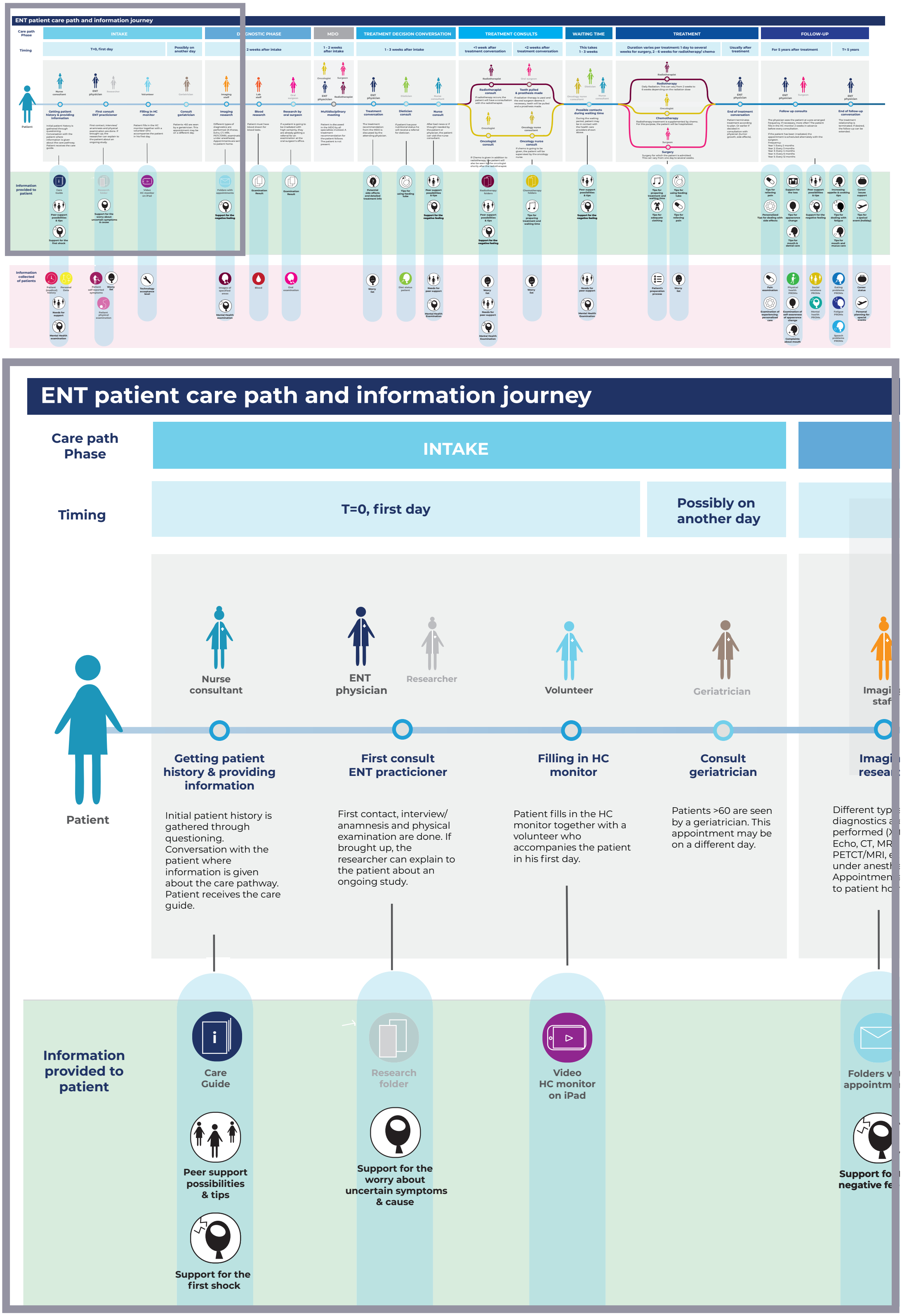


Figure 0-5. Result from Chapter 2, existing experience data at community-level as a means for integrating design into public health research and practice

Chapter 3 develops a design tool that allows designers to use existing (already collected) people's experience data of community level. It is also an effort to apply data technology (machine learning) to improve a design tool for communicating patient perspectives. Thus, this chapter poses the following question:

> (1) How can designers have a data-driven approach to understanding patients' needs using existing people's experience data of community level?

Designers use the patient journey map as their main tool for developing and communicating patient perspectives. In the current patient journey mapping approach, designers face a major challenge in expressing the complexity of the journey when representing a broader patient population in terms of interdependencies, constraints, perspectives, and the contexts of the experiences. This challenge initially stems from the limitations of the current qualitative data collection and analysis method of journey mapping, which is often labour- and time-intensive (e.g. multi-disciplinary meetings, interviews, or ethnography). It limits the number of patients explored to a smaller number (usually 10–15), which can be problematic in representing the variety of patients. The selection bias arising from the small sample size might also preclude designers from noticing distinctive but crucial moments in the (care-path) experience of some (groups of) patients. Therefore, this chapter explores a novel tool, the so-called 'Patient Community Journey Map' based on existing online patient stories and using two procedures of text mining. The tool is developed in the field of oncology (one of the outcomes is presented in Figure 0-6), based on a collaboration with data scientists who have supported designers in quantifying the experiences of a wide range of patients, the detection of relationships between co-occurring experiences within the journey, and the detection of new design opportunities and directions. The tool helps designers gain a large-scale yet qualitative and inspiring understanding of a complex context in healthcare with reduced time and cost investments. This chapter is under review process in a peer-review design journal under the title of '*Advancing design approaches through data-driven techniques: Patient community journey mapping using online stories and machine learning*.'



Initial patient history is gathered through questioning. Conversation with the patient where information is given about the care pathway. Patient receives the care guide.

First contact, interview/ anamnesis and physical examination are done. If brought up, the researcher can explain to the patient about an ongoing study.

Patient fills in the HC monitor together with a volunteer who accompanies the patient in his first day.

Patients >60 are seen by a geriatrician. This appointment may be on a different day.

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Figure 0-6. A part of the Chapter 3 ooutcome, an example of Patient Community Journey Mapping (modified from (Peters, 2021))

0.4 Philosophical and methodological position

The studies in this doctoral thesis were carried out from a constructivist mindset. This means that I was actively positioned within the studies to generate knowledge (Crotty, 1998). The research outcomes are built, not just discovered, through applying my knowledge to exploring the world (Elkind, 2005). The constructivist mindset was required because finding out knowledge for an upcoming technology-enabled context is knowledge to shape the future that is about not-yet-here and there is not enough existing knowledge around the future I am drawing. In that sense, the proposed knowledge was built by *action research* with the help of previous literature, informant interview, framework comparison, and constantly evolving design projects. Through this constructivist mindset, I aimed for a most robust prediction of what is to come to designers with upcoming technological transitions. It was the way to explore the future of design activities in a *designerly* way (Cross, 1982; Van Aken & Romme, 2012) and *reflection-in-action* (Schön, 1983).

0.5 Concluding words

To conclude my introduction, I am a design researcher who has lived through the transitions in conducting design research due to technological development. Such context, together with the opportunity to explore the relevance of in-depth design research theory and methodology, led me to construct the research question of this thesis, particularly for the field of (digital) healthcare. My contribution is developing a fundamental design vision, a knowledge-generating approach, and a design tool for such context: the future impact of design in (digital) health, given the rise of data collection and analysis technologies.

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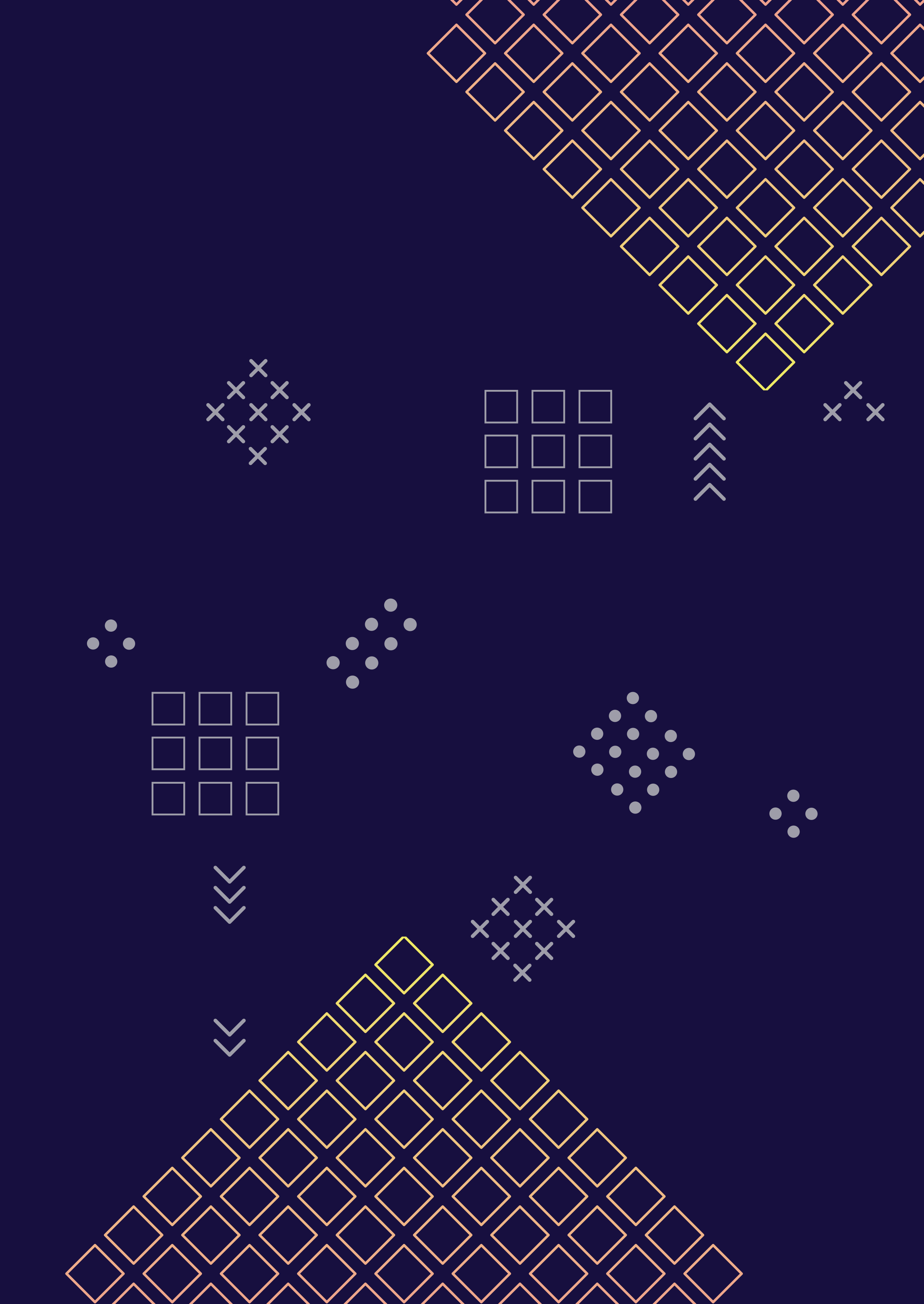

CHAPTER

1.

A vision for design in the era of collective computing

This chapter has been published in

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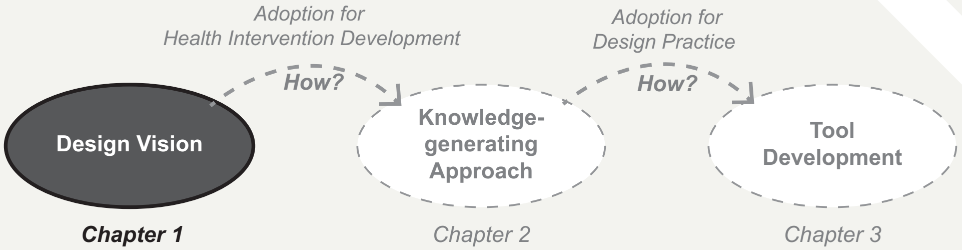

My doctoral thesis consists of three levels of knowledge: a design vision, a knowledge-generating approach, and a design tool. **In this chapter, I construct a design vision around the transition in design activities due to the advancement of modern computing, including data collection and analysis technologies.** In later chapters, I further explore an approach of generating knowledge to realise some central tenets of the vision in the domain of (public) health intervention development. Finally, my doctoral thesis continues by developing a design tool to realise the approach in design practice.

Summary

In Chapter 1, I constructed a design vision for upcoming design activities arising from modern computing developments, that have complex systems of massive social interaction through various connected computing devices and data technologies. I constructed the vision through literature reviews (compared to the design activities in previous computing eras) and interviews with 24 world-renown design experts. My vision argues that designers have a 'complex system(s)' as the expanded design task, and should view 'society as a lab' in dealing with such expanded design tasks. Designers are guided to tackle their expanded tasks by 'addressing the community by engaging with their data'. Moreover, my vision introduces an expanded form of the design process as an almost simultaneous 'co-exploration' of design problems and solutions. Designers are guided 'to consider the flexible combination and analysis of mixed data', 'to work on social forces at a systems level', and 'to develop multiple soft launches with a modular design'. Finally, the envisioned designer's role is to conduct 'accountable implementation' by 'incorporating a transdisciplinary vision of the value and control of the design output'.

* ** The word 'engineering design' in the published journal article is changed to 'design' in this doctoral thesis. The change is to make seamless and logical connections to other chapters.
*** Definition of the *crowd* is modified (compared to the published journal article) to describe it more precisely.

1.1 Introduction

Several design researchers have indicated the relationship between the evolution of the design field and developments in computing (Bayazit, 2004; Cross, 2018; Dubberly, 2008). They argue that both design process and designed artifacts have been evolving with respect to developments in modern computing. In their opinion, the connection between computing developments and design became especially prominent during the era of *personal computing* that began in the early 1980s, followed by the current era of *ubiquitous computing* from the 1990s onwards.

Abowd (2016) introduced a new era of modern computing called *collective computing*. This era describes a new stage in modern computing where many people interact with one another through many computing devices, with a prevalent influence on the physical world, and on economic and social values. Based on past and current developments in shareable information systems of collective intelligence (Malone & Bernstein, 2015) and combined with recent observations by design scholars (e.g., (Chan et al., 2018; Cooper, 2019; Coulton & Lindley, 2019; Giaccardi & Redström, 2020; Höök & Löwgren, 2021) about the new complex forms of computing which designers engage with (e.g., the economic and social structure changes from the various technological development), collective computing can be expected to influence the content and the organisation of the design process. Therefore, this article explores the transformations of design activities during collective computing to establish a future vision of the role of design in the collective computing era, with practical and actionable guidance for designers.

Below, we introduce collective computing as a third era of modern computing, followed by two studies. In Study 1, we review the characteristics of design activities for collective computing compared to preceding eras in modern computing, and reflected on by the authors based on their past design work in data-enabled design. Moreover, we develop an initial future vision, describing how the collective computing era is likely to require changes in the activities of designers.

In Study 2, we further review and improve this initial vision, by enriching it through an exploration of the potential guidance for designers to adapt to new challenges posed by the collective computing era. The study was conducted by interviewing 24 informants with expertise on design in relation to computing. Thereafter, we combined the results to produce a comprehensive vision of design activities in the collective computing era, a practical guidance for designers.

The two studies build on a tradition in design research of describing upcoming design activities (including education and research) in relation to advances in computing, either through expert interviews (Spence, 1995), or through personal reflection on developments in the design discipline (Andreasen, 2011; Cross, 2018; Holt, 1993). We therefore aim to contribute to an established, yet dynamic discipline (following Duffy, 2011) by proactively addressing new challenges and proposing new design activities for design in collective computing.

1.2 Three eras of modern computing

Thus far, modern computing has been characterised by reference to three generations of computing eras: mainframe, personal, and ubiquitous computing (Pew, 2002; Want, 2010). In this section, we discuss the last two eras of personal and ubiquitous computing along with additional literature regarding a predicted future or upcoming era of collective computing. In this context, we excluded the first era of mainframe computing, as we did not find any literature on design processes being directly affected by mainframe computing.

The personal computing (PC) era began in the early 1980s as a consequence of two technological developments (Grudin, 2008; Pew, 2002). First, technology companies started introducing less expensive but adequately capable mini-computers in the consumer market, e.g., IBM PC 5150 (1981), Xerox Star 8010 (1981), and Apple Lisa (1983). Second, the commercial Internet was released for public use in 1989. With these technologies, programmers as well as ordinary individuals started using computers for entertainment and work. Inevitably, the release of the Internet favoured the development of various Internet-applications such as instant-messaging, music players, and weblog tools. In addition, asynchronous and distant communication such as online discussion and e-mail became widespread and highly popular. Thus, the need for user-friendly computers arose owing to the regular use of PCs by non-experts. Instead of controlling the computers as in the mainframe computing era, PC users interacted with computers through numerous software and Internet-based applications (Ritter et al., 2014). Therefore, the further fragmented structure and flow of computer system evolution required the development of intuitive interfaces to ensure that users do not feel frustrated or confused when using PCs. Thus, superior user-friendliness and intuitiveness became the key selling point for PC vendors (Grudin, 2008; Pew, 2002), and designers actively collaborated with computer engineers to optimise and evaluate design proposals from a more user-friendly and intuitive mindset (ISO/IEC., 1998; Ritter et al., 2014).

Ubiquitous computing (or Ubicomp) was initially coined by Weiser (1991) and started to garner increased attention in the 1990s when companies began exploring the potential of portable computer products operating in small networks (Grudin, 2008; Pew, 2002; Want, 2010). As such, the products resulting from these explorations included Apple Newton, EO pad, Palm Pilot, and Sharp Zaurus. Eventually, Ubicomp progressed past its exploratory stage and was adopted by markets in the 2010s (Want, 2010). Since then, individual users have increasingly purchased several types of computers such as smartphones, PDAs, and embedded computers, and the miniaturisation of computers has driven the rise of ubiquitous computing. Moreover, cheap sensors, actuators, and convenient programming platforms reduced the barriers to the development of embedded computing applications (Grudin, 2012; Pew, 2002; Want, 2010). Based on these developments, context-awareness and unobtrusiveness became two main characteristics of Ubicomp (Grudin, 2012; Pew, 2002; Want, 2010). Context-awareness signifies that devices can adapt to a specific user context in their operations to provide a more ideal user experience. Developers can create contextual awareness by employing on-platform sensors to detect, for instance, the location of a device, nearby devices, and environmental factors such as sound, motion, and temperature (Grudin, 2012; Pew, 2002; Want, 2010). Unobtrusiveness refers to the seamless integration of computers with common objects such as tables or floor mats (Barton & Kindberg, 2001; Kidd et al., 1999). Therefore, the unobtrusive usage of computing devices embedded in the surrounding context is an essential quality of the Ubicomp paradigm (Grudin, 2012; Pew, 2002; Want, 2010). These two characteristics of Ubicomp allowed designers to actively explore new technological possibilities to unobtrusively change user behaviour through the awareness of a user context (Brush, 2016; Rogers, 2011).

As practice-oriented design researchers and educators, we observe the evolution of complex new forms of computing under active development and design at present, other than those described by ubiquitous computing. These new forms depict many Ubicomp users (individuals possessing multiple computing devices) as interconnected to one another via networks and sharing data widely. Figure 1-1 visualises the differences between three computational generations. These new forms of computing resemble those described in 'Visions of Design for 2020' by Spence (1995) together with twelve experienced design engineers:

> Underlaying the visions, and with profound implications for data and information handling, was a general acceptance of the personal ownership of huge amounts of data (some gathered by PIGs [(personal information gatherer)] over a number of years), the company ownership of similarly extensive volumes of data concerning such matters as design histories, a worldwide communications network characterised

by negligible communication charges, and the ability to plug a personal computing device into the network as easily as one plugs an electrical appliance into a power network. All these factors will lead to more effective information generation and use (p.135).

Other recent design scholars have followed this vision while describing the new complex forms of computing with which designers engage. Cooper (2019), Giaccardi and Redström (2020), and Coulton and Lindley (2019) argue that designers face contextual and methodological transformation owing to the changes in the economic and social structures made by the advancement in connectedness through Internet of Things technologies, big data, and artificial intelligence (including algorithm and machine learning). Höök and Löwgren (2021) specify the economic and social structural changes from an interaction design perspective: a movement towards a hybrid of physical and digital materials, an emergence of a complex and fluid digital ecology accessible to many, and constant autonomous changes (updating based on the usage behaviour) in the system we design. The recent special issue in the Journal of Engineering Design: 'affective design using big data' introduces various novel approaches of using hugely connected data generated from advanced technologies to capture people's affective needs (Chan et al., 2018).

Abowd (2016), a well-known ubiquitous computing scholar, proclaimed a highly similar view of connections between many users through interoperable data generated from many computing devices, as a new era of *collective computing*.

Considering the technological changes across computing's first three generations, how might the next serve humanity? Three critical technologies-the cloud, the crowd, and the shroud of devices connecting the physical and digital worlds-define the fourth generation of collective computing (p.17). (…) Weiser's vision [of ubiquitous computing] did not really expose the opportunities to enhance interaction across individuals. Our research communities have long recognized computing's importance as a means of supporting human-human interaction. Fourth-generation technologies directly address this gap, recognizing that many people interact with one another through many devices, and vice versa (p.19).

Our exploration of new forms of complexity in computing systems is inspired by Abowd's notion of collective computing, and we retain the term throughout the present work. Abowd's concept of collective computing highlights new challenges that thus far have not received much attention in design engineering. More than, for instance, the literature on the design of product-service systems (PSS), collective computing allows for the integration of social aspects in complex technological systems. As Abowd argues, collective computing has been enabled by technological advancements in crowd, cloud, and shroud. Crowd presents the individuals who connected together to produce valuable information cooperatively (often for the problems that need solutions), through the benefits of the Web and cloud computing (Abowd, 2016). Cloud technology implies massive computational resources, data storage, and access, as well as the integration of various types of data generated through the use of multiple devices (Dillon et al., 2010). Lastly, the shroud describes the large number of connected, highly performing, and small sensing computing devices generating tremendous real-time and real-world data (e.g., 27 billion IoT products in 2025, (Sinha, 2021)) (Höök & Löwgren, 2021; "Technology and Innovation Report 2021," 2021). Together, the crowd and cloud intelligence establish a new form of omnipresence, supported by a layer of digital technology that Abowd termed the shroud. The shroud connects the physical world to a continuously updated and socially interactive digital system.

In design (and other design disciplines), we see the collective computing context as a major driving force behind the current push for designers to work on complex socio-technical challenges involving multiple different stakeholders and contexts, such as climate change, resource depletion, and healthcare (Costa Junior et al., 2018; Sevaldson, 2009; Van der Bijl-Brouwer & Malcolm, 2020). In an upcoming collective computing era, designers face new issues requiring critical decisions, which must inevitably be made with limited knowledge of the context of a massive scale of complex, interconnected community-level data.

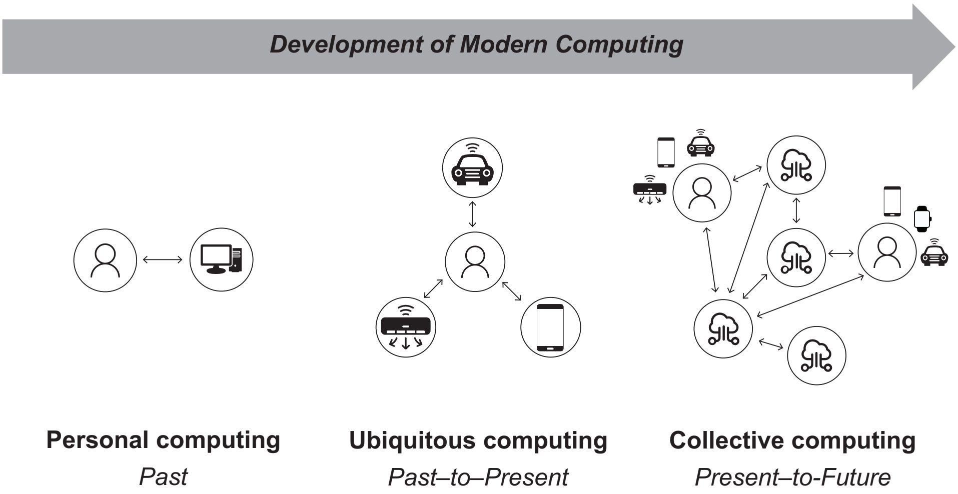

Figure 1-1. Design-relevant developments in modern computing

1.3 Study 1: Exploring transformations of design activities in collective computing era

Abowd and other designer researchers hint at a rough outline of the collective computing concept. However, the understanding of design activities in the collective computing era remains limited, as this is a relatively new concept. Thus, we conducted Study 1 with the following research question:

- What are the aspects of design activities transforming in the prospective era of collective computing compared to the PC and Ubicomp eras?

1.3.1 Research Method

In the first part of Study 1, Study 1a, we reviewed the literature on modern computing and design with a focus on design activities and considerations related to computing developments that are currently relevant or that might become relevant in design practice.

For the second part of Study 1, Study 1b, we adopted a constructivist approach (Crotty, 1998; Elkind, 2005) to explore the future outlook of collective computing in a *designerly* way (Cross, 1982; Van Aken & Romme, 2012). The inherent interpretation linked to this approach is accounted for by the authors combined perspectives, based on 10–25 years of experience (in various countries in Europe and Asia) with design activities, underlying theories, and methodologies related to various kinds of digital innovation such as websites, 3G/4G devices, smart home appliances, smart health and traffic environments, biometrics, social media, chatbots, and so on. We draw the conclusions presented herein based on knowledge sources from design research, education, and practice on human-computer interaction, collaborative design, strategic design and design. In this part of the study, we constructed our understanding of the literature on modern computing as an initial vision on design activities in collective computing era (Figure 1-2).

1.3.2 Results

Study 1a consisted of a literature review. The results are summarized in the table presented in Appendix 1-1 and the text below. The result provides an overview of design activities for the PC, ubiquitous, and collective computing eras where these developments are classified based on the nature of design methods and techniques for a design task, the prevalent design process, and the role of the designer (Dorst, 1997, 2016). The overview of the collective computing era is based on our extrapolations from the PC and Ubicomp eras.

During the PC era, designers were actively involved in the design process of interfaces and interactions (Burns et al., 2006; Powell & Cooper, 1994; Winograd, 1996). This was because the user-friendliness of interface and interaction was an essential factor to attract non-expert PC users (Löwgren, 1995; Pew, 2002; Shneiderman, 1980; Winograd, 1996). Also, the design of the webpage was directly related to information retrieval time (Grudin, 2008; Pew, 2002). Thus, conducting design research in a controlled room was effective enough to explore the user-friendliness and retrieval time for specific moments in computer usage (Hughes et al., 1994; Rogers, 2011). As a result, in the PC era, the problem was often already defined and formulated by the software developer in the problem-solving design process (Burns et al., 2006; Jokela et al., 2003; Pew, 2002). In this process, the role of designers became one functional optimisation of current practices and evaluation of final design proposals (ISO/IEC., 1998; Ritter et al., 2014).

During the Ubicomp era, designers have actively expanded their design tasks to enhance the quality of interaction between the user and the product, in terms of experience and service (Desmet & Hekkert, 2007; Secomandi & Snelders, 2013). Portable computers with low-cost tagging and transmission technologies made the inherent embedment of computers in everyday products possible (Want, 2010). Thus, the computing device's contextualised experience and services gained more attention than the computing device itself in isolation (Pine II & Gilmore, 1998). To explore the users' expanded and overarching experience related to the computing devices designers used the living lab concept (Brush, 2016; Dell'Era & Landoni, 2014; Feurstein et al., 2008; Rogers, 2011; Taylor, 2016). The design process in such real-life settings can best be characterised as one of co-evolution, implying that problem and solution spaces cannot be defined at any specific point in the design process but they evolve over time and can be continually modified (Crilly, 2021; Dorst & Cross, 2001; Hatchuel, 2001; Poon & Maher, 1997). In this sense, the living lab condition can be seen as influencing the designers' prevalent process towards greater co-evolution of problem-solution spaces. Co-evolution allowed designers to exploring newly emerging technological possibilities in novel interactions and experiences, going beyond simpler optimisation processes (Brush, 2016; Rogers, 2011).

We extrapolated the design activities of the collective computing era that can be distinctive from ones of the PC and Ubicomp eras. Regarding the *design task* in the collective computing era, advanced technologies have enabled uniquely massive, complex connections between multiple computers and users (Abowd, 2016; Höök & Löwgren, 2021). Höök and Löwgren (2021) describe this complex context as 'everything is connected to everything else.' Consequently, *complex systems* emerge in which the crowd's physical world blends with a constantly updating digital world (Friedman, 2019; Höök & Löwgren, 2021; Speed & Oberlander, 2016; Verganti et al., 2020). System complexity here is characterised by numerous layers of social, technical, and economic contexts (Friedman, 2019) with conflicting agendas between different stakeholders (Höök & Löwgren, 2021). These tightly linked systems between the digital and physical world allow data-driven and AI solutions to become a part of our system design, based on autonomous analysis or prediction (Höök & Löwgren, 2021; Verganti et al., 2020). Thus, many tech companies deliver their values by using algorithms that connect digital and physical worlds (Iansiti & Lakhani, 2020) and deliver users what they want seamlessly (Magistretti et al., 2021). In this context, designers must learn to create designs relating to these more diverse and extensive contexts, which requires a scaling-up of design research (Brown et al., 2017; Maeda, 2018), and an understanding of users not just at personal but also social and societal levels (Gardien et al., 2014; Whitworth et al., 2006). In collective computing, designer research becomes a more constant occupation, and more integrated with the rest of society to allow for a seamless, iterative process (Höök & Löwgren, 2021). This development implies a shift from single-contextual research to cross-contextual research, i.e., transiting from one focused context (living labs) towards the crossing multi-contexts-based *society as a lab*. Overall, the design task is now based on rapid iterations between research and development, with users as co-developers, and designers more intensely engaging with their data.

Along with having society as a lab, developments in sensor and computing algorithm technologies (i.e., machine learning, neural networks, artificial intelligence) are also affecting the *design process*. These technologies facilitate the acquisition, analysis, and synthesis of extensive amounts of user data across various usage contexts of use by designers in real-time (Gorkovenko et al., 2019), and without any scale-limitation (Verganti et al., 2020). Sensors embedded in products and services (e.g., smartphones) collect countless behavioural and location data almost real-time (Höök & Löwgren, 2021; Van Kollenburg et al., 2018) from their actual use in the wild (Churchill, 2017). The use of an algorithm, such as of machine learning, implies that a system will evolve by the collection of continuous streams of data (Verganti et al., 2020). Höök and Löwgren (2021) argue that this design process will always be 'a work in progress' or 'perpetual beta' through continuous evolvement. Giaccardi and Redström (2020) add that the design process no longer happens before production; instead, development and deployment processes are becoming intertwined — technologies we designed learn while in use and change and adapt over time. This 'constant becoming' (Giaccardi & Redström, 2020) implies that the problem and solution spaces in the design process not only co-evolve in conjunction (Dorst & Cross, 2001), but can also be simultaneously explored while these new digital technologies are being used (Magistretti et al., 2021). Stienstra et al. (2015) coined the term '*co-exploration*' for this process.

In terms of the *role of designers* in building collective computing systems, designers can assume to have much less control over the consequences of their design (and thus, over its meaning and value) as arising with time and use within society (e.g., the offensive tweet controversy involving the Microsoft AI chatbot Tay (Lee, 2016; Wolf et al., 2017)). This suggests that designers should examine their natural optimism regarding the desirability of their solutions and more appropriately review projects for unexpected and unwanted consequences, particularly considering *ethical and privacy issues* (Benton et al., 2018; Bourgeois & Kortuem, 2019; Giaccardi & Redström, 2020; Lazar et al., 2016; Nelson & Stolterman, 2014). The ethical issues that collective computing should address include privacy issues, but they are broader than that due to its societal involvement. Thus, designer may also need to reflect more than before on issues of freedom and human rights (Ibiricu & van der Made, 2020). Other scholars are exploring how responsible innovation can be realised in data-enabled devices, focusing on ethical concerns to design IoT products such as (Bourgeois & Kortuem, 2019), (Boenink & Kudina, 2020), and (Wehrens et al., 2021).

In Study 1b we constructed Figure 1-2 as the initial vision for the collective computing era, based on those distinctively transformed design activities identified in the literature and summarized in Appendix 1-1. The figure lists the crucial distinctions of collective computing activities compared to those in the PC and Ubicomp eras. Similar to Appendix 1-1, the horizontal axis in Figure 1-2 distinguishes the three computing generations (Abowd, 2012, 2016; Weiser, 1991), and the vertical axis lists the three groups of design activities (Dorst, 1997, 2016). Figure 1-2 was also used as input for Study 2, as a help in discussing developments in design activities in relation to advances in modern computing, and as starting point in constructing a vision on collective computing.

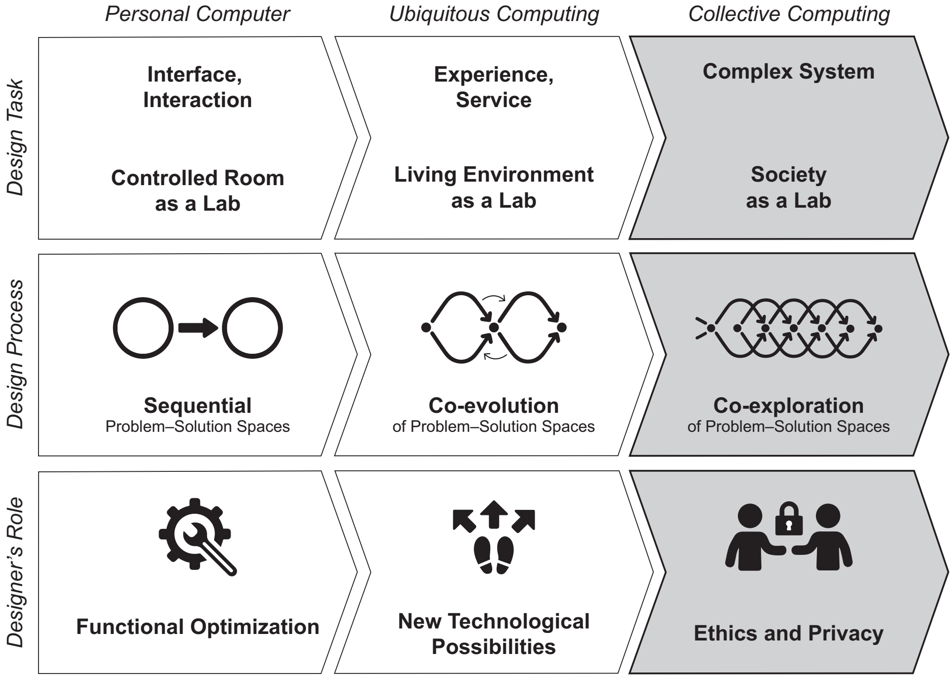

Figure 1-2. Initial vision on the main design activities across three computing eras

1.4 Study 2: Building a vision of design activities for the collective computing era

Study 2 also consists of two parts. In the first part, Study 2a, we interviewed and analysed the answers to the following research questions from 24 informants:

- What improvements do the informants see in the initial vision (Figure 1-2) to reflect past, current, and future design activities in relation to advances in computing?
- What is the potential guidance for designers managing the transformations in the near future of (collective) computing in terms of the design task, process, and designer's role?

In the second part, Study 2b, we constructed our vision of collective computing, based on our interpretation of the analysis result of the interviews (see Figure 1-4). Consequently, our vision was the outcome of our reading of the literature on design activities in relation to modern computing (in Study 1), and on sharing and discussing our initial findings with key informants.

1.4.1 Study 2a: Interview study

Research Method : Sampling and Interview Strategy

Twenty-four informants were recruited per a key informant sampling strategy (Patton 1980), and they had a range of experience in design from industry and academia (see Table 1-1). Informants were approached through various channels, including e-mail requests, recommendations by other informants, and face-to-face approaches at conferences (i.e., CHI 2019, ICED 2019, IASDR 2019).

The interview was open and consisted of three sections, including comments on the initial vision, forces that enable new design activities for collective computing, and guidance for developing new design activities for the collective computing era. The interview guides (with the indicated sections) developed before the interview allowed to slightly deviate and reformulate the way and order in which the questions were asked to investigate the relevant issues accordingly (Blessing & Chakrabarti, 2009; Patton, 1980). The guide allowed us to cover the same topics for all interviews. We also conducted six pilot interviews before Study 2; we learned to change the initial vision (interview stimuli) to be a simple visual (fewer details) and form the interview to be an open interview. Audio of the interview was recorded with the consent of the informants.

Table 1-1. Details of the key informants for Study 2

Informant	Informant Details		Interview Details	
	Job Title (years of experience)	Affiliation	Venue	Duration (approx. min)
Inf 1	Principal Design Manager (25)	Technology Company, Multinational	CHI	60
Inf 2	Professor (21)	University, America	CHI	60
Inf 3	Design Technologist (20)	Technology Company, Multinational	CHI	60
Inf 4	Assistant Professor (8)	Design School, Asia	CHI	60
Inf 5	Professor (19)	Technical University, Asia	CHI	60
Inf 6	Professor (17)	Technical University, Asia	CHI	30
Inf 7	Design Research Lead (15)	Electronics Company, Asia	CHI	30
Inf 8	UX researcher (13)	Digital Company, America	CHI	30
Inf 9	Associate Professor (10)	Technical University, Asia	CHI	30
Inf 10	Senior Designer (5)	Consumer Electronics Company, Multinational	CHI	30
Inf 11	Assistant Professor (5)	University, Europe	University	60

Table 1-1. Continued.

Informant	Informant Details		Interview Details	
	Job Title (years of experience)	Affiliation	Venue	Duration (approx. min)
Inf 12	Professor (22)	University, America	ICED	30
Inf 13	Assistant Professor (4)	University, America	ICED	30
Inf 14	Assistant Professor (11)	Polytechnic, Asia	IASDR	30
Inf 15	Senior Innovation Specialist (4)	Management Consultancy, Multinational	IASDR	30
Inf 16	Professor (40)	University, Europe	Online	60
Inf 17	Assistant Professor (2)	University, Europe	Online	60
Inf 18	Strategy Advisor (9)	Digital Platform Agency, Multinational	Company	60
Inf 19	Senior Designer (6)	Consumer Electronics Company, Multinational	Online	60
Inf 20	Service Design Lead (4)	Consultancy in-housed Design Agency, Multinational	Company	30
Inf 21	Senior Service Designer (4)	Consultancy in-housed Design Agency, Multinational	Company	60
Inf 22	Assistant Professor (14)	Technical University, Europe	University	60
Inf 23	(ex-) Senior Director (35)	(ex-) Healthcare Device Company, Multinational	Online	60
Inf 24	Professor Emeritus (54)	University, America	Online	60

Note. Years of experience of informants is counted from their final academic degree acquisition (most often Ph.D.). The order follows the date of interview.

Research Method : Interview Analysis

We followed the procedure of inductive qualitative data coding from (Patton, 2014), (Miles et al., 2014), and (Blessing & Chakrabarti, 2009). This is a stepwise procedure (Figure 1-3) and double coding[1]. Involvement of the two other authors who are highly experienced senior design researchers, and a highly qualified senior design practitioner in the analysis procedure helped reduce interpretation bias as they were not a part of the interview process (Miles et al., 2014). This analysis extracted the topics and themes of informants' answers and comments to our research questions.

We conducted five steps to extract the final themes as described in Figure 1-3. Also, Table 1-2 describes a typical instance of this procedure with an actual interview excerpt. The first step was separating sections in each interview. Each interview text

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[1] Double coding means to have a time delay in between two iterative cycles of coding process by same person or coded by two independent researchers for higher reliability of the coding results Blessing, L. T., & Chakrabarti, A. (2009). *DRM: A design reseach methodology*. Springer.

was divided into three sections, namely, the issues of interview: comments on the initial vision on collective computing (Section 1), forces that call for new design activities in this upcoming era of collective computing (Section 2), and guidance for developing new design activities for the upcoming era of collective computing (Section 3). The following steps were separately performed for each section.

The second step was interpreting individual interview using descriptive coding. Within a section of each interview, the first author recited the interview text and segmented it in order of flow of various episodes. In addition, all the episodes were marked with a unique descriptive code (Miles et al., 2014).

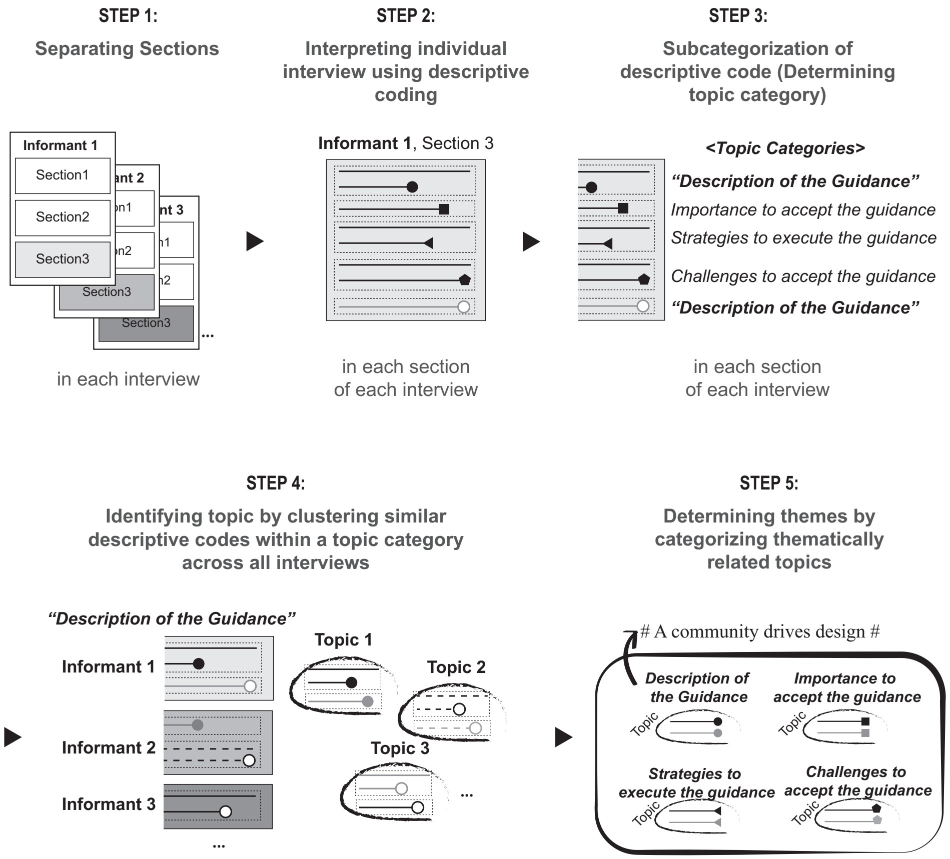

Figure 1-3. Procedure for structuring the information derived from the interviews

The third step was the sub-categorisation of descriptive code into a topic category, typically related to particular interview questions. It was to have some structural and conceptual order to help the coding process and determine the breadth of data (Blessing & Chakrabarti, 2009; Miles et al., 2014). The column headers listed in Tables 1-3,1-4, and 1-5 (under columns of ‘Step 3 & 4’), are the topic categories we used for each section.

The fourth step was searching and clustering similar descriptive codes within a particular topic category to identify and organise topics across all interviews of each section. The clustering of similar codes across all interviews was a challenging task, especially for Section 3, which had multitudes of unique descriptive codes. Thus, filtering similar codes only within a specific topic category provided an outline to the author to navigate and effectively locate similar codes. Subsequently, the author labelled each cluster with a small narrative (Miles et al., 2014) and considered it as a topic. In Table 1-2, the first topic in ‘Step 4’ column describes an example of deriving such a narrative topic by combining four descriptive codes. Moreover, the complete results of Step 4 are reported in Table 1-3.1-4, and 1-5, under the column ‘Step 3 & 4’. Other two authors, who are highly experienced senior design researchers, also reviewed and provided feedback on the logical consistency and codes in the second cycle of this step.

The last step was determining themes by categorising thematically related topics. The first author thematically categorised the narratives of related topics across all topic categories of all interviews (within a Section) to determine the final themes. Subsequently, the first author labelled them with initial thematic phrases. In the second cycle, the two other authors and a senior design practitioner co-developed the final labelling of themes together on which we all agreed together, as presented in the first column (i.e., Step 5) of Table 1-3,1-4, and 1-5

Table 1-2. An example of the analysis of the interviews (Step 1-5)

Step 1		*Step 2*	*Step 3*	*Step 4*	*Step 5*
Section	Interview Quote	Descriptive code	Topic Category	Topic	Theme
Guidance	Designers are imperialists. They are the dictators. The designers go into a little village in South Korea. They look and send the ethnographers in, who study what's going on. Then you (designer) go back and do your ideation, prototyping, and testing. Then you (designer) go back to the people and say, 'here is a solution to the problem you (user) didn't even know you had'. 'Here's what you want.' It doesn't work. So, what we are saying is that we have to move towards community-based design, where the community knows their issues. They don't need to do ethnography; they live there. Designers have to change. They (designers) have to be mentors and facilitators, but not somebody who comes in and says, 'here's what you need'. (Informant 24)	Designers should not be the one who provides the solution. The community itself needs to be the one who knows their issue and creates the solution.	Description of the guidance	A community by itself needs to act as the researcher. Designers should not provide the solution but be facilitators in aiding the community to realise their own problems and create solutions.	A community drives design
	In this community work, I still follow the principles of human-centered design but are implemented differently. You still want to know as much as you can about the people you're working with and use all the clues. But again, the real change is we are not telling people (community), but we're trying to work with them and help them shape their ideas. We don't take their ideas and just use them because most of the time, the ideas are not going to be complete at any point designers are leaving the project. (Informant 24)	Designers help the community shape its ideas and not just take its ideas because the designer's ideas won't be completed at any point of project.			
	In management, there's a well-known philosophy: if you want to convince somebody about your idea, the best way is to make them think it's their idea. Design is all about changing behavior. Those are things that will change behavior. But we want to do it more in a collaborative way. And especially with these complex social problems. (Informant 4)	Make community think design idea is their idea to deal with complex problems.			
	I agree that with the vision that you're putting forward under collective computing. We need more sort of producers and maintainers if you want to have a distributed vision of computing in collective computing. It's not just enough to facilitate imagination. We need somebody from them, maybe from the community, to take these ideas forward, do prototyping, and maybe see how it works and maintain the system. (Informant 4)	Someone from the community should take the ideas forward to maintain and build the system.			

Table 1-2 Continud.

Step 1		*Step 2*	*Step 3*	*Step 4*	*Step 5*
Section	Interview Quote	Descriptive code	Topic Category	Topic	Theme
	…	…	Importance to accept the guidance	Unless the solution is derived from the community itself, the community would not sustainably comply with the solution provided by the designers.	
	…	…	Strategies to execute the guidance	Be sensitive to the diverse cultures of each community. ….	
	…	…	Challenges to accept the guidance	The community would not recognise the underlying problem and will tend to solve just the symptoms. ….	

Result of interview (Study 2a)

Table 1-3, 1-4, and 1-5 present the results of Study 2a. Table 1-3 presents the comments on the initial vision. First, multiple informants recommended presenting the design activities as a continuum between various computing eras because the characteristics of the previous era do not disappear but co-exist with successive eras. Second, informants recognised ethics and privacy concerns in the role of design as a component of a broader 'accountable implementation' for designs of collective computing.

Table 1-4 reports the enabling forces, with the informants mentioned, that will trigger the origination of new design activities. The first theme is 'data as a part of society at large' owing to the multiple and daily-life connections between humans and computers. The generated data can provide a rich understanding of people's actual (and unconscious) behaviour. The second force is 'hyper-connection' within the system that exists by reason of the connectedness and openness of the collective computing system and allows for new combinations of relations, functions and contexts. The third force is 'continuous reconfiguration' that originates as a result of continuous and iterative system updates. Continuous reconfiguration leads to new versions of software and the addition of new functionality and services over the system's lifetime.

Finally, Table 1-5 describes the eight themes of guidance mentioned by the informants to approach the design activity changes in collective computing. The representative quotes of each theme provide by the informants are shared in Appendix 1-2. The first theme of guidance is to make the community drive their design themselves; unless the community themselves drives the solution, the community would not sustainably comply with the solution given by designers. Second, designers can have flexible combinations and analyses; designers can analyse the meaning of the data into multiple different values and opportunities, including values and opportunities that depart from the original purpose of data collection. Third, designers need to use mixed data to supplement each data for accuracy and biases. Fourth, the informants also recommended designers to be comfortable in re-designing societal transformative forces without focusing on the single-user or single-issue problems. Fifth, designers would develop multiple soft launches with a modular design. It helps to have a constant loop between learning-from-users and development. Sixth, the implementation should happen in an actual living context of users – to allow them to experience a potential future (technological) situation that is difficult to imagine or has quite not happened yet. Seventh, informants mentioned exploring and being careful about unintended consequences. There are constant new risks and responsibilities owing to the complexly interrelated contexts, real-time changes, and the systemic nature of collective computing. Eighth, designers need a transdisciplinary vision of the value and control of the design output. This means to adapt various approaches/perspectives from various disciplines, such as extracting meaningful information, identifying valuable data resources, dealing with ethics or privacy issues.

Reflection on the result of interview (Study 2a)

Of the 24 informants, 11 from academia and six from industry contributed new insights over and above those already found in the existing literature in Study 1. Thus, we conclude that the empirical part of Study 2 contributes to the existing literature, and perhaps a little more as a new field for academic exploration than as a sufficiently matured design practice in industry. An example of new insight is that design activities gradually change over the different eras, with new activities growing out of older, more established activities. This view diverges from the literature that portrays *changes in design activities* without pointing to how *old and new design activities are related*. This insight will be used in Study 2a to improve the initial vision.

Reflecting on the particular contributions of those who added novel insights, we could not clearly distinguish between academic and industry informants. No persistent differences arose between the two groups, and the likely reason is that most informants held positions that allowed for considerable access to insights from both fields. Finally, we note that all the informants accepted the central tenet of our initial vision. They agree that there is a new upcoming era in modern computing that is relevant for designers, and that the initial vision of collective computing (Figure 1-2) is an appropriate starting point for discussing upcoming changes in design activities.

Table 1-3. Comments on initial vision (modifications based on Figure 1-2)

Step 5	Step 3 & 4 (*Inf* denotes informant)	
Themes of Changes	**Description of suggested change**	**Reasons for change**
Continuum of design activities	Presenting the distinct design activities between various computing eras as a continuum that induces co-existence instead of a sequential development: 'just like fractal' and 'multi-levels rather than timeline.'	Previous design activities were not forbidden. The low-level design activities (e.g., interface, interaction, or experience) should still occur as fundamental tasks to execute the high-level changes (e.g., system).
	Inf 5, 9, 13, 20	*Inf* 9,13
Accountable Implementation (alternative to 'ethics and privacy' in initial vision, Figure 1-2)	Designers face a more considerable challenge than 'ethics and privacy' in the collective computing era: understanding the implementation of the design in the user's context without naively thinking that implementation will occur anyway.	The 'ethics and privacy' constitute a part of 'implementation concern,' but it does not cover all the concerns. Designers in collective computing face difficulty in realising various products with other discipline experts from the early design stage.
	Inf 1,2, 21	*Inf* 1, 2, 21

Table 1-4. Forces enabling changes in design activities towards collective computing era

Step 5	Step 3 & 4 (*Inf* denotes informant)		
Themes of Forces	**Description of force**	**Importance of accepting the force**	**Challenges against accepting the force**
Data as a part of the society at large	A large quantity of computing is embedded and connected to all the contexts and diverse societal aspects of people's lives, thereby generating high accessibility to data.	There is already abundant data aggregated for people's behaviour; moreover, people are unaware of their own behaviour in a holistic view.	Only large companies possess complete access to the data, as they have tracked it with their existing services.
	Inf 1, 5, 14, 17	*Inf* 1, 12, 17	*Inf* 10
Hyper-connection	The advanced intelligence of computing (each computer can collect as well as analyse data on its own without communicating to a central computer) allows connectedness and openness between contexts and connection to various subsystems and extensions.	Computing is already well-embedded in society and has established its relationship with the society, e.g., collective computing tracks people's behaviour (through smart objects) and decides on its own the actions required in a related context.	A nonlinear, complicated user journey (multiple entry and exit points) is created. Thus, only certain corporations with enormous database can correctly predict the complicated user journey.
	Inf 15, 16, 22	*Inf* 16	*Inf* 15
Continuous reconfiguration	The system is iteratively and continuously reconfiguring over a single human lifetime by adding several contexts and versions to each other.	Software aspect is emphasised in collective computing. Companies do not create new products, but they produce new versions or extensions of the existing products or services.	This continuous reconfiguration may continuously pose the designers with novel risks and responsibilities as compared to that at current disposal.
	Inf 9, 16	*Inf* 2, 13	*Inf* 1

Table 1-5. Guidance for the design changes in collective computing era

Step 5		Step 3 & 4 (*Inf* denotes informant)		
Themes of guidance	**Description of guidance**	**Importance of accepting the guidance**	**Strategies to execute the guidance**	**Challenges against accepting the guidance**
A community drives design	A community by itself needs to act as a researcher. Designers should not provide the solution but be facilitators in aiding the community to realise their own problems and create solutions.	Unless the solution is derived from the community itself, the community would not sustainably comply with the solution provided by the designers. The system continuously reconfigures so is never completed with the designer's solution at any instance. Therefore, the community itself needs to know to build the system by continuously exploring itself.	Be sensitive to the diverse cultures of each community. Designers are required to design the platform that will be used by the community to design the process on its own.	The community would not recognise the underlying problem and will tend to solve just the symptoms. The community can comprise billions of individuals, where each individual follows unique cultural/social norms.
	Inf 4, 23, 24	*Inf* 23, 24	*Inf* 5, 13, 24,	*Inf* 24
Flexible combination and analysis	Be aware that the perceived meaning of data can be utilised for multiple, different values and opportunities in comparison to the original purpose for which it was collected.	Data can explain the users as well as the surrounding contexts. This provides a new approach that the designers are unable to formulate on their own.	Story-telling and inferencing skills assist designers in flexibly interpreting data. This is less fixated on user-centeredness. Data can be used to represent and be used by an individual other from the source of data.	-
	Inf 2,17	*Inf* 2, 4	*Inf* 2, 14	-

Table 1-5 Continued.

	Step 5	Step 3 & 4 (*Inf* denotes informant)		
Themes of guidance	**Description of guidance**	**Importance of accepting the guidance**	**Strategies to execute the guidance**	**Challenges against accepting the guidance**
Use mixed data	Presence of constant combination loops between qualitative and quantitative data.	Be less biased or determine the root cause of deviation/variation to supplement each data with accuracy and target the most impactful opportunities.	Use quantitative data for identifying anomalous patterns, and use qualitative data for exploring the driving cause of the pattern.	The data format is often not formatted in a way that designers would prefer to use, because the data was usually collected for a different purpose. Decisions made on the selection of data sources can be biased as well.
	Inf 12, 14,15,21	*Inf* 2,12, 21	*Inf* 2, 12	*Inf* 21
Work on social forces at a system level	Be comfortable with changes in high levels of problems without focusing on the individual-level of user problems to create transformations in the society, e.g., Re-arrange stakeholders—identify the benefits of various stakeholders and discover the stakeholders with hidden potential. e.g., Consider policy with a higher priority in the design process. The policy effectively triggers a large-scale change and poses a direct influence on the user behaviour.	Current design issues are broader and more complex than designers consideration. Therefore, designers are required to work on the most impactful area to modify that complex issue for best results.	Hypothesise the greatest risk situation during the design process, e.g., lacking properties at the industry, high product cost, or policy problem. Outline the system by focusing more on interaction than users, such as capturing values in data flows between stakeholders, intangible values, and experience. The alterations in this complex system are never achieved only through the designers' efforts. Thus, interacting with other disciplines is necessary, such as policymaker.	-
	Inf 2, 5, 23	*Inf* 2, 5, 24	*Inf* 2, 20, 21	-

Table 1-5 Continued.

Step 5		Step 3 & 4 (*Inf* denotes informant)		
Themes of guidance	**Description of guidance**	**Importance of accepting the guidance**	**Strategies to execute the guidance**	**Challenges against accepting the guidance**
Develop multiple soft launches with modular designs.	Designers dissect a design project into various granularity levels that continuously expand to new levels (modular design) during implementing minimum viable products and constantly develops its design in its course (soft launch).	Provides constant chances for testing assumptions and determining the correct design rationale with continuous exposure to new problems for resolution. Designers are relieved from attempting considerable risk (a small negative change does not account significantly in the end). Provides adequate time for learning and building the trust with clients by demonstrating continuous progress toward completing a huge system design.	Start from the most impactful or short-term future problem and continuously explore in terms of completeness of design (e.g., function), number of the target group, types of stakeholders involved. Establish a seamless connection between the generative question pertaining to user behaviour and building the prototypes.	Determining the finishing mark of the current step and transmission to the following stage is challenging.
	Inf 2, 17, 21, 24	*Inf 21*	*Inf 15,20, 21*	*Inf 20*
An experiment in users' living environment.	Implementing the prototypes in users' living environment to be constantly interactive between users' feedback and design development.	To allow users experience and opine on the potential future technological situation that has 'quite not happened yet,' as users often cannot adequately describe an experience that they are yet to experience. To identify the interdependencies and unexpected problems of the system that are too complex to easily imagine, such as an emotional relationship in a family. Convenience and openness to releasing high-fidelity prototypes with reasonable costs.	Establish the appropriate KPI of each experience moment to measure the reflection on the technological vision.	Characterisation of performance with appropriate KPIs—the corporation often requires to modify its original methods of measuring the performance, which is extremely difficult to adjust with.
	Inf 1,9, 16, 21	*Inf 1,5,16, 22*	*Inf 21*	*Inf 21*

Table 1-5 Continued.

Step 5		Step 3 & 4 (*Inf* denotes informant)		
Themes of guidance	**Description of guidance**	**Importance of accepting the guidance**	**Strategies to execute the guidance**	**Challenges against accepting the guidance**
Transdisciplinary vision on the value & control of the design output	Integrate the working approaches from various disciplines, industries, and companies at the most fundamental stage to realise the design; adapt various approaches from alternative domains on the values and control of design output. e.g., extract meaningful information or design opportunity, identify valuable data resources, and communicate the reasons influencing the decision. One discipline, industry, or company cannot solve entire aspects of the systems.	The design realisation of this complex system is not achieved only through the designers' efforts or one industry/company. Various stakeholders require different values (being aware of the distinct challenges) to implement a new design variation, e.g., the designer is aware of the people's needs/desires, whereas data scientists are aware of the information that can be extracted from the data. For instance, both economic growth and social prosperity are required to be simultaneously explored for building a new city.	Manage all concessions between the various disciplines and industries involved in the scenario. Be flexible and constantly negotiate to modify ideas according to the claim of each other's domains, e.g., negotiation with policymakers to promote adequate regulations regarding the design task. Build trust among various stakeholders by showing that they are working on the same project in different parts and scales.	–
	Inf 1, 2, 20, 21, 24	*Inf* 2, 20, 23	*Inf* 2, 5, 21	–

Table 1-5 Continued.

Step 5		Step 3 & 4 (*Inf* denotes informant)		
Themes of guidance	**Description of guidance**	**Importance of accepting the guidance**	**Strategies to execute the guidance**	**Challenges against accepting the guidance**
Explore and be wary regarding unintended consequences	Traversing from utopian perspectives to be willing to explore unintended consequence: thinking about the appropriateness of the designers' selection for building and being careful regarding unintended consequences and manage unanticipated situations.	Technological companies are currently asked to be more careful (owing to AI development) regarding respecting people's privacy, e.g., users have even started questioning the purpose of data acquisition and are concerned regarding the personnel managing the user information, such that privacy is respected. Design research constitutes the final task for people, in which designers should not impose negative influence by conducting design research.	Employ a speculative design approach to visualise ultimate futures that is currently more accepted in many technological companies. Start questioning the ethical consequence of the designers' creation. Raise the correct question during the design process, prior to focusing on the development of the artifact.	-
	Inf 1, 2	*Inf* 1, 4, 14	*Inf* 12, 17, 22	-

1.4.2 Study 2b: Constructing a vision (based on the interview results)

Research Method

As in Study 1b, we created a vision based on a constructivist mindset, with the same accounts for this approach's inherent interpretation as before (see Study1b). The goal of Study 2b was to create a vision of design activities in relation to collective computing, based on the interviews with informants (Study 2a). For this purpose, we interpreted and synthesised the themes from the interviews, and created Figure 1-3 with the vision, as an improved and more complete version of the initial vision of Figure 1-2.

We compiled the results of the interview study into the vision on which we co-reflected with experts from academia (N=2) and industry (N=3), seen by their peers as frontrunners in the field to validate our interpretations. These design experts had not been informants in the interviews in Study 2a, nor were they involved in the analysis of the interviews. They were a vice president and two senior directors of the design sector of a front-runner company in design methodology (a multinational major health technology company with more than 400 design employees), and two professors of a computing-driven design lab in Europe and a social innovation design lab in Asia.

Results of Study 2b: Synthesized themes of guidance

The first synthesized guidance included 'addressing a community by engaging with their data,' which results from rephrasing a guidance interview theme: 'A community drives design.' This was executed to express the designers' need to incorporate direct and extensive community involvement in design processes more appropriately. As several informants suggested, unless the need for design is derived from the community itself, the community would not sustainably comply with the solution provided by the designers. Further, the community requires its own information regarding the continuous redesign of the system, because systems in the collective computing era are never completed at any instance of the solution delivered by the designers. However, we rephrased this as designers 'engaging with community data,' instead of letting all the community members directly drive a design process, as the ideal of certain informants—to let a complete community drive a design process—might pose an insurmountable challenge and neglect the fact that community-level data are already becoming publicly available and abundant for designers to work with. As an example, members of an online community can publish their opinions or data traces on online social platforms, reflecting the entire digital presence of the community. In such circumstances, designers can act as the creators of information systems that continuously self-learn and self-analyse based on data that communities publish in digital spaces. Accordingly, communities can self-define their problems and independently develop solutions with such systems in a continuous manner.

The second element of synthesized guidance is that designers should progress toward the ‘flexible combination and analysis of mixed data,’ which results from combining the two interview themes: ‘flexible combination and analysis of data,’ and ‘use of mixed data.’ The integration of these interview themes provides concrete and integrated guidance that designers can simultaneously execute within a design process. Moreover, designers are reminded of the various possibilities of data, other than the original purpose for which it was collected, and potentially for other users than those providing the original data. At the same time, designers can be reminded to use various data types to boost data accuracy and reduce unwanted biases in the data interpretation.

The third synthesized guidance theme is that designers must ‘work on social forces at a system level,’ instead of merely focusing on individual users’ problems. Currently, designers address complex collective computing systems that are hyper-connected to widely diverse parts of the society. As suggested by (Van der Bijl-Brouwer & Malcolm, 2020), a societal impactful force cannot be addressed by a single design effort, i.e., designers cannot create an entirely new world. This indicates that designers should be comfortable with the notion of executing small adaptational steps of redesigning system parts, such as working with policymakers to realise system changes for effectively influencing society.

The fourth synthesized guidance theme specifies that designers in collective computing should start ‘developing multiple soft launches with modular designs.’ Two interview themes are combined in this: ‘an experiment in users’ living environments,’ and ‘developing multiple soft launches with modular designs.’ It is because soft launches already mean to continuously release and implement new updated versions in a living social context. Moreover, ‘modular design’ signifies that designers will gradually progress toward more complete designs in collaboration with larger networks. As the design and development process would decompose into numerous small steps, learning from small failures (as a powerful learning mode) could therefore become a more acceptable and tenable option.

The fifth synthesized guiding item is about a ‘transdisciplinary vision of the value and control of the design output,’ which is the result of a larger interpretation of the interview theme under the same name, together with another interview theme, ‘explore and be careful about unintended consequences.’ This second interview theme can be seen as a component of displaying a transdisciplinary vision on the control of design output. Such a vision implies the acceptance of various approaches and perspectives from various domains of expertise, learning to speak the languages of these different domains more fluently to extract meaningful information, identifying valuable data channels, and managing implementation issues such as ethics or privacy concerns. In contrast to the more utopian perspectives on the contribution of design in past eras of personal and ubiquitous computing, our vision considers the degree of control over design outputs as a matter of debate, with an open mind toward the unintended consequences of design and a more critical stance towards the appropriateness of design considerations. In collective computing, there are constant new risks and responsibilities arising from the complexity of interrelated contexts and real-time group dynamics of using new designs. In other words, no one specific industry or discipline can work alone to make a completely working collective computing systems, but rather, widely varying groups must work together to varying extents to operate productively in the new environment.

Establishing a vision figure

The vision of design activities in the collective computing era is presented in Figure 1-4. It yields a comprehensive overview of the design activities to be carried out in the collective computing era.

The left-hand side of Figure 1-4 is the modified version of the initial vision from Study 1 (Figure 1-2), portraying the design activity changes over three computing eras. Based on the interviewee's comments on Figure 1-2, modifications were conducted to organise the design activities between different computing eras in a continuum. In addition, the designer's role in the collective computing era is currently indicated as 'accountable implementation' (ethics and privacy concerns being only one aspect of accountability).

The right-hand side of Figure 1-4 shows the identified enabling forces (top) and the five synthesized guidance themes (white ovals) driving design activity changes toward the collective computing era. The five guiding themes were assigned to the corresponding design activity related to the design task, the design process, and the designer's role.

In addition, we explored the impact of the synthesized five guiding items (white ovals, guidance) on one another and indicated the influence flow using black arrows between the guidance themes presented in Figure 1-4. As observed, the guidance on design tasks influenced the execution of the design process, which consequently influenced the designer's role and vice versa.

Finally, the relationship between the left- (design activity changes) and right-hand sides (guidance) was indicated using driving questions on the application of the renewed design activities in the collective computing era.

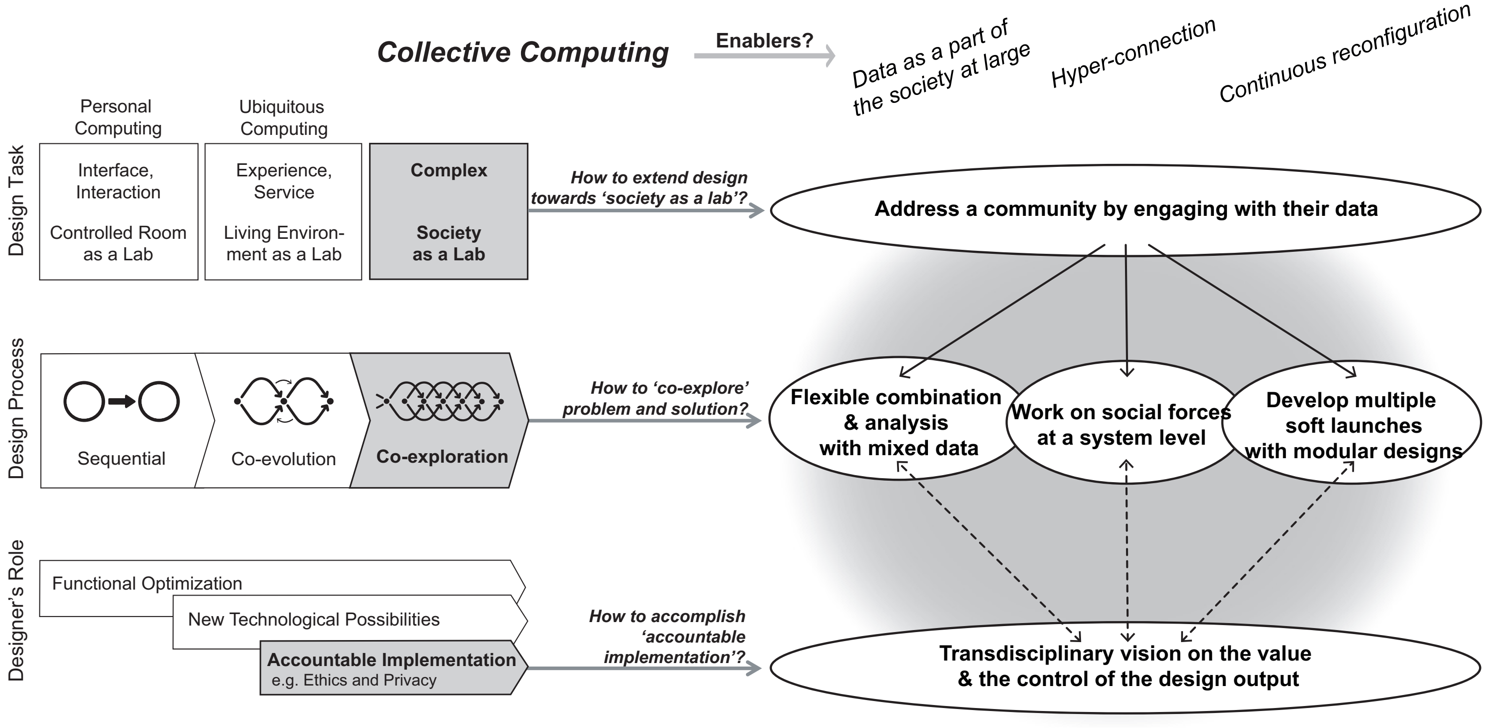

Figure 1-4: A vision for design activities in collective computing era

1.5 Contribution to design practices and methods: Applying the vision to a design project

We tested if the vision could be supportive for designers, and if the guidance it provided was actionable. We asked a graduate (master) student to design a new digital healthcare system while using our vision of collective computing for inspiration and guidance. The aim of this project was to design a system that promotes the physical activities of children with congenital heart defects (CHD). The student found the solution to this problem in co-creation with medical experts from a Dutch university-level hospital. Figure 1-5 illustrates the storyboard and shows the system map of the solution. It consists of an activity tracker for the child, a chatbot for parents with which they can talk to medical experts in case of concerns or emergency, and a dashboard for the medical experts. By sharing data about the conditions of the child, it is possible to generate a better understanding regarding the condition and share responsibility between the caregivers and the medical staff regarding the children's safety boundaries.

The actionable guidance of the vision that the student mainly applied while designing the collective computing system was based on the guide items: 'address a community by engaging with their data', 'work on social forces at a system level', and 'develop multiple soft launches with modular designs'. The student's strategy to address the community was to analyse hundreds of online parental stories from various social platforms used by patients (using text mining techniques) and extract the parents' behaviour towards their children given a timeframe. This analysis defined fundamental issues regarding parents' overprotective behaviour; the student found that parents constantly and restlessly looked for symptoms. The student worked on how the responsibility of parents, who are worried about themselves being unaware of the symptoms, can be addressed (addressing a community), and shared (social forces at the system level). The student then divided the system into three levels: modules, sub-modules, and functions (as described in Appendix 1-3) and soft-launched one sub-module in six CHD children's families (sub-module titled 'real-time worry line' and as described in Figure 1-5). The project is currently in progress, with new iterations and soft launches on various sub-modules. One added sub-module is illustrated in Figure 1-6; clinical researchers support the medical staff decision making through bio data-driven prognostic models, while the CHD children (parents) provide valuable health and activity data for child exercise activity studies. Eight other sub-modules are described in Appendix 1-3.

Figure 1-5. Storyboard and system map of the first sub-module on which the vision is applied (Storyboard is retrieved from a master student thesis, (Morales Ornelas, 2020))

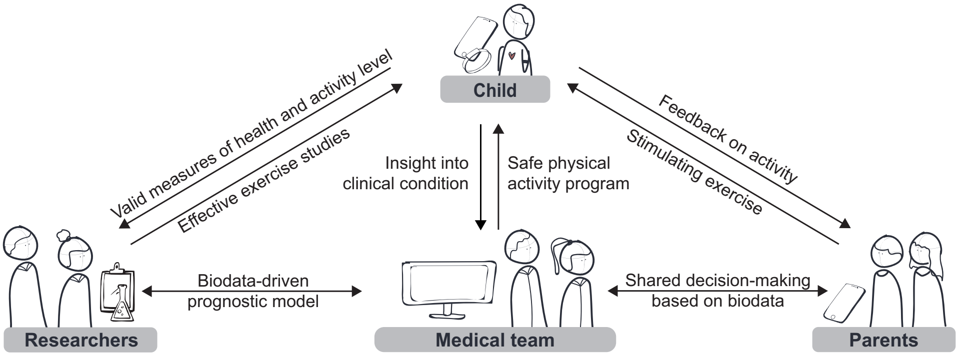

Figure 1-6. System map of the second sub-module added on the first sub-module.

The student stated that the experience of using this vision was inspirational, by reminding and reinforcing herself on becoming a successful system designer throughout her design process. Applying the vision and guidance brought new directions to the existing design processes in multiple ways. First, the designer (student) could identify the collective needs and challenges and compare them with those of individual patients (going beyond the inclusion of only a limited number of users in a conventional design practice). Second, the insights from community-level data allowed solutions at a system level because these data indicate a broader perspective on users' challenges and needs. This allowed the designer to involve a new stakeholder group (i.e., clinical researchers) and assign an additional role to them. In this way, the vision helped the designer expand her approach to improving the system and information value for a broader 'collective' of patients, parents, the medical team and clinical researchers. It is different from designing more user-friendly interactions and experiences between the already selected stakeholders of the first sub-module (i.e., parents, child, and medical experts). Third, the modularity approach provides the designer continuous resources (e.g., sharing the implementation result of the first sub-module awarded the project a grant and attracted other experts to join the project). Moreover, it provided the designer with a manageable workload and a better-defined set of responsibilities than when she would be designing a complete system at once (e.g., while receiving the clinical research approval, defining potential risks that may raise to the patients within the limited context was more accessible than exploring them in the complete design).

1.6 Discussion and conclusion

The present work contributes to the existing historical and visionary literature on disruptive changes in *what we design* (see e.g., DesignX (Norman & Stappers, 2015), fourth generation design (Jones, 2014), the fourth order of design (Buchanan, 2001)), and it does so in connection to another, more ongoing discussion on how modern computing continues to change *our way of designing* (see e.g., (Andreasen, 2011; Cooper, 2019; Cross, 1999, 2018; Liddament, 1999). Regarding the latest developments in modern computing, several design researchers and practitioners have noted that disruptive modifications are taking place that challenge the way we design. Hence, in Study 1 we developed our initial vision on advised changes in design activities for the collective computing era, and thereafter, tested and revised this vision in Study 2. In the envisaged collective computing era, we argue that designers use 'society as a lab' by addressing communities and engaging with their data. Moreover, designers can 'co-explore' design problems and solutions almost simultaneously by considering the flexible combination and analysis of mixed data, working on social forces at a system level, and developing multiple soft launches with a modular design. Finally, designers act to ensure an 'accountable implementation' by incorporating a transdisciplinary vision on the value and control of the design output. The potential of this vision to inspire designers was accurately gauged by presenting the vision to several decision-makers in design fields.

A potential weakness of our approach may be a degree of what Manzini (2016) (Manzini, 2016) termed as 'solutionism.' The limitation of the constructivist mindset might be that it solely focuses on the functional and/or practical benefits of an approach, and thus that it is lacking in depth and unable to motivate participants or inform a social conversation with all affected, regarding the designed future of computational systems. While we see this limitation in our approach, we have tried to remedy this by initiating open discussions in Study 2 through the interviews with key informants. This helped to further explore and validate our vision, and consequently, we compiled their advice as a single model of guidance. We also found that all the informants were keen to remain within our framing of collective computing, even when we invited them to widen the discussion and go beyond this framing. Further, the potential of this vision to inspire designers was accurately gauged by several decision-makers in design fields—both at industrial organisations and academic institutions, including a leading company in design methodology (a major multinational health technology company), a computing-driven design lab in Europe, and a social innovation design lab in Asia. They confirmed the conceptual clarity and novelty of the vision, and were ready to accept this vision and adapt it according to their practices. From a constructivist perspective, we could express that the vision is 'a house built with many borrowed bricks.' Thus, we believe that our constructivist mind has been open to debate and criticism, allowing us to create a firm vision of a future of design in relation to upcoming computing developments.

In addition, our results have significant implications and potential in social design, which focuses on solving social challenges. According to Manzini, 'social innovation' is a new design stimulus and objective, different from technical innovations from the past (Manzini, 2015). Presently, designers incorporate positive social changes such as sustainability (Manzini, 2014). Irwin et al. argued that 'transition design' can design for a societal transition toward more sustainable futures by addressing grave problems such as climate change, loss of biodiversity, depletion of natural resources, and the widening economic inequality (Irwin, 2015; Irwin et al., 2015; Tonkinwise, 2015). However, in the concept of collective computing, these social challenges are prevalent in a world where many individuals interact with many others through multiple computing devices. Thus, the designers' attempts to solve societal challenges should inevitably consider the technology-embeddedness of society. We believe that our research can act as the conceptual bridge between technology-driven and social design; it further allows us to explore the meaning of 'society' from a technology-oriented perspective and that of 'technology' from a perspective rooted in social innovation design.

Our future research focus is to develop and validate design tools that support designers in the era of collective computing, to *co-explore* with *community-level data* while designing *complex systems* in healthcare. The next step will be applying the vision and its actionable guidance in design settings that are broader than a student project. In addition, we will explore how technological solutions such as machine learning (including text mining and artificial intelligence) can benefit from the application of the vision to design practice. Lastly, we will further explore how community-level data can be combined with individual-level data to design collective computing systems. For example, how can we effectively combine highly private medical data (e.g., bio-data) with publicly available community-level data (e.g., online stories).

To conclude, we believe that the vision of the upcoming design activities of the collective computing era formulated herein can inspire both industry and academic designers with guidance that actively promotes design at the leading edge of the collective computing era.

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1.7 Appendix

Appendix 1-1. Design activities for the personal, ubiquitous and collective computing eras

	Personal Computing (PC)-relevant design activities	**Ubiquitous computing (Ubicomp)-relevant design activities**	**Collective computing-new design activities (extrapolated)**
Key technological issue	Competition on the user-friendliness of computer systems and development of the Internet (Grudin, 2008; Pew, 2002)	Portable computers with low-cost tagging and transmission technologies (Want, 2010)	Cloud computing and digitalised behaviour of crowd through advanced Ubicomp devices (Abowd, 2016)
Task (design object)	**Interfaces and interaction** (Burns et al., 2006; Powell & Cooper, 1994; Winograd, 1996)	**Experience and service** (Desmet & Hekkert, 2007; Secomandi & Snelders, 2013)	**Complex systems** (Buchanan, 2001; Jones, 2014; Norman & Stappers, 2015)
Underlying reasoning	Interface and interaction designers considered human factors (Löwgren, 1995; Pew, 2002; Shneiderman, 1980; Winograd, 1996). The design of webpages or software applications is directly related to information retrieval time (Grudin, 2008; Pew, 2002). Internet applications such as World Wide Web, e-mail, and online games changed the ways users (including designers) work, communicate, and entertain themselves (Grudin, 2008; March, 1994; Pew, 2002; Rodgers & Huxor, 2000; Zimmerman et al., 2007).	Devices carry less significance than the experience they provide; extensive user journey included before and after using the computing devices, instead of exploring only the specific moments of use (Pine II & Gilmore, 1998) Inherent embedment of computers in everyday practices increased the degrees of freedom in the design (Want, 2010)	Advanced technologies have enabled unique massive connections between multiple computers and users (Abowd, 2016; Höök & Löwgren, 2021). The physical world of people blends with a constantly updating digital world (Friedman, 2019; Höök & Löwgren, 2021; Speed & Oberlander, 2016; Verganti et al., 2020). Involves multiple layers of social and economic contexts sourced from the crowd (Friedman, 2019) with conflicting agendas between different stakeholders (Höök & Löwgren, 2021). System with autonomous analysis and prediction (Höök & Löwgren, 2021; Verganti et al., 2020).

Appendix 1-1 Continued.

	Personal Computing (PC)-relevant design activities	Ubiquitous computing (Ubicomp)-relevant design activities	Collective computing-new design activities (extrapolated)
Task (design research)	**Controlled Room** (Hughes et al., 1994; Rogers, 2011), e.g., effectiveness of the interface design for construction information sharing multimedia system (Powell & Newland, 1994), virtual window on media space (Gaver et al., 1995), meaningful gestures for HCI (Hummels & Stappers, 1998), age factors in layered user interface (Rama et al., 2001).	**Living Lab** (Brush, 2016; Dell'Era & Landoni, 2014; Feurstein et al., 2008; Rogers, 2011; Taylor, 2016), e.g., Aware Home (Kidd et al., 1999), Cooltown project (Barton & Kindberg, 2001), Projects from ENoLL (Dell'Era & Landoni, 2014).	**Society as a Lab** (Baek et al., 2018; Baek et al., 2015; Gardien et al., 2014; Hummels & Frens, 2008, 2009), e.g., Lighthouse project (van Galen et al., 2020), The Box ("The Box", 2020), SynchroniCity ("SynchroniCity", 2020).
Underlying reasoning	Explore certain moments in computer usage, e.g., the moment of locating the menu button on screen (Mayhew, 1999). Retain users' attention from being distracted or from anything else that could confound the user testing results, such as family assistance (Rogers, 2011)	Explore such overarching user behaviour (Brush, 2016).	Issues pertaining to scaling up (Brown et al., 2017; Maeda, 2018). Design a complex system that requires both societal and personal understanding of users (Gardien et al., 2014; Whitworth et al., 2006); research in design becomes a more constant occupation, and more integrated with the rest of the society to allow for a seamless and iterative process (Höök & Löwgren, 2021).

Appendix 1-1 Continued.

	Personal Computing (PC)-relevant design activities	Ubiquitous computing (Ubicomp)-relevant design activities	Collective computing-new design activities (extrapolated)
Prevalent Design Process	**Problem-solving** process (Shneiderman, 1980) -term is from (Simon, 1988) Problem definition is independent from the delivery of solution spaces in the design process, and can therefore, be handled sequentially, e.g., Virtual window on media space (Gaver et al., 1995), GUI for laboratory instruments (Herman & Aburdene, 1991)	**Co-evolution** of problem and solution- term is from (Dorst & Cross, 2001) Problem and solution spaces constantly change and influence each other, e.g., Smart rehabilitation shirt (Ten Bhömer et al., 2013).	**Co-exploration** of problem and solution (Giaccardi & Redström, 2020; Höök & Löwgren, 2021; Hummels & Frens, 2008, 2009; Stienstra et al., 2015) Analyse the problem and implement the solution in overlapping processes. The problem space and solution space are extensively merged and became increasingly coupled, e.g., Connected bottle project (Van Kollenburg et al., 2018).
Underlying reasoning	Problem space frequently formulated by software developers as a form of user-requirements & usability efficiency (Burns et al., 2006; Jokela et al., 2003; Pew, 2002).	Extensive user journey explored in living lab indicated that the design problem cannot be defined at a certain point of the design process, but it continually evolves and modifies based on the results (Dorst, 2006; Hatchuel, 2001).	New developments in sensor and computing algorithm technologies facilitate the acquisition, analysis, and synthesis of extensive amounts of user data across various usage contexts of use by designers in real-time (Gorkovenko et al., 2019), and without any scale-limitation (Verganti et al., 2020). Sensors embedded in products and services (e.g., smartphones) collect countless behavioural and location data in real-time (Höök & Löwgren, 2021) from their actual use in the wild (Churchill, 2017). The use of an algorithm, such as machine learning, implies that a system will evolve by the collection of continuous streams of data (Verganti et al., 2020).

Appendix 1-1 Continued.

	Personal Computing (PC)-relevant design activities	Ubiquitous computing (Ubicomp)-relevant design activities	Collective computing-new design activities (extrapolated)
Role of the Designer	**Functional optimisation** of current practices and evaluation of final design proposals (ISO/IEC., 1998; Ritter et al., 2014), e.g., The Eight Golden Rules of Interface Design (Shneiderman, 1997), Criteria for effective interaction design (Alben, 1996).	**Exploring new technological possibilities** that can alter and disrupt user behaviour (Brush, 2016; Rogers, 2011), e.g., Research through Design Projects (Stappers & Giaccardi, 2017).	**Consider the ethical and privacy issues** to address unintended misuse (Benton et al., 2018; Bourgeois & Kortuem, 2019; Giaccardi & Redström, 2020; Lazar et al., 2016; Nelson & Stolterman, 2014), e.g., Ethical tools for designers (Gispen, 2017), IDEO's Ethical AI Card and Principles (Sampson & Champman, 2019).
Underlying reasoning	Design standards, structured principles, and guidelines were often developed to guide other designers (Ritter et al., 2014; Shneiderman, 1980).	Technological development such as actuators, sensors, and easy-programming tools (Grudin, 2012; Pew, 2002; Want, 2010). More attention on novel interactions and experiences of emerging technologies in design practice (Brush, 2016). The emergence of speculative design—design is provocative rather than predictive or prescriptive (Dunne & Raby, 2013).	Changes to complex systems that can impact society (Jones, 2014; Norman & Stappers, 2015). Design constantly learns user behaviour and updates/changes its form through its embed learning system (Friedman, 2019; Speed & Oberlander, 2016) Designers decides on changing product design without complete knowledge or certainty (Nelson & Stolterman, 2014).

Appendix 1-2. Representative example excerpts from the interviews for each theme of guidance (Study 2a)

Themes of Guidance	Representative Example Quotes from Informants
A community drives design	'Unless the community buys into the argument and understand-and-accept this is what we've been talking about, they won't accept it. They won't use it. … But again, the real change is we (designers) are not telling people (community), but we're trying to work with them and help them shape their ideas. We don't take their ideas and just use them because most of the time, the ideas are not going to be complete at any point designers are leaving the project.' - Informant 24 'End-users nowadays design and create their own things or even systems but they are not design experts. So, the designers' role would be designing the platform for them. Building such a platform is closely related to the current design researcher's role: the design researchers develop design methods for research. It seems that the design practice level is gradually becoming closely connected to the design research. Designers are needed to design a platform for co-exploration and co-evolution for a community- end users. These days, there is a lot of studies about social innovation and community-driven innovation because it is easier to get societal and communal insights.' - Informant 5
Flexible combination and analysis	'With user cantered design, we only considered with users' needs. We were fixated. The users use emails but they do not tell designers 'oh email is resource.' But designers need to further think about 'what can I do with this?' … Because it is a sort of reversing your perspective looking out to say what are my possibilities in the other direction and to start looking at (the data) resources … There is a core dependency of data. If you do not have data, you cannot build a data model. So, when you do upfront research, you need to be sensitive for seeing data. We need to be less fixated on users. …. But we still keep the user at the centre; when we are fluid, we have to let it go. Because when you make a discovery out of data, it's almost never about the user. It's about everybody that is not the user that is creating data. That's probably valuable for someone else.' – Informant 2
Use mixed data	'Now in collective computing era, you can actually combine qualitative data and quantitative data. So, it is much easier to persuade your client. You can start with the user behaviour data and find the reasons behind the data. … The qualitative data helps you to understand where to look; these are 20 problems or opportunities that have found. Then, by using quantitative data, we find out which problem or opportunity impacts people or organisations the most. So, by combining the qualitative and quantitative data, I've got these three the most important ones among these 20 opportunities. Then, we go back to qualitative to contextualise further these three problems today and deep into them again. So, it's like a constant loop of putting qualitative and quantitative data next to each other to see where there is overlap. … It makes you far more effective as a designer in choosing what problems to tackle because you have all of the sudden access to this huge amount of data. You will not have the time to research the entire context of all the stakeholders of all the interactions in the complete ecosystem. But mapping those ecosystems allows you to understand where to deep dive in.' – Informant 21

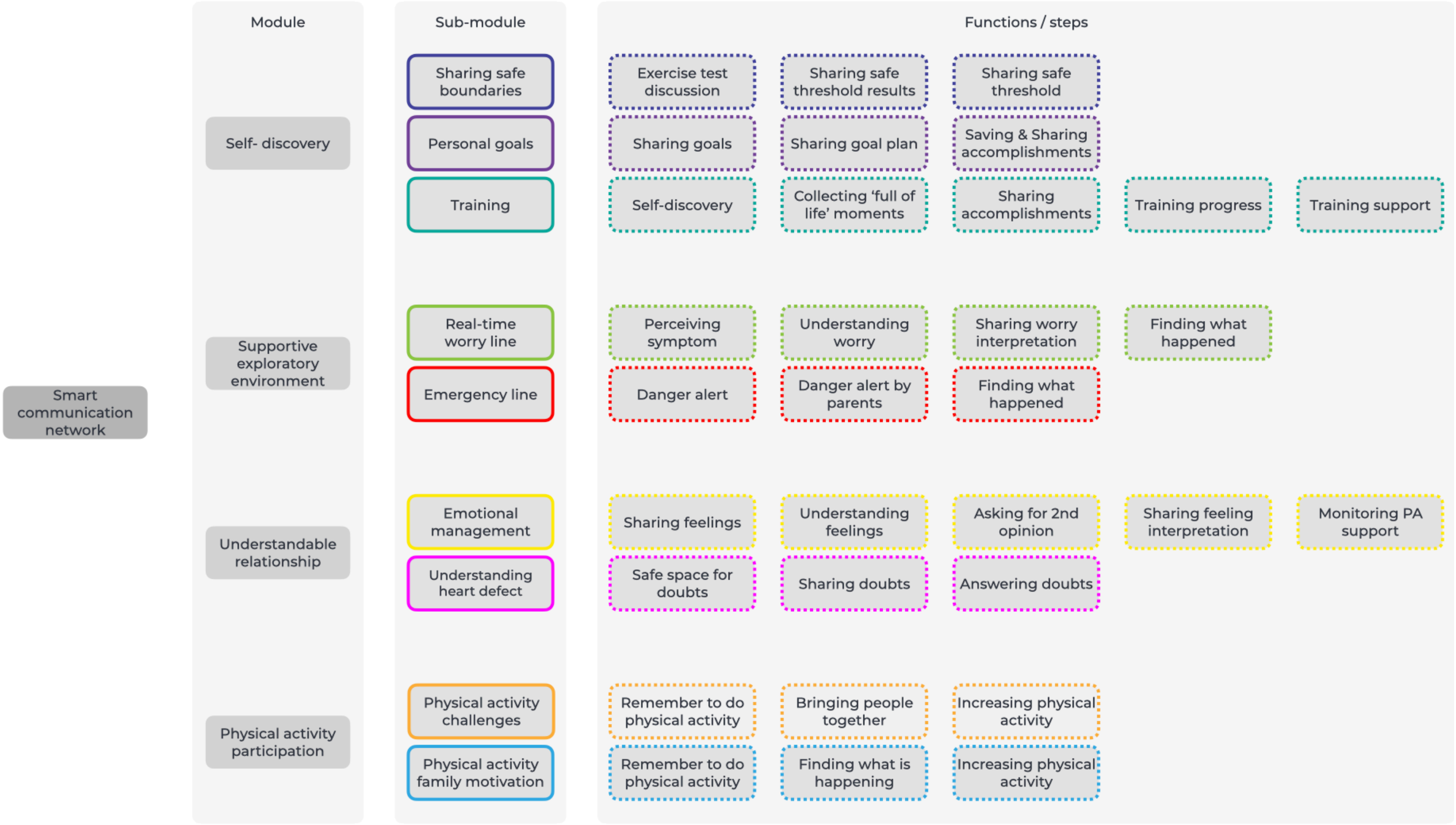
Appendix 1-2 Continued.

Themes of Guidance	Representative Example Quotes from Informants
Work on social forces at a system level	'In these times, we also are sending and receiving data. We were also going through a co-evolution process of users and companies. Because we see the implications of data now, we suddenly have to zoom out of the personal level to a societal level. Because we can see also the impact on society through data.' – informant 20 'We have this very formal manufacturing point of view; how do I resolve what the design is… This is not what we do anymore (in collective computing era). Because we're trying to fundamentally make a system. So, we need to look and say what is the thing that will kill my system. … You sort of need to see which the big forces are sort of locked into a functional ecosystem. How would I rearrange those to be disruptive? But, I don't actually need to go super down when I'm trying to get into the individual behaviour of a person. I don't need the detail of the whole system. … But then there are almost always policy approaches that are just going to be way more effective at triggering large scale change. … We are moving to a new place where we will design things and policy at the same time. Because in some cases, rules are more effective than things. … Often, it's the intersection of the two that actually get us where we want to be.' - Informant 2
Develop multiple soft launches with modular designs.	'So, you might start with a very small problem. You're trying to understand and make a few artifacts which help you understand that problem. It is also called as 'world-building' because you can then keep adding pieces on. If that raises a new problem or a new issue you can make another artifact expand it and expand it. It's never going to be a virtual simulation of the world. You can grow from that focused context to a slightly larger one over time.'- informant 17 'The next project will take the learnings from the first one and slowly understand what that means.' – informant 23 '[T]ry not to go overly deep in your first few iterations. We start to do something quite simple first and to test. We can never be sure until we visit to more people. So increasingly as we move from smaller experiments and tasks to a larger group. We try to then increase the resolutions of each of the prototype to make it more and more real.' – informant 15
An experiment in users' living environment.	'Implementing in real world is not a different method than what we have used before. But it's more applicable in collective computing era because you can start to think about the interconnections that might occur. People can't imagine. It's very difficult to imagine all the different levels of interconnections and also the levels of security breaches, the ethics issues, the trust issues and the privacy issues. Then, you start with a system of interconnected to which objects in the space. … What we're doing is experimental. I mean, you have to set up the experiment in order to understand the different inter-dependencies. So, the living room of the future we actually had three exhibitions where we put the lab in the Tate Modern in London. The visitors come to the museum into the lab and we were extracting their reactions to it. Their reactions on privacy, ethics, trust, the whole thing. That's why we came to be thinking about designing.' – Informant 16

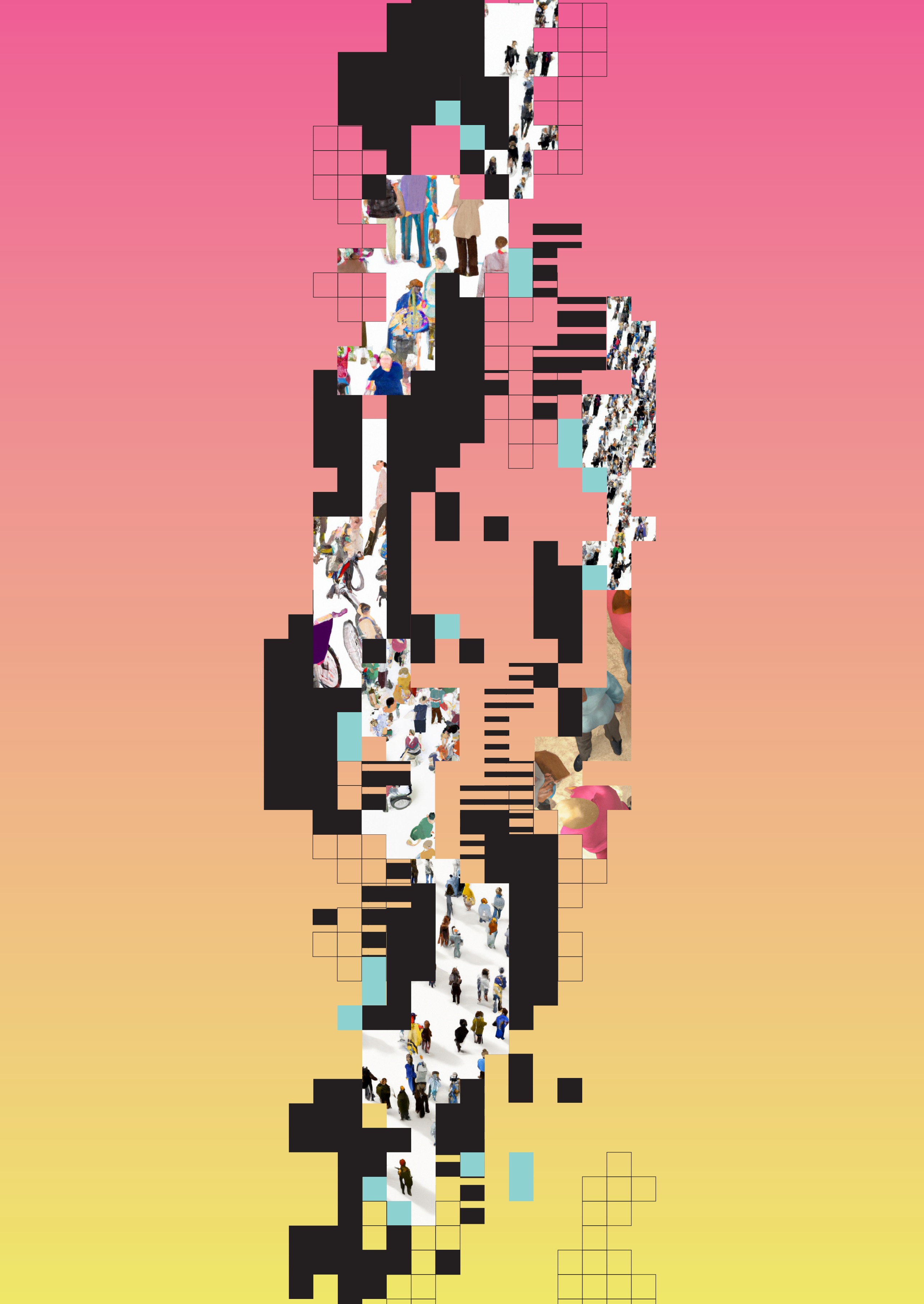
Appendix 1-2 Continued.

Themes of Guidance	Representative Example Quotes from Informants
Transdisciplinary vision on the value & control of the design output	Now the world is so complex that you cannot know everything. So, you need to know how to pair up or team up with different expertise. Different people guard different parts. – informant 20 Starting to understand how other disciplines think and work is needed to designers - involving in your facilitation skills. People work in entirely different ways and have a different way of thinking. You need to understand why they do their job, what their secret agenda is, or what they are trying to achieve. … Make sure your idea is desirable to the people, the stakeholders in the ecosystem. It's a constant conversation with people who bring other expertise. – informant 21 Designers have to be careful that they don't think that they can you do it all. There's been a sense where social scientific design think they own the issue of AI ethics. But actually, it's our legal team and our sales force that who've also done some really deep thinking- brought a different perspective on thinking about ethics. I think you also have to be more humble about thinking about what the roles are. Kind of triumvirate of engineering, design, and social science, what the roles are for these other disciplines that bring kind of different perspectives. So again, it asks a lot of designers in terms of collaboration to learn to engage with. – informant 1
Explore and be wary regarding unintended consequences	'Most technological companies like (Name of Major Tech Company) have been quite utopian about what our technology in the past will make. These kinds of corporate videos had very slick and have everything work seamlessly in this imagined world which technology is doing amazing things. I think one thing that collective computing era or AI has pushed us to do is to think about the consequences. It means that certain design approaches like thinking about speculative design, which are really about saying about ultimate futures are more acceptable. Those have always sat outside of companies like (Name of Major Tech Company) a little bit and been seen as kind of strange- they're a little bit alien, a bit unapproachable; a bit difficult to digest. But now I think companies like (Name of Major Tech Company) are more willing to say well we do want to explore that unintended consequences. We are willing to take a lesson utopian view around the technology. … (Name of Major Tech Company) like most technology companies was quite incautious about the research done we did in the past. Appropriately we're being asked to be a lot more careful about respecting people's privacy and thinking about the roles and what they do here.' – informant 1

Appendix 1-3. Designing a system in modularity (retrieved from a master student thesis (Morales Ornelas, 2020))



	Module	Sub-module	Functions / steps				
Smart communication network	Self- discovery	Sharing safe boundaries	Exercise test discussion	Sharing safe threshold results	Sharing safe threshold		
		Personal goals	Sharing goals	Sharing goal plan	Saving & Sharing accomplishments		
		Training	Self-discovery	Collecting 'full of life' moments	Sharing accomplishments	Training progress	Training support
	Supportive exploratory environment	Real-time worry line	Perceiving symptom	Understanding worry	Sharing worry interpretation	Finding what happened	
		Emergency line	Danger alert	Danger alert by parents	Finding what happened		
	Understandable relationship	Emotional management	Sharing feelings	Understanding feelings	Asking for 2nd opinion	Sharing feeling interpretation	Monitoring PA support
		Understanding heart defect	Safe space for doubts	Sharing doubts	Answering doubts		
	Physical activity participation	Physical activity challenges	Remember to do physical activity	Bringing people together	Increasing physical activity		
		Physical activity family motivation	Remember to do physical activity	Finding what is happening	Increasing physical activity		



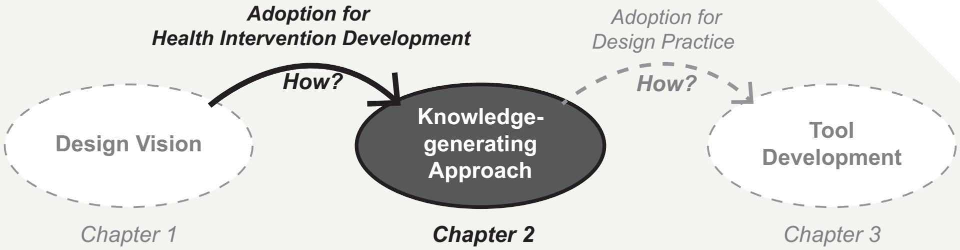
CHAPTER 2.

Integrating public health knowledge to design activities for developing complex interventions

This chapter is under review in a peer-reviewed design journal:

Jiwon Jung, Dirk Snelders, Judith Rietjens, Maaike Kleinsmann. Integrating public health knowledge to design activities for developing complex interventions

Position



My doctoral thesis consists of three levels of knowledge: a design vision, a knowledge-generating approach, and a design tool. In the previous chapter, I construct a design vision around the transition in design activities due to the advancement of modern computing, including data collection and analysis technologies. **In this chapter, I further explore an approach of generating knowledge to realise some central tenets of the vision in the domain of health intervention development.** In the following chapter, I develop a design tool to realise the approach explored in this chapter.

Summary

In Chapter 2, I study a knowledge-generating approach to realise some central learnings from the design vision developed in the previous chapter in the domain of health intervention development. The approach is to gain increased acceptability of design research from health-related disciplines. This research is conducted by identifying the core strengths of the frameworks from the Design Council and the Medical Research Council, both describing a preferred mode for developing interventions in complex systems. The study shows that the core strength of design lies in generating knowledge iteratively, by using in-situ experience data at the individual level to creatively explore and test both problem and solution areas. In health-related research, the core strength lies in generating knowledge from the past in a given problem area and by using existing scientific behavioural data at the population level. Based on this interpretation, this doctoral thesis proposes a novel design knowledge-generating approach required in the domain of health intervention development. The approach integrates the core strengths of both frameworks by existing (already-collected) people's experience data of the community level (midscale between individual and population levels). It shares both characteristics of the data from design research which focuses on people's experiences and health research which focuses on comprehensive behavioural trends.

** The phrase 'our earlier work' in the submitted journal article is changed to 'previous chapter study' in this doctoral thesis. The change is to make seamless and logical connections to other chapters.

2.1 Introduction

Public health is one of the emerging applied contexts for complex systems that designers have recently started to design for. Designers currently contribute to public health challenges by developing novel opportunities and solutions, such as services around healthcare and behaviour-changing interventions for public health design (Tsekleves & Cooper, 2017). Thus, design contributes to public health mostly through non-pharmacological complex intervention development. Designers do this by mapping the individuals' subjective needs and contextual challenges (e.g., social preferences, desires, emotions, and motivations) (Altman et al., 2018; Scholten & Granic, 2019; Whitney & Nogueira, 2020).

Despite this design opportunity to contribute to public health, the interventions that designers create continue to face the challenges of being accepted by the wider public health community (Altman et al., 2018; Bazzano et al., 2017; Huang et al., 2018; Neuhauser & Kreps, 2014). These challenges hamper designers from making a larger impact. We contend that this is because design tries to develop complex interventions in public health without understanding public health's approach for generating knowledge and finding solutions, given that both fields have different epistemological origins. As Krogh and Koskinen (2022) argue, to work with and in other disciplines, designers must understand their epistemic differences—how other disciplines interpret and build knowledge. Therefore, we argue that design researchers and practitioners must learn about the core knowledge-generating (epistemological) strength of public health to develop complex interventions, in order to impact the wider public health audience.

To compare approaches to generate knowledge between design and public health, we utilize two key frameworks for design and health innovation, both of which stem from comparable institutions and have been recently revised. The latest versions of both frameworks have moved towards more iterative processes of innovation and stakeholder participatory approaches. Thus, the two frameworks form an interesting basis for exploring each discipline's way of building knowledge.

The first framework is the 'Framework for Innovation', introduced in 2019 by the British Design Council as an updated version of their widely applied framework, the 'Double Diamond'. The revised framework aims to support designers designing for complex societal, economic, and environmental challenges, going beyond the product and graphic/UX design (Ball, 2019; Drew, 2019; *Framework for Innovation: Design Council's evolved Double Diamond*, 2019). The second framework is the 'Framework for Design and Evaluation of Complex Interventions', introduced and recently revised framework by the British Medical Research Council, focusing on evaluating non-pharmacological complex interventions in the field of medical research (Skivington et al., 2021) and widely accepted by public health community. To improve the synergy between design and public health and to increase the impact of design in the public health field, in this article, we compare the epistemological bases for these two frameworks and propose ways to understand and bridge their core strengths in knowledge-generating approaches. We show that the core strength of design lies in a principle of 'deferral of judgement' (Drew, 2019). This means that judgements about a design direction and its final deliverables should be postponed, which allows for a more iterative generation of knowledge about interventions. In this process, problems and solution areas will be creatively explored and tested, based on in-situ experience data of users and other stakeholders. Consequently, knowledge about (potential) interventions is developed through multiple iterative loops, going back and forth between the process phases. In public health the core strength lies in generating knowledge about interventions by 'measuring improvement' from the past status in a given problem area. This is done by setting directions and making decisions for interventions based on existing scientific evidence. In this way, public health research develops knowledge by identifying to which extent new interventions can lead to improvements in a given problem area. Previous chapter study shows that community-level data could support and bridge these two core epistemological strengths (Jung et al., 2022). One example of community-level data is already available (collected) people's experience data due to the benefits of collective computing (that consists of crowd, cloud computing, and shroud), explained in the previous chapter. The existing (already-collected) people's experience data that exist in community-level stands in between the data source scales and characteristics used for deferring judgement and measuring improvements from the past. The deferral of judgement occurs using in-situ people's experience, captured through the context's unique and situational behaviour at an individual level. Measuring improvement arises from existing theories and scientific data of aiming of understanding generalisable population-level behaviour in an established problem area (based on existing studies and systematic reviews of them). Existing people's experience data of the community-level lie in between these two scales and characteristics, by being in-situ experience data that exist at scale, for larger parts of a population.

To demonstrate the possible increase in the impact of design for public health by using the proposed integration approach based on existing people's experience data of the community-level, we present two design projects and their social and economic impacts. The two demonstrations of integrating design and public health approaches are not perfect examples, but rather two of the many possible ways of making a societal impactful design work within public health challenges. We aim to inspire designers to adopt this integration approach in their own creative, 'designerly' way (Cross, 1982) for a broader social and economic impact on the public health audience.

In the following sections, we first discuss the core strengths of knowledge-generating approaches in design and public health frameworks. Next, we suggest strategies for integrating these strengths with further explanation of existing people's experience data of the community-level. Finally, we discuss the use of the integration strategy in two design projects for the public health audience and describe their societal impact.

2.2 Identifying core strengths of design and public health frameworks for developing a complex intervention

Design Council created a framework that became a universally acceptable design process for product and graphic/UX design in 2004 (Drew, 2019). This framework was called the 'Double Diamond'. Recently, the Design Council renewed this framework to make it applicable for innovation processes related to complex problems/societal challenges (Ball, 2019; Drew, 2019; "Framework for Innovation: Design Council's evolved Double Diamond", 2019) (Figure 2-1). The key principles for knowledge creation in the model are iteration and co-evolvement of problem and solution (displayed by the circular nature of the model). Similarly, Medical Research Council presented a framework for developing and evaluating complex non-pharmacological interventions in public health. These interventions vary from group psychotherapies to community-based programmes to preventing heart diseases (Campbell et al., 2000). While the framework was developed in 2000, the most widely accepted version was released in 2008 (Craig et al., 2008). Recently, like the Design Council, the Medical Research Council amended their framework to allow for iterative and circular innovation processes required to solve today's complex public health problem (Skivington et al., 2021) (Figure 2-2).

The recent changes to the frameworks of the Design Council and Medical Research Council were motivated by a similar need to deal with the increased complexity of their domains with evident similarities in their developments. Both emphasise the context in which the design/interventions would be implemented by acknowledging the value of participatory approaches by empowering and explicitly naming their interests and relevant activities. The Design Council framework remarks that stakeholder ‘engagement’ is one of the two main cultures of success and ‘collaborate and co-create’ is one of the four core design principles. In addition, the public health framework also considers ‘engaging stakeholders’ as the core element. It describes dissemination of innovation through the bottom-up term of ‘uptake’ in addition to ‘impact’ in the implementation phase of the public health framework. However, both frameworks have distinctive strengths should be understood to integrate both approaches. Therefore, in this study, we explore the core strength of each framework—how knowledge is generated and how each framework is being put into practice while developing complex interventions.

2.2.1 Design framework by Design Council

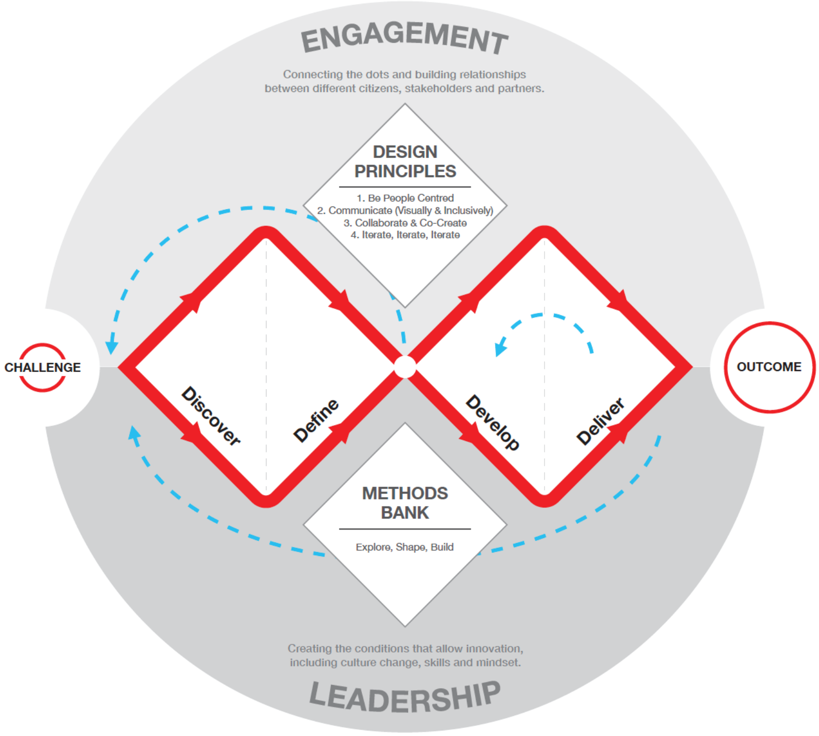


Figure 2-1. A framework for innovation from Design Council (Drew, 2019)

Knowledge in the design innovation framework is generated through iterative loops (blue dotted arrows in Figure 2-1); that is, the complexity is dealt with through multiple rounds of ‘deferral of judgement’ (Drew, 2019). The full anticipation of all the variables and interdependencies, in the context of people, is unnecessary and impractical, and as Rittel and Webber (1973) describe, are 'wicked' problems. Thus, in the framework, designers collect experience data (i.e., user needs) of people (who use the developing solution) by 'launching a solution' directly in the context of people (Ball, 2019). The context can determine the limits and effects of the solution (Rittel & Webber, 1973; Vermaas & Pesch, 2020). People confront the unanticipated misfits with the potential solution launched in terms of technological, economic, and legal feasibilities and requirements. The launch of the intervention happens on a small scale with the resources to observe the natural dynamic of the system. The small resource investment still provides the designers with more flexible boundaries to reshape the solution (Van der Bijl-Brouwer et al., 2021), even if designing in the context of public health may be less flexible than design contexts in general, as patients' wellbeing should be protected.

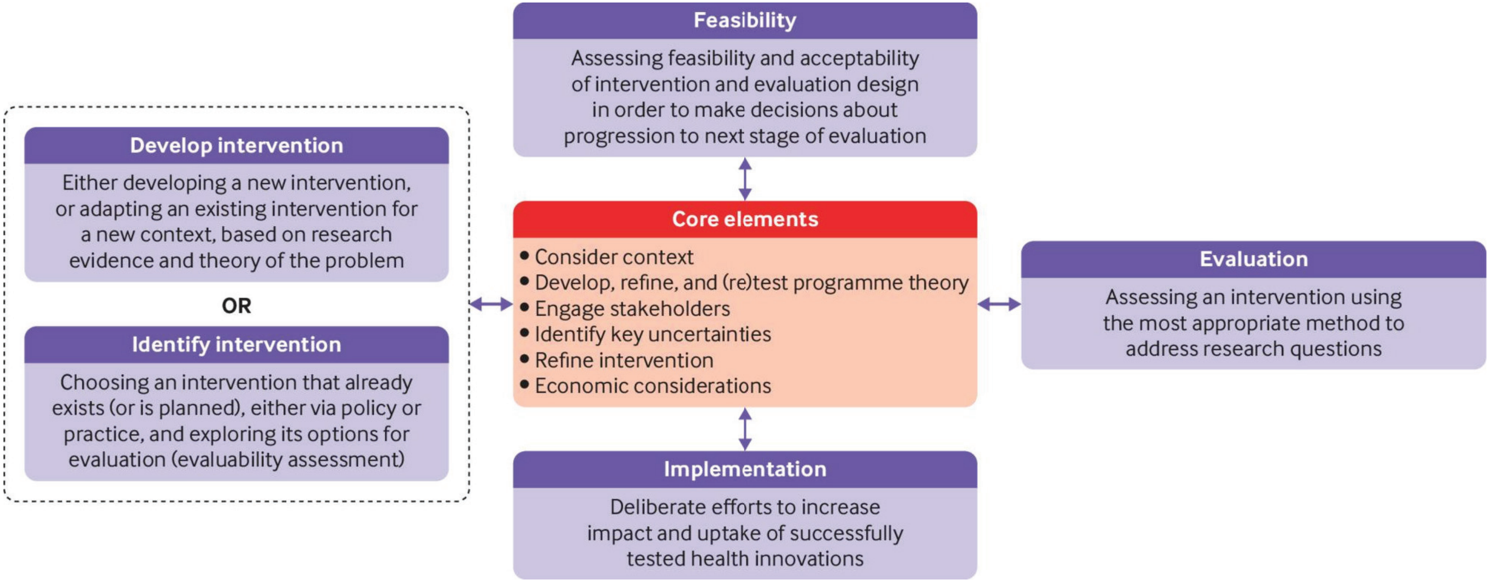
The first deferral of judgement happens at the end of the 'define' phase of the framework. Designers start with a broad problem (i.e., challenge) and diverge to discover various issues and contexts related to the problem. Collecting people's needs and experiential data related to the problem are the ways to discover them. It is often both to understand the context of the problem and to inspire designers. Speaking to the people (i.e., interviews) and spending time with them in the context (i.e., ethnography) ("Framework for Innovation: Design Council's evolved Double Diamond", 2019) are usually the methods to enable this process. The collected data make designers converge to define the initial problem as essential and sharpen the problem's definition — meaning 'defining the challenge in a different way' ("Framework for Innovation: Design Council's evolved Double Diamond", 2019). The way to define this is by compiling the collected data (e.g., using journey mapping) with the users (who may use the developing solution), a design team, or other stakeholders. Thus, designers perceive and understand the problem situation from new and critical perspectives—by building a hypothetical pattern of relationships between the experiential data and the problem situation (Dorst, 2015). When designers believe that the redefined problem situation is not a satisfying an essential issue or that further exploration is necessary, they conduct a deferral of judgement—iteratively going back to the first step ('discover') of the framework. This involves collecting the people's contextual and experiential data about the redefined issue and diverging to find a more satisfying problem situation. The second deferral of judgement happens at the end of the 'deliver' phase to return to the 'develop' phase. If the redefined problem is satisfying, designers diverge to develop (i.e., ideate) various solutions to the problem with the people (who may use the solution), other stakeholders or designers (e.g., employing co-designing/co-creating). Next, they converge to select and 'deliver' (i.e., implement), at a small scale, the most feasible solution as a prototype in the living context where the problem has arisen. The prototype's fidelity level can vary from rough (quick to build) to closer to a final product. It is situated in the people's context to collect experiential data (e.g., usage behaviour of the prototype). The experiential data reveals whether the potential solution (prototype) fits with the living context and solves the defined problem. If not, designers would make a deferral of judgement and iterate the development phase for a better or improved solution (still on a small-scale and prototype level) before proceeding to the 'deliver' phase.

The third deferral of judgement also happens at the end of the 'deliver' phase, but now the judgement moves back to the 'discover' phase. During the delivery phase, designers collect experiential data by situating the potential solution prototype in people's living context. Based on the data collected from the living context, designers can discover and define problems into more essential and sharpened outputs. Thus, designers constantly re-adjust and re-frame the essential issues of the initial and the revised problems (i.e., challenges) by observing the effects, limits, and gaps between the launched solution and the people. The collected experiential data leads to deferral of judgement to find a more satisfying problem-solution pair by being influenced by and influencing each other. This process is known as the 'co-evolution' (Dorst & Cross, 2001) of the design problem and solution spaces.

2.2.2 Public health framework by Medical Research Council

The complexity of developing interventions in the new public health framework is handled by 'measuring the improvements' from the past. This measurement is enabled by considering six core elements (red block in Figure 2-2). Public health researchers and practitioners identify known and unknown key uncertainties and examine economic considerations compared to other alternatives — the fourth and sixth core elements. In addition, they keep refining the programme theory (e.g., the key components of the intervention and how they interact, mechanisms of intervention, features of the context that influence the mechanisms) and the interventions (e.g., refining feasibility and acceptability of intervention based on data collected and programme theory) — the second and fifth core elements. Furthermore, they consider various types of contexts (i.e., physical, organisational, social, and cultural) and enable stakeholder engagement throughout the intervention process to make it meaningful for them — the first and third core elements.

The first 'measuring of improvement (from the past in a given problem area)' in the public health framework happens in the 'development' phase (i.e., develop an intervention or identify an already existing intervention). In this phase, public health practitioners and researchers develop an overview of the existing body of relevant research about the given problem and about already existing interventions



Feasibility

Assessing feasibility and acceptability of intervention and evaluation design in order to make decisions about progression to next stage of evaluation

Develop intervention

Either developing a new intervention, or adapting an existing intervention for a new context, based on research evidence and theory of the problem

OR

Identify intervention

Choosing an intervention that already exists (or is planned), either via policy or practice, and exploring its options for evaluation (evaluability assessment)

Core elements

- Consider context
- Develop, refine, and (re)test programme theory
- Engage stakeholders
- Identify key uncertainties
- Refine intervention
- Economic considerations

Evaluation

Assessing an intervention using the most appropriate method to address research questions

Implementation

Deliberate efforts to increase impact and uptake of successfully tested health innovations

Figure 2-2. A framework for development and evaluation of complex interventions by Medical Research Council (Skivington et al., 2021).

(Skivington et al., 2021). The existing scientific knowledge may include previous empirical studies (either single studies or integrated systematic reviews or meta-analysis) and theories. Based on the body of knowledge, the most appropriate intervention is selected (to be used or further developed), or a new intervention is developed. The improvement is measured by modelling the expected effects of the intervention through describing the expected working mechanism and selecting appropriate variables that measure the working mechanism and outcomes. In case of a further developed or new intervention, an impression is gained of whether the new version has the potential to better address the problem compared to the existing alternatives. This is usually done without stakeholder involvement.

The second improvement measurement occurs in the 'evaluation' phase. The 'evaluation' phase involves a larger set of population (compared to the feasibility phase). It concerns measuring the effects of the intervention, the working mechanism of the intervention, and the effect of contextual factors on the intervention. To reach this aim, often, a combination of methods is used, also referred to as the mixed methods approach. The golden standard is a randomised controlled trial, but other quantitative methods may be used as well, combined with in-depth qualitative methods, and sometimes, an economic evaluation. Additionally, the intervention fidelity is assessed. The evaluation variables are identified from the existing scientific data from the previous phases. Improvement measurement in the evaluation phase provides a clear rationale for intervention implementation for the population with a higher prospect of success and effective use of resources (Rychetnik et al., 2004).

The third improvement measurement occurs in the 'implementation' phase of the public health framework. This phase happens when the improvement measurement from the previous phase (evaluation) indicates an improvement in the problem due to the (re) developed intervention. In this phase, researchers and practitioners pay attention to both the direct components of the intervention and other external influencing factors, such as implementation strategies (how to introduce the intervention to the public) or contextual factors (including economic questions and situations of different stakeholders related to the intervention). This is done to observe whether they support or hinder the improvement of the problem situation with the intervention. It also helps increase the adaptation and maintenance of the intervention in the real-world setting. The framework recommends that the researchers and practitioners anticipate the influencing factors based on theories (i.e., existing scientific data) and other framework stages (i.e., development, feasibility, and evaluation) and control the influencing factors with some extend flexibility.

2.3 Integrating design and public health frameworks

The Design Council's and the Medical Research Council's frameworks have different core epistemological strengths for developing complex interventions. The design framework builds knowledge through 'deferral of judgement', while the public health framework builds knowledge through 'measuring improvements' over past data. We argue that the design framework must integrate the core strength of the public health framework to broaden its acceptance among public health researchers and practitioners. The proposed integration acknowledges the existing and widely accepted public health practices and closes the gaps between the design and the public health frameworks.

One way of achieving integration is to place the 'deferral of judgement' of the design framework as a part of the 'feasibility' testing phase of the public health framework. The feasibility phase of the public health framework intends to examine the uncertainties through a pilot evaluation process on a smaller scale (e.g., acceptability of and compliance with interventions and recruitment and retention of the participants). Thus, the feasibility phase is conducted on a small scale and has the flexibility to adjust without measuring improvement. To explain the integration process step by step starting with the 'development' phase of the public health framework, the most appropriate intervention (solution to the problem context) is modelled. Researchers and practitioners measure the improvement using the modelled intervention in the problem context about the variables identified from the existing scientific data (e.g., the measures to achieve the goal or overcome the challenge and the ways to evaluate their effectiveness). Second, if the model captures the effective improvement in the first step, the researchers and practitioners build and launch the intervention in a small-scale population. This step is a part of 'feasibility' phase of public health but is also where the deferral of judgement (of design framework) happens iteratively. Specifically, the small population uses the intervention and generates in-situ experience behavioural data. Such data lead to a deferral of judgement help redefine the given problem/issue. Based on the redefined problem, researchers and practitioners create and re-launch a more satisfying solution in a small-scale population. This deferral of judgement repeats until a satisfying problem-solution matching is developed. Third, in the evolution phase of the public health framework, the interventions are examined to measure improvements in the effectiveness, fidelity, and quality of the proposed solutions for a larger population. Lastly, the effective solution is re-measured for improving issues that may occur during 'implementation' for a larger population and a longer period.

However, when the integration happens, each design and public health framework uses different scopes and levels of data sources to generate knowledge and develop a complex intervention. The design framework uses the in-situ people's experience data on a small-scale—i.e., individual-level—and the public health framework uses existing scientific data for population-level insights about people's behaviour. This is because the in-situ behavioural data emerge from user studies of a particular case, while existing scientific data are derived from theories, previous studies, and systematic reviews. There is a huge gap between in-situ people's experiences and existing scientific data in terms of expression, evaluation, and structure (Stappers & Giaccardi, 2017). The in-situ experience data capture the intervention context's unique and situational behavioural characteristics, while the scientific data provide abstracted data, providing generality and guidance regarding people's behaviour (Gaver & Bowers, 2012). Thus, the in-situ experience explores the overall and re-emerging experience of all the aspects of the intervention at an individual level; however, scientific data measure the controlled experience for the isolated variables influencing the intervention at the population level (Stolterman, 2008). An abrupt integration of two different scales and characteristics of data sources within one integrated process can cause interface challenges and confusion in fluid decision-making between the different phases.

To overcome the interface challenges, we propose that design and public health research meet each other mid-way, in a space between individual-level and population-level data, namely community-level data as Figure 2-3 (left arrow) indicates. An example of community-level data is the already existing (collected) experience data that are shared by a community (not a population or individual but it is a group of many people having a particular common characteristic). These data emerged because of recent data technological developments, such as cloud, sensor, and artificial intelligence (AI) technologies, allowing for large-scale accessibility to extensive behavioural data and the required analytical ability (Jung et al., 2022). The existing experience data include online user behaviours on specific social community platforms (e.g., Twitter (messages around particular topics), PatientsLikeMe (patients' stories and questions) and Instagram (images and texts around tagged topics).

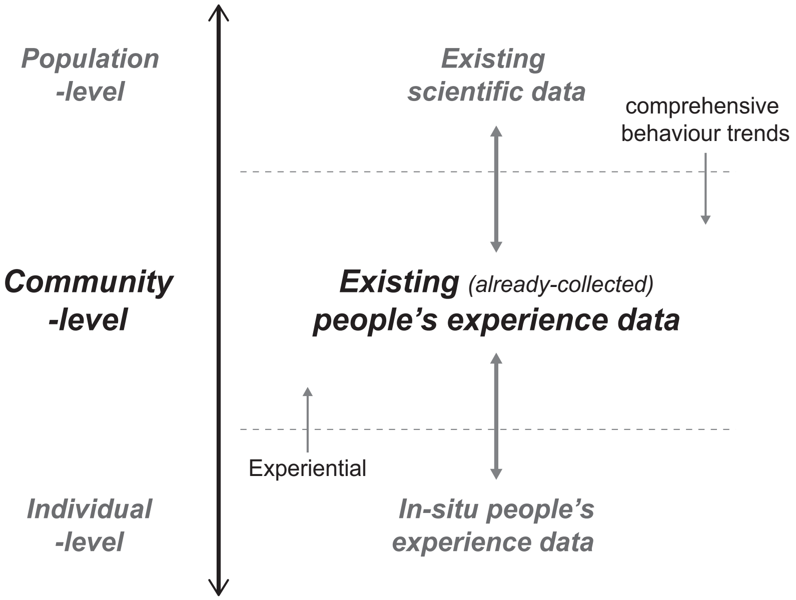


Figure 2-3. Description of existing people's experience data of community level, inspired and modified by 'the bridging concept diagram' (Dalsgaard & Dindler, 2014).

Existing people's experience data differ from the in-situ experience data since they are pre-existing (pre-collected/tracked) and shared data that are not related to the research purposes. Nonetheless, they provide relevant experiential insights about people's use of potential interventions (solutions), both because the data are produced within relevant contexts, and/or there is a vast amount of contextual data points that can be analysed from the relevant perspective. For example, through the patients' community platform posts, researchers can understand patients' understanding of the disease such as coping strategies, concerns about the disease, barriers to health behaviour changes, and symptoms related to the disease (Chen & Wang, 2021).

Furthermore, existing people's experience data can reach a significant scale, which can provide insight into the comprehensive population behaviour trends. They include data entries from tens of thousands of people but are not limited to this scale and can be much larger or smaller number as long as they can show comprehensive population behaviour while still capturing some aspects individual experience. Thus, they contribute to the individual-level data by providing contextual data in resource-efficient ways (almost no resources are needed to recruit the people and collect data from them) and enables 'improvement measurement', as aimed by the public health framework. In addition, they contribute to population-level data by including the contextual, emotional, and situational behaviour in relevant contexts on a large scale and enable 'deferral of judgement' to find a satisfying problem–solution pair in larger scale data. Therefore, the existing people's experience data at the community level combine experiential data (common to individual-level data) and comprehensive and comprehensive behavioural trends data (common to population-level data).

2.4 Design projects

We applied the proposed integration approach into practice by using exsiting people's experience data of community-level in two exemplary design projects. In the design projects, we asked two fifth-year graduate design students to create digital healthcare systems while adopting the proposed design-public health integration strategy. The purpose of Project 1, by Ward Hendrix, was to re-design a given intervention and Project 2, by Hosana Morales, was to develop a new intervention. We present these projects as examples of adopting the proposal in the context of public health. The process of adopting the integration proposal is depicted further below.

2.4.1 Design project 1: An intelligent question-and-answer platform by Ward Hendrix

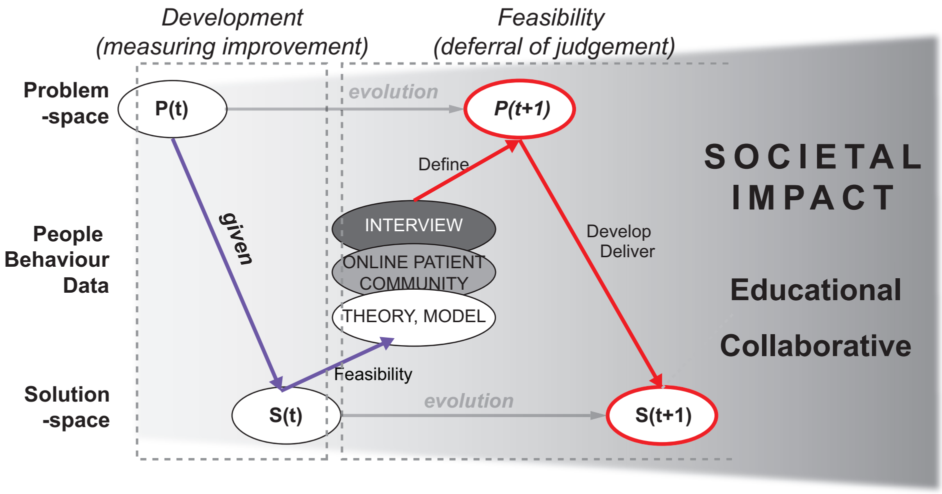


Figure 2-4. The process of Design Project 1 (the figure is inspired and modified from the depiction of 'design exploration as co-evolution (Maher et al., 1996)').

Figure 2-4 depicts the integration process. In Project 1, the problem [P(t)] is given; Dutch cardiac patients have limited follow-up meetings with their cardiologists after being treated at the hospital. The patients have to wait for several months before their next visit. In the meantime, patients often turn to the online social platform, Hartvolgers (now *streetdr.org*), as a solution [S(t)] to the problem, wherein they interact with other patients or healthcare professionals and use it as a self-healthcare management tool. The platform is managed by a small group of cardiologists who seek to inform patients about making efficient use of the limited time at the hospital.

To innovate the current solution (health-based social platform), the design graduate student investigated the existing scientific data (i.e., theory and models from literature) about self-management in healthcare (e.g., reasons for emerging paradigms, attributes, consequences, and antecedents of self-management supporting technological development). Simultaneously, the student analysed data from the Hartvolgers platform as existing people's experience data at community level—both quantitatively (e.g., number of posts and users) and qualitatively (e.g., forum category and post contents). The data analysis of existing people's experience data in the community level illustrated that the platform community has an increasingly large group of cardiac patients with only a small group of available cardiologists (Figure 2-5). In addition, the number of discussion posts in the 'askUs' category (where users ask questions directly to the cardiologists) is much higher than the number of posts on board categories where users can socialise with peers. Based on this understanding, the student further interviewed two cardiologists to discuss and validate the findings.

Consequently, the student could redefine the problem [P(t+1)] as an urgent community need requiring new solutions that lower the burdens of the cardiologists answering posts of the patients and their family members while satisfying the culture of direct interaction with the cardiologists. To address this problem, the student reshaped the main function of the platform Hartvolgers from a patient social network platform to an intelligent question-and-answer platform (question wizard) as a new solution [S(t+1)]. This new solution enables patients and their families to find existing but relevant information more efficiently and effectively using the question wizard (reported in (Hendrix, 2019)). As a core component of the question wizard, a novel search engine was developed that employed a deep learning model to capture the semantics of words on the platform posts. Through the search engine, the patients and their families could search with short questions and retrieve relevant posts addressed by cardiologists in the past, even when the posts may not contain the exact words of the new questions.

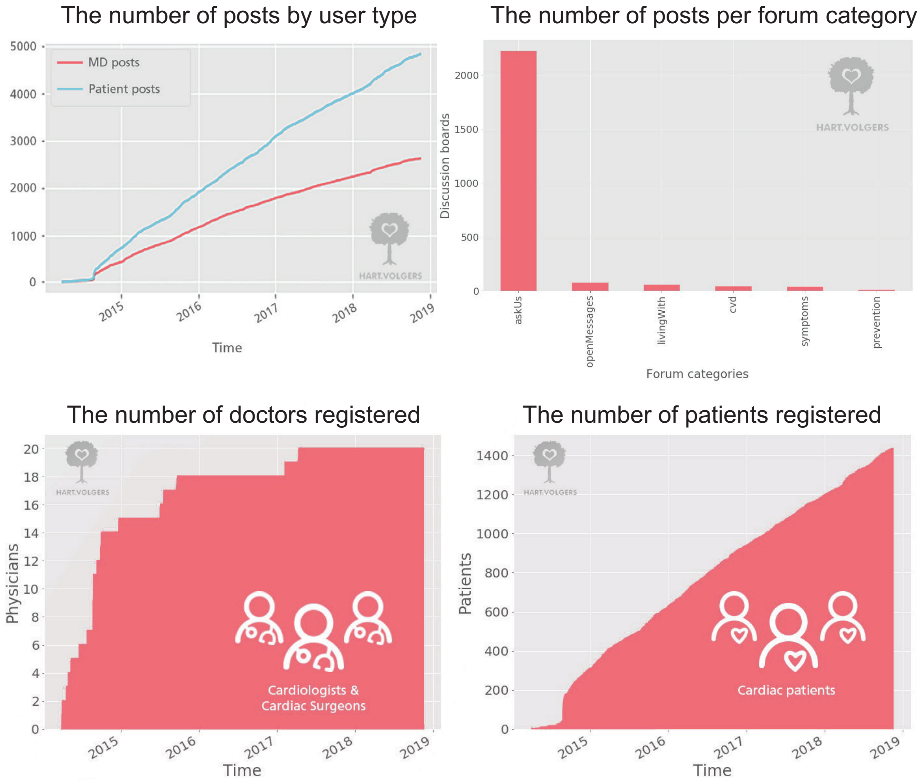


Figure 2-5. Existing people's experience data at community-level analysis result in Project 1 (retrieved from a student master thesis, Hendrix (2019))

This design project, by using the proposed integration approach, impacted public health education and collaboration. The student became an AI-based automatic lung cancer detection PhD researcher at a university research hospital. This implies that medical specialists acknowledged the research methodology used in the graduation project and were keen to use similar skills in their PhD research. Further, the student, who understood the proposed integration strategy, is currently working in health research, which implies that the process nurtured a researcher to disseminate research inspired by the integration approach to a broader public health audience. Furthermore, we were invited to an open internal employee seminar at a major multinational health technology company with more than 400 design employees. We shared the approach with the internal data-enabled design methodology research and development team to inspire them to use community-level data in their methodology development. Regarding the collaboration and network impact, we could build a persuasive collaboration with various medical research groups, including the team for Design Project 2 — a paediatric cardiology group at a research university hospital.

2.4.2 Design project 2: A supportive chatbot self-discovering safe limits in physical activities of child cardiac patients by Hosana Morales

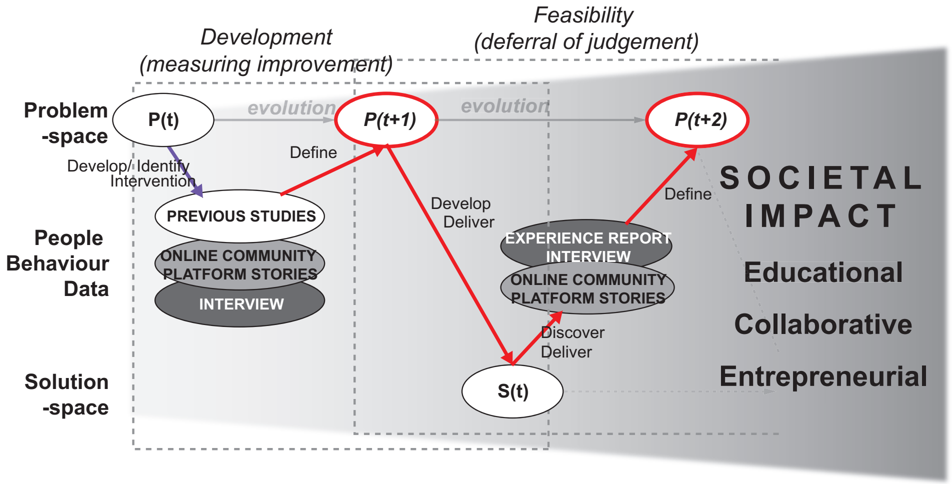


Figure 2-6. The process of Design Project 2 (the figure is inspired and modified from the depiction of 'design exploration as co-evolution (Maher et al., 1996)').

As Figure 2-6 depicts, as a project partner, a university research hospital, provided the problem context [P(t)]— children with congenital heart defect (CHD) often lack the opportunity to perform physical activities, which may decrease their cognitive maturity, motor development, and autonomy. Through his PhD thesis on this topic, the partner (paediatric cardiologist) identified that the lack of physical activity is due to the overprotective behaviour of the parents who are unaware of the extent to which their child can safely exercise (Deutekom, 2017).

To develop a solution for this problem context, a master's student investigated previous experiments and studies for existing scientific knowledge about physical activities for CHD children (e.g., medical dimensions, benefits, and limitations) and over-protective parental behaviour (e.g., causes and consequences). Additionally, the student used parental stories from child-heart foundation platforms to gather existing people's experience data at the community level. Around 300 stories, written by parents about how they raised their children with CHD, were collected. The main purpose of the stories was to communicate with and support other parents in the same situation. The story contents varied from past medical procedures to current lifestyle details. The student analysed the stories using supervised text mining to understand parental behaviour towards children. Based on the analysis, and with the help of the proposed ideation support, the student created a lifetime journey map of parents with CHD children (Figure 2-7).

The journey map would allow the designer to have an in-depth understanding of the lifelong journey of the parents with their children (e.g., the aspects and memories of parents that trigger and manifest as anxiety and overprotection during their children's childhood). In addition, based on the story analysis, the student developed interview questions and tools and conducted semi-structured interviews with seven children with CHD and their parents. The examples of interview questions are how to perceive the intensity of physical activity, how to understand if the symptom is related to CHD, and how to understand when to stop physical activity.

Based on the investigation of the incorporated data, the student, instead of developing a solution, redefined (sharpened) the problem context [P(t+1)] as the need to share parents' responsibilities as they restlessly look for CHD symptoms in their children. Based on the redefined problem, the student conducted a co-creation session with five medical experts and four designers. Based on the ideas from the co-creation session, the student developed a satisfying possible solution [S(t)]. The solution consists of an activity tracker for the child, a chatbot for parents to interact with medical experts during concerns or emergencies, and a dashboard for medical experts (reported in (Morales Ornelas, 2020)). Sharing data about the child's condition through the activity tracker would enable designers to generate a better understanding of the condition and a shared responsibility between the caregivers and the medical staff for the CHD children's safety boundaries.

The solution was a system comprising three levels: modules, sub-modules, and functions. The student implemented one module out of the eight as a prototype for six children's families for three weeks. It aimed at understanding the influences of the solution on parental overprotection. The chatbot (a part of the solution) was embedded with user experience tracking functions (i.e., communicating and reporting behavioural changes). Thus, the emotional and behavioural changes influenced by the prototype were observed and reported daily through the chatbot function. In addition, the student conducted in-depth interviews with the families after using it for three weeks. The users' experience reports (through a chatbot) and interview answers were integrated with the user behaviour analysis outcome from parents' online stories (i.e., community-level data). Based on the integrated results, the problem space was reframed into the need to have more connected communication about the children's symptoms and emotions through diverse stakeholder involvement (e.g., schoolteachers, physical coaches, and other children using the chatbot) [P(t+2)]. The project is currently in progress, with new iterations to implement seven other sub-modules.

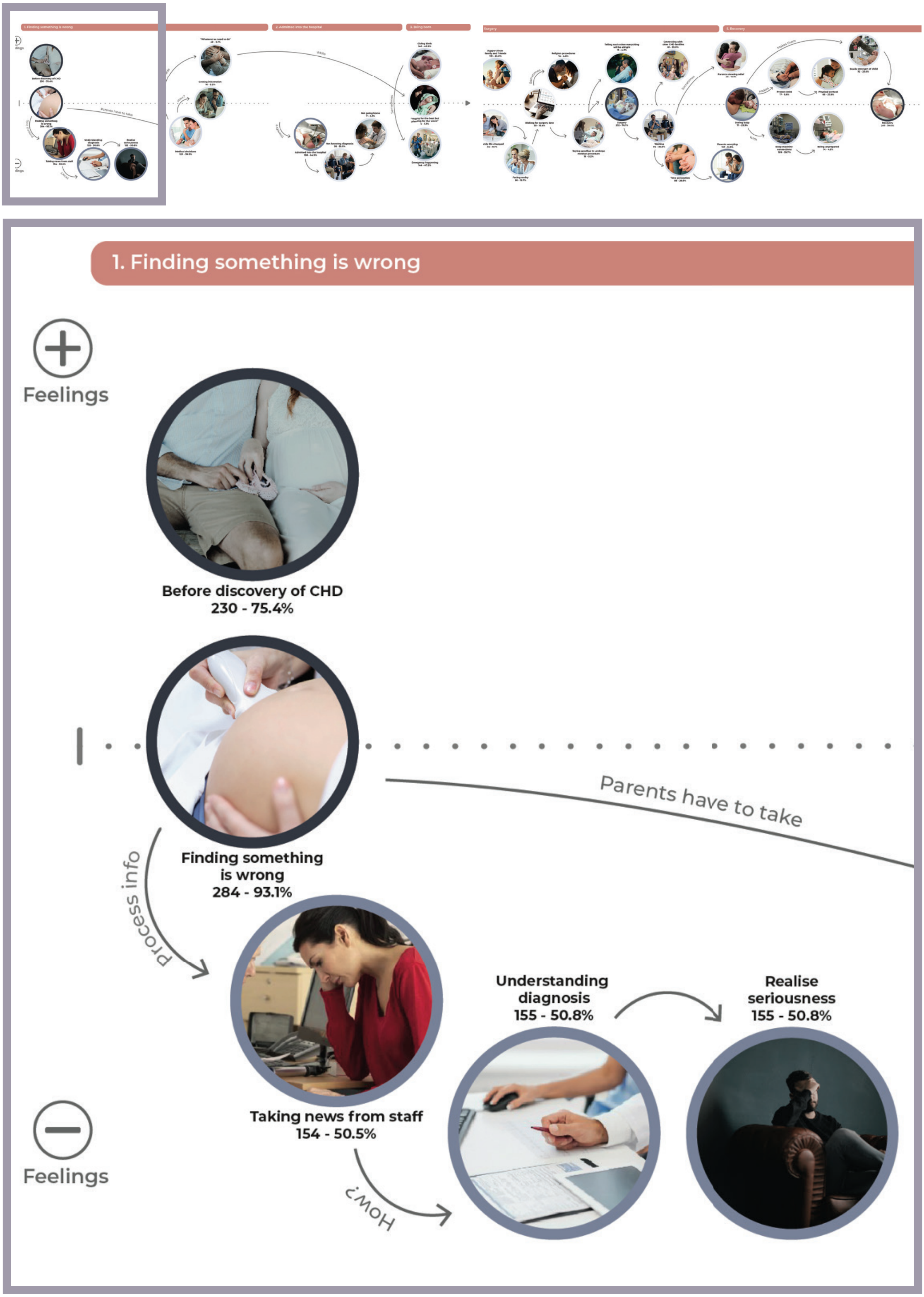


Figure 2-7. A part of analysis results from existing people's experience data at community-level in Project 2—a lifetime journey map of parents with CHD children (Retrieved and modified from (Morales Ornelas, (2020))

The student's design project, which adopted the proposed integration approach, had several societal and economic impacts on education, collaboration, and entrepreneurship. The student became a PhD scholar researching on evidence-based healthcare system design; thus, the project nurtured a healthcare design researcher who understood the proposed integration strategy. In addition, the project inspired other master's graduate students to continue their projects with our research lab and adopt the integration strategy. We delivered a value-based healthcare summer school lecture at a research university hospital regarding Design Project 2 and disseminated the knowledge to other medical and public health experts. We built continuous and strong collaborations (networks) with new medical research groups (i.e., medical practitioners and health policy researchers) and awarded multiple research grants to build future patient monitoring systems, consultation systems and novel patient experience analysis methods (using existing people's experience data in community-level and machine learning) with public health, medical, health policy, and governance researchers. In addition, the fourth author was invited to lead a (province-scale) convergence consortium between a medical centre, a social science university, and a technical university in the Netherlands to conduct research collaboration regarding the topic of this project. Particularly, the design solution [P(t+2)] awarded a local patient organisation (Stichting Hartekind) grant to further develop its idea to next level. Thus, we would say we even could built a collaboration with direct user groups (patient organisations). We are also currently making an economic impact on public health in the Netherlands by establishing a start-up based on the integration approach. We have been awarded two governmental entrepreneurship grants (grants to shift research ideas to socially impactful spin-offs). The patient community journey mapping tool, used in Design Project 2, is the initial model for a new venture awarded the entrepreneurship grant. This spin-off has been selected as a part of the pre-incubating programme of the university. It is being led by a team consisting of some of the authors, a service designer, a data scientist, and a business developer.

2.5 Discussion and Conclusion

Recently, many design practitioners and researchers have tried to contribute to the public health discipline as a part of their contribution to complex systems. However, their impact is still limited as they have not been fully adopted by the broader community of public health researchers and practitioners. This limited impact stems from design researchers and practitioners developing their interventions for public health without understanding how public health researchers and practitioners interpret and build knowledge. Therefore, in this article, we identified the core epistemological strength of each design and public health framework to develop complex interventions. We argued that the core characteristic of the design framework to build its knowledge is the 'deferral of judgement' and the public health framework is 'measuring improvement'. The exploration is based on two British Council frameworks for developing complex interventions: one from design and another from medical research councils. Thus, we proposed a design to integrate the public health core strength using existing people's experience data of community-level, to broaden the impact of the design works on public health audiences. Such data lie between in-situ people's experience and existing scientific data, which are the user behaviour data sources input to develop complex interventions in design and public health frameworks. Thus, the community-level data bridge the sources of user behaviour data to solve the interfacing issues when two different frameworks are integrated and used to leverage their core strengths. To support these frameworks, we introduced two design projects using the integrated approach and described their impact on the public health audience.

While this study focused on designers' contributions towards contribute to public health, integration is also essential for public health researchers and practitioners. Designers often create interventions based on individual-level behavioural data gathered through interviews or ethnography of dozens of individuals, even when the intervention is meant for a much broader population (Figure 2-8). Conversely, public health researchers and practitioners often develop interventions based on population-level data, even when they seek to apply their intervention at an individual level. These scale discrepancies can cause significant hesitation among individuals towards public health-based interventions and policies. Thus, efforts exploring the ways to integrate design and public health frameworks should provide public health researchers and practitioners with insights into how these interventions could be successfully implemented at the individual level.

Critical works remain to be done in the future to observe the success of the proposed integration strategy. As this study aimed to bring the design and public health development of complex interventions closer, the two example projects did not go through a complete cycle of public health framework (i.e., evaluation and implementation phases). In a future study, we will find more interesting aspects of the integration by proceeding further: such as a comparison of the advantages and challenges of various integration moments. It is possible because the project is granted for further solution development from its user group (patient organisation) directly as described on societal collaboration impact on Design Project 2. This may inspire the design and public health contexts to integrate into different innovative ways.

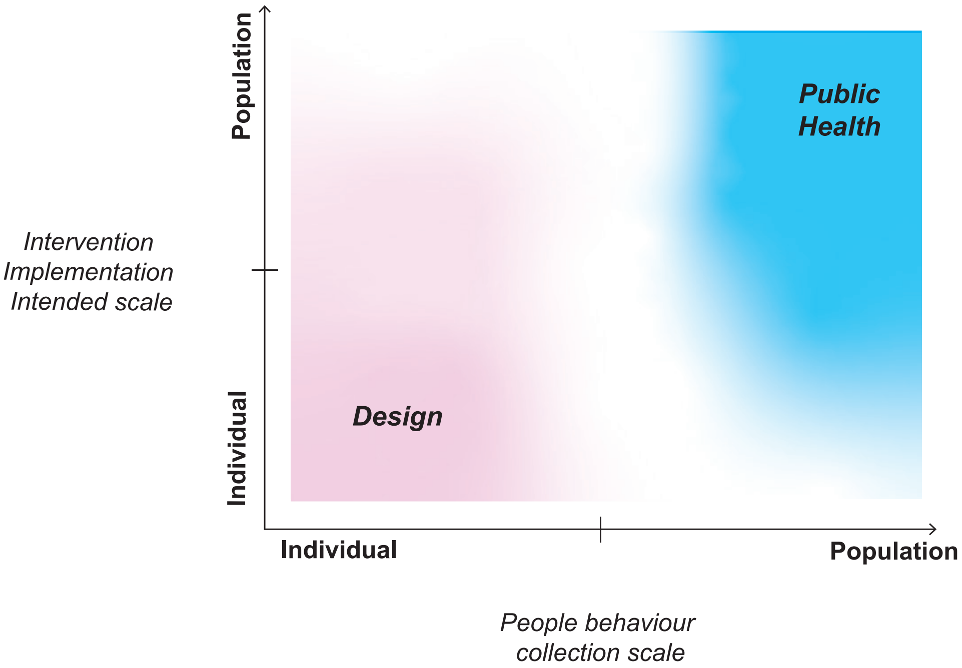


Figure 2-8. Comparing the complex intervention framework spaces in the fields of design and public health.

Nevertheless, the two design projects introduced in this article have contributed to various societal and economic impacts—education, collaboration, and entrepreneurship. The projects also enabled us to disseminate the integration approach through education, and by nurturing healthcare designers and researchers who understand the integration strategy. In addition, we built continuous and strong collaborations with new medical research groups (i.e., medical practitioners and health policy researchers) and multiple grants-supported start-ups for healthcare designers and data scientists, with an integrated approach mindset, to work together. Therefore, we envision that future designers would develop complex public health interventions by engaging existing people's experience data of community level to broaden their impact on the public health audience.

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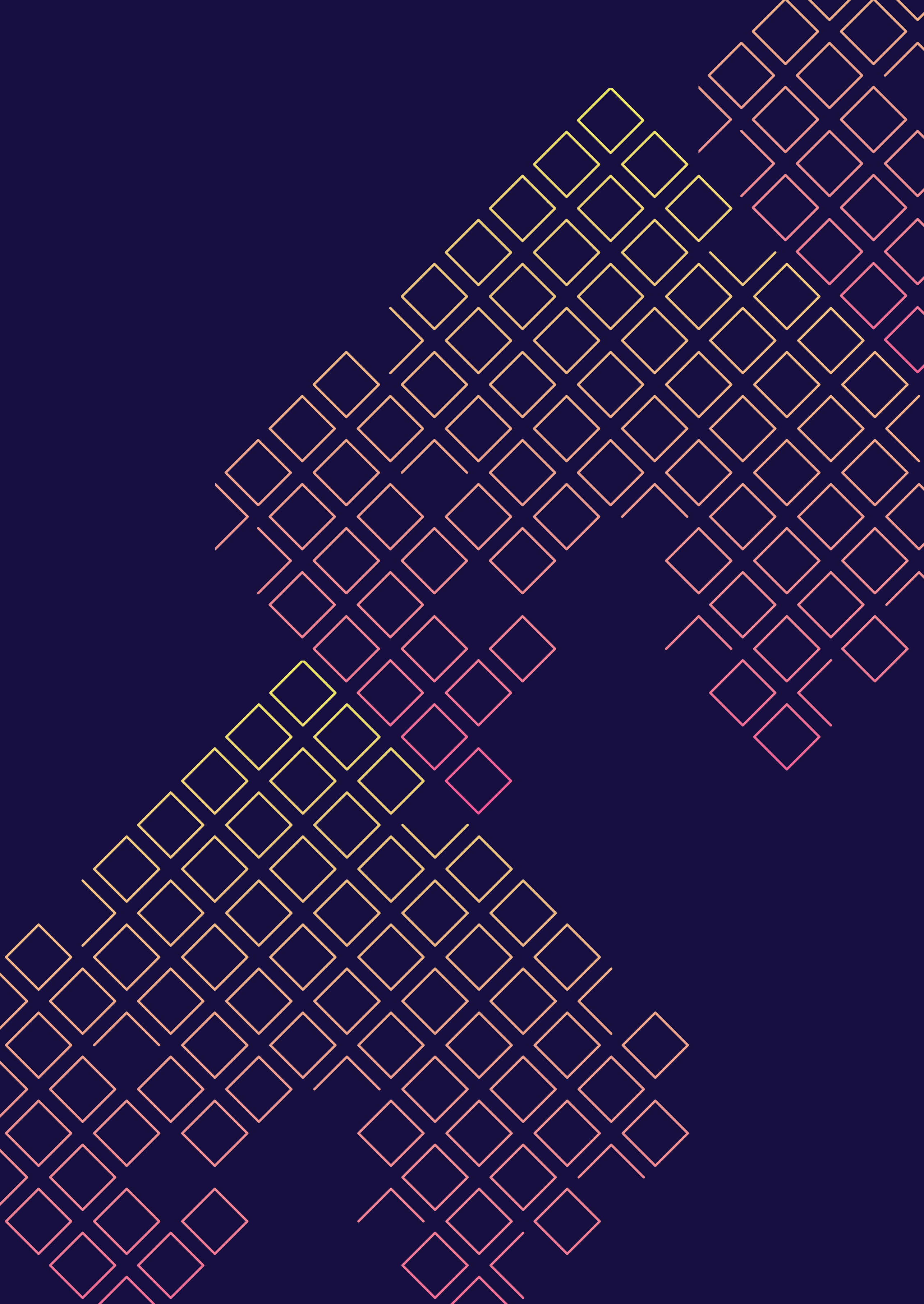


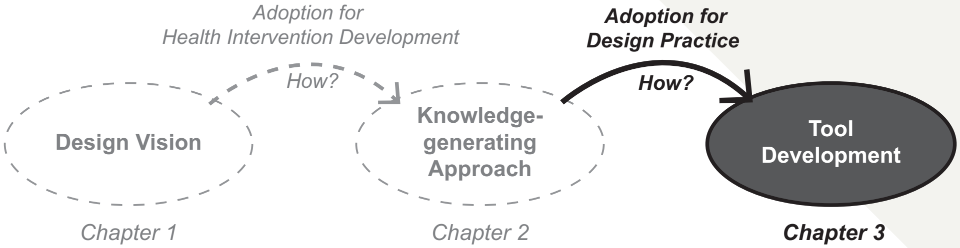
CHAPTER
3.

Advancing design approaches through data-driven techniques:

Patient community journey mapping using online stories and machine learning

This chapter is under review in a peer-reviewed design journal:
Jiwon Jung, Ki-Hun Kim, Tess Peters, Dirk Snelders, Maaike Kleinsmann. Advancing design approaches through data-driven techniques: Patient community journey mapping using online stories and machine learning

Position



My doctoral thesis consists of three levels of knowledge: a design vision, a knowledge-generating approach, and a design tool. In the previous chapter, I constructed a design vision around the transition in design activities due to the advancement of modern computing, including data technologies. I also explored an approach of generating knowledge to realise some central tenets of the vision in the domain of (public) health intervention development. **Finally, in this chapter, I develop a design tool to realise the approach that argues to use existing people's experience data at community level.**

Summary

In Chapter 3, I have developed a design tool to use existing people's experience data at community-level in developing complex healthcare interventions. The tool is called the 'Patient *Community* Journey Map'. The most common design tool for incorporating patient experiences and perspectives in healthcare design—patient journey mapping—served as the basis for this tool's development. Patient experiences provide valuable information to improve the quality of care and reduce healthcare costs. Nevertheless, the current tool, patient journey mapping, is time- and labour-intensive (based on qualitative data), which results in the inclusion of only a limited number of patient voices. The 'Patient *Community* Journey Map' offers a complementary answer to these limitations by applying natural language processing to online patient experience stories (e.g. blogs and forum posts). This allows the broad patient population's self-motivation and various moments of experience to be effectively (and cost- and labour-efficiently) included in improving care pathways, products, and services. The tool is a new data-enabled approach that eventually helps designers gain a large-scale yet qualitative and inspiring understanding of a complex context in healthcare with reduced time and cost investments.

3.1 Introduction

Design research is currently exploring collaborations with data scientists to develop new data-driven design approaches for understanding user needs and prototyping design outcomes by using large-scale data and analysing them using smart technologies such as machine learning (Cooper, 2019; Giaccardi et al., 2016; Speed & Oberlander, 2016; Verganti et al., 2020). This new development builds on an emerging challenge in design to creatively address and represent user group experience (on a community level) to inform the design processes within societal transition (Daalhuizen et al., 2019; Stolterman, 2021). Moreover, it builds on a rich tradition in design (Andreasen, 2011; Cross, 2018) in improving design research and practice through innovations in technology-driven design approaches. Healthcare is an impactful domain to explore such tech-driven design approach tackling the group experience challenges because the designers have recently started to contribute in maintaining the population wellbeing (Tsekleves & Cooper, 2017) and aim for the greatest health benefits for the society collectively.

In this article, we present a new design approach to create community-based patient journeys that are generated with the use of community-level data (i.e., a large-scale data from a community such as online patient stories from a patient social platform) and machine learning techniques. The aim of this approach is to show how collaborations with data-scientists could support designers to contribute to the societal transition from traditional care delivery models towards a value-based healthcare system centred around the patient's experience (Reader et al., 2014). The design discipline is already increasingly recognised as a valuable contributor to addressing patient-centred views in the development of new healthcare systems (Bate & Robert, 2006; Høiseth & Keitsch, 2015; Mullaney et al., 2012). Designers use the patient journey map as the premier tool for developing and communicating patient perspectives (Carayon et al., 2020; McCarthy et al., 2016). However, these traditional journey maps are criticised for not being representative as designers cannot generate the quantification of and correlations between the identified experience moments or touch-points.

The patient journey map is a visual tool that explicates the perspectives of patients on their experience of their care path (i.e., touchpoints with healthcare services, staff, and organisations). In addition, it can be used to detect barriers and undesirable scenarios that can occur in the care path (Ben-Tovim et al., 2008; Madathil et al., 2020; Trebble et al., 2010), and to identify opportunities for developing new healthcare delivery services from a patient-centric point of view (Kushniruk et al., 2020; Manchaiah et al., 2013). The current methods for patient journey mapping are, however, highly labour intensive in terms of the time required for data collection from patients and analysis. The qualitative nature of the journey mapping makes it impossible to include data from large samples, which can be problematic to represent the variety (Rodrigues et al., 2021) and preclude designers from noticing distinctive but crucial moments in the (care-path) experience.

Given the above problems, we explore a novel approach for patient journey mapping using existing databases of patient stories from online patient communities. These databases provide a source for tens of thousands of first-hand patient stories about their care path and illness experiences. The approach is explored following two procedures of text mining techniques that allow for the inclusion of data from a broader population. In Study 1, we apply supervised machine learning, based on topic classification and association rule mining (ARM), to analyse stories written by cancer patients on a peer-to-peer social platform of the Canadian Cancer Society. In Study 2, we apply unsupervised machine learning, based on topic modelling, to analyse stories from patients belonging to a British online community for head and neck cancer that can be found on the website of the Macmillan Cancer Support.

From these two studies, we learned that analysing online patient stories with machine learning techniques can lead to patient community journey maps that provide a large-scale, yet qualitative and inspiring understanding of a complex context in healthcare with reduced time and cost investments. In addition to these basic qualities of a patient journey, we also identified the frequency in which a particular experience occurred, interesting co-occurrences between experiences, and an ideation of possible new data types to be collected and provided.

Notably, our approach is the result of a close collaboration between data scientists and designers. As such, our article contributes to a current fundamental discussion of design research and methodology about how data-driven methods and smart technologies could improve the design process and its outcomes. In particular, service design highlights the need for understanding the currently under-represented plurality in co-existing perspectives, scopes, and unique differences between people, and the tension between them (Karpen, 2021). Thus, when it comes to delivering diverse stories in current service design activities, Duan et al. (2021) have stressed that it does not suffice that designers rely on a single, dominant narrative about user experiences (Duan et al., 2021). Therefore, our article aims to develop a design approach that can inspire other designers to have the mindset of understanding diversity and to adapt it to their practices, be this within or outside patient journey mapping or the healthcare domain.

In the following sections, we will first discuss the characteristics of the patient journey map, online patient stories, and machine learning. This is followed by Studies 1 and 2 that present the approach used to analyse online patient stories, based on supervised and unsupervised machine learning techniques, and to apply the analysis result to the traditional journey mappings. Finally, we will discuss and critically evaluate the use of our approach and provide our conclusion.

3.2 Characteristics of patient journey mapping, online patient stories, and machine learning in text mining

3.2.1 Patient journey mapping

A patient journey map is a specific application of customer journey mapping that visualises the sequence of all events and touchpoints (i.e. before, during, and after) that a customer experiences in interacting with a service or product (Richardson, 2010; Zomerdijk & Voss, 2010). When such journey mapping is focused on the experience of a patient during their interaction with various formal and informal healthcare services provided under healthcare settings (Carayon et al., 2020; Carayon & Wooldridge, 2020; McCarthy et al., 2016; National Academies of Sciences & Medicine, 2018), it is called a patient journey map. The patient journey map is an effective tool for including patient-centric perspectives to improve the quality of the care path by investigating and visually expressing various behavioural, social, and psychological factors that can affect the experience of patients in regard to health services (Kushniruk et al., 2020; Manchaiah et al., 2013; Wheelock et al., 2014).

In the current patient journey mapping approach, designers face a critical difficulty in expressing the complexity of the journey when representing a broader patient population in terms of interdependencies, constraints, perspectives, and the contexts of the experiences (Carayon et al., 2020; McCarthy et al., 2016; Rodrigues et al., 2021). This difficulty stems from the limitations of the current data collection and analysis methods. The conventional data collection method employed for constructing a journey map is often qualitative data collection (e.g., multi-disciplinary meetings, interviews, or ethnography) (Ben-Tovim et al., 2008; Madathil et al., 2020; Trebble et al., 2010). The labour intensiveness of qualitative data collection limits the number of patients explored to, at most, 'tens' of patients, which limits the full representation of a broader patient population. Further, qualitative thematic analysis is the conventional data analysis method used for constructing a patient journey map (Ben-Tovim et al., 2008; Madathil et al., 2020; Trebble et al., 2010). This too limits the number of patients studied because of the intensive time and procedural effort required for the analysis.

In this paper, we therefore explore a novel approach in two procedures that can add value to patient journey mapping by innovating data collection methods using existing online patient stories and by the use of machine learning in text mining as a data analysis method.

3.2.2 Online patient stories

Online patient stories are a valuable, largely available, and relatively assessable source that reflect the experiences of patients regarding their care paths through self-narrations about their daily experiences of living with their illness and undergoing treatment services (e.g., experience, emotion, psychological suffering, and the need for support). These online patient stories are an outcome of Web 2.0, where large groups (i.e. online communities (Preece & Maloney-Krichmar, 2003) with common interests share their experiences through intense interactions (Pramanik et al., 2020). The patient stories are written with the intention of asking questions of peers and care providers, as well as for *merely* sharing experiences among peers (Pramanik et al., 2020). These stories provide a unique and rich database of patient experiences, which often also include both satisfaction and challenges with healthcare services and teams, or discussion regarding other determinants of health such as social, cultural, and behavioural factors (Chakraborty & Church, 2021; Kilaru et al., 2016; Tran & Lee, 2017), that are not captured in a hospital database (Botto et al., 2019).

The advantage of machine learning technology is that it permits analysis scalability given the vast amount of data that can be collected from social media, chat logs, online forums, and blogs (after appropriate privacy protection and permission). Although employing machine learning to patient story analysis still requires qualitative analysis work, such as building initial journeys and labelling topics, it requires less effort than conventional journey mapping given the same amount of patient experience to be analysed. This means that massive data from online stories can be analysed with a reasonable effort.

Online patient stories for patient journey mapping exhibit three characteristics that assist us in overcoming the difficulty of representing a broad patient population (plurality):

(1) A continuously growing, large-scale dataset: Online patient stories exist on a large scale (e.g., tens of thousands of stories on social platforms), which adds quantity to the journey maps. Further, new and existing users continuously generate new additional content.

(2) Patient-driven qualitative experience data: Online patient stories are driven and written from the patient's motivation to share their experiences with others, which increases the reliability of the data because the patients on social platforms can describe their experience more spontaneously, sincerely, and extensively. This overcomes the risk of formal studies, for example, interviews, that ask specific questions and are prone to the giving of socially desirable answers (Beusterien et al., 2012; Verhoef et al., 2014).

(3) Low-cost data collection method: Using online stories is a relatively low-cost (time- and effort-efficient) method for large-scale data collection (Dellarocas, 2003); user data are collected without the time and effort spent to set up the studies (e.g. patient recruitment and time to collect data). With adequate retrieving technologies and paying attention to ethical considerations, thousands of in-depth experiences of patients can be collected in a considerably shorter amount of time compared to that when employing conventional methods.

The use of online patient stories continues, however, to have several limitations that need to be focused on. These include that the patients analysed still do not represent the entire patient population (Huppertz & Otto, 2018; Klein et al., 2018), there is still the likelihood of selection bias arising from biased and one-sided content and self-selection bias is possible in that patients' stories may be influenced by previous contents (Li & Hitt, 2008). Further, online stories may lack contextual cues such as socio-economic background and emotional or situational modes (Dellarocas, 2003; Hu et al., 2008; McCaughey et al., 2014), unless users reveal such information online. These selection biases, self-selection biases, and lack of contextual cues can, however, be more extreme in a traditional setting where patient access is limited. Therefore, we use this analysis results only as inspirational material, not as evidence of patient behaviour; to explore the behavioural aspects, with the least bias, we need to supplement patients' online story analysis results with other studies that have adequate patient sampling methods such as systematic and stratified methods. In summary, exploring ways of using online patient stories for patient journey mapping is important to advancing the use of patient experience mapping. Table 3-1 summarises the advantages and limitations of online patient story use.

Table 3-1. Advantages and limitations of using online patient stories as a user data collection method for patient journey mapping

Advantages
Continuously growing large-scale dataset
Patient-driven qualitative experience data
Low-cost data collection method
Limitations
Selection bias
Self-selection bias
Lacking contextual cues

3.2.3 Machine learning in text mining

Machine learning is a form of artificial intelligence (AI) that mimics how humans learn in broad scalability (Jordan & Mitchell, 2015; Verganti et al., 2020). The algorithms used in machine learning detect or predict patterns within large amounts of data, thereby unveiling hidden insights automatically (Murphy, 2012). In this study, the online patient stories used comprise sentences in written without any predefined data format. The extraction of meaningful patterns, through machine learning algorithms, from such unstructured text is called text mining (Hotho et al., 2005). We explore machine learning for text mining to add novel perspectives to patient journey mapping by accessing larger-scale opinion and contexts of patients. This approach allows designers and researchers to utilise the value of online patient stories efficiently (McRoy et al., 2018; Murphy, 2012).

There are two types of machine learning approaches: supervised and unsupervised learning (Murphy, 2012). Supervised learning predicts patterns within the data using the labelled (training) datasets created by humans (e.g., designers). In text-mining, designers and researchers use supervised learning to build the classifier that learns how meaning is to be established (i.e., how designers labelled and categorised dataset). The learned classifier classifies data using the most probable label from the pre-defined labels created by the designers. At this stage, the supervised machine learning algorithm (i.e., the classifier) also enriches and quantifies the meaning (by generating patterns). Thus, the good performance of supervised learning requires a training dataset with a large number of and high quality of labelled text and creating such a training dataset (e.g., by manually labelling text documents) requires a significant amount of labour.

Unsupervised learning, on the other hand, discovers clusters or patterns within unlabelled datasets. Unsupervised learning does not provide an explicit explanatory description of the pattern's meaning. In text mining, designers and researchers use unsupervised machine learning to build an algorithmic model that allocates the unlabelled text dataset to the required number of different clusters. To make the clustering meaningful, designers and researchers need to uncover and interpret the potential reasons for the resultant clustering. Consequently, designers and researchers who do not have sufficient knowledge about the context of the data analysed may find it challenging to contextualise the patterns (i.e., interpret the meaning) generated from unsupervised machine learning.

In this article, we explore both supervised and unsupervised machine learning techniques to study how patterns arising from such techniques support the development of patient journey maps. Table 3-2 illustrates the different procedural approaches of supervised and unsupervised learning for patient journey mapping.

Table 3-2. Different procedures taken by designers and researchers in supervised and unsupervised machine learning in text mining for patient community journey mapping

Machine learning types	Initial step	Follow-up step
Supervised	Designers and researchers label the dataset using a part of the given dataset. This leads to the first and rough identification of patient's experience topics for patient journey mapping.	Machine learning (classifier technique) learns how the designers have labelled the dataset. After learning, it assigns other unlabelled datasets to one of the most probable labels. Machine learning techniques (another technique) can further quantify and reveal correlations in the patients' experience topics.
Unsupervised	Machine learning allocates the entire dataset (patient experiences) into an adequate number of clusters that do not have a specific contextual label.	Designers and researchers interpret, contextualise, and label each cluster of experience topics. It leads to another set of information lists identified, related to patient experience to be added on patient journey mapping.

3.3 Studies for approaching patient community journey mapping through data-driven techniques

We present two studies to explain the potential value of using online patient stories with machine learning to create patient community journey maps: Study 1 creates a general cancer journey based on supervised machine learning, and Study 2 creates a head and neck cancer journey based on unsupervised machine learning.

Each study comprised three steps: preparation, analysis, and creation of additional patient experience information on the patient journey map; these three steps are summarised in Figure 3-1.

We also considered the ethical and privacy concerns of using online patient stories for both studies. Although data on social platforms are considered publicly available data (Moreno et al., 2013), we believe that designers and researchers should inform platform developers or the authors of the stories about the research. We sought guidance from the university's human research ethics committee in this regard so that ethical and privacy concerns were met and the study design was subsequently approved by the University Human Research Ethics Committee. Based on the committee's advice, we removed all direct (e.g., name, address, zip code, telephone number, voice, and picture) and indirect identifiers (e.g., institutional affiliations, occupation, and geographic region) before analysing the data. Further, we informed the platform developers (via email) about the research.

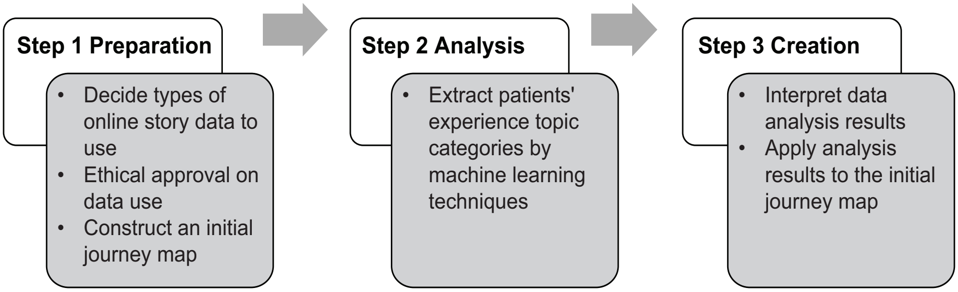


Figure 3-1. Procedure for analysing and applying patient experiences to patient community journey maps (as used in Studies 1 and 2)

3.3.1 Study 1: Supervised machine learning to develop a patient community journey mapping

Step 1 'Preparation': To decide online patient story data and construct an initial journey map

The first step required determining and preparing the dataset for the study. To do so, we searched for an online platform to collect data that matched the requirements of our study. We identified whether the platform had stories written by the target audience of the study (in our case, cancer patients), had a large number (tens of thousands) of stories for effective and useful machine learning analysis, and which were written in English to be understandable by all the researchers in determining the types of online patient stories analysed. We decided to use patient stories from the Canadian Cancer Society (https://cancerconnection.ca/) social platform. It has a 'Forum' section, which comprises 11 sub-sections, wherein patients discuss their care-path experiences (see Appendix 3-1). In each sub-section, there are threads that include first posts and replies to the first posts (see Appendix 3-2). We did not distinguish between the two and considered each as independent individual stories. Thus, each post is a story unit that was included in our study.

A designer (the third author) and five master design students constructed the initial patient journey map based on a thematic analysis of 137 stratified, randomly sampled posts from all 11 sub-sections. They applied a sentence-by-sentence analysis approach (separating posts based on punctuation) to inspect the types of experience topics mentioned in each post. Since each post contained multiple sentences with different topics, it was sufficient to analyse these posts on a sentence level for identifying all patient story topic categories within each post. Four main phases within the cancer patient journey were distilled by this analysis: '*receiving a diagnosis*', '*undergoing tests and making a decision for treatment*', '*undergoing treatment and suffering side effects*', and '*living life after cancer*' and several experience topic categories were identified (the white square cards within each phase, as indicated in Figure 3-2).

Step 2 'Analysis': To extract the experience topic categories in online patient stories and apply supervised machine learning to find patterns between the experience topic categories

The second step extracted the topic categories of the care path experiences of the patients from the entire dataset of online patient stories. We detected valuable patterns between experience topic categories by applying a supervised machine-learning algorithm in text mining. This step included two sub-steps, as indicated in Figure 3-3: Step 2a-supervised, which manually extracted the experience topic categories from a portion of the entire dataset to be used as the training dataset for the algorithm, and Step 2b-supervised, which ran the machine learning algorithm to quantify and find the relationships between experience topic categories within the entire dataset.

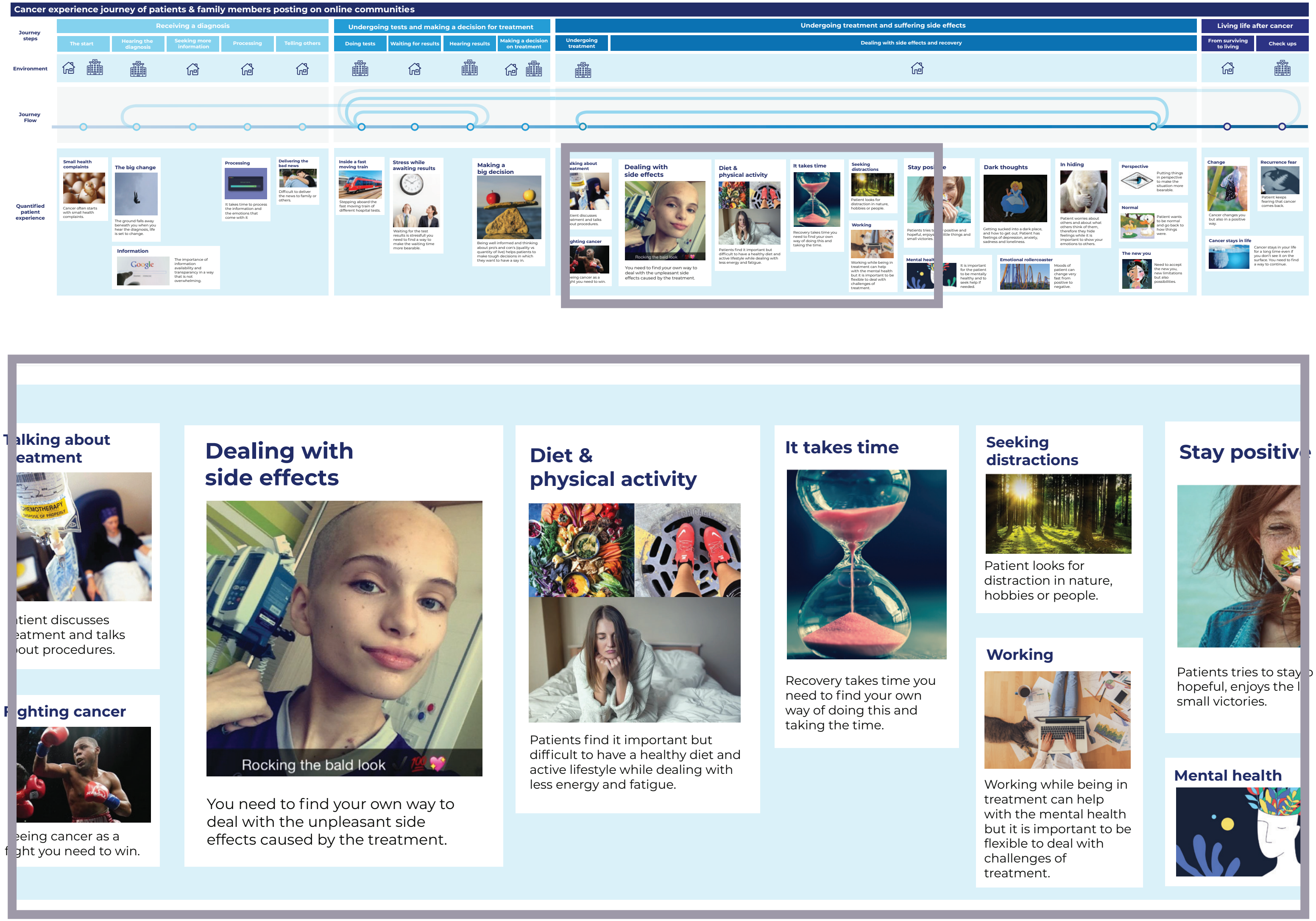
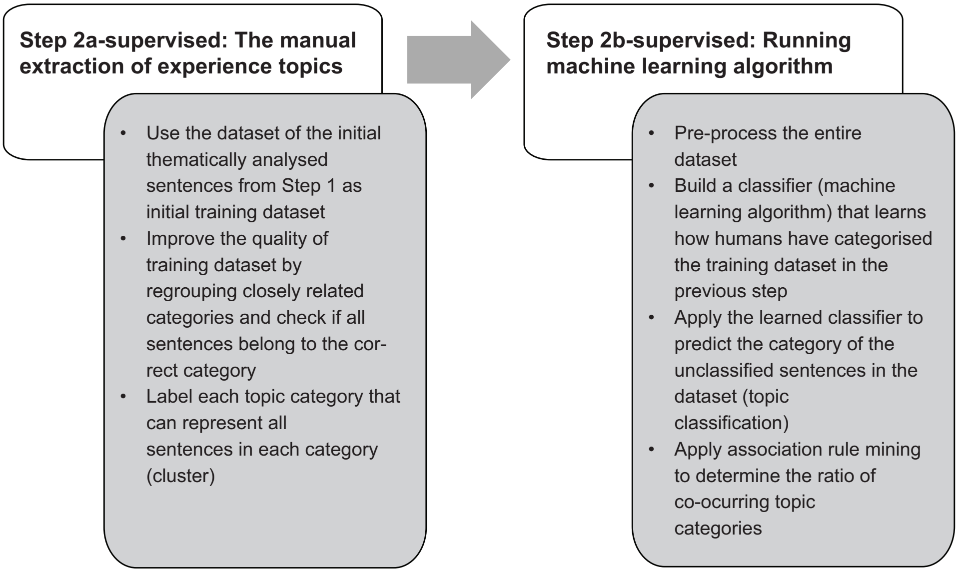


Figure 3-2. A part of initial cancer patient journey map (Retrieved and modified from (Peters,2021))



Step 2a-supervised: The manual extraction of experience topics

- Use the dataset of the initial thematically analysed sentences from Step 1 as initial training dataset
- Improve the quality of training dataset by regrouping closely related categories and check if all sentences belong to the correct category
- Label each topic category that can represent all sentences in each category (cluster)

Step 2b-supervised: Running machine learning algorithm

- Pre-process the entire dataset
- Build a classifier (machine learning algorithm) that learns how humans have categorised the training dataset in the previous step
- Apply the learned classifier to predict the category of the unclassified sentences in the dataset (topic classification)
- Apply association rule mining to determine the ratio of co-ocurring topic categories

Figure 3-3. Procedure for Step 2 (Analysis) with supervised machine learning techniques (topic classification and association rule mining)

Given the topic of our study and the efficiency of building high quality learning datasets within limited time, we focused, in this step, on one of the four identified phases of the initial patient journey map elicited in Step 1. We selected the stories within ‘undergoing treatment and suffering side effects’ which comprised a total of 14,391 posts (with 112,758 sentences). We applied a sentence-by-sentence analysis approach (separating posts based on punctuation) to inspect the types of experience topic categories written by the patients. Each post contained multiple sentences with different story topics and the analysis of these stories on a sentence level was sufficient to identify all topic categories within each post.

A data scientist in our team applied two machine-learning techniques to extract valuable patterns from the entire dataset: topic classification and topic association. Topic classification assigns the entire dataset into specific topic categories by learning classification rules based on pre-labelled examples that were previously created as training data. It is because our project was particularly focused on head-and-neck cancer patients. The topic association was done by applying association rule mining (ARM) which finds a co-occurring relationship between each experience topic category. It is an ‘if-then’ rule comprising an antecedent and a consequent. It provides the value of the ratio of users mentioning a set of co-occurring topics compared to all users.

To apply these two techniques, we carried out the following steps: the data scientist used the set of sentences belonging to the 'undergoing treatment and suffering side effects' phase (a total of 492 sentences) from Step 1 to manually extract the experience topic categories from a part of the given dataset (as step 2a-supervised). The initial manual analysis generated fifteen topic categories. The percent of sentences classified to the correct topic category, after running the machine learning algorithm (the first three steps of 2b) on the learning dataset (so called cross-validation) was, however, low. To increase the quality of the training dataset, the designers in our team modified the dataset by re-grouping topic categories if they were closely related and difficult to distinguish. Further, the designers closely inspected whether all classified sentences belonged to the correct category. To this end, we, designers and a data scientist, conducted five cycles of cross-validation and improvements to the learning dataset, which resulted in twelve topic categories. The labels of each topic category obtained from categorising (thematic analysis) sentences and the number of labelled sentences for each theme are presented in Table 3-3. A total of 492 labelled sentences were used as the training dataset that the algorithm uses to learn how we assigned each sentence to one of the twelve topic categories.

Table 3-3. Number of sentences labelled to each topic.

Category	Label of each topic category	Number of labelled sentences
0	Being/attempting to be positive in the cancer journey	20 (4%)
1	Dealing with overwhelming fatigue in daily life	28 (6%)
2	Performing appropriate physical exercise for better recovery	40 (8%)
3	Experiencing eating/drinking issues and finding (diet-related) solutions	64 (13%)
4	Experiencing negative feelings (depression, anxiety, and loneliness) in the cancer journey	30 (6%)
5	Experiencing physical side effects from the treatment and finding ways to counter-act these	97 (20%)
6	Finding out how to combine work with treatment recovery	16 (3%)
7	Getting support from family, friends, and peers but also dealing with misunderstanding and estrangement	32 (7%)
8	Making a conscious decision for personal care/health by comparing quality and quantity of life	32 (7%)
9	Sharing cancer news with others using a medium that suits the patient	22 (4%)
10	Undergoing treatment procedures	78 (16%)
11	Wanting to have an understanding relationship with the medical team (effective communication, information, and respect)	33 (7%)
	Total	492 (100%)

Step 2b-supervised required four steps in running the machine learning algorithm to find the valuable quantification (frequency) of and relations (co-occurrence) between experience topic categories within the entire dataset. In the first step, the data scientist pre-processed the sentences of the training dataset by eliminating stop words (e.g., 'you', 'but', and 'in'), changing all terms (i.e., words) to lowercase (e.g., from 'Cancer' to 'cancer'), and lemmatising all terms (e.g., from 'pills' to 'pill'). Further, he applied customised rules to delete sentences in which words or phrases were common in the sentences but non-contextual.

In the second step, the data scientist built a classifier by applying the following machine learning methods: term frequency-inverse document frequency (TF-IDF) vector (Salton & Buckley, 1988), non-negative matrix factorisation (NMF) (Févotte & Idier, 2011), random forest (RF) (Breiman, 2001), and grid search approaches (Pedregosa et al., 2011). The classifier learns how designers categorised the sentences into certain clusters, and then categorises unlabelled sentences to the most probable category (cluster) created by the designers. Specifically, each pre-processed sentence of the training dataset was first transformed into a TF-IDF vector, which is a set of numerical weights indicating how important a particular word is to each sentence. A high TF-IDF value is given to a term in a sentence when the term frequently appears in the sentence but occasionally appears in other sentences. The training dataset is assigned its TF-IDF vector and its topic category (one of the twelve identified previously). The classifier then learns the patterns for classifying each sentence into a particular topic category by applying NMF and RF. The classifier uses NMF to transform the TF-IDF vector into a meaningful input of RF. The grid search approach was applied to optimise the classifier performance and tune the hyperparameters.

In the third step, the learned classifier (machine learning algorithm) is applied to the entire dataset (112,758 sentences) which were pre-processed and each sentence was assigned to the most relevant topic category among the twelve topic categories. Table 3-4 summarises the number of sentences assigned to each category in the 'number of assigned sentences.' The number and percent of posts that belong to each category were counted, and are presented in the last column of Table 3-4, to observe how often the posts (not sentences) claim each experience topic category. Thus, the designers could obtain a numerical weighted value (frequency) for the patient's experience and identify how many posts include the sentence belonging to one of the twelve topic categories identified by the designers. As an example, 3356 posts (23 percent of all posts) of patients talk about 'being and attempting to be positive' in the treatment and side effect phase of their cancer journey.

Table 3-4. Number and percent of stories raised the experience topic

Cate-gory	Label of each topic category	Number of assigned sentences	Number of stories (% of total stories)
0	Being/ attempting to be positive in the cancer journey	4207	3356 (23%)
1	Dealing with overwhelming fatigue in daily life	8261	5154 (36%)
2	Performing appropriate physical exercise for better recovery	3670	3356 (23%)
3	Experiencing eating/drinking issues and finding (diet-related) solutions	10786	6286 (44%)
4	Experiencing negative feelings (depression, anxiety, and loneliness) in the cancer journey	5718	4044 (28%)
5	Experiencing physical side effects from treatment and finding ways to counter-act these	23081	10282 (71%)
6	Finding out how to combine work with treatment recovery	2824	1990 (14%)
7	Getting support from family, friends, and peers but also dealing with misunderstanding and estrangement	10746	6320 (44%)
8	Making a conscious decision for personal care/health by comparing quality and quantity of life	7324	4877 (34%)
9	Sharing cancer news with others using a medium that suits the patient	7215	4848 (34%)
10	Undergoing treatment procedures	21945	9454 (66%)
11	Wanting to have an understanding relationship with the medical team (effective communication, information, and respect)	6981	4712 (33%)

In the final, fourth, step, the data scientist applied ARM to the entire dataset already classified into each corresponding topic category in the previous steps. The ratio of the co-occurrence relationship between each topic category was determined. The ARM identifies the confidence values which indicate how often the identified rule—if a set of topic categories (antecedent) is discussed in a patient, another set of categories (consequence) is also mentioned by the same patient—is valid for all patients (Agrawal et al., 1993). This resulted in sixty co-occurring relationships, which are partially presented in Table 3-5. As an example, rule 0 shows that if more than one sentence of a patient talks about 'being and attempting to be positive in the cancer journey', there is a 79% chance that more than one sentence of the patient also talks about 'experiencing physical side effects from treatment and finding ways to counteract these.'

Table 3-5. Some results of association rule mining (extended version is in Appendix 3-3)

Rule	Antecedents	Consequents	Confidence
0	Being/ attempting to be positive in the cancer journey	Experiencing physical side effects from treatment and finding ways to counteract these	0.79
1	Experiencing physical side effects from treatment and finding ways to counteract these	Being/ attempting to be positive in the cancer journey	0.26
2	Undergoing treatment procedures	Being/ attempting to be positive in the cancer journey	0.26
3	Being/ attempting to be positive in the cancer journey	Undergoing treatment procedures	0.72
4	Experiencing eating/drinking issues and finding (diet-related) solutions	Dealing with overwhelming fatigue in daily life	0.44
…	…	…	…
55	Making a conscious decision for personal care/health by comparing quality and quantity of life	Undergoing treatment procedures	0.74
56	Sharing cancer news with others using a medium that suits the patient	Undergoing treatment procedures	0.70
57	Undergoing treatment procedures	Sharing cancer news with others using a medium that suits the patient	0.40
58	Undergoing treatment procedures	Wanting to have an understanding relationship with the medical team (effective communication, information, and respect)	0.37
59	Wanting to have an understanding relationship with the medical team (effective communication, information, and respect)	Undergoing treatment procedures	0.74

Step 3 'Creation': Applying the analysis outcome to the initial patient journey map

The third step applied the findings from the previous steps to the initial patient journey map. The online patient stories and supervised machine learning of topic classification and ARM created two outcomes: quantification (frequency) of patients' experience topics and interesting relationships (co-occurrence) between these topics. As already mentioned, the analysed data were only for the '*undergoing treatment and suffering side effects*' phase and the designers therefore explicitly applied the result to this phase. Figure 3-4 shows an overview of the final patient journey map (for a detailed interactive online version, https://ts26m3.axshare.com). The final patient community journey map comprises twelve experience topic cards for the '*undergoing treatment and suffering side effects*' phase. There are three layers, as shown in Figures 3-4, 3-5, and 3-6, respectively. The first layer (Figure 3-4) shows the label of the experience topic with the relevant image. In this layer, one can already sense the quantification of each experience through the size of the card (proportional to the number of stories mentioned in the topic) and the darkness of colour (with darker indicating a higher number of stories mentioned). Figure 3-5 presents the second layer in which a numeric quantification of each experience topic is provided (percent of the topic mentioned out of the entire stories, found from the topic classification machine learning algorithm) together with some representative quotes (which the first and third authors selected from the sentences in the training dataset). Figure 3-6 shows the third layer, which displays interesting relationships between the experience topics found through the ARM machine learning algorithm. The card displays the link with other cards and the numerical value (%) of the relatedness. The thickness of the linkage-line between the antecedent and consequent cards (with thicker indicating higher relevance) and the numerical value in the circle (on the consequent cards) indicates relatedness.

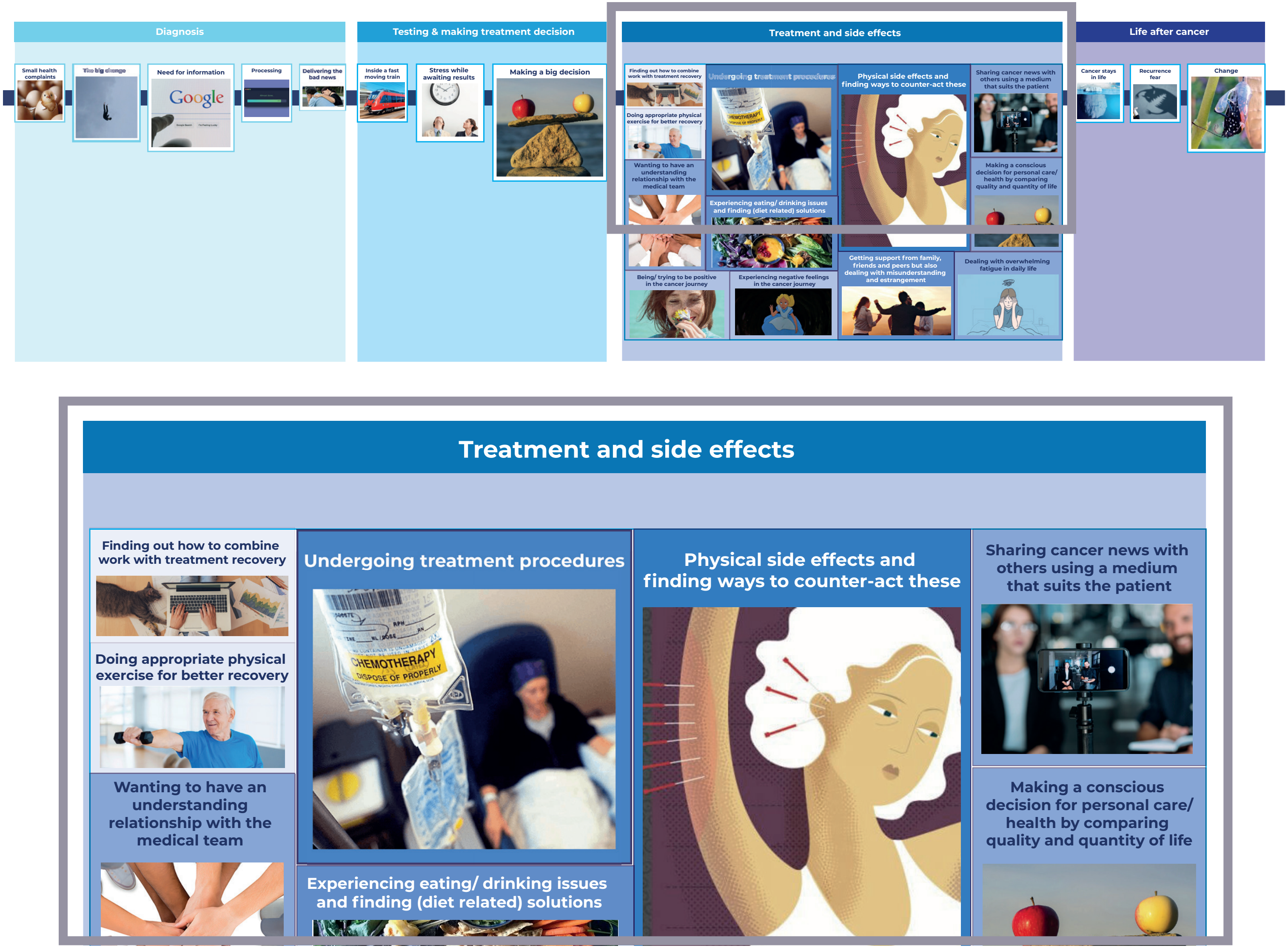
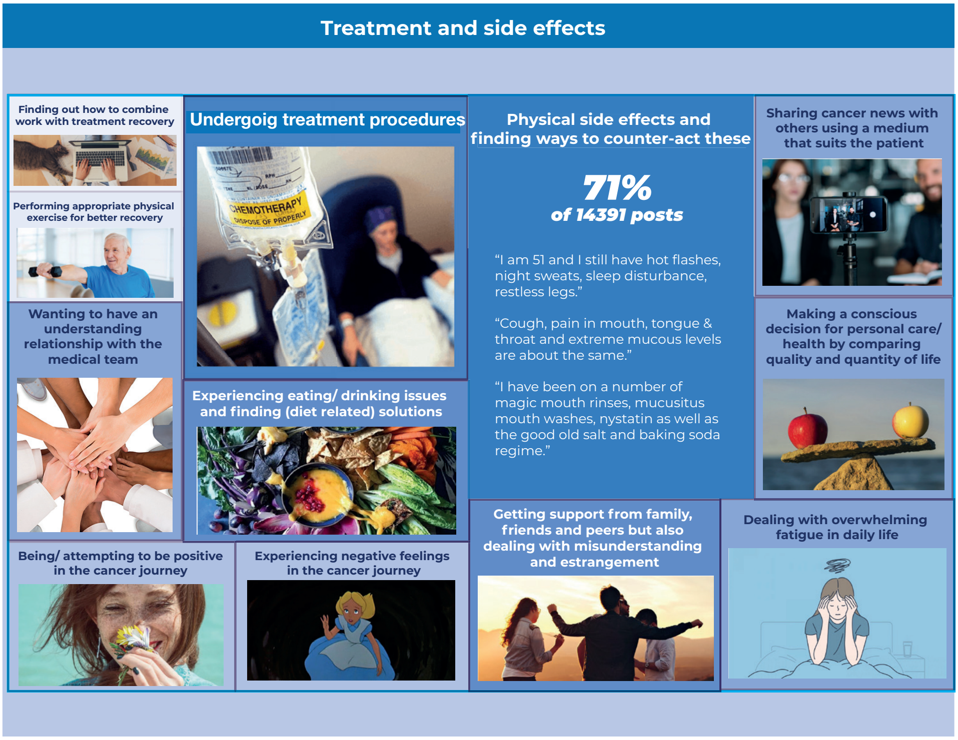


Figure 3-4. A part of an overview of cancer patient community journey map including supervised machine learning analysis result (Retrieved and modified from(Peters, 2021))



Treatment and side effects

Finding out how to combine work with treatment recovery

Performing appropriate physical exercise for better recovery

Wanting to have an understanding relationship with the medical team

Undergoig treatment procedures

Experiencing eating/ drinking issues and finding (diet related) solutions

Physical side effects and finding ways to counter-act these

71%
of 14391 posts

"I am 51 and I still have hot flashes, night sweats, sleep disturbance, restless legs."

"Cough, pain in mouth, tongue & throat and extreme mucous levels are about the same."

"I have been on a number of magic mouth rinses, mucusitus mouth washes, nystatin as well as the good old salt and baking soda regime."

Sharing cancer news with others using a medium that suits the patient

Making a conscious decision for personal care/ health by comparing quality and quantity of life

Being/ attempting to be positive in the cancer journey

Experiencing negative feelings in the cancer journey

Getting support from family, friends and peers but also dealing with misunderstanding and estrangement

Dealing with overwhelming fatigue in daily life

Figure 3-5. Second layer of one experience topic card with percent of the topic mentioned out of the entire stories (result of topic classification) and quotes (Retrieved from a master student thesis (Peters, 2021))

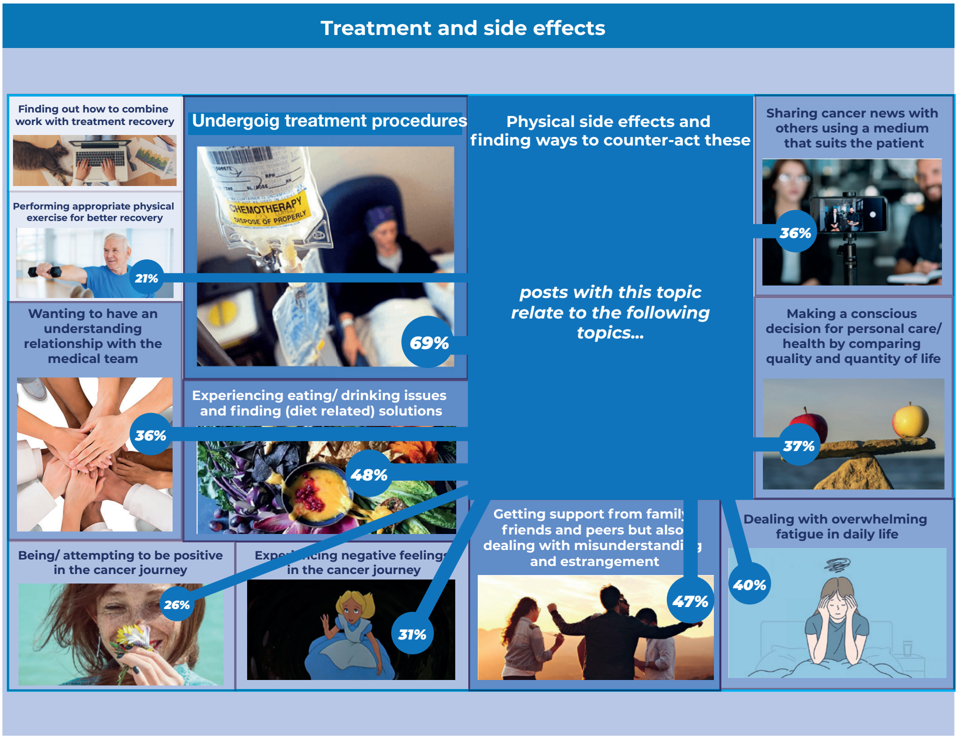


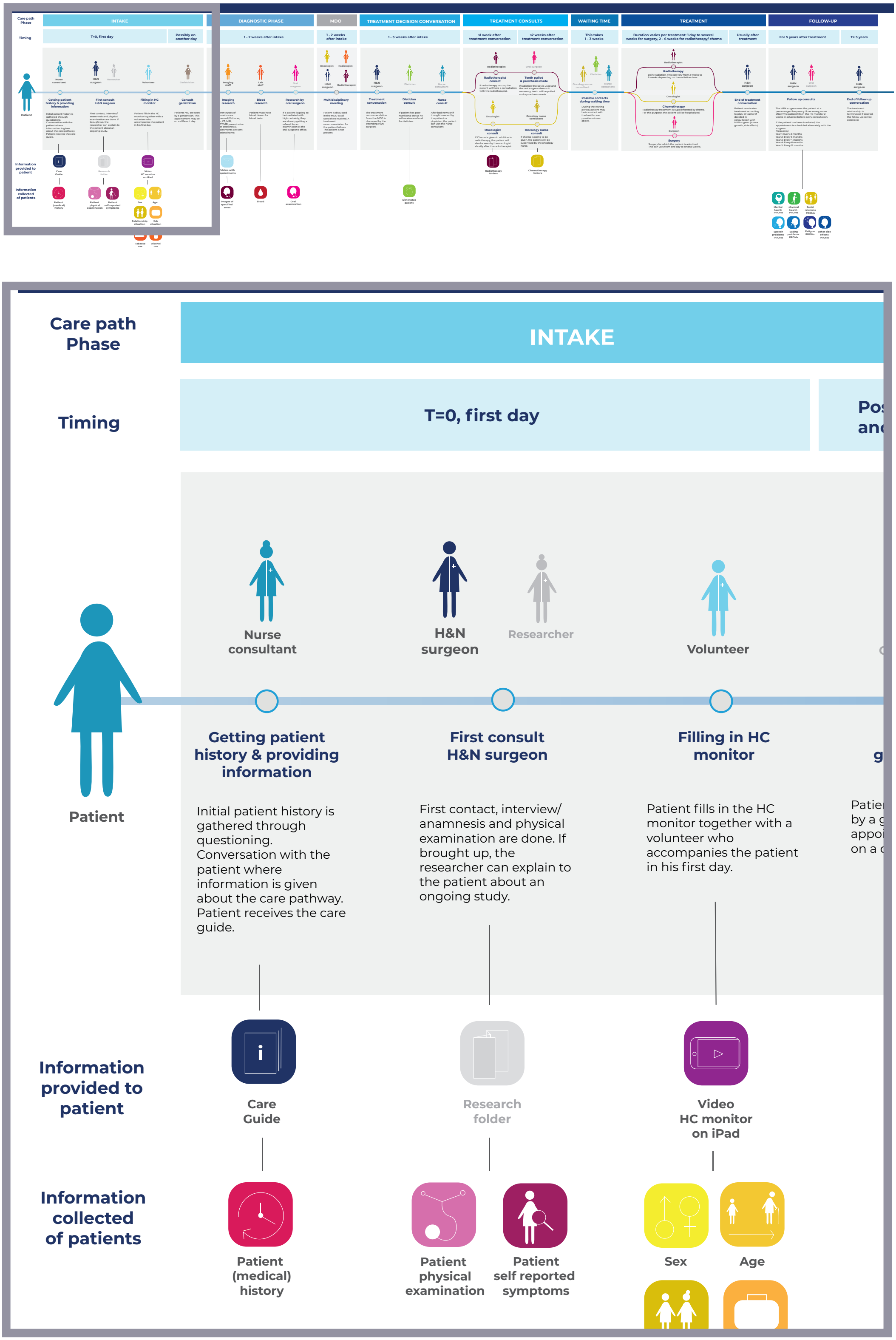
Figure 3-6. Third layer of one experience topic card showing the co-occurrence relation between the experience topics (result of association rule mining) (Retrieved from a master student thesis (Peters, 2021))

3.3.2 Study 2: Unsupervised machine learning to develop a patient community journey mapping

Step 1 ‘Preparation’: To decide online patient story data and to construct an initial journey map.

The first step in Study 2 was the selection of the dataset to explore and develop an initial journey map based on the three criteria explained in Study 1. We decided to use the head-and-neck cancer patient group forum in the Macmillan Cancer Support Online Community (https://community.macmillan.org.uk/cancer_types/head-neck-cancer-forum). We collected both first posts and replies as individual stories (giving a total of 30,037 posts; an example is given in Appendix 3-4). We removed all direct and indirect identifiers to adhere to the confidentiality requirements.

To construct the initial patient journey map, we used the head-and-neck cancer patient care path, that our project partner, a medical doctor from a Dutch academic hospital, shared in the form of a flowchart. The flowchart, along with the *phases of the care path,* included the types of *stakeholders* involved and the *types of information* provided to and collected from the patient. Further, we referred to the information booklet given to patients for their first cancer diagnosis visit. The third author took all the information from the flowchart and the booklet and visualised it as a patient journey map, as indicated in Figure 3-7. The top part of the journey map shows types of care path phases, activities, and stakeholders involved. In the bottom part, the map shows the information and data currently provided to and collected from patients in each care path phase.



Initial patient history is gathered through questioning. Conversation with the patient where information is given about the care pathway. Patient receives the care guide.

First contact, interview/ anamnesis and physical examination are done. If brought up, the researcher can explain to the patient about an ongoing study.

Patient fills in the HC monitor together with a volunteer who accompanies the patient in his first day.

Patie
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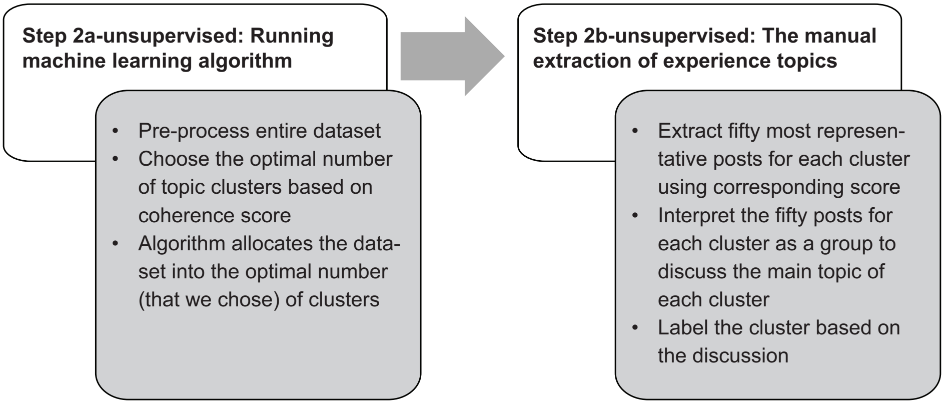
Figure 3-7. A part of visualised version of initial patient journey map (Retrieved and modified from (Peters, 2021))

Step 2 'Analysis': Extraction of experience topics from patient stories using an unsupervised machine learning algorithm



Step 2a-unsupervised: Running machine learning algorithm

- Pre-process entire dataset
- Choose the optimal number of topic clusters based on coherence score
- Algorithm allocates the dataset into the optimal number (that we chose) of clusters

Step 2b-unsupervised: The manual extraction of experience topics

- Extract fifty most representative posts for each cluster using corresponding score
- Interpret the fifty posts for each cluster as a group to discuss the main topic of each cluster
- Label the cluster based on the discussion

Figure 3-8. Procedure of conducting Step 2 (analysis) with unsupervised machine learning (topic modelling)

The second step used an unsupervised learning algorithm to extract topics of the online patient stories collected from the first step. This step included two different phases as shown in Figure 3-8. Step 2a-unsupervised involved applying the machine learning algorithm to the dataset to cluster the stories in the dataset according to topic similarity. Step 2b-unsupervised involved extracting topics manually from the discovered clusters. The data scientist in our team chose latent Dirichlet allocation (LDA) (Blei et al., 2003) to apply unsupervised machine learning. Three phases were required to extract the topic clusters in the dataset using LDA (Step 2a-unsupervised).

In the first phase, the dataset was pre-processed to enhance LDA performance. This was done to remove all stop words, digits, and hyperlinks (via algorithm), make all words lowercase and lemmatised (via algorithm), and delete the words or phrases common in the posts but non-contextual (by manually scanning the stories).

In the second phase, the LDA was applied to the pre-processed dataset. The LDA automatically discovers sets of keywords that appear frequently in certain documents, but not in others (Blei et al., 2003). Given that a sentence consists of too few words, a post-by-post analysis (instead of sentence by sentence) was performed to extract good keyword combinations.

In the third step, the optimal number of topic clusters based on the coherence score (Newman et al., 2010) was selected; the higher the score, the better was the quality of the extracted topic cluster. Accordingly, we chose twenty-five as the optimal cluster number for the topics used (See Appendix 3-5). The twenty-five extracted topic clusters are listed in Table 3-6. Designers assessed the quality of cluster numbers by checking if the clusters are distinctive and informative enough for designers to understand the patient experience.

For each post, the LDA model estimates probabilities that the post corresponds to each topic cluster and assigns each post to a topic cluster with the highest probability. The 'number of posts' and 'percent' columns of Table 3-6 present the topics' distribution across the stories. Further, LDA shows ten keywords that summarise the main content of the online patient stories cluster that differentiates it from the others. The 'Ten representative keywords' column of Table 3-6 shows the most representative keywords for each cluster.

Table 3-6. Topic modelling results

Cluster	Ten representative keywords*	No. of posts	Percent
0	regard, suggest, kind, story, carcinoma, book, dissection_reconstruction, flap_postoperative, holiday, comment	1388	5%
1	soup, soft, calorie, dietician, meal, ensure, add, diet, milk, cream	1790	6%
2	information, forum, party, join, link, line, number, member, thread, medical	1494	5%
3	symptom, specialist, nose, test, worried, refer, ent, blood, voice, concern	1543	5%
4	stuff, slowly, tip, stick, lack, improvement, appetite, eating, hot, slow	897	3%
5	pay, job, local, health, lucky, nhs, form, medical, system, benefit	1136	4%
6	spread, lymph_node, primary, mri, left, sign, large, cell, gland, lung	1518	5%
7	wife, man, fight, daughter, son, child, strength, age, heart, young	1554	5%
8	bed, eye, minute, sit, spend, watch, close, drive, listen, move	1186	4%
9	rest, half, tired, walk, step, fatigue, road, ready, plenty, sense	1192	4%
10	type, option, decide, explain, outcome, decision, cure, chance, info, discuss	1071	4%
11	word, metastatic_scc, run, fact, learn, load, pass, describe, wake, bother	842	3%
12	relief, morphine, drug, painkiller, painful, hurt, prescribe, tablet, dose, liquid	1168	4%
13	skin, exercise, heal, scar, speech, flap, arm, muscle, shoulder, swell	1476	5%
14	return, dani_squamous, continue, update, progress, hpv, fingers_crosse, pleased, quick, therapy	1202	4%
15	advise, chemotherapy, cisplatin, loss, complete, difference, ear, due, hair, short	815	3%
16	write, message, phone, chat, forget, contact, add, profile, ring, detail	1193	4%
17	saliva, mucus, ulcer, buy, burn, cough, mouthwash, rinse, spray, product	1705	6%
18	affect, afraid, floor, concern, extremely, main, person, procedure, reaction, depend	901	3%
19	realise, nice, amazing, light, wonderful, lovely, cold, share, lucky, wear	949	3%
20	sick, rig, stomach, med, nausea, admit, ensure, awful, nutrition, fluid	1135	4%
21	yesterday, meet, touch, honest, date, guy, lol, bring, totally, lovely	1072	4%
22	dentist, low, top, jaw, dental, bone, mine, oral, leg, bite	985	3%

Table 3-6 Continued.

Cluster	Ten representative keywords*	No. of posts	Percent
23	partner, infection, feeling, turn, fear, scary, situation, scare, stress, horrible	1071	4%
24	quickly, guess, move, imagine, ahead, grateful, process, prepare, begin, shock	754	3%
Total		30037	100%

*The keyword position indicates its representativeness for the topic (the first keyword is the most representative).

Step 3 'Creation': Applying the analysis result to the initial journey map by interpreting the cluster topics

Given that the online stories are patients' questions and discussions about their care-path experience, the designers interpreted the topic labels as information that the patients have doubts about or need guidance on during their care path. As an example, Topic group 3 ('symptom, specialist, nose, test, worried, refer, ent [ENT: ear, neck, and throat], blood, voice, concern') was labelled as 'their [patients'] worries related to potential cancer symptoms and need for guidance on these uncertainties'. Designers interpreted this label as the patients need for the 'support to alleviate the worry about uncertain symptoms of having cancer'. The designers also could identify the moment patients expressed this need in their journey by looking at the contexts of the associated representative stories (posts). For this need (Topic group 3), the designers found that patients expressed it mostly in the 'intake' phase, the first phase of the initial care path. In a similar fashion, the designers could identify patient (information) needs based on the found patient experiences for all twenty-five topic groups and assign these needs to the appropriate moment in the patient care path. The fourth column (i.e., 'Interpretation') in Appendix 3-6 shows our interpretation of the needs expressed by patients and their relevant phase in the care path. The full interpretation is given in Appendix 3-6. These needs can add valuable new information to the initial patient journey map about what information should be collected from or provided to the patient at what moment. By plotting these needs on the journey map with the identified moment (phase) of the needs, designers could easily recognize opportunities to improve the patient experience.

As our next step, we plotted the identified (information) needs and moments (phase) on the initial patient journey map, as shown in Figure 3-9. The added information needs can be found in the lower section of the patient journey map. In the green bar, information icons are placed that show the information that needs to be/is provided to the patient. The red bar shows information icons related to the information that should be/is collected from the patients. We illustrated the information provided and collected in the current practice with full-colour icons. The new opportunities to collect and provide information, relative to the patient needs found in the analysis, are presented as black-and-white icons.

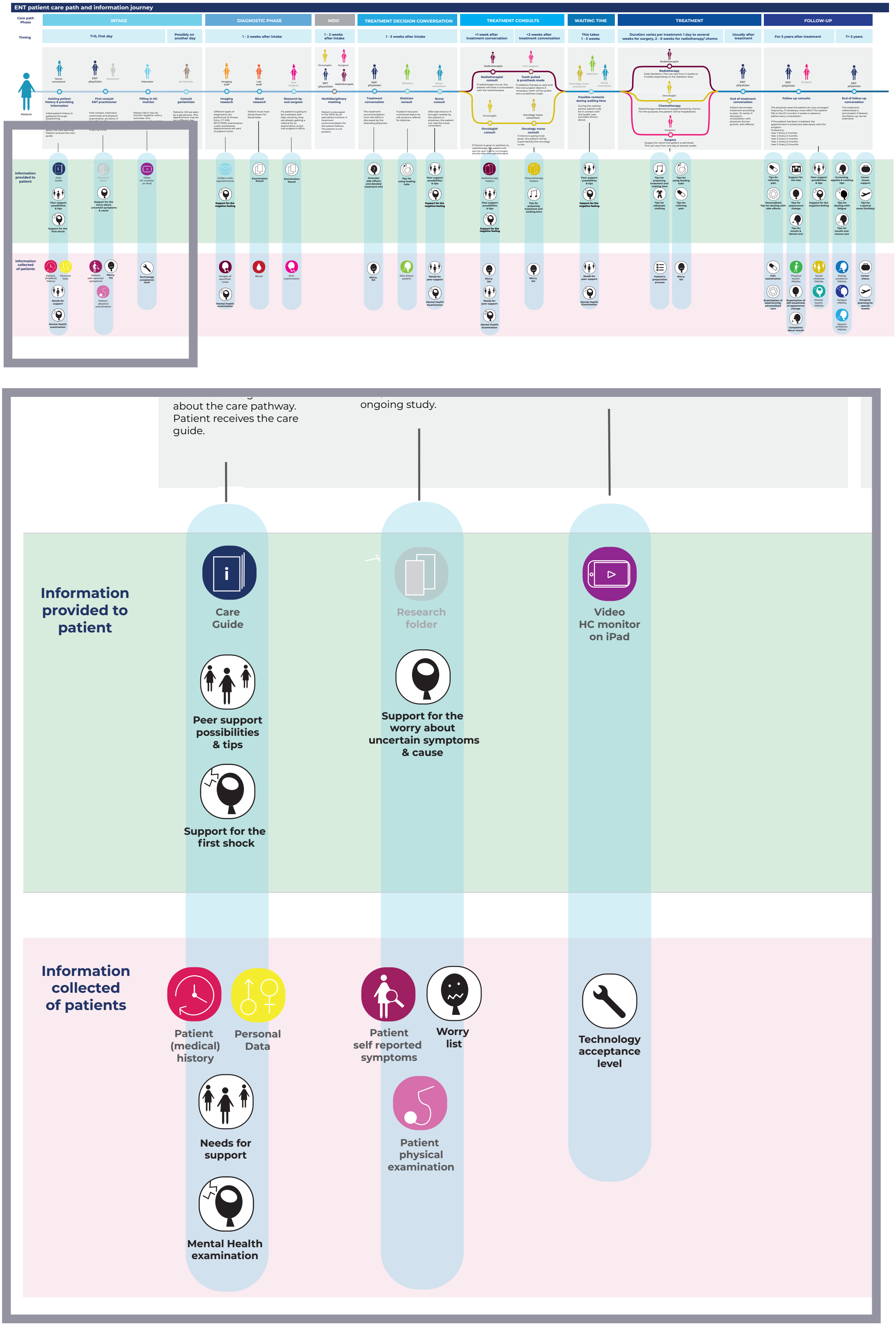


Figure 3-9. A part of patient community journey map applied with unsupervised machine learning techniques for online patient stories (modified from master student thesis (Peters, 2021))

3.4 Discussion and conclusion

We, as a team of designers and data scientists, developed a novel approach for overcoming the challenges related to representing user group experience in the design process of a societal transition in this study. Our approach, demonstrated in a healthcare context, captured broad and community-level data using online stories. This enabled the inclusion of tens of thousands of patient experiences derived from online platforms. We applied manual qualitative analysis techniques, such as thematic analysis for building training data, combined with automated text mining techniques using supervised and unsupervised machine learning to analyse the stories. These techniques allowed us to include community-level data in the patient journey map in a relatively labour-efficient manner. Based on the results with patient community journey mappings in Studies 1 and 2, we demonstrated the following new valuable additions and modifications to traditional journey mapping techniques: (1) the quantification of (patient) experience frequency, (2) the detection of relationships between co-occurring experiences within the journey, and (3) the detection of new design opportunities/directions (potential data types to be provided and collected). These additions and modifications are of value to designers who need to gain a deeper understanding of complex societal transition contexts in a variety of fields such as, but not limited to, healthcare, with a low-cost investment.

We presented our outcomes to possible future stakeholders who were not involved in the development process per se (four specialist doctors, a psychologist, two healthcare policy researchers, an artificial intelligence (AI) researcher at a hospital, and two data scientists at a hospital). Overall, everyone confirmed the novelty and conceptual clarity of the patient community journey mapping. They were positively surprised by the high level of understanding that was developed in a short period of time about the targeted patient group. They appreciated using everyday life experience data (i.e., online patient stories) instead of data from randomised trials or internal logistics, in a community-level. For them, the fact that the large-scale data were mostly coming from patients' everyday life (instead of in a hospital) meant that community journey maps provided credible insights for improving the quality of life, value-based health care, and patient-centric care. As one of the specialist doctor said, the data from the community platform established a broader perspective on patient care path experiences that they could better relate to compared with the feedback of a few assertive patients during consultations (traditional patient journey can also be dangerous by having a few assertive opinions from patients). Our new patient community journey map not only helps designers but also other related stakeholders to better understand the patients and generate credible picture of the patients experience in the care-path by adding plurality to the traditional patient journey mapping.

Finally, far from arguing for a set of rules to be followed, we merely seek to inspire designers, and encourage them to adapt and adjust our approach to their practices and needs (as suggested by Daalhuisen et al. (2019). Yet, in this process, we would recommend that design researchers closely and continuously collaborate with data scientists, as we have done in the research reported here. Whereas the data scientist can imagine the possibilities for machine learning techniques in analysing community-level data, designers can imagine and explain which data analysis results can provide high-quality information that can serve as an inspiration to the design of new services or systems. For instance, in our collaboration we discussed the various options of machine learning techniques that could provide meaningful and relevant insights in support of the design process for new services that could empower cancer patients. These discussions resulted in innovative and effective decisions on how to create this new type of journey map. The most effective way was building an abductive, collaborative problem-solving loop (as described by (Dorst, 2011; Stoimenova & Kleinsmann, 2020)), in deciding what to analyse, and in which way and for what purpose that could provide value for patients and others.

In this collaborative reasoning process, we learned that it is necessary to have an appropriate language to communicate what designers and data scientists want from each other. We, as a team of designers and a data scientist, therefore propose a change from the traditional way data scientists and designers work together (see Figure 3-10, left) to a more far-reaching and integrated collaboration (see Figure 3-10, right). One to be noticed is that the designers' involvement is larger than that of data scientists in the preparation and creation phases to interpret the initial given care-path information to construct an initial journey map and interpret the analysed community data to construct community journey map. Whereas, our entire collaboration process involves the seamless and continuous sharing of knowledge and outcome from and between designers and data scientists.

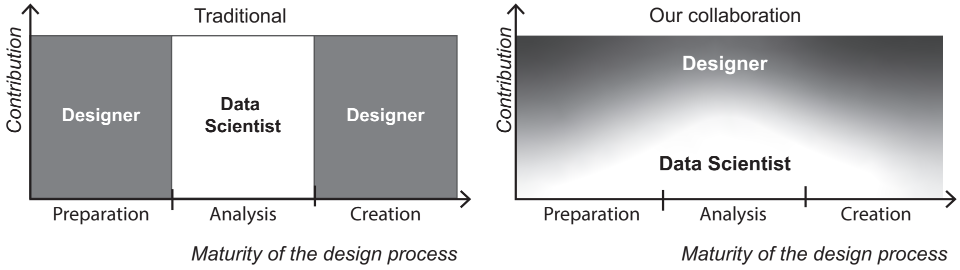


Figure 3-10. Traditional collaboration process between a data scientist and designers (left) as opposed to the collaboration process in Studies 1 and 2 (right)

3.5 Reference

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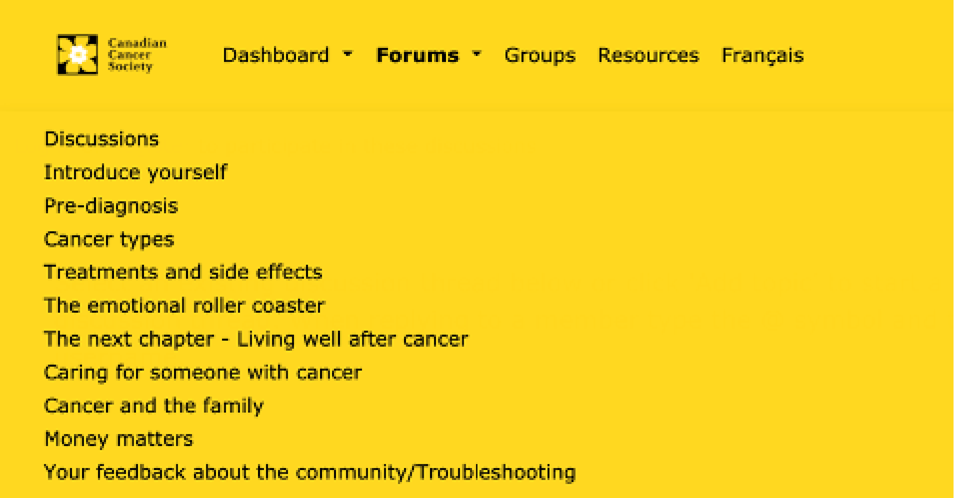
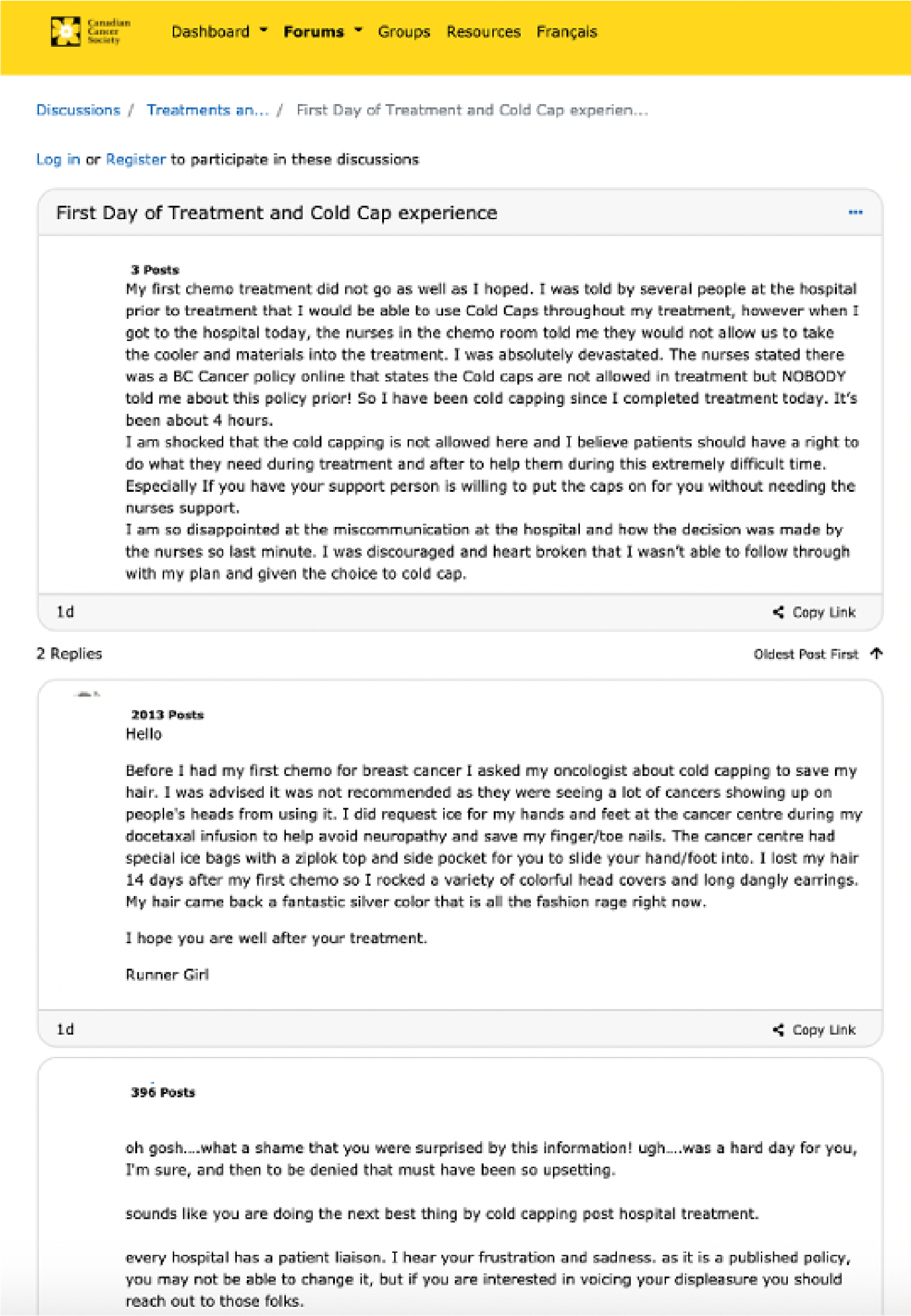
3.6 Appendix

Appendix 3-1. List of sub-sections in 'Forums' (captured from https://cancerconnection.ca/)



Discussions
Introduce yourself
Pre-diagnosis
Cancer types
Treatments and side effects
The emotional roller coaster
The next chapter - Living well after cancer
Caring for someone with cancer
Cancer and the family
Money matters
Your feedback about the community/Troubleshooting

Appendix 3-2. Example of online patient stories (thread with one first post and two replies)



Log in or Register to participate in these discussions

First Day of Treatment and Cold Cap experience

3 Posts

My first chemo treatment did not go as well as I hoped. I was told by several people at the hospital prior to treatment that I would be able to use Cold Caps throughout my treatment, however when I got to the hospital today, the nurses in the chemo room told me they would not allow us to take the cooler and materials into the treatment. I was absolutely devastated. The nurses stated there was a BC Cancer policy online that states the Cold caps are not allowed in treatment but NOBODY told me about this policy prior! So I have been cold capping since I completed treatment today. It's been about 4 hours.
I am shocked that the cold capping is not allowed here and I believe patients should have a right to do what they need during treatment and after to help them during this extremely difficult time. Especially If you have your support person is willing to put the caps on for you without needing the nurses support.
I am so disappointed at the miscommunication at the hospital and how the decision was made by the nurses so last minute. I was discouraged and heart broken that I wasn't able to follow through with my plan and given the choice to cold cap.

2 Replies

2013 Posts

Hello

Before I had my first chemo for breast cancer I asked my oncologist about cold capping to save my hair. I was advised it was not recommended as they were seeing a lot of cancers showing up on people's heads from using it. I did request ice for my hands and feet at the cancer centre during my docetaxal infusion to help avoid neuropathy and save my finger/toe nails. The cancer centre had special ice bags with a ziplok top and side pocket for you to slide your hand/foot into. I lost my hair 14 days after my first chemo so I rocked a variety of colorful head covers and long dangly earrings. My hair came back a fantastic silver color that is all the fashion rage right now.

I hope you are well after your treatment.

Runner Girl

396 Posts

oh gosh....what a shame that you were surprised by this information! ugh....was a hard day for you, I'm sure, and then to be denied that must have been so upsetting.

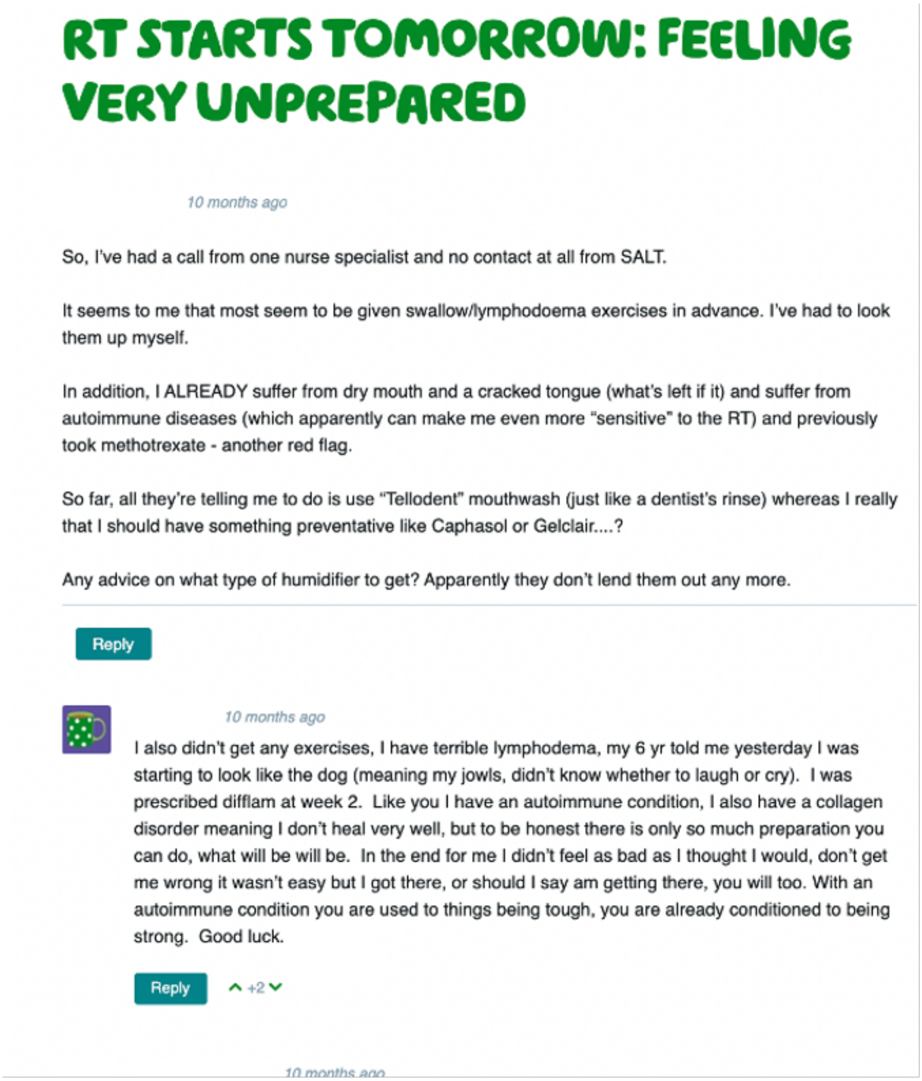
sounds like you are doing the next best thing by cold capping post hospital treatment.

every hospital has a patient liaison. I hear your frustration and sadness. as it is a published policy, you may not be able to change it, but if you are interested in voicing your displeasure you should reach out to those folks.

Appendix 3-3. Extended version of Table 3-5. Some results of association rule mining

Rule	Antecedents	Consequents	Confidence
0	Being/ attempting to be positive in the cancer journey	Experiencing physical side effects from treatment and finding ways to counter-act these	0.79
1	Experiencing physical side effects from treatment and finding ways to counteract these	Being/ attempting to be positive in the cancer journey	0.26
2	Undergoing treatment procedures	Being/ attempting to be positive in the cancer journey	0.26
3	Being/ attempting to be positive in the cancer journey	Undergoing treatment procedures	0.72
4	Experiencing eating/drinking issues and finding (diet-related) solutions	Dealing with overwhelming fatigue in daily life	0.44
...	...	...	...
21	Getting support from family, friends and peers but also dealing with misunderstanding and estrangement	Experiencing eating/drinking issues and finding (diet-related) solutions	0.50
22	Experiencing eating/drinking issues and finding (diet-related) solutions	Making a conscious decision for personal care/health by comparing quality and quantity of life	0.41
23	Making a conscious decision for personal care/health by comparing quality and quantity of life	Experiencing eating/drinking issues and finding (diet-related) solutions	0.53
...	...	...	...
43	Experiencing physical side effects from treatment and finding ways to counter-act these	Undergoing treatment procedures	0.69
44	Experiencing physical side effects from treatment and finding ways to counter-act these	Wanting to have an understanding relationship with the medical team (effective communication, information and respect)	0.36
45	Wanting to have an understanding relationship with the medical team (effective communication, information and respect)	Experiencing physical side effects from treatment and finding ways to counter-act these	0.78
...	...	...	...
55	Making a conscious decision for personal care/health by comparing quality and quantity of life	Undergoing treatment procedures	0.74
56	Sharing cancer news with others using a medium that suits the patient	Undergoing treatment procedures	0.70
57	Undergoing treatment procedures	Sharing cancer news with others using a medium that suits the patient	0.40
58	Undergoing treatment procedures	Wanting to have an understanding relationship with the medical team (effective communication, information and respect)	0.37
59	Wanting to have an understanding relationship with the medical team (effective communication, information and respect)	Undergoing treatment procedures	0.74

Appendix 3-4. Example of the first post and a reply for study 2



RT STARTS TOMORROW: FEELING VERY UNPREPARED

10 months ago

So, I've had a call from one nurse specialist and no contact at all from SALT.

It seems to me that most seem to be given swallow/lymphodoema exercises in advance. I've had to look them up myself.

In addition, I ALREADY suffer from dry mouth and a cracked tongue (what's left if it) and suffer from autoimmune diseases (which apparently can make me even more "sensitive" to the RT) and previously took methotrexate - another red flag.

So far, all they're telling me to do is use "Tellodent" mouthwash (just like a dentist's rinse) whereas I really that I should have something preventative like Caphasol or Gelclair....?

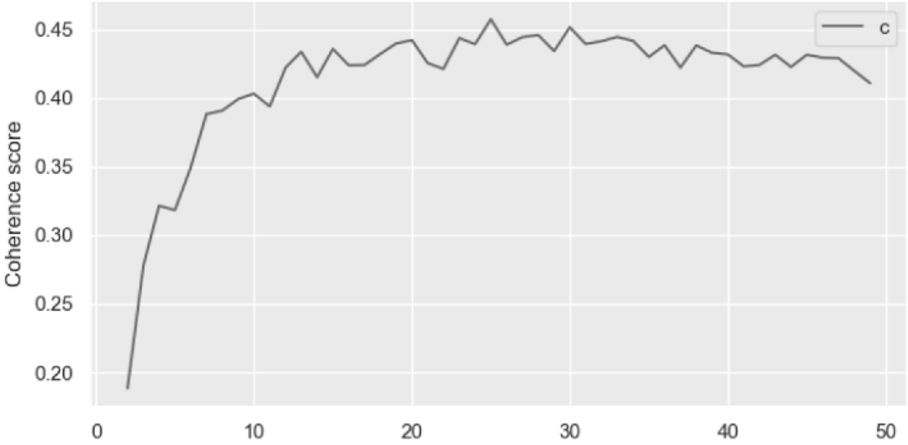
Any advice on what type of humidifier to get? Apparently they don't lend them out any more.

10 months ago

I also didn't get any exercises, I have terrible lymphodema, my 6 yr told me yesterday I was starting to look like the dog (meaning my jowls, didn't know whether to laugh or cry). I was prescribed difflam at week 2. Like you I have an autoimmune condition, I also have a collagen disorder meaning I don't heal very well, but to be honest there is only so much preparation you can do, what will be will be. In the end for me I didn't feel as bad as I thought I would, don't get me wrong it wasn't easy but I got there, or should I say am getting there, you will too. With an autoimmune condition you are used to things being tough, you are already conditioned to being strong. Good luck.

10 months ago

Appendix 3-5. Coherence score for each number of topics ranging from 2–49

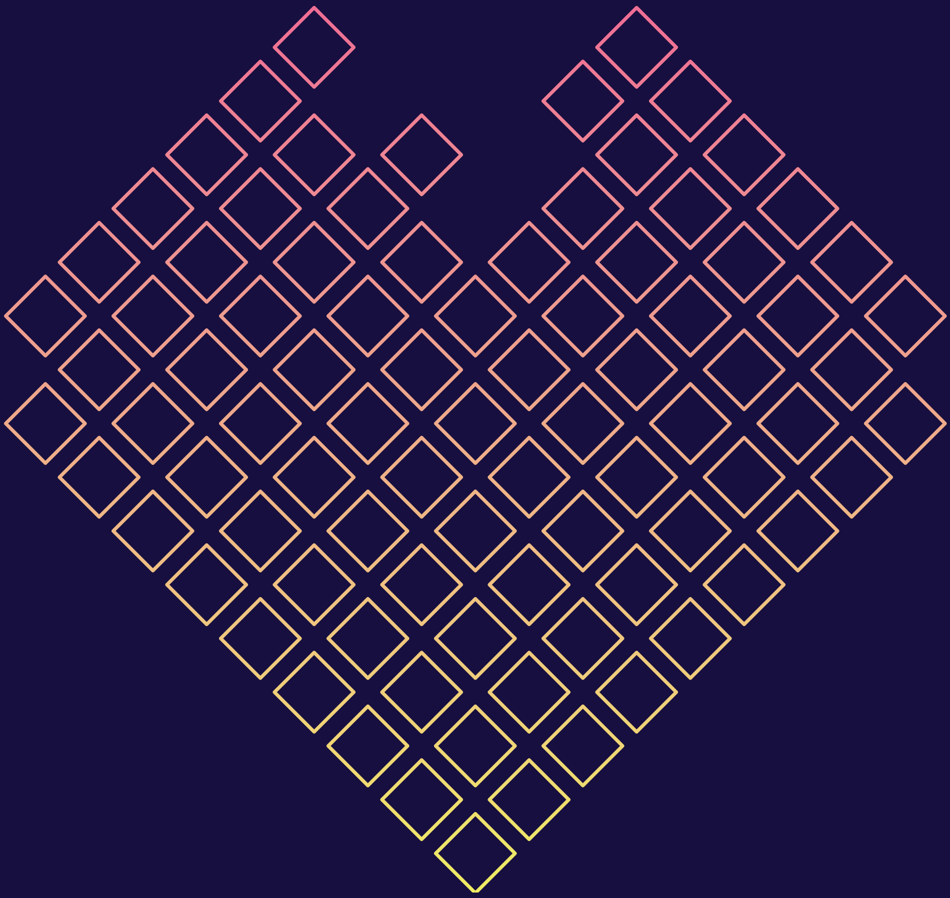


Appendix 3-6. Designer's interpretation of the topic for each cluster

Topic group	Ten representative keywords	Topic label (Patients discuss and share their experience about ...)	Interpretation (Patients need for .../ Phase of care path belong to)
0	regard, suggest, kind, story, carcinoma, book, dissection_reconstruction, flap_postoperative, holiday, comment	Having holidays, and how to arrange them with travel insurance.	Tips for a special event / follow-up
1	soup, soft, calorie, dietician, meal, ensure, add, diet, milk, cream	What they can eat/drink and recipes to make it edible during their recovery phase.	Tips on food and drink ingredients and cooking recipes / treatment & follow-up
2	information, forum, party, join, link, line, number, member, thread, medical	What each treatment does and what the side/late effects are.	Sufficient information about treatment and side effects / treatment decision conversation & consult
3	symptom, specialist, nose, test, worried, refer, ent, blood, voice, concern	Their worries related to potential cancer symptoms and need for guidance	Support to alleviate the worry about uncertain symptoms of having cancer / intake
4	stuff, slowly, tip, stick, lack, improvement, appetite, eating, hot, slow	Eating and appetite issues	Tips for increasing appetite / treatment & follow-up
5	pay, job, local, health, lucky, nhs, form, medical, system, benefit	Career and financial issues	Tips for a career during a cancer journey/ follow-up
6	spread, lymph_node, primary, mri, left, sign, large, cell, gland, lung	Cancer status and treatment process can be very different for each individual	Personalised information / throughout all phases
7	wife, man, fight, daughter, son, child, strength, age, heart, young	Experience related to supportive family	Family support / throughout all phases
8	bed, eye, minute, sit, spend, watch, close, drive, listen, move	Identifying how to prepare for treatment and spend time in the hospital between treatments	Tips for preparing for treatments and the waiting time / treatment decision conversation
9	rest, half, tired, walk, step, fatigue, road, ready, plenty, sense	How to deal with fatigue	Tips for dealing with fatigue / follow-up
10	type, option, decide, explain, outcome, decision, cure, chance, info, discuss	Having the essential knowledge about the potential consequences and side effects of treatment procedures	Having enough information about treatment outcomes and side effects/ treatment decision conversation, treatment consult
11	word, metastatic_scc, run, fact, learn, load, pass, describe, wake, bother	Knowing the importance of peer support when dealing with physical and psychological side effects	Peer support / throughout all phases

Appendix 3-6 Continued.

Topic group	Ten representative keywords	Topic label (Patients discuss and share their experience about …)	Interpretation (Patients need for …/ Phase of care path belong to)
12	relief, morphine, drug, painkiller, painful, hurt, prescribe, tablet, dose, liquid	How to relieve pain	Tips for relieving pain / follow-up, treatment
13	skin, exercise, heal, scar, speech, flap, arm, muscle, shoulder, swell	How to recover from treatment and surgery sequelae and side effects	Tips for dealing with side effects from the treatment/ follow-up
14	return, dani_squamous, continue, update, progress, hpv, fingers_crosse, pleased, quick, therapy	Concerns related to HPV (virus that can infect and cause mouth and throat cancers)	Support information for uncertain worry about cancer-related cause / intake, throughout all phases
15	advise, chemotherapy, cisplatin, loss, complete, difference, ear, due, hair, short	How to deal with hearing and hair loss from the treatment	The support for the losses from the treatment / follow-up
16	write, message, phone, chat, forget, contact, add, profile, ring, detail	How to update platform peers about the user's cancer journey	Peer support possibilities/ throughout all phases
17	saliva, mucus, ulcer, buy, burn, cough, mouthwash, rinse, spray, product	How to deal with dry/sensitive mouth and mucus problem	Tips for the mouth and mucus care / follow-up
18	affect, afraid, floor, concern, extremely, main, person, procedure, reaction, depending	How reaction during the treatment procedure can be very different for individuals	The personalised information / throughout all phases
19	realise, nice, amazing, light, wonderful, lovely, cold, share, lucky, wear	How to wear adequate clothing against the cold and radiation burn from the treatment	Tips for adequate clothing for treatment/ treatment
20	sick, rig, stomach, med, nausea, admit, ensure, awful, nutrition, fluid	How to deal with the awful feeling of sickness caused by the feeding tube and pipe	Tips for using feeding tube / follow-up
21	yesterday, meet, touch, honest, date, guy, lol, bring, totally, lovely	The positive feeling about meeting, sharing stories, and helping between platform peers	Peer support possibilities/ throughout all phases
22	dentist, low, top, jaw, dental, bone, mine, oral, leg, bite	How to deal with the mouth-related issues (reconstruction and appearance) after jaw surgery	Support for appearance change after the surgery / follow-up
23	partner, infection, feeling, turn, fear, scary, situation, scare, stress, horrible	Negative feelings that their partners are also often worried	Support for dealing with negative feelings / throughout all phases
24	quickly, guess, move, imagine, ahead, grateful, process, prepare, begin, shock	Being shocked after being diagnosed with cancer	Support for the first encounter with cancer/ intake & diagnostic



CHAPTER

4.

Discussion and Conclusion

4.1 Main findings of the thesis

In this chapter, I reflect on the main findings of my doctoral thesis in relation to my main research question: **what can be the future impact of design (activities) in digital health, given the rise of data collection and analysis technologies?**

The first finding concerns the changes in design activity caused by the rise of data collection and analysis technologies. In this thesis, I focus on the rise of data technology in the upcoming modern computing era of collective computing, compared to the previous modern computing eras of personal and ubiquitous computing. The collective computing era is the technological context of complex systems of massive social interaction through various connected computing devices. According to the design vision of this thesis (Chapter 1), the target and location of the design task are 'complex system(s)' and 'society as a lab'. To deal with such design tasks, designers need to address communities by engaging with their data. Moreover, the design process almost simultaneously becomes the 'co-exploration' of design problems and solutions. Designers conduct such a process by considering the flexible combination and analysis of mixed data, working on social forces at a system level, and developing multiple soft launches through modular design. Finally, the designer's role changes to conduct an 'accountable implementation' by incorporating a transdisciplinary perspective on the value of and control over the design output.

The second finding concerns, while reflecting on such a design vision, how designers can achieve health's core strength of developing complex interventions. For the design discipline to impact healthcare, particularly in developing complex health interventions, design needs to understand and integrate with the healthcare field's core strength in generating knowledge (epistemology), while continuing to maintain its own core strength. In Chapter 2, we argue that the core strength of the design lies in the principle of 'deferral of judgement'. This means that knowledge is generated iteratively, using in-situ experience data to creatively explore and test both problem and solution areas. In public health, the core strength lies in generating knowledge by 'measuring improvement' in each problem area using existing scientific and behavioural data. Based on this interpretation, we argue that the design activity in the public health field can integrate the frameworks of the core strengths by employing existing people's experience data at the community-level. The existing people's experience data of the community-level are at the mid-scale, placed between individual (design research) and population (public health) scales for data collection. The data also share characteristics with data from design research (which focuses on people's experiences) and public health research (which focuses on trends of behaviour from existing scientific data). Thus, the community-level existing experience data functions as a bridging data source that can solve the interfacing issues when two frameworks are integrated.

Chapter 3 of this thesis created a data-driven approach (a design tool) for understanding patients' needs using existing people's experience data of community-level and analysing them using data technologies to impact the healthcare domain widely using the recommended knowledge-generating approach of integration. The tool is called the 'Patient Community Journey Map'. It is based on existing online patient stories and uses unsupervised and supervised text mining techniques. Through this tool, designers, in collaboration with data scientists, gain a large-scale (often tens of thousands) yet qualitative and inspiring understanding of a complex context in healthcare with reduced time and cost investments. The developed tool could quantify the experiences of a wide range of patients, detect the relationships between co-occurring experiences within the journey, and detect new design opportunities and directions. By doing so, it overcomes the difficulties in conventional design tools (e.g. patient journey mapping based on interviews and ethnography) in terms of representing the variety of patients and observing crucial moments in the patients' care-path experience.

4.2 Implications for society: Societal embedding of design activities in digital health

The knowledge developed in this thesis for future design in digital health has various societal impacts in the fields of education, research and development collaboration, and economic benefits. Through the impact of the knowledge generated in this thesis, I demonstrate how a local society recognises that design can be an essential and prominent element in building digital health.

First, the learnings generated in my doctoral thesis impacted the *field of education* as Figure 4-1 depicts. More details of the impacts are listed in Appendix 4-1. The knowledge generated in this thesis (vision, knowledge-generating approach, and tool) educated my supervised master's design students to start their successful careers in the field of digital health such as design academia (evidence-based healthcare design PhD, TU Delft), healthcare academia (AI-based lung cancer detection PhD, Radboud Medical Centre & Jeroen Bosch Hospital), and entrepreneurship (Patient Community Journey Mapping tool-based design consultancy start-up, Qaring). Further, I have been invited to present this thesis outcome to various disciplines including social scientists (e.g., public policy master students), computer scientists (e.g., artificial intelligence researchers), and professional designers (e.g., Philips Healthcare) to educate design to be an essential element of building digital health. The knowledge further motivated medical experts (e.g., a paediatric cardiologist and a psychologist) to continue developing design outcomes on their own and to learn the role of design in the development of digital healthcare. Finally, the knowledge supported the construction of several interdisciplinary research environments for TU Delft design master's students to experience to contribute to real-life digital health development. Both students in training and experts moving towards digital health adopted the knowledge generated from this thesis and even further modified them through their distinctive expertise. Therefore, I would proudly say that this thesis contributes to that society continuously recognises and embeds the potential of design as an essential and leading part of education for building digital health.

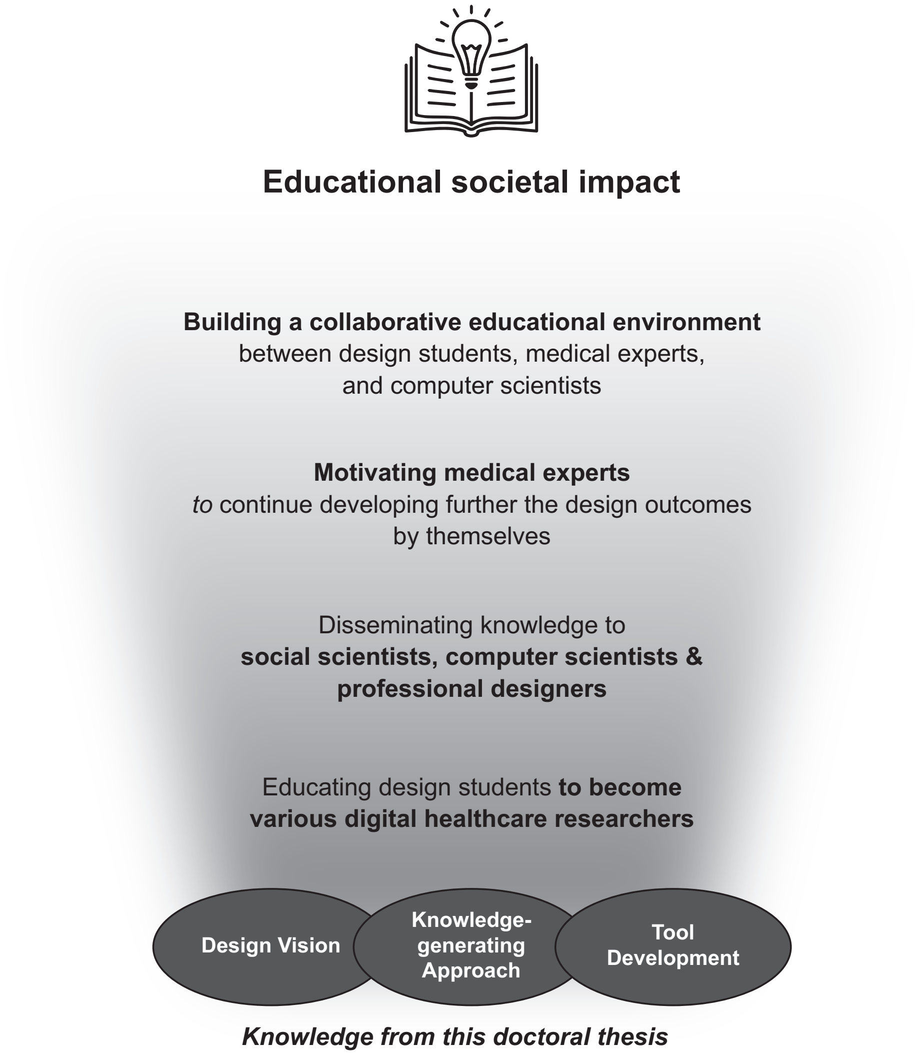


Figure 4-1. Educational impacts delivered through this doctoral thesis

Second, the knowledge and learnings generated in my doctoral thesis impacted society through research and development collaborations, as Figure 4-2 demonstrates. The knowledge generated in this doctoral thesis has expanded my research collaboration; I could be invited to participate in working with various discipline experts, receive collaborative research grants, and take a leadership role in an interdisciplinary research consortium. A detailed description of the collaboration is written in Appendix 4-2. The paediatric cardiologist and public health professor, with whom I worked collaboratively respectively for Chapters 2 and 3, continue to co-develop the knowledge even further with CardioLab and me. Further, a collaborative grant proposal called <Patient sc-AI-nce: A method for integrating patient experiences in text mining analysis> was awarded a short-term research grant from Open Mind Call (20,000 euro), Health & Technology, Convergence. With a health management researcher and a psychologist, the research aimed to develop a novel transdisciplinary method to understand mental health patients using patient-authored books and text mining. Another longer-term and larger collaborative research grant proposal that I am a part of, <Consultation Room 2030, Continuity of care from hospital to home> was further awarded from Flagship, Health & Technology, Convergence (2 million euros). This proposal consists of sixteen medical researchers from ten different departments; nine social scientists from the health policy, governance, and law departments; and four design researchers. The project aims to develop a centre of expertise on digital health by identifying the most promising approaches to embedding technologies in care networks and facilitating structural inter-organisational learning. Beyond writing the proposal, I was invited to participate in a Dutch Research Council research proposal that aims to collaborate between a research university and applied science (practice-based) from the nursing department of Hogeschool Rotterdam and social scientists from health policy and public health. The nursing department of an applied science university invited me to find values for people with dementia by using the Chapter 3 tool (patient community journey mapping). Lastly, through the knowledge I generated in this thesis, I now have a successful leadership role as a young board member of Healthy Start, an interdisciplinary research consortium between behavioural scientists, neuroscientists, paediatric epidemiologists, medical doctors, engineers, and designers. I have only described ongoing collaboration achievements directly derived from my PhD trajectory; however, CardioLab has established many more networks and collaborations as a group. In the society of developing digital health systems in the Netherlands, CardioLab members and I play pivotal roles in digital health development, its evaluation, and implementation with patient groups (which is often the expertise of healthcare), having been invited to be an essential part of their research grant proposals, projects, and research. Thus, as a body of diverse disciplines, the healthcare field in the Netherlands gradually embeds design activities and knowledge as the key drivers of digital health development.

Research and development collaboration societal impacts

Taking a **leadership role** (i.e., young board) in a large interdisciplinary research consortium with diverse disciplines **(e.g., behavioural scientists, neuroscientists, medical doctors, epidemiologists, psychologists)**

Being **invited** to join in a digital health grant proposal (to use my tool) by **a practice-based nursing school**

Receiving a large (**25 medical researchers and health-related social scientists**) and long-term (5 years) **research grant** about digital health transition

Receiving a short-term (4 months) collaborative **research grant** with two researchers (**a health management researcher and a psychologist**)

Working **continuously** with researchers collaborated in this thesis: **a paediatrician and a public health researcher**

Knowledge from this doctoral thesis

Figure 4-2. Collaborative impacts delivered through this doctoral thesis

Finally, the knowledge and insights generated in my doctoral thesis have impacted society by producing economic benefits, as depicted in Figure 4-3. Appendix 4-3 describes the benefits in detail. The knowledge generated in this doctoral thesis expands its economic impact by transferring its knowledge to entrepreneurship (i.e. Qaring) and industry (i.e. Philips Experience Design). The Patient Community Journey Mapping tool developed in Chapter 3 is currently in a spin-off process. Initially, a university, TU Delft, captured its economic value. TU Delft Enterprise (valorisation centre) invited me to build entrepreneurship around the Patient Community Journey Mapping. My supervised master's student (Tess Peters) also believed in this knowledge and leads this start-up with two other TU Delft graduates and named the company, Qaring (Qaring, 2022). Qaring was selected as part of a pre-incubating program at TU Delft. As a broader economic impact, the PhD research outcome then received its economic value recognition from national research bureaus. Qaring received several entrepreneurship grants from them. Further, the research outcome even received its market and economic value recognition from other private companies. Various other health-related businesses (i.e. consultancy and digital hospital) stayed as paying customers. Qaring further has been selected as a semi-finalist for the Philips Innovation Award, the largest student entrepreneurship award in The Netherlands. Therefore, various individuals and communities have already captured market and economic values created from my research in this thesis. They have further invested their efforts to further develop the knowledge with their own insights. Therefore, the knowledge generated in this thesis did not just stay inside academia or published paper, but actively found its economic value from society.

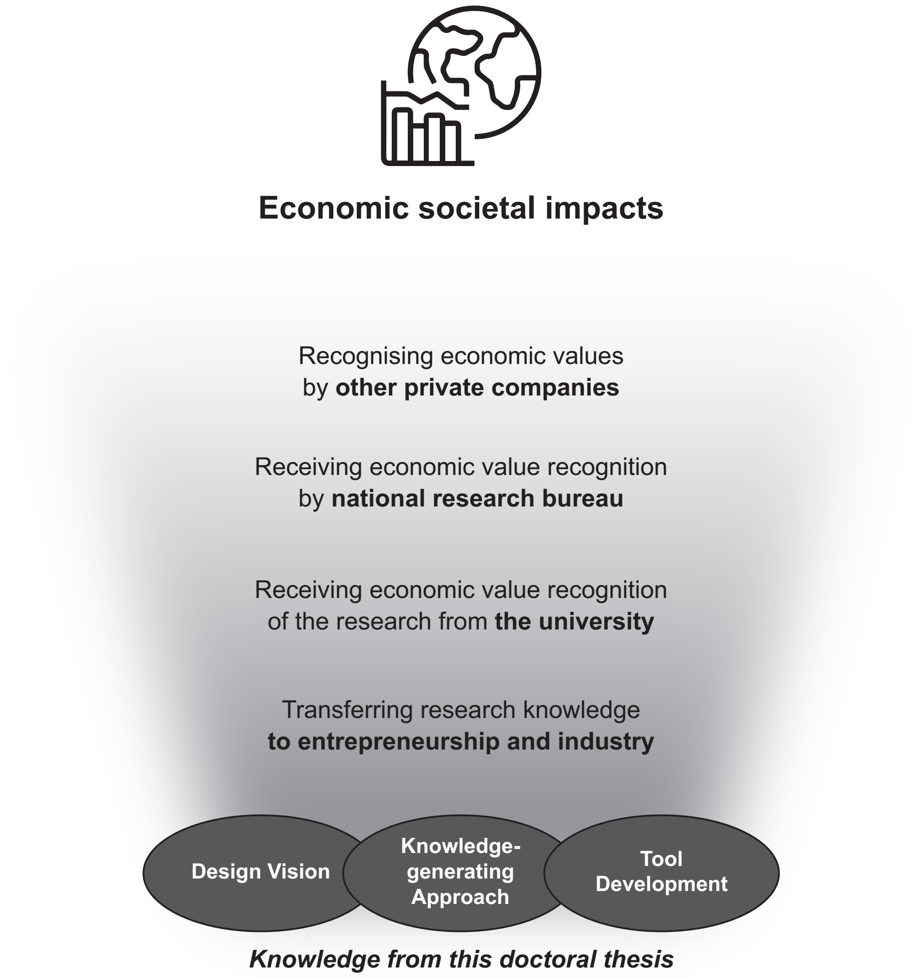


Figure 4-3. Economic impacts delivered through this doctoral thesis

4.3 Implications for design research and the practice of Data-enabled Design

This section highlights the implications for design research and practise based on the knowledge gained from this thesis. The Data-enabled Design (DED) from Philips Experience Design introduced in the introductory chapter already reflects the development of data technologies in design research and practice. However, it does not yet achieve societal embedding of digital healthcare design activities. To achieve this, DED needs to add the community context loop to the user context, as presented in Figure 4-4 (the grey dotted line). The community context loop provides a larger scale (e.g. tens of thousands) that allows employees of the vision user society as a lab to address the community by engaging with their data and to impact (public) health by integrating its knowledge-generating approach of developing a complex intervention.

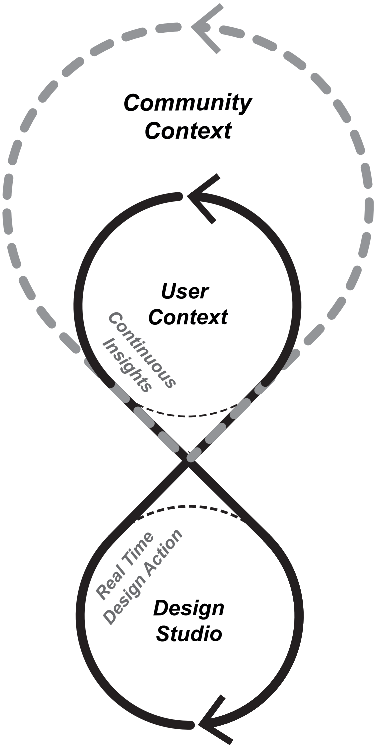


Figure 4-4. Enhanced Data-enabled Design approach (the grey dotted line describes the learning from this thesis)

The community context in design practise can provide a way to adopt the vision of this thesis, the knowledge-generating approach, and the tool to increase the impact of design in digital health. In addition, it can provide a collective value to the individual context that is usually studied in design practice. Moreover, it can also provide insights into the institutional arrangement of digital health. The institutional arrangement refers to how social rules, norms, meanings, symbols, and cultures are created, diffused, and adopted (Scott, 1995). People's behaviour is highly integrated into their society; therefore, considering collective values in the design process is key to successful design implementation.

Second, involving the community context increases the likelihood of design acceptance by the (public) health researchers and practitioners. This is because exploration in the community context bridges the gaps between how design and health researchers conduct research, as Chapter 2 describes. The community context can mediate to solve the interface issues between the two disciplines' ways of working.

Third, and as Chapter 3 elaborates, involving a community context enables designers to act on the complexity of representing a broader patient population in terms of interdependencies, constraints, perspectives, and the contexts of the experiences and profiles. Having the community context of patient experience refers to a broader innovation opportunity to include not only the actions of a specific scope of patients but also diverse user profiles (Dekkers, 2020; Wieland et al., 2016). Particularly, healthcare design should include not only the average performance of people but also very rare conditions (Rasmussen, 2000). By including the community context in the design process, the design studio is exposed to more chances of discovering rare conditions or cases because of the plurality of characteristics in the data.

4.4 Limitations and recommendations for future research

The design vision I have drawn in Chapter 1 is broader and richer than what I could explore in Chapters 2 and 3. Thus, there is more to explore in relation to the vision. Most of the guidelines developed for the design vision are used throughout the two chapters. 'Addressing a community by engaging with their data' has been dealt with by developing a knowledge-generating approach and a design tool for including community data to address the community. In addition, 'flexible combination and analysis with mixed data'. 'work on social forces at a system level', and 'transdisciplinary vision on the value and control of the design output' are all used in design projects described in Chapters 2 and 3, respectively. This was achieved by combining conventionally used study and community data, designing for a social relationship (parent-child patient relationship and patient's peer-to-peer relationship), and by transdisciplinary working with data scientists and medical experts. To add more knowledge to the vision, 'multiple soft launches with the modular design' and 'flexible combination and analysis with mixed data' can be further explored.

First, the concept of modularity has already been used and designed, as reported in Chapter 1 (and Appendix 1-3). However, only one of the various designed modules was soft-launched because of limited time and resources. Other designed modules could not yet reach the soft launch level. The two end products (the first modules) from two master's student projects that adopted this thesis's vision, knowledge-generating approach, and tool are now being developed in other modules. The medical researchers (one paediatric cardiologist and a psychologist, as described in Figure 4-1 & Appendix 4-1) of each project group stepped forward to develop the next module of the systems developed by awarding grants to develop the next module.

Considering the future work related to the vision, 'the flexible combination and analysis of mixed data' can also be explored further. In Chapters 2 and 3, I have already tried to combine existing people's experience data of community-level with other sources (i.e. scientific data and interview data) (Hendrix, 2019; Morales Ornelas, 2020; Peters, 2021). Endless flexible combinations of different types of community-level and other data sources continue to exist in many forms. Exploring more of these combinations could provide new insights and new complementary benefits for each data type. As an example, patient community platform data could be related to patients' clinical and national records. This would allow for a comparison between user/patient profiles derived from community-level data and conventional population cohort study outcomes. This approach can even lead to an opportunity to explore the different biases in each data type. Researchers can conduct deliberate and additional studies to mitigate the biases.

Digital health is inherently a transdisciplinary and collaborative effort. Various fields such as policy, economics, medical research, and behaviour science are involved in positively impacting digital health. Within such a context, my thesis explores how design can be more accepted and influence the development within another discipline in medical research. This means that I investigated how strategy can work better with other fields but it was still one-directional towards medical research. However, it is essential to research how all the various fields can organise and work together (not just be accepted or impacted) and how research in the field of digital health can be achieved as a collective and collaborative activity.

Therefore, we further need the transdisciplinary and collaborative exploration of adopting a common vision, methodology, and the tools for digital healthcare. All fields and disciplines have their own existing and widely accepted ways of working. They act as barriers to various disciplines successfully embedding each other's processes of digital health development. Other related disciplines that this thesis did not have a chance to explore, such as health policy, would also have a distinctive knowledge-generating approach for developing digital healthcare interventions. To achieve this future work, CardioLab and I are preparing a series of research seminars with various fields of experts to identify various ways to work together. This will further develop digital health as a form of collaborative and transdisciplinary research.

4.5 Concluding remark

I would like to conclude my doctoral thesis by saying that design researchers should be sensitive to the emergence of new technologies and understand how emerging technologies change design activities. Only then will design researchers develop new tools to support such changes, and only then will design stay societally embedded and open to various new research domains such as digital health. Through this doctoral research, I believe I could achieve both improvements in the field of design research and improvements in the design's impact on health.

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4.7 Appendix

Appendix 4-1. Educational impacts delivered through this doctoral thesis.

Educational societal impact	
1	**Educating design students to become various digital healthcare researchers** • A PhD student in AI-based lung cancer detection at Radboud Medical Centre & Jeroen Bosch Hospital o A supervised master student with prof.dr.ir. Maaike Kleinsmann, the case reported in Chapter 2 (Hendrix, 2019) • A PhD student in evidence-based healthcare design at TU Delft o A supervised master's student with prof. dr. Gerd Kortuem, the case reported in Chapter 2 (Morales Ornelas, 2020) • An entrepreneur for *Qaring*, a company based on the Patient Community Journey Mapping tool o A supervised master's student with prof.dr.ir. Maaike Kleinsmann, the case reported in Chapter 3 (Peters, 2021)
2	**Disseminating knowledge to social scientists, computer scientists, and professional designers** • Invited for lectures and seminars at Erasmus University of Rotterdam o 'Design Thinking for Data-Driven Prevention' master's student course at the School of Health Policy and Management o Social Artificial Intelligence (Social AI) research group including behavioural scientists, economists, and computer scientists o Library repository team • Invited to several internal employee seminars at Philips Experience Design o Data-enabled Design team o Various design employees including executive levels
3	**Motivating medical experts to continue developing further the design outcomes by themselves** • Medical partners of the graduation projects continue to develop the master's graduation project outcomes that adopted the knowledge developed in this thesis o Paediatric cardiologist—partially reported in Chapters 1 and 2, awarded his research grant by Hartekind (Dutch Children Heart Foundations), together with the director of CardioLab (Delft Design Labs, n.d.) o Psychologist—partially reported in Chapter 3 and (Peters, 2021), continues the project by awarding her research grant as a part (palliative care) of Consultation Room 2030, Flagship, Convergence ("Flagship Consultation Room 2030", n.d.)
4	**Building a collaborative educational environment between design students, medical experts, and computer scientists** • For remote patient monitoring systems: colorectal cancer, pulmonary fibrosis, and sarcoidosis • Through Patient Community Journey Mapping (Chapter 3) to increase patients' health-related quality of life (HRQoL) and patient empowerment • Collaboration between various stakeholders o Faculty of Industrial Design at TU Delft (master's research elective courses & master's graduation projects) o Faculty of Electrical Engineering, Mathematics, and Computer Science at TU Delft (master's graduation projects) o Erasmus University Library Repository Team o Cancer Institute, Department of Pulmonary Medicine, Surgery Department at ErasmusMC, & Netherlands Cancer Institute o Dutch patient communities (e.g. Stichting Darmkanker)

Appendix 4-2. Collaborative impacts delivered through this doctoral thesis.

Research and development collaboration societal impacts

1. **Working continuously with researchers collaborated in this thesis: a paediatrician and a public health researcher**
    - A proposal by Hartekind was awarded and continuing collaboration with CardioLab
        - Based on the Hosana project (Chapters 1 and 2) that adopted the vision, knowledge-generating approach, and tool of this thesis
    - Continue our collaboration for knowledge-generating approach development for design to contribute effectively to public health/ medical research
        - A series of workshops have been planned to further develop concepts from Chapter 2
2. **Receiving a short-term (4 months) collaborative research grant with two researchers (a health management researcher and a psychologist)**
    - Health policy experts and management of social scientists at the Erasmus University of Rotterdam and psychologists at ErasmusMC
    - Together awarded a grant <Patient sc-AI-nce: a method for integrating patient experiences in text mining analysis>, Open Mind Call by Health & Technology of Convergence ("Open Mind Symposium 2021", 2021)
    - To develop a novel transdisciplinary method to understand mental health patients using patient-authored books and text mining.
3. **Receiving a large and long-term research grant about digital health transition**
    - With sixteen medical researchers, nine social scientists, and four design engineers
        - Surgery, psychiatry, plastic and reconstructive surgery, obstetrics and gynaecology, anaesthesiology, oncology, dermatology, radiology, respiratory medicine, and otorhinolaryngology
        - Law, health management, and health governance
        - Design in healthcare, digital transformation design in healthcare, physical ergonomics
    - Awarded a five-year grant to establish seven PhDs and two post-doctoral researchers
    - <Consultation Room 2030, Continuity of care from hospital to home>, Flagship by Health & Technology of Convergence ("Flagship Consultation Room 2030", n.d.)
    - To aim to become 'a centre of expertise' on digital health by identifying the most promising approaches to embed technologies in care networks and facilitate inter-organisational learning structurally
4. **Being invited to join in a digital health grant proposal by a practice-based nursing school**
    - RAAK-PRO proposal by NWO, <Beter leven met dementie: de waarde van patiëntervaringsverhalen> (NWO, 2022)
    - The Nursing department at Rotterdam University of Applied Sciences
    - To use the design tool developed in chapter 4 (patient community journey mapping) to explore the way to find the value of existing patient experience stories, particularly for people with dementia
5. **Taking a leadership role (i.e., young board) in a large interdisciplinary research consortium with diverse disciplines** (i.e., Healthy Start ("Healthy Start", n.d.))
    - A research consortium between the Erasmus University of Rotterdam (e.g. behavioural scientists, neuroscientists, psychologists), Erasmus Medical Centre (e.g. medical doctors, epidemiologists), and the Delft University of Technology (e.g. designers)
    - To foster collaboration opportunities for young researchers
    - To aim to solve the early-life origins of disparities in health and wellbeing from a transdisciplinary perspective

Appendix 4-3. Economic impacts delivered through this doctoral thesis.

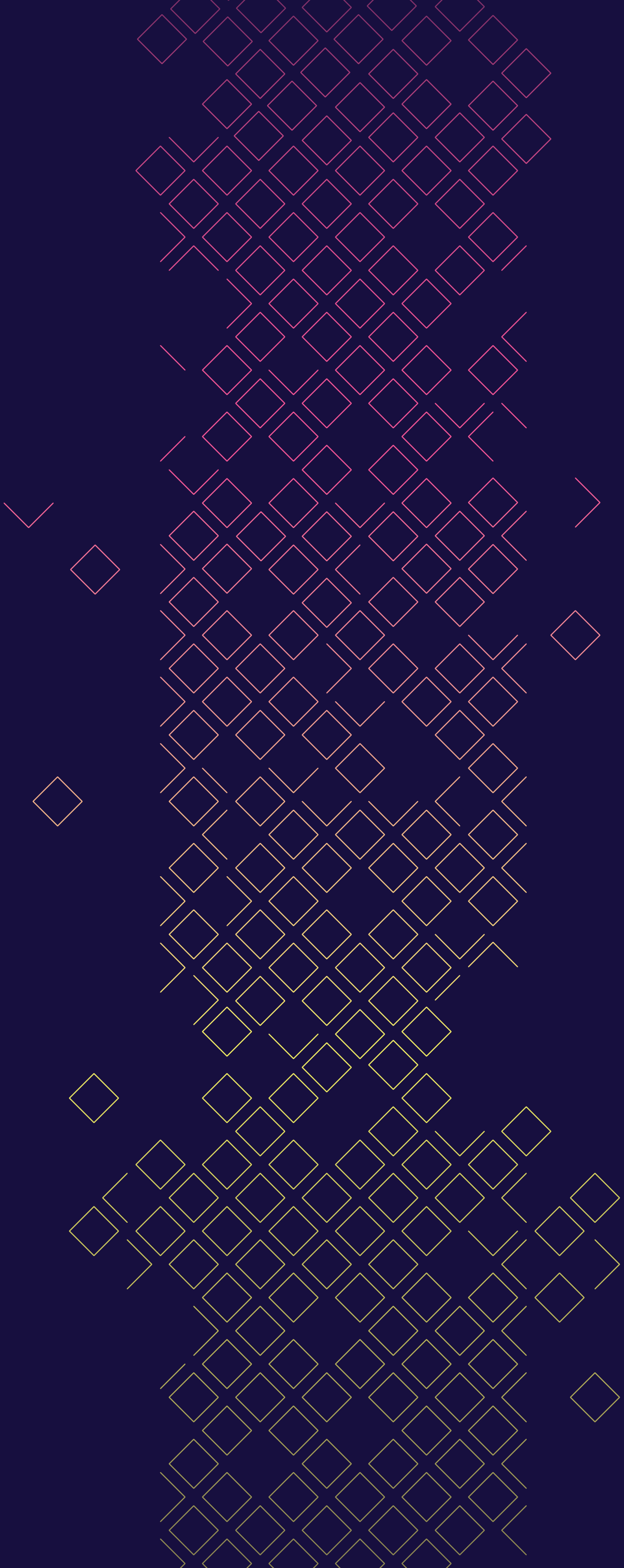
Economic societal impacts

1 **Transferring research knowledge to entrepreneurship and industry**
- An entrepreneurship company, Qaring, is created based on the Chapter 3 research outcome, ‘patient community journey mapping’ (Qaring, 2022)
    - Qaring runs by three TU Delft graduates: Tess Peters (previously, my supervised master student), Oskar Zakrzewski, and Shreyan Biswas
- Continuous and extensive connection with Philips Experience Design

2 **Receiving economic value recognition of the research from the university**
- Delft Enterprise (the valorisation centre of TU Delft, Yvonne Greeuw) approached me and suggested expanding the knowledge developed in this thesis as entrepreneurship
- Qaring was selected to be in Impact Studio: Pre-incubating program
    - In a process of interviews and market research to discover how the method can positively impact the market
- Qaring is now in a Validation Lab program by Yes!Delft
    - Examining the start-up idea if it fits with the market

3 **Receiving economic value recognition by national research bureaus**
- *Qaring* received two government entrepreneurship grants
    - Take-Off Grant phase 1 grant from Dutch Research Council (NWO) and Dutch Organisation for Health Research and Care Innovation (ZonMw) (NOW, 2023)
    - Voucher for transferring medical technology research knowledge to a practical application (*Thematic Technology Transfer*) from the Netherlands Organisation for Applied Scientific Research (TNO) and four Dutch technical universities federations (4TU) (Thematic Technology Transfer. n.d.)

4 **Recognising economic values by other private companies**
- Philips Innovation Award 2023, Semi-finalist
- Qaring has paying customer companies



Addenda

Summary in English

The research question of this doctoral thesis is: What can be the future impact of design (activities) in digital health, given the rise of data collection and analysis technologies? I answered this question on three knowledge levels: design vision, knowledge-generating approach, and design tool. In Chapter 1, I envision design activities for the collective computing era (an upcoming modern computing era with complex systems of massive social interaction through various connected computing devices) that data collection and analysis technologies are a part of. Based on the literature review and informants' interviews, I developed a design vision that demonstrates the changes posed in design activities (design tasks, processes, and the designer's role) due to the upcoming collective computing era, and provides guidance for adopting the changes. Consequently, the vision proposes that design tasks in the collective computing era move towards designing 'complex system(s)' and testing these within 'society as a lab'. The vision's guidance states that designers can approach these tasks by addressing communities and engaging with their data. In terms of the design process, the vision claims the 'co-exploration' of the design problem and solution spaces. To tackle such change, the guidance suggests designers: the flexible combination and analysis of mixed data, working on social forces at a system level, and developing through multiple soft launches with modular designs. Finally, the designer's role becomes conducting an 'accountable implementation.' The vision recommends approaching accountable implementation by incorporating a transdisciplinary vision of the value and control of the design output.

In Chapter 2, I studied a knowledge-generating approach to realise some central learnings from the design vision developed in the previous chapter in the domain of health intervention development. The approach is to gain increased acceptability of design research in health-related disciplines. I conducted this research by identifying the core strengths of the frameworks from the Design Council and the Medical Research Council, both describing a preferred mode for developing interventions in complex systems. The study shows that the core strength of design lies in generating knowledge iteratively, by using in-situ experience data at the individual level to creatively explore and test both problem and solution areas. In health-related research, the core strength lies in generating knowledge from the past in a given problem area and by using existing scientific behavioural data at the population level. Based on this interpretation, I propose a novel design knowledge-generating approach required in the domain of health intervention development. The approach integrates the core strengths of both frameworks by using existing (already-collected) people's experience data at the community level (midscale between individual and population levels), that share characteristics with data from design and health research. Design research focuses on people's experiences, and health research focuses on comprehensive behavioural trends. The chapter further elaborates on two design projects adopting the design approach in health intervention development using existing people's experience data at the community level. It also explains the result of societal impacts that the two projects made.

In Chapter 3, I developed a design tool that allows designers to leverage 'existing people's experience data at the community level' in the integration approach suggested in the previous chapter. The most common design tool for incorporating patient experiences and perspectives in healthcare design—patient journey mapping—served as the basis for this tool's development. Patient experiences provide valuable information to improve the quality of care and reduce healthcare costs. Nevertheless, the current method for patient journey mapping is time- and labour-intensive (based on qualitative data), which results in the inclusion of only a limited number of patient voices. The 'Patient Community Journey Map' method, developed in this chapter, offers an answer to these limitations by applying text data analysis to available online patient experience stories, such as blogs and forum posts. This allows the broad patient population's self-reported moments of experience to be effectively (and cost- and labour-efficiently) included in improving care pathways, products, and services. The tool is a new data-enabled approach that utilises existing people's experience data at the community-level, namely online patient stories, with the help of text mining (machine learning). It eventually helps designers gain a large-scale yet qualitative and inspiring understanding of a complex context in healthcare with reduced time and cost investments. The chapter demonstrates the tool in two cases in the field of oncology: one using supervised machine learning and the other using unsupervised machine learning.

To conclude, I contributed to various societal impacts in education and research and development collaboration, and to economic societal impacts through the design vision, knowledge-generating approach, and design tool developed in this thesis. Through the impacts, society is a step closer to recognising that design is an essential element in building digital health.

Summary in Dutch: Samenvatting

De onderzoeksvraag van dit proefschrift is: Wat kan de toekomstige impact zijn van ontwerp(activiteiten) in digitale gezondheid, gezien de opkomst van technologieën voor dataverzameling en -analyse? Ik heb deze vraag beantwoord op drie kennisniveaus: 'design vision (ontwerpvisie)', 'knowledge-generating approach (kennisgenererende benadering) en 'design tool' (ontwerpinstrument). Hoofstuk 1 voorziet ontwerpactiviteiten voor het 'collectieve computing' (een opkomend tijdperk in de moderne informatica met complexe systemen van massale sociale interactie via verschillende verbonden computerapparaten) waar technologieën voor dataverzameling en -analyse deel van uitmaken. Op basis van een literatuurstudie en interviews met 'informants' heb ik een ontwerpvisie ontwikkeld die de veranderingen in ontwerpactiviteiten (ontwerptaken, -processen en de rol van de ontwerper) als gevolg van het opkomende computertijdperk laat zien en een leidraad biedt voor het invoeren van de veranderingen. De visie stelt voor dat ontwerptaken in het collectieve computertijdperk zich richten op het ontwerpen van "complexe systeem(en)" en het testen daarvan binnen "de maatschappij als laboratorium". Volgens deze visie kunnen ontwerpers taken benaderen door zich tot gemeenschappen te richten en gebruik te maken van hun data. In termen van het ontwerpproces stelt de visie het gelijktijdig verkennen van het ontwerpprobleem en de oplossingsgebieden voor. Om dergelijke veranderingen aan te pakken, stelt de leidraad voor dat ontwerpers werken op basis van de flexibele combinatie en analyse van gemengde gegevens, ontwerpen op sociale krachten op systeemniveau, en ontwerpen via meerdere 'soft launches' met 'modular design' (modulair ontwerp). Ten slotte wordt de rol van de ontwerper het uitvoeren van een "verantwoorde implementatie." De visie beveelt aan om verantwoorde uitvoering te benaderen door een transdisciplinaire visie op de waarde en controle van de ontwerpoutput te gebruiken.

In hoofdstuk 2 bestudeerde ik een 'knowledge-generating approach' (kennisgenererende benadering) om enkele centrale lessen uit de (in het vorige hoofdstuk) ontwikkelde ontwerpvisie te realiseren in het domein van de ontwikkeling van gezondheidsinterventies. De aanpak beoogt een grotere acceptatie van ontwerponderzoek in gezondheidsgerelateerde disciplines. Dit onderzoek wordt uitgevoerd door de kernkwaliteiten te identificeren van de raamwerken van de Design Council en de Medical Research Council, die beide een voorkeurswijze beschrijven voor het ontwikkelen van interventies in complexe systemen. De studie toont aan dat de kernkracht van design ligt in het iteratief genereren van kennis, door in-situ ervaringsdata op individueel niveau te gebruiken om op creatieve wijze zowel probleem- als oplossingsgebieden te verkennen en te testen. In gezondheidsgerelateerd onderzoek ligt de kernkracht in het genereren van kennis uit het verleden in een bepaald probleemgebied en door gebruik te maken van bestaande wetenschappelijke gedragsgegevens op populatieniveau. Op basis van deze interpretatie stelt dit proefschrift een nieuwe 'knowledge-generating approach' (kennisgenererende benadering) voor die nodig is in het domein van de ontwikkeling van gezondheidsinterventies. De benadering integreert de kernkwaliteiten van beide kaders door bestaande ervaringsdata van mensen op 'community-level' (gemeenschapsniveau - middenschaal tussen individueel en populatieniveau) te gebruiken, die kenmerken delen met gegevens uit ontwerp- en gezondheidsonderzoek. Ontwerponderzoek richt zich op ervaringen van mensen, en gezondheidsonderzoek richt zich op uitgebreide gedragstrends. Het hoofdstuk gaat verder in op twee ontwerpprojecten waarbij de ontwerpbenadering werd toegepast bij de ontwikkeling van gezondheidsinterventies met behulp van bestaande ervaringsdata van mensen op gemeenschapsniveau, en licht het resultaat van de maatschappelijke effecten van de twee projecten toe.

In hoodstuk 3 ontwikkelde ik een ontwerpinstrument waarmee ontwerpers gebruik kunnen maken van bestaande ervaringsdata van mensen op 'community-level' (gemeenschapsniveau) in de integratieaanpak die in het vorige hoofdstuk werd voorgesteld. Het meest gebruikte ontwerpinstrument voor het opnemen van patiëntervaringen en -perspectieven in het ontwerp van de gezondheidszorg - patient journey mapping - diende als basis voor de ontwikkeling van dit instrument. Ervaringen van patiënten leveren waardevolle informatie op om de kwaliteit van de zorg te verbeteren en de kosten van de gezondheidszorg te verlagen. De huidige methode voor het in kaart brengen van 'patient journeys' is echter tijd- en arbeidsintensief (gebaseerd op kwalitatieve gegevens), waardoor slechts een beperkt aantal stemmen van patiënten wordt meegenomen. De 'Patient Community Journey Map' methode, ontwikkeld in dit hoofdstuk, biedt een antwoord op deze beperkingen door tekstanalyse toe te passen op beschikbare online-ervaringsverhalen van patiënten, zoals blogs en forumberichten. Hierdoor kunnen de zelfgerapporteerde ervaringsmomenten van de brede patiëntenpopulatie effectief (en kosten- en arbeidsefficiënt) worden meegenomen in het verbeteren van zorgpaden, producten en diensten. De tool is een nieuwe datagedreven aanpak die gebruik maakt van bestaande ervaringsdata van mensen op 'community-level' (gemeenschapsniveau), namelijk online patiëntenverhalen, met behulp van text mining (machine learning). Het helpt ontwerpers uiteindelijk een grootschalig maar kwalitatief en inspirerend begrip te krijgen van de complexe context van de gezondheidszorg met minder investeringen in tijd en kosten. Het hoofdstuk demonstreert het hulpmiddel in twee voorbeelden op het gebied van oncologie: één waarbij gebruik wordt gemaakt van supervised machine learning en één van unsupervised machine learning.

Tot slot heeft de ‘design vision (ontwerpvisie)’, de ‘knowledge-generating approach (kennisgenererende benadering) en de ‘design tool’ (ontwerpinstrument) die in dit proefschrift zijn onderzocht en ontwikkeld, reeds maatschappelijke bijdragen geleverd op het gebied van onderwijs, samenwerkingen in onderzoek en ontwikkeling, en kennisbenutting naar industrieën. Door de impact van dit onderzoek, kon ik de maatschappij laten zien dat design een essentieel element is in het opbouwen van digitale gezondheid.

Summary in Korean: 요약

본 박사 논문에서는 데이터 수집 및 분석 기술의 급진적인 발전 속에서 디지털 헬스(Digital Health)에서의 디자인 활동이 나아가야 할 방향과 미칠 영향에 대해 크게 세 가지 지식 범주, 즉 1) 디자인 비전(Design Vision), 2) 지식 생성 접근 방식(Knowledge-generating Approach), 3) 디자인 도구(Design Tool)로 나누어 논의하였다.

1장에서는 데이터 수집 및 분석 기술에 기반한 집단 컴퓨팅 시대(Collective Computing, 다양한 컴퓨팅 장치를 통한 대규모 사회적 상호 작용의 복잡한 시스템의 초연결 시대)의 디자인 활동을 구상하고자 하였다. 문헌 검토와 informant 인터뷰를 바탕으로 다가올 시대의 디자인 활동(디자인 과제, 디자인 프로세스, 디자이너의 역할) 변화를 제시하고 이를 수용하기 위한 디자인 가이드를 제공하는 ‘디자인 비전(Design Vision)’을 개발하였다. 결과적으로, 이 디자인 비전은 집단 컴퓨팅 시대의 디자인 작업이 ′복잡한 시스템(Complex Systems)′을 디자인하고 ′실험실로서의 사회(Society as a Lab)′ 내에서 이 시스템을 탐구하는 방향으로 이동한다고 제안한다. 이 디자인 가이드는 디자이너가 커뮤니티를 다루고 데이터 수집 및 분석에 참여함으로써 이러한 작업에 접근할 수 있다고 제안한다. 또한, 디자인 과정 측면에서는 디자인 문제와 솔루션 공간의 ‘동시 탐색(Co-exploration)′의 중요성을 강조한다. 이러한 변환을 위해 디자인 가이드는 디자이너가 혼합 데이터의 유연한 조합 및 분석을 기반으로 작업하고, 시스템 수준에서 사회적 힘에 대해 작업하고, 모듈식 디자인(Modular Design)으로 소프트 런칭(Soft Launch)을 통해 디자인 프로세스를 가지도록 제안한다. 마지막으로 디자이너의 역할에 있어서 ′책임 있는 구현(Accountable Implementation)′의 수행을 강조한다. 즉, 이 비전은 디자이너가 디자인 결과물의 가치와 제어에 대한 초학문적 비전을 통합하여 책임 있는 구현에 접근할 것을 권장한다.

2장에서는 헬스 개입 개발(Health Intervention Development) 영역에서 이전 장에서 개발된 디자인 비전의 핵심 내용을 실현하기 위한 ‘지식 생성 접근 방식(Knowledge-generating Approach)’을 연구하였다. 이 접근법은 의학연구 분야에서 디자인 연구의 수용성을 높이는 것을 목표로 한다. 이 연구는 Design Council과 Medical Research Council의 복잡한 개입(Complex Intervention)을 개발하는 데 선호되는 프레임워크(Framework)의 핵심 강점 분석을 바탕으로 수행되었다. 이 연구는 디자인의 핵심 강점이 ‘디자이너의 판단 유예(Deferral of Designer’s Judgement)’에 있음을 보여주는데, 이는 개인 수준의 실제 경험(In-situ Experience) 데이터를 사용하여 문제 영역과 솔루션 영역을 반복적으로(Iteratively) 재탐색하고 재조사하는데 기반한다. 의학 연구에서 핵심 강점은 주어진 문제 영역에서 과거의 연구와 비교하여 ‘개선을 측정(Measuring Health Improvement)’하고, 이를 전인구 수준의 기존의 과학적 행동 데이터

(Existing Scientific Data)를 사용하여 수행하는 것에 있다. 이러한 해석을 바탕으로, 헬스 개입 개발 영역에서 필요한 새로운 디자인 지식 생성 접근 방식을 제안하였다. 이 접근 방식은 커뮤니티 수준(Community-level, 개인 및 전인구의 중간 규모)에서 수집된 경험 데이터(Existing People's Experience Data)를 사용하여 두 프레임워크의 핵심 강점을 통합하였다. 더하여, 이 장에서는 이러한 접근법을 채택하여 헬스 개입 개발 (Health Intervention Development)한 두 가지 디자인 프로젝트에 대해 자세히 설명하고 두 프로젝트가 끼친 사회적 영향의 결과를 설명하였다.

3장에서는 이전 장에서 제시한 통합적 접근 방식에서 디자이너가 '커뮤니티 수준에서 수집된 경험 데이터(Existing People's Experience Data at Community Level)'를 활용할 수 있는 디자인 도구를 개발하였다. 환자의 경험과 관점을 헬스케어 디자인에 통합하기 위한 가장 일반적인 디자인 도구인 환자 여정 지도(Patient Journey Mapping)가 도구 개발의 기반이 되었다. 환자 경험은 치료의 질을 개선하고 의료 비용을 줄이는 데 유용한 정보를 제공한다. 그럼에도 불구하고 환자 여정 지도 개발을 위한 기존의 방법은 시간과 노동 집약적(정성적 데이터 기반)인 특성으로 인해 한정된 수의 데이터만 포함한다. 본 장에서 개발한 'Patient Community Journey Map' 디자인 도구는 블로그, 포럼 게시물과 같은 온라인 환자 경험 스토리(Story)에 텍스트 마이닝(Text Mining)을 적용하여 이러한 한계에 대한 해답을 제시한다. 이를 통해 광범위한 환자 모집단의 경험을 치료 경로, 제품 및 서비스 개선에 효과적으로(그리고 비용 및 노동 효율적으로) 포함시켰다. 이 도구는 커뮤니티 수준에서 수집된 경험 데이터를 활용하는 새로운 데이터 기반 (머신 러닝) 디자인 도구가 될 것이다. 궁극적으로 디자이너는 시간과 비용 투자를 줄이면서 헬스케어 디자인 분야의 복잡한 맥락에 대한 거시적인 관점을 얻는 동시에 환자 경험에 대한 정성적인 이해를 얻을 수 있었다. 더해서, 이 장에서는 종양학 분야에서 'Patient Community Journey Map'을 사용한 헬스케어 디자인 프로젝트를 자세히 설명했다.

종합하면, 이 논문에서 탐구하고 개발한 디자인 비전, 지식 생성 접근 방식 및 디자인 도구는 이미 다양한 분야의 교육, 연구 및 개발 협업, 산업에서의 지식 확산 부문에 경제적 그리고 사회적 영향에 기여하고 있다. 이 논문에서 생성된 지식의 영향을 통해 디자인이 디지털 헬스(Digital Health)를 구축하는 데 있어 필수적인 요소임을 사회가 인식하는데 기여할 것으로 기대한다.

List of publications

Journal paper (During PhD)

- **Jung, J.,** Kleinsmann, M., & Snelders, D. (2022). A vision for design in the era of collective computing. *Journal of Engineering Design*, 33(4), 305-342.
- (Under review, *a peer-reviewed design journal)* **Jiwon Jung,** Dirk Snelders, Judith Rietjens, Maaike Kleinsmann. Integrating public health knowledge to design activities: for developing complex interventions
- (Under review, *a peer-reviewed design journal*) **Jiwon Jung**, Ki-Hun Kim, Tess Peters, Dirk Snelders, Maaike Kleinsmann. Advancing design approaches through data-driven techniques: Patient community journey mapping using online stories and machine learning

Conference paper (Before and During PhD)

- **Jung, J**., Kleinsmann, M., & Snelders, D. (2019, September). Reviewing Design Movement Towards the Collective Computing Era: How will Future Design Activities Differ from Those in Current and Past Eras of Modern Computing. In *International Association of Societies of Design Research Conference*.
- (Short paper) **Jung, J.,** Yoon, S., Kim, S., Park, S., Lee, K. P., & Lee, U. (2016, May). Social or financial goals? Comparative analysis of user behaviors in Couchsurfing and Airbnb. In Proceedings of the 2016 CHI conference extended abstracts on human factors in computing systems (pp. 2857-2863).
- (Short paper) **Jung, J**., & Lee, K. P. (2017, May). Curiosity or certainty? A qualitative, comparative analysis of Couchsurfing and Airbnb user behaviors. In *Proceedings of the 2017 CHI Conference Extended Abstracts on Human Factors in Computing Systems* (pp. 1740-1747).
- (Short paper) **Jung, J.,** Nam, H., Lim, Y. K., & Lee, K. P. (2017, June). Beauty and the beast: an IoT design method based on improvisational acting. In *Proceedings of the 2017 ACM Conference Companion Publication on Designing Interactive Systems* (pp. 61-66).

Acknowledgement

I would like to start my doctoral dissertation acknowledgement with the same sentence as my master's thesis acknowledgement.

> *"For the great doesn't happen through impulse alone, and is a succession of little things that are brought together."*

This sentence is from Vincent van Gogh's letter to his brother, Theo, in 1882. I had never known that I will conduct my PhD research and even pursue my further career in the country of my favourite artist. What a wonderful life it is!

As Vincent writes, this 'great' finish of PhD research journey does not happen through impulse alone but is achieved through all the little things during PhD journey.

The most important 'little things' are support and trust (but, they are not 'little' at all!) that I have had from my supervisors, colleagues, students, friends, and family. To remember that I am here because of their support and trust, I write short words of my appreciation to them on this page.

First and utmost, I appreciate my PhD supervisors: Maaike Kleinsmann and Dirk Snelders. You are the best supervisor and guide I could ever have had. I could satisfy my academic curiosity about design as a discipline through your actively shared knowledge. At the same time, you gave me enough room that my research to include my true interest (data-enabled design), not just focused on the given project scope. You have provided me a strong root to be a societally impactful 'designerly' researcher and educator (rather than just focused to publish papers). Because of your sincere supervision, I could become a visionary and scientific design researcher to contribute my knowledge to this society. My PhD experience with you was the best moment of my life to grow myself into who I always dreamed to become. The reason that I can be confident about what I am doing is all because of your trust and support towards me. This acknowledgement space is never enough to describe all my appreciation to you. Thank you so much!! I will grow as a good design academic researcher to be just like you.

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Next to my supervisors, I appreciate my students utmost. They trusted my designerly way of working and researching. Integrating design and data science in the field of healthcare is not a common or not-yet well-known concept to designers and computer scientists. However, all my (both design and computer science) students trusted me and actively explored data-enabled design in healthcare together. Ward Hendrix, Hosana Morales, Tess Peters, Ruixuan Zhang, Rembrandt Oltmans, Yingtao Sun, Ayush Patandin, Heleen Kicken, and Bhavika Dhar. Because of your input and creativity shared during your graduation projects and research elective courses, this doctoral thesis could be made! Thank you all for trusting me and my knowledge!

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2023 April 1
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About author

Jiwon Jung was born on February 4, 1992 in Seoul, Republic of Korea.

Jiwon did her PhD research at CardioLab, Faculty of Industrial Design Engineering, Delft University of Technology (TU Delft). CardioLab is a research collaboration between Philips Experience Design and TU Delft. It further has support from Dutch Heart Foundation (Hartstichting). Jiwon was supervised by Professor Dirk Snelders and Professor Maaike Kleinsmann (director of CardioLab). Also, she was supervised by industry supervisor, Jeroen Raijmakers (Senior Director from Philips Experience Design).

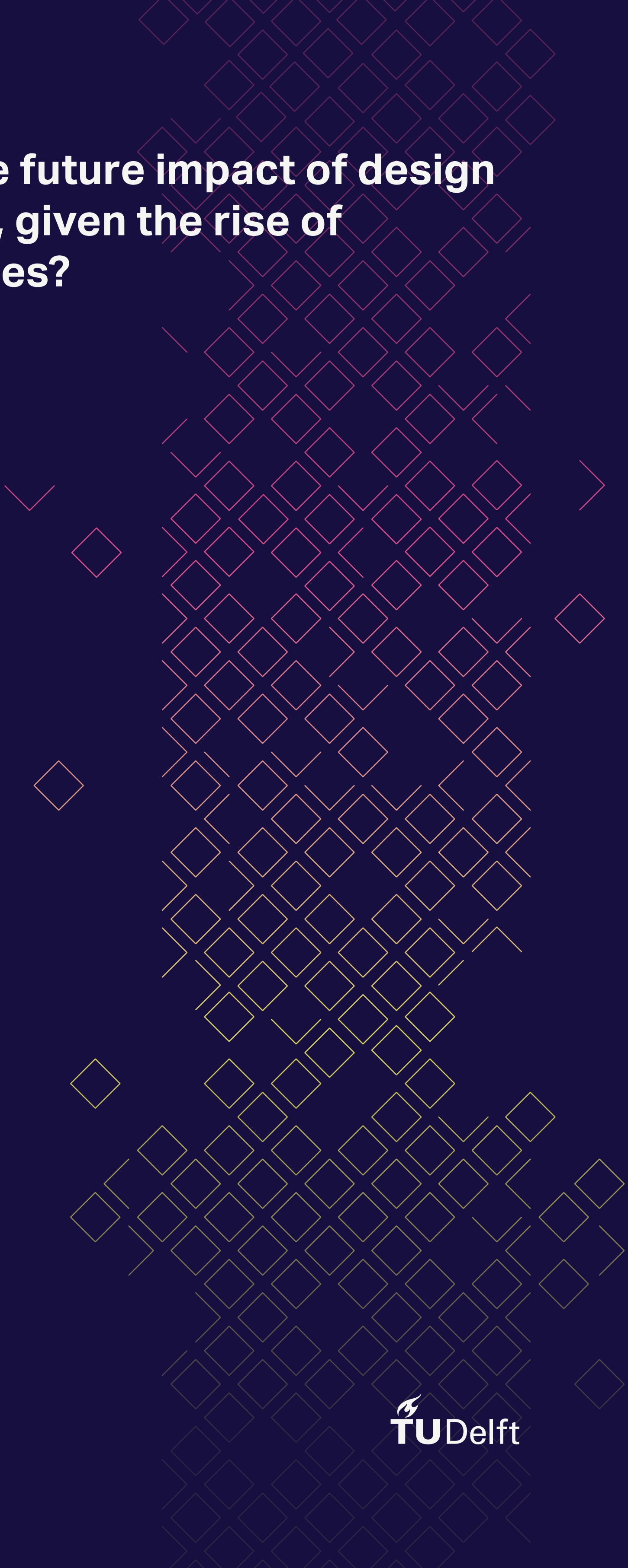
Before her PhD trajectory, Jiwon graduated (research master) with a master of science (M.Sc.) in industrial design at KAIST (Korea Advanced Institute of Science and Technology) in 2017, with Korea National Scholarship (국비장학생). Jiwon was supervised by Professor Kun Pyo Lee, an honorary fellow of the Design Research Society, at the Human-Centred Interaction Design Lab (HCIDL), a world-leading design research lab that studies user experience through developing user-centred design research methods and tools. Jiwon's master thesis is called '*Design Tool Development for Non-Monetary Accommodation Sharing Platforms: Understanding Couchsurfing User Behaviors for Profiles and Stay Requests.*'

Jiwon did her bachelor's study at Korea University (Seoul) with double majors in Industrial and Information Design (B.F.A.) and Business Administration (B.B.A.) in 2015. She received an International Baccalaureate (IB) Diploma from Shanghai American School with an Extended Essay on design (graduation thesis titled '*The Importance of Design in the Modern Society*') in 2010.

Jiwon is currently working full-time as a scientific researcher at the Surgery Department, Erasmus Medical Center (ErasmusMC). She belongs to the Consultation Room 2030 flagship program, a convergence research consortium between TU Delft, Erasmus Medical Center, and Erasmus University of Rotterdam. Her research aim is to identify essential patients' encompassing needs in designing a remote patient monitoring system throughout various disease types and contexts. She employs machine learning (natural language processing), patient stories, and design knowledge. Jiwon has started her exploration with three different types of patient groups: colorectal cancer, pulmonary fibrosis, and sarcoidosis in order to find encompassing needs. Professor Joke Hendriks (Head of the Surgery Department and Consultation Room 2030) is the main supervisor of the project. Professor Richard Goossens (TU Delft, Convergence health & Tech), Dr Dirk Grünhagen (Cancer Institute), Professor Kees Verhoef (Cancer Institute), and Professor Marlies Wijsenbeek (Respiratory Medicine Department) provide the disease- and context-specific supervision. For this research, Jiwon has constructed the interdisciplinary research collaboration between ErasmusMC medical experts, TU Delft Faculty of Industrial Design Engineering, TU Delft Faculty of Electrical Engineering, Mathematics and Computer (Dr. Jie yang), the Library Repository team (data analysis group, Nick Jelicic) of the Erasmus University of Rotterdam, and the patient communities.

Jiwon is an initial inventor for Patient Community Journey Mapping that is used as the centre of the business for a pre-incubating start-up, Qaring. Jiwon serves on an advisory board for the company. Qaring runs by three enthusiastic entrepreneurs: Tess Peters, Oskar Zakrzewski, and Shreyan Biswas with successful progress.

Jiwon is also a young board of 'Healthy Start' research networks to foster research collaboration opportunities for early career researchers between TU Delft, ErasmusMC, and the Erasmus University of Rotterdam. Healthy Start aims to explore the early-life origins of disparities in health and well-being from a transdisciplinary perspective.



What can be the future impact of design in digital health, given the rise of data technologies?

DEVELOPING DATA-ENABLED DESIGN IN THE FIELD OF DIGITAL HEALTH

Jiwon Jung
2023