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STAKEHOLDER INVOLVEMENT IN GENERATIVE CO-DESIGN FOR DIGITAL HEALTH

Stakeholder involvement in generative co-design for digital health

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Stakeholder Involvement in Generative Co-design for Digital Health

Het betrekken van belanghebbenden in generative co-design voor digitale zorg

Thesis

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Prologue

As a matter of direct experience, having been diagnosed with leukemia at the age of 14 radically changed how I lived my life, and it changed how I look at healthcare.[1]

Fundamentally this experience engraved a question in my mind which led me to this PhD project: Why are patients suffering due to problems with the health system and how can this be improved? This question was difficult to answer. I started to tackle it in practice by teaching patients and care professionals philosophical tools. I realized that the philosophical, emotional, and existential problems I wanted to solve for young adults with cancer were much bigger than I thought. In fact, the entire healthcare system seemed to lack this deeper human approach and I realized that I could not solve these challenges on my own. My philosophical background prompted me to ask deeper questions and to look beyond the existing health systems and scientific culture and towards future solutions including digital health applications. I knew that these complex problems would have to be tackled in a collaborative way with the relevant stakeholders, patients, care professionals, technology experts and many more. So when I heard about a PhD opportunity at Erasmus School of Health Policy and Management about co-creation and eHealth in early October 2017 it sounded like the perfect chance to explore how that could be done. Even though I feared I might end up being a lonely academic in a dark office, thankfully this PhD journey turned out to be immensely rewarding both on a personal and on a research level. So I want to thank both dr. Marleen de Mul and Prof. dr. Antoinette de Bont, for having given me this wonderful opportunity.

Before jumping into the content of my research I want to give some context to the bewildering but fantastic PhD trajectory. For the unexperienced it may look like a linear process of years of planned work, but it was not. There were a lot of challenging uncertainties but there were a great number of beautiful detours, tough hurdles, quick pit stops and adventures. I feel infinite gratitude towards everyone involved to have been able to experience them. Just to name a few of these events: I had inspirational conversations at conferences about young adults in The Netherlands, Belgium, USA and Australia. I also talked to digital health researchers and industry partners in Sweden and Saudi-Arabia and I met incredibly interesting people at creative design thinking training events such as the training at the Hasso Plattner Institute.

My research curiosity about the interactions between people in collaborative processes had always been there since my studies in philosophy and health economics, policy and law and my experience as a consultant and workshop organizer in London. But during my PhD, my attention drifted towards the black box or the magical moment of these interactions between

1 [♪] to transfer the emotional gravity beyond the text, please listen to “Summer 3 -2012 by Max Richter” (see also on the spotify playlist “Stakeholder involvement in generative co-design for digital health (Original Manuscript Soundtrack)”

people. I wondered about the spark that gave people new ideas. I was particularly inspired by what world leading Chef Grant Achatz said:

> "Early on in Alinea, we had this realization that there are other disciplines that we can draw on for inspiration. We would go to art galleries, and you would see these giant-scale pieces of art. And I would always say: Why can't we plate on that? It frustrated me that chefs were limited to scale that was determined by plate manufacturers. Why not a tablecloth…that we can eat off?' (Chef Grant Achatz, Netflix episode of Chef's Table)"

I wanted to gain a better understanding of how people got inspired by others to new mind-blowing insights of an entirely different order. The role of art has different meanings here, which I now realize have all inspired me. Firstly, art is limitless so artistic work can inspire us with endless possibilities. Secondly, anything can be transformed by others into something new during an artistic activity. Actually, when you start to realize the scale and the opportunity of co-creation it becomes incredibly exciting to work together with others and think about challenging problems in healthcare. Art can be a facilitating activity in this sense but a piece of art in many different forms can also stimulate one to think in a different way. I wanted to hone in on this process of new idea generation, which lingered on the border between art and science.[2]

Naturally, I struggled to get a grasp on this field which belonged both to the world of the artists and the scientists. I started with design research, particularly human-centered design. In Chapter 2 I used the term *generative participatory design* as participatory design is predominantly used in research about the development of digital health. I added the term generative to the term participatory design to indicate the creative exercises, in which stakeholders are involved in GCD. In Chapter 3 I used the term *participatory design* to refer to design practices with active stakeholder engagement and sometimes creative exercises. Further, in Chapter 4 I used the term *design thinking* to describe a minimum viable version of GCD. Finally, I settled on the term generative co-design (GCD) to follow the terminology of Sanders & Stappers, given that I am focusing on a theoretical foundation in that field and by adding the word 'co' to emphasize the strong collaboration between stakeholders (see Introduction).

Besides defining the field, articulating a research question was equally challenging. Initially, I started with a broad research question 'How is GCD applied to develop digital health in scientific research publications and in GCD practice?'. As I found that the choices about stakeholders and outcomes were much less justified compared to the tools, I started to focus the exploration phase on the role of stakeholders. The purpose of the research in this phase was beyond exploring how GCD is used in care practice to provide lessons to use GCD to the

2 [♪] To guide you towards Figure 2, please listen to "The Expanse by Clinton Shorter"

Figure 1: Tate Modern let visitors transform the floor of the Turbine Hall into a giant work of art (Photo from Andrea de Santis on Unsplash)

adolescent and young adult with cancer research community, given that there is a growing interest to use design approaches in healthcare. In addition, I wanted to learn more about the GCD practice. I took the opportunity during Covid-19 to help develop a video consultation in a hospital setting of my father (which was a great experience as my father went on pension soon after that). There I used a minimally viable form of GCD as a design thinking process which involved indirectly different stakeholders. As such, I did not directly focus on the role of stakeholders, but it helped me to explore better how GCD is used in practice. Eventually, the initial research question of the exploration phase was reformulated into: 'How are stakeholders involved in GCD to develop digital health?', which became the broad overarching question of this thesis. I am grateful to everyone who helped me along this process, as I only name a few here in the prologue.

My iterative research approach facilitated the explorative process. Even though the chapters of the exploration phase and creation phase are ordered in a chronological way both phases started almost simultaneously. I realized from the beginning that a theoretical foundation was missing, even though I was not sure what aspects of theory were precisely missing and what kind of theory would be useful to design or healthcare researchers. Intuitively I wanted to focus on epistemology as the field of philosophy, which occupies itself with the development of knowledge. I was inspired by the quote of the physicist David Deutsch:

> "Anything is achievable, within the laws of physics, given the right knowledge." (David Deutsch, The Beginning of Infinity: Explanations that Transform the World)

To get a better grasp on the theoretical foundations I spoke for instance with prof. dr. Pieter-Jan Stappers, who wrote a key book about GCD. He introduced me to research through design and literature about the theory of participatory design. At this time, I also went back to my philosophy background, and I started to explore the literature on epistemology, logic and philosophy of scientific discovery. My theoretical reflections continued, and my growing theory was initially a by-product of Chapter 3 where I started to make visualizations of the GCD process and attempted to make the role of diversity more explicit.

These theoretical insights turned into what is now Chapter 5. However, it was not easy to get the paper published. Design Studies rejected the paper after a round of revisions as the authors could not fully grasp where my contribution fit with design theory. They also seemed to have a different understanding of the terms of philosophy of science I was wielding. I revised the paper substantially together with my supervisors and increasingly started to engage with philosophers and designers to find the silver lining for effective communication as I was looking for the most useful vocabulary. However, this was not easy. It was tough to find philosophers who were working in applied scientific discovery on collaborative processes. Some of the philosophers

I wanted to build on were Prof. dr. Batens, who taught me when I was at the University of Gent, and Prof. dr. Nickles, but both were already emeritus. However, this path of philosophy (or Tao) further guided my research into the broader field of logic and philosophy of science. As I started to realize that the field of scientific discovery and the early insights of Batens had not been further developed I started to collaborate more intensely with a multi-disciplinary philosopher and friend, dr. Job Timmermans, who has experience with philosophy of science, technology, and co-design. I went back and forth between him, design researchers as prof. dr. Ann Heylighen and prof. Dr. Maaike Kleinsmann, and health researchers to find out how I could crystallize my contribution and describe it in a way that people from different disciplines would understand. Due to Covid-19 and the timing of my theoretical work, I did not manage to present it at scientific conferences, however I did present it in a research seminar at TU Delft and at a research seminar at my own faculty of Health Services Management & Organization. This further helped me to revise the paper and submit it to the journal of Co-Design, where it was rejected as a paper, because it was considered too theoretically focused and did not fit the empirical nature of their research. This highlighted to me that current design research journals were not focusing on interdisciplinary theoretical research as much as I had hoped. Eventually I revised the paper as a theoretical paper and submitted it to a theoretically oriented design journal called Design Issues.

After the exploration phase and during the creation phase, I wanted to test the prototype of my GCD stakeholder theory, however it was still a long way from being an operational procedure. That is why in Chapter 5 in the theoretical paper I already attempted to make the first step and provide some suggestions to use these theoretical insights to recruit stakeholders. In the testing phase in Chapter 6 I finally tried to operationalize the theory in a full procedure. This process of operationalization helped me further to refine the theory in Chapter 5 and therefore there was a strong iterative process between Chapter 6 and Chapter 5. So the entire process included many zigzag movements and circular movements, which I hope you may recognize in each chapter if you keep this prologue in the back of your mind.

[3]Throughout my PhD trajectory I had the support of many people, which I would like to thank from my heart. In the first place the continuous support of my supervisors, Prof. dr. Antoinette de Bont and dr. Marleen de Mul. You both helped me in a great complementary way to finish this fantastic project. We really grew into a great team. Antoinette, you always helped me to stay afloat and look at the bigger picture and you taught me to carefully listen to others. Marleen, you were great at inspiring me to explore many research directions and you helped me to get a grip on big tasks and my daily work. I also want to thank both of you for helping me stay true to my mission which is to assist patients in daily care practice and in particular young

3 To accompany my laudations please listen to Rossini's ouverture (Sinfonia) of "L'Italiana in Algeri"

adults with cancer. It was wonderful to experience that you also gave me the freedom to build further on my background in philosophy.

In addition, I want to thank all my colleagues of Erasmus School of Health Policy and Management. Thank you Kees for supporting me in my PhD process when I needed a wise mentor and with my fantastic academic visit at Politecnico Milano, where I met Prof. Giuseppe Andreoni. Thank you also to all other colleagues and visiting scholars as prof. Steven Howard I met at the department. Thank you Thomas Reindersma for helping lift up the day with interesting research facts (patio and non patio related), funny jokes and inspiring coffee conversations. Thank you dr. Kasia Tabeau for your help to get on track with co-design research. Thank you dr. Isabelle Fabricotti, dr. Jeroen van Wijngaarden, prof. Anne Marie Weggelaar and dr. Hilco van Elten for mentoring me along my path. Also special thank you to Hilco for the extremely dry humor, metal shirts Monday and tasty tosti lunches. Thank you also to the colleagues who moved on as Mathilde and Kirti for helping me find my way as I just started with my PhD. Thank you also to colleagues from the other departments as Frederick Thielen for the inspiration and your support at my NRC Live event in Utrecht. Next to my direct colleagues, I want to thank my in-direct colleagues and brothers in health A.F.A.D. Schauwvlieghe MD (PhD cum laude) and Bernard Schockaert MD. Many times we found ourselves dining in a beautiful restaurant (once a star restaurant) in the center of Rotterdam pondering about life, the universe and everything, which I truly enjoyed. Alex, I was always fascinated about how you took the care for patients so close to your heart. I am also very happy I could confide in you being a nomad PhDer yourself and being able to mutually benefit from unexpected sleepovers in each other's places (in my narrow hallway in Rotterdam, in hotels or in a guest room).

To my beautiful wife Lucrezia: you helped me see through the chaos and see the bright side of things so that I could make very important but difficult decisions. My lovely son Raffaele-Raoul helped me in the last stages to reinvent my workflow and sleep pattern and see the benefits in how this can help me be more creative. Thank you, dad, for being a great fan of my work and even wanting to do research together and become a co-author. Thank you, mom, for having (subtly) suggested that I could actually put aside my prejudice to do a PhD and convince me to start this great adventure during our trip in Capri. Thank you to my brothers and sister for frequently asking me what in the heavens I was constantly doing, this helped me to explain myself and find reason in chaos. Christophe, a sub-species of homo universalis, without you, the world would be a little darker and more serious place. Thank you for helping me get through the Covid lockdown with our jolly 'critical coffee considerations' (check the YouTube channel!), thank you for keeping the philosopher inside me alive and for the many inspiring walks we took in Venezia, Brugge, Gent, Brussels, Medina, Antwerp, Rotterdam (see the Erasmus University sponsored, Co-Design Health podcast) and Delft. Thank you to my best man and innovation expert, Jasper for our inspirational conversations in Amsterdam about innovation, startups, good food, board games, thank you for giving a guest lecture for our course on Health technology innovation and thank you for those awesome recommendations for science fiction books. Thank you, Thomas Arnout, for our great times in Stockholm and Brugge and inspiring me for the international working life. Thank you, Frederick Persyn, for our many conversations about digital innovation, AI, startups and how the future might change because of these developments. And thank you Sophia for the many retreats, with all the other great people at your wonderful villa in Italy!

Finally, I also realized that I am most creative and productive in an inspiring environment, that is probably why I enjoyed working while traveling around the world during my PhD in buses, trains (including Thalys) and airplanes, lobbies, bars and restaurants. For that reason, I would also like to thank all the people I met during my travels around the world in Belgium, Germany, Sweden, Italy, Atlanta (US) and Sydney (Australia).

CHAPTER 1

General Introduction

Even though digital health, since the Covid-19 pandemic, has proven itself essential in rapidly transforming care, it continues to have a troublesome legacy. In this thesis, we focus on the challenges involving the roles of various stakeholders who are directly and indirectly involved in digital health development.

The World Health Organization promotes digital health, defining it as: the development and use of digital technologies such as Internet of Things, advanced computing, artificial intelligence including machine learning, and robotics to improve health [1]. Digital health is considered to be promising in making healthcare systems more sustainable by, for instance, allowing care to be delivered over long distances as indeed became clear during the Covid-19 pandemic [2,3]. It may also provide a means for prevention, self-management, and improved decision-making [4–6]. The expected high value of digital health applications with, for instance, artificial intelligence has led many to speculate, perhaps rightly so, about various useful opportunities [5–10]. This has led to a rush to pluck these technologies from the market and implement them in care practice. However, some of these technologies were not originally designed to improve care. For instance, artificial intelligence was originally built solely for computational challenges [11,12], and if artificial intelligence algorithms were to be directly used in care systems they would not tackle the complex problems facing stakeholders in such settings. Further, even though evidence increasingly suggests a positive impact of digital health, robust evidence to support the claimed improvements in the quality and safety of care has been lacking [13]. There have also been negative effects reported concerning large-scale costly technologies, such as electronic medical records, which have disrupted interpersonal relationships [7] and increased the administrative burden on care professionals, which has fostered burnout [14,15]. In addition, this has led some authors to criticize the hasty implementation of digital health as a quick fix without considering the ethical implications [16,17]. This raises the question: how can digital health be successfully implemented such that problems are solved for a range of stakeholders?

In this respect, researchers from the field of human-centered design have become increasingly interested in involving patients and care professionals in the development of digital health [18–20]. In the field of human-centered design, Generative Co-Design (GCD) is considered to be especially promising as stakeholders are actively involved from the very beginning in the making of products and services, ensuring that their needs are taken into account [19–23]. A key hypothesis is that involving stakeholders is crucial as they provide important knowledge about their needs, which would otherwise be overlooked [2,4,18,20,21,24–26]. Therefore, several authors claim, since the needs of stakeholders are better expressed through a co-design process, that they can be better addressed in digital health solutions, for example through user guidance, specific reminders, and personal tracking [27–30].

Even though it would seem that stakeholders could play a key role in GCD and so improve digital health, there is little evidence to support the involvement of stakeholders in the field of co-design [31,32]. More broadly, Badke-Schaup et al. [33,34] have stressed that the lack of solid evidence supporting design practice is widespread in design research.

Although there have been attempts to clarify the contribution of stakeholders in the broader field of co-design, this has not been very rigorous. For instance, Steen et al. [28] argue that there are benefits of co-design on the whole, but without specifying the contribution of stakeholders. Further, their findings are based on case studies, of which only one is about healthcare. Pirinen [35] interviewed co-design stakeholders such as healthcare organizations and highlighted the enabling role played by individually committed stakeholders. However, this was not further empirically evaluated, and no theory was proposed that could evaluate how stakeholders could influence the co-design process and its output. DeSmet et al. [36] did evaluate the contribution of stakeholders in the co-design literature on serious games and failed to find a significant effect. Again, no theory was described to evaluate the involvement of stakeholders in the co-design process. To conclude, there have only been a few studies evaluating the role of stakeholders in co-design, and these do not specifically address the contribution of stakeholders. As such it is unclear *how important* stakeholders are in GCD, even though they could play a vital role in digital health development.

Further, when considering the scientific evidence regarding GCD, and in particular stakeholder involvement, researchers from health services and from design have different perceptions of the required evidence. Health service researchers and care professionals typically prefer evidence-based medicine [37] and are used to a specific type of evaluative evidence, such as randomized controlled trials and systematic literature reviews. Both these study designs have rigorous selection procedures for involving specific patients and literature, which are then transparently reported. Consequently, health researchers expect to find well-documented validated GCD approaches, including the role of stakeholders, which can deliver carefully developed and rigorously evaluated digital health interventions. However, in design research, there is generally still a large reliance on case studies both in the use of methods and concerning the results of the design process [32–34,38,39]. From the healthcare research perspective, this type of evidence is traditionally considered to be of low value as there is little room for extrapolation to a large patient population group or a different setting. Therefore, from a scientific evidence perspective, there remains a large challenge in communicating the effectiveness of GCD, and the resulting digital health products and services, from design research to health research. To start to bridge this gap, a first step would be to establish a more robust theoretical foundation for stakeholder involvement in GCD.

In this thesis, we take this first step by exploring the importance of stakeholders' GCD contributions in developing digital health. Based on these insights, a theory can be developed that could then help in evaluating the contribution of stakeholders in a scientifically rigorous approach. This route may appeal to health researchers and design researchers wanting to improve digital health.

1. DEFINING STAKEHOLDER INVOLVEMENT

Early in the process of developing digital health through GCD, choices have to be made about which stakeholders to involve. These decisions can have a significant impact on the GCD process and the resulting digital health product or service. However, there are both practical and conceptual challenges when involving stakeholders in the development of digital health that raise theoretical questions.

Practical challenges to involving stakeholders relate to the difficulties in gaining trust, managing multiple stakeholders, and time pressures when trying to involve patients and physicians [35,40–44]. Next, there are conceptual challenges regarding definitions of the words stakeholder and involvement as there are various interpretations. Each of these interpretations is related to broad normative principles, and these may contradict each other. Therefore, it is theoretically challenging to define what 'stakeholder' and 'involvement' mean and, given the difficulties, to formulate a coherent definition that could be respected in GCD practice. Therefore, we first provide a brief historical background of co-design as this has a strong influence on how we understand the words *stakeholder* and *involvement* in GCD. Following this we provide a working definition for use in this thesis.

1.1. Noble yet vague historical heritage

When authors from collaborative design traditions argue that stakeholders should be involved in the development of digital health, there is a strong reference to the history of participatory design (PD). The PD tradition highlights several normative values, such as democracy, equalizing power relations, mutual learning, and situation-based action, that have become enshrined in PD practice as described by Luck and by van der Velden and Mörtberg [45,46]. This influences how stakeholders should be selected, and how they should be involved in PD, and this is reflected when it comes to stakeholder involvement in the more specific field of GCD.

PD principles of democracy and equalizing power relations were developed after a period in Scandinavia when workers became dissatisfied because they were not involved in the design process [20,45,46]. This political movement started in the 1970s in Scandinavian countries [20,21]. After realizing that workers had little influence on their working conditions, researchers and workers joined forces to re-design their working situation. The aim was to re-establish equal power relations and democratize working environments in which stakeholders are actively involved in the process of developing a solution.

These historical roots of PD have led to the involvement of both designers and non-designer stakeholders in GCD, and the normative belief that they should be able to do so as acknowledged members of the team as 'experts of their experiences', given appropriate tools to express themselves [47]. Implicitly, in this way, GCD strives to increase diversity of experience, values, and knowledge. This includes giving a voice, and decision-making power, to those who may be invisible or weak in the community's power structures. In a care environment, this could be seen as relating to patients [45]. Further, this democratic involvement of those affected by the problem is believed to foster trust among those involved, to facilitate a learning process, and a commitment to taking responsibility for each other and the design result.

These democratic motivations are related to the PD principle of situation-based action [46,48–50]. Situation-based action is based on the assumption that the activities of people are always performed somewhere as an interaction between people and objects such as digital technologies and are, therefore embodied, and situated. In addition, it is assumed that every design situation is unique and, when tackling a design problem, one should involve specific expertise on the day-to-day activities of affected stakeholders.

Based on PD roots, these values seem to be implicitly respected in GCD as both designers and non-designers, affected by a design problem, can be involved. Especially for the non-designers, there is a strong emphasis on the creative ability of every person [21,51]. However, it is not clear which non-designers are best suited to participate in a GCD project. This begs the question as to how far values such as democracy can be stretched. Further, the principle of situation-based action might conflict with the democratic principle. For instance, when following democratic values, it would be seen as noble and ethically responsible to involve a stakeholder with a low education level. However, this stakeholder's understanding of their situation and their ability to express their ideas may significantly influence the GCD process. These questions are generally left unanswered. More generally, even when agreeing in principle with these values, the question remains as to which type of stakeholders, with which knowledge, should be involved in a specific GCD project.

1.2. A broad working definition

We define GCD stakeholders in a broadly similar way to co-design scholars but we want to avoid labelling all stakeholders as co-designers or users, and adopt a broader definition given the various types of stakeholders involved in a healthcare setting.

Users, or future users, are those people who are currently using a product or service, which is being developed, or who may use it in the future [20,52]. However, the term user is too narrow given the various people who are involved in the digital health process from idea generation to implemented solution, and then when it is in use. Various, indirectly involved, stakeholders have also been suggested as playing vital roles. For instance, the rapid uptake of digital health consultations during the Covid-19 pandemic was considered to be due the improved alignment between financial and policy stakeholders [3,53]. Therefore, in considering the democratic value, we define a stakeholder as someone who is directly or indirectly involved in the development, use, or management of, or who is affected by, digital health [21,46]. They could be involved in the development of digital health as a designer or software developer. They might use digital health solutions, or may be potential future users, such as patients or care professionals. Further, they might be people who are directly or indirectly managing digital solutions such as hospital managers or policymakers.

In addition, following the principle of equal power relations, one aspires for equal contributions from the stakeholders in the GCD process. Finally, adopting the situation-based principle, a stakeholder in this thesis is someone who takes part in a GCD process that is aiming to develop digital health products or services.

To summarize, we define a GCD stakeholder as someone who is directly or indirectly involved in the development, use, or management of digital health and who is expected to play an equal role in the process of developing digital health products and services.

2. ARE STAKEHOLDERS IN GCD FORGOTTEN?

GCD is a collective creative and iterative process whereby stakeholders actively participate in the development process, through creative exercises that allow them to express their deeper needs, to develop a product or service [21,22,51,54,55]. Based on this definition of GCD, we can offer three key reasons why GCD is a promising approach to developing digital health. First, stakeholders are actively involved, giving them plenty of opportunity to express their ideas. Second, GCD is an iterative process that focuses on the early innovation phase and therefore enables stakeholders to impact the development of digital health from the start. Third, GCD focuses on leveraging stakeholder knowledge through creative exercises. This allows stakeholders to express their deeper needs, and these may have a significant impact on the project. Stakeholders play key roles in all these good reasons for using GCD to develop digital health. Despite this, the literature pays little attention to the specific roles of stakeholders in GCD. In this section, we will now briefly describe the position of stakeholders in GCD research and practice.

2.1. GCD research and practice

GCD can be both a design practice and a research approach. This relates to the wider history of design itself. Broadly speaking, before the industrial revolution, design could be considered to be as an intuitive job involving arts and crafts but, since the industrial revolution, professional design has gained much more attention as a practice, and as a subject of research [56,57]. Further, since the 1960s, new design methods have been proposed by, for instance, Alexander and Jones as modern industrial design was considered too complex for an intuitive approach [58,59]. Further, Cross notes that, since the first half of the twentieth century, there has a growth in the scientific underpinnings of design, with design growing as a research approach [57]. Therefore, Cross considers the field of design, since the second half of the twentieth century, to be a scientific field wherein both intuitive and non-intuitive design methods are used [60–62].

However, the tension remains between those who consider design to be an intuitive craft or art, and not to be seen as a research approach, and others who consider design to be a rational procedure, which can be developed as a science [33,34,57]. On this basis, Cross highlights that the development of design, as a science, is still a work in progress, not least because the view of design as a science remains controversial to those who consider design to be an intuitive activity. In this light, we should see the field of GCD as a developing field, both as a practice and as a science, with an inherent tension between these two evolutions.

Here the map of types of human-centered design (Figure 1) developed by Sanders and Stappers is instructive in positioning GCD on a scale of research-led (research emphasis, downwards) vs. design-led (practice emphasis, upwards) and on a scale of stakeholder involvement, less involved (to the left) and more involved (to the right) [21]. Since the authors do not fully detail why they have positioned all the design types where they have on the map, we offer a brief personal interpretation below.

GCD, or generative design research in the terminology of Sanders and Stappers, is positioned in the upper right quadrant, thereby with the emphasis on design practice and high stakeholder involvement. It seems contradictory that Sanders and Stappers used the term generative design research and positioned it in the upper right corner, which would imply based on this position in the quadrant that the focus lies heavily on design. They also elaborate much more about GCD practice and less on GCD research methods and do not explain how practice and research are interwoven in GCD. GCD typically involves design-focused activities such as workshops with creative exercises to make something together using creative materials - paper, markers, photographs - to engage all stakeholders in contributing to the product or service. Although GCD is not yet widely used in healthcare innovation, researchers have recently argued for the added value of GCD in healthcare innovation [22,23].

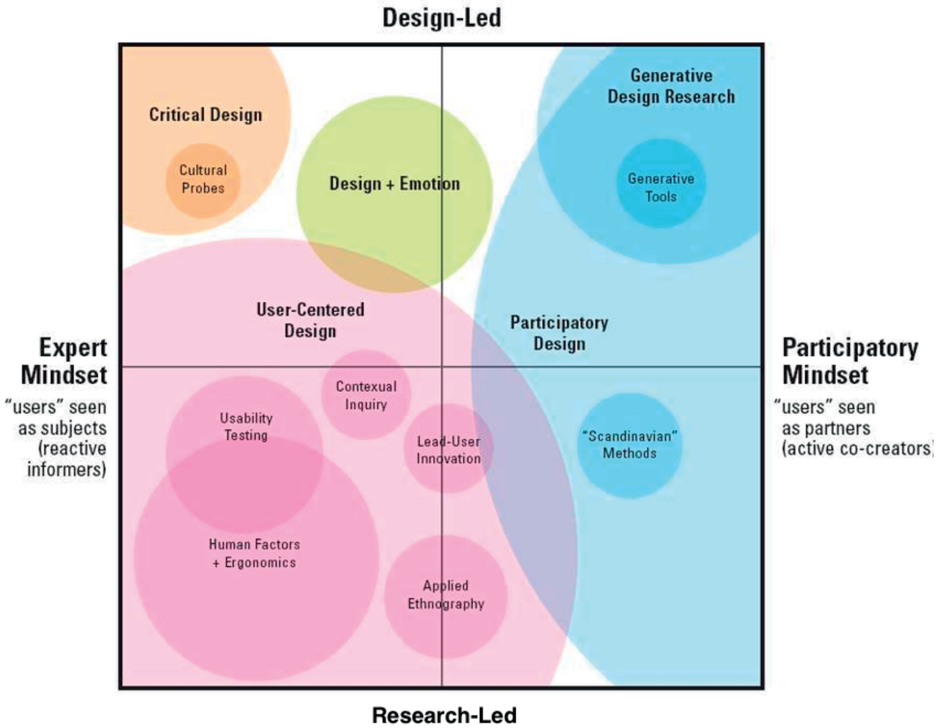

Figure 1: Overview of human-centered design forms by Sanders & Stappers 2012

In the same upper-right corner, one could also position another popular form of co-design used in healthcare, known as experience-based co-design, where the involvement of patients as experience experts is also emphasized [26]. However, experience-based co-design would be positioned closer to the participatory design axis (i.e. below GCD) as there is little direct involvement of designers or much of an emphasis on active creative collaboration between all stakeholders simultaneously, and also there seems to be a larger emphasis on the research output of the process [22,26,42].

The lower right quadrant includes various Scandinavian design methods that all follow the same historical traditions based on values of democracy, the explicit discussion of values in design and imagined futures but, compared to the quadrant above, they are less geared towards the design of products and services and more seen as research approaches to solve wider societal problems [63]. For instance, participatory design research can be used in various fields related to community services or urban planning [32].

GCD is different to the user-centered designs (lower-left quadrant) that originated in the US and involve users as subjects and have a more research-focused approach. In these approaches, reflecting an expert mindset, users are much less involved and considered as subjects of the research [47]. For instance, in a form of user-centered design, designers, in usability testing, indirectly retrieve information about users' preferences, for example, through surveys or questionnaires [20,21]. Users are seen as passive subjects who are given instructions. They are asked about a few aspects of a product or service being developed, such as colors or feelings about the product in a later stage of development. Thus, GCD is clearly different from the user-centered approaches since these are more focused on seeing stakeholders as passive subjects and less on actively involving stakeholders as equal partners through creative exercises.

The upper-left quadrant includes critical design approaches that are more focused on design practice but with cultural probing. These highlight artistic proposals, with much more focus on evoking inspiring responses from individual participants [55]. Here designers interpret and use these responses according to their own objectives, and stakeholders are less directly involved. This process is less deliberate and facilitated than in GCD approaches.

To summarize, GCD seems to be largely interpreted as a form of participatory design, with a strong tradition in design practice and with active stakeholder involvement, but seems to lack the research counterpart. When GCD is considered as a research approach, references are made to various research traditions such as (participatory) action research, and the theory surrounding certain GCD exercises has been further developed by researchers into the context-mapping approach [54,55]. However, little theoretical research has been published on the role of stakeholders in GCD despite their involvement being seen as an important and promising strength of GCD. This is especially the case in the field of digital health given the range of stakeholders who are both involved and needed for its successful adoption and use in healthcare practice.

Finally, given the lack of GCD stakeholder theory, one needs to draw on theoretical propositions from the overarching fields of co-design and even design itself. We will also engage with an entirely different but relevant discipline: the philosophy of science (see section 4).

2.2. Positioning stakeholders: starting from a design thinking cycle

GCD is considered to be a highly appropriate approach in the early, or fuzzy front end, part of the design process [21,55]. At this stage, both the problem and possible solutions are very vague and a clear direction has still to be identified, and therefore this period is ambiguous and chaotic [51]. At the same time, at this point in the development process, there is a great potential for stakeholders to steer the development of new digital health services and products since no clear direction or goals have been set.

GCD is described as a three-phase process: a pre-design phase to explore the context of the problem and the potential solution; a generative phase to produce ideas and insights for the solution; and an evaluative phase to measure the effectiveness of the identified solution

[55]. With these three steps, GCD follows a similar iterative process to both Clemensen's PD process and the process used in action research, which are broadly similar to the popular design thinking process [20,21,64–68]. The GCD process is also similar to the action research cycle in its cyclical nature in the exploration and creation or planning phase, albeit that the desired outcome is a product, service, or an integrated system whereas, with action research, the desired outcome of a cycle is knowledge and reflective insights [64–66,69].

For the purposes of this thesis, we refer to the GCD process as a design thinking cycle as this is a well-known process promoted by IDEO and the Design Council among others [67,68,70,71]. It is also used in healthcare innovation and embedded in pioneering centers including the Mayo Clinic and Sidney Kimmel Medical College [39,70,72–74]. This process is characterized as three phases in an iterative cycle, but without explicitly discussing the role of stakeholders:

- Exploration: the aim is to find out more about the problem and needs, to reach a problem definition;
- Creation: the aim is to generate ideas to develop a prototype to solve the problem identified in the previous exploration phase;
- Testing and evaluation: the aim is to test the prototype and see if it satisfies the needs of the stakeholders with further iterations of the exploration and creation phases if necessary.

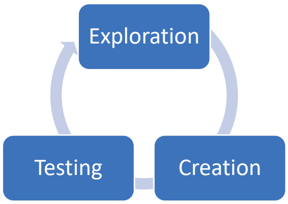

Figure 2: The three iterative GCD phases

It should be noted that using the design thinking cycle to describe the GCD process is somewhat of a simplification. Although design thinking is a popularized form of the design process, one that is often used in healthcare practice, it is has grown apart from research about the design process itself [34,67,75]. Nevertheless, given that we are seeking to explore the role of stakeholders in the GCD process in an interdisciplinary field of health research and design research, it can serve as a useful introduction to the GCD process.

Although considering GCD practice to be a design thinking cycle has its limitations since it fails to capture the full range of GCD tools and exercises available to involve stakeholders in the process, it is a useful initial conceptualization of the GCD process from which to start exploring the role of stakeholders.

3. BUILDING A THEORETICAL FOUNDATION

Given the limited research that evaluates the role of stakeholders in GCD (see the introduction to this chapter), a logical first step is to explore the theoretical foundations regarding the roles of stakeholders as such. In this section, we briefly discuss why theory development is controversial in design research and then consider a few of the key theoretical steppingstones in the role of stakeholder knowledge, which we then use as a starting point in this thesis.

3.1. The controversial role of GCD stakeholder theory

GCD is continuously developing and can be situated in the broader development of co-design and design science as previously mentioned (2.1). In this respect, it is important to note that design fundamentally grew out of craftsmanship and, as such, was essentially considered to be a practice [56]. This practical tradition resonates in design research and it is only relatively recently that a considerable amount of empirical research is presented at design research conferences. Such conferences have been established only relatively recently compared to, for instance, The British Association for the Advancement of Science which organized its first event in 1831 [76]. It was not until 1971 that the first conference of the Design Research Society was organized, marking a pivotal moment in 'design thinking' as a form of design research combining design practice with scientific reflection [57,77]. A series of Design Thinking Symposia was established in 1990, focusing on design cognition and the computational modelling of design processes [57,59]. Alongside various design conferences, design research, often involving case studies, is published in scientific design journals [32].

Broadly speaking, the research culture linked to design does not have a strong focus on theoretical development. Consequently, we agree with Cash that, in design research, its theoretical development is lagging [38]. Indeed, Badke-Schaub and Voute emphasized that the new design approaches, frequently presented by design researchers, which are claimed to be 'better' than other approaches tend to lack the scientific underpinning required to support these claims [34]. From a health research perspective, it is unimaginable that a care professional would prescribe a drug they believe to be better without any scientific support. However, considering the arguments of Cash, the lack of this development of scientific evidence in design may be due to a lack of a classical empirical and theoretical interaction process, a shortcoming also observed in other branches of science. On this basis, we argue that it is the lack of theoretical developments to justify why some approaches are better than others that is stalling design science and, as a consequence, the field of GCD.

However, one should not be too quick to interpret the absence of theoretical development as a lack of theoretical interest by design researchers. Cross argues that the entire enterprise of developing theory for design practice is still considered as controversial by some. The formalization of the design process, through logic, is seen as a move towards a purely non-intuitive formalization of design [57]. For instance, design researchers, such as Rittel, have cautioned against formalizing the design process as a rational scientific process, arguing that design is an intuitive process, with more difficult 'wicked' problems than scientific problems [78].

Given this tension, Love argues that design theory encompasses the subdisciplines of design science, design methods, and design methodology, whereas Simon and others claim that design science encompasses design theory [79]. In this sense, we follow Simon who defines design science in broad terms encompassing the field of design theory. Further, we believe that it is necessary to develop design theory if one is to make progress in design science and, in line with Badke-Schaub and Voute, to justify why some approaches are better than others.

Regarding GCD as a field of research, one can consider the evolution of GCD research in the wider development of design science. As such, the development of a GCD stakeholder theory could also be considered as controversial, or even irrelevant, if one adheres to a strictly intuitive definition of design as a craft. However, from a scientific development perspective, a theory on stakeholder involvement in GCD could serve to position, test, and guide assumptions about stakeholders in the proliferating empirical research. Further, such a theory could be further developed, along with other theories and empirical research, to help advance design research more broadly [38].

In this thesis, we therefore aim to contribute to the theoretical development of GCD as an approach that can be used to develop successful digital health. Our goal is to take the first step by developing a theory about stakeholders' knowledge and ways of thinking in GCD. Later, this theory could be further developed into a full-fledged methodology for stakeholder involvement in GCD [33,60,80,81]. To this end, the theory developed in this thesis should consist of a coherent set of assumptions and arguments, organized in a systematic way, about the role of stakeholders. Once this theory is established, it should be able to help GCD researchers and practitioners substantiate the choices made to involve specific stakeholders, and to evaluate these choices.

A tangible starting point in developing a theory about stakeholders in GCD is to address potential stakeholders' knowledge. Several hypotheses have been made, albeit sometimes implicitly, about the role of knowledge in GCD. Therefore, in the following sections, we focus on hypotheses concerning the role of stakeholders' knowledge.

3.2. Knowledge expectations in GCD

A key aspect of GCD is the expected exchange of knowledge between stakeholders that would enable the generation of new knowledge [21,22,82]. Here, the stakeholders' knowledge can be a key contribution to the development and success of digital health.

Mutual learning, as a PD principle, further emphasizes the importance of sharing knowledge among stakeholders. This principle states that all stakeholders should learn from each other, thereby highlighting that knowledge exchange between stakeholders is key and should be promoted in GCD practice [20,45,46]. Further, Kleinsmann et al. [83] have discussed the importance of stakeholders understanding each other and finding a common ground in the design process. However, questions remain unanswered as to how the knowledge of different stakeholders can form a common ground, what the added value is of bringing different stakeholder together to form this common ground, and which stakeholders are relevant in achieving this.

3.3. GCD theory: knowledge hypotheses

GCD theorists Sanders and Stappers [21,47,55] have made specific claims about stakeholder knowledge in the GCD process (Figure 3). First, they hypothesize that when the diversity in the background knowledge of stakeholders (A, B, C) increases, then the knowledge output (the lightbulb) increases [21]. Second, they posit that, since stakeholders have different ways of processing knowledge (the black arrows), the connections (orange arrows) that are made are improved, and new insights (lightbulb) will occur on many levels in the GCD process.

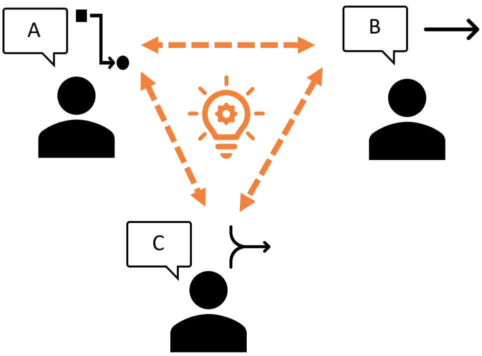

Figure 3: The role of diversity in the GCD process

These hypotheses can serve as a starting point when seeking further clarification and specification. Sanders and Stappers refer to broad concepts from the fields of psychology [84,85], decision-making theory, and the philosophy of science [86]. However, they do not explain why these concepts are relevant and how they relate to their specific hypotheses. As such, the definitions are somewhat implicit in terms of key terms such as *diversity* and *knowledge*. In addition, they do not explain how diversity improves the design process.

If these hypotheses could be embedded in a broader theory addressing stakeholder knowledge and its processing in GCD, this larger theory could be used to justify the involvement of specific stakeholders.

Further, without referring to the above hypotheses, Sanders and Stappers claim that tacit and latent knowledge play an important role in GCD. More broadly, in design science, tacit knowledge is also claimed to play a key role in the design processes [87]. Sanders and Stappers [21,88] defined tacit needs as conscious thoughts that are not expressed (such as, implicit feelings):

> *Tacit knowledge refers to things we know but are not able to verbally communicate to others. For example, you probably know how to make a phone call when your hands are full of stuff, but this would be difficult to explain to someone else.*

They define latent needs as subconscious needs that cannot be expressed in words such as wishes or dreams [21,88]:

> *Latent knowledge refers to thoughts and experiences that we haven't experienced yet, but on which we can form an opinion based on past experiences. Latent knowledge will be knowable in the future. It is not easy for people to express this type of knowledge. For example, 'I'd like to be able to automatically postpone meetings when I have trouble with my car'.*

The tacit and latent needs of stakeholders could also play an important role when developing care services [22], for example by expressing dreams about digital health [89]. Even though this deeper-lying knowledge is not easily expressed, it may contain important information for the GCD process such as explicit and implicit day-to-day technological expertise from the present, future, and past [55]. To this end, specific generative or creative making exercises have been developed to help stakeholders express this knowledge in a GCD process [21,55].

In this way, Sanders and Standers clearly emphasize the importance of employing tacit and latent knowledge in the GCD process and they also provide a myriad of possible tools to help stakeholders express this knowledge [21]. However, there is no associated theory to explain why these types of knowledge are so important and how this relates to the hypotheses about diversity. That is, why the combination of the tacit or latent knowledge of diverse stakeholders is important.

3.4. Ways in which designers think

Addressing Sanders and Stapper's (2012) hypothesis concerning the different ways of thinking in GCD, we briefly highlight the way designers think as this has been extensively discussed in design science theory [50,56,90–92].

The understanding of the way designers think has changed over time due to the changes in understanding of the design process itself [34,57,60,78,93]. Various design theorists consider design to be an intuitive activity, one which is quintessentially human [94]. In an effort to formalize the activity of design, Herbert Simon described design as a process which occupies itself with what ought to be, and therefore focusing on the artificial, in contrast to the analytic sciences focusing on what is [93,95]. Simon saw design as a process of changing existing situations into new, preferable, ones. Influenced by advancements in philosophy and computer science, he characterized the design process as a problem-solving activity. However, for describing design as a mere problem-solving process, he was criticized by Rittel and others as being too formal and not sufficiently taking into account the creative and chaotic nature of the design process [78,96]. Rittel feared that this view would not be able to capture the fuzzy and complex nature of design and therefore proposed that the design process should instead be described as a balance between the initially too rationalistic and a more rhetorical process understanding of design [96].

Schön argued that thinking of professional design as an iterative framing process could be seen as fitting between rationalist and non-rationalist views [49]. Here, by using generative metaphors, one considers a given situation from different perspectives [97]. Cross further described the designer's way of thinking as a 'designerly' way of thinking – an approach involving problem formulation, solution generation, and process strategy formulation [94]. More recently, the distinct ways of thinking have been formalized further by using a categorization of ways of thinking developed by the philosopher Pearce, with special attention given to abductive-2 thinking [86,98,99]. In this way, it is argued that a designer can have a different way of thinking to other stakeholders, and that this can make a key contribution in GCD as a design-led process.

To conclude, several authors have hypothesized that GCD is a knowledge-driven process in which diverse knowledge, diverse ways of thinking by stakeholders, and tacit and latent knowledge all play a role. However, it remains unclear what is meant precisely in the associated hypotheses and how these fragmented hypotheses relate to one another in constructing a coherent theory about stakeholder involvement.

4. THE POTENTIAL ROLE OF THE PHILOSOPHY OF SCIENCE

Given the lack of theory about stakeholders in GCD, and the fragmented theoretical hypotheses in design science and GCD, we draw on the field of the philosophy of science. We do this in two ways. First, we use ideas from the philosophy of science to help construct more explicit and specific theoretical hypotheses about stakeholders in GCD. Second, we use the philosophy of science to further develop a GCD stakeholder theory with new theoretical insights.

4.1. Clarifying with explication

As a way of clarifying existing assumptions, explication, which is a philosophical method to make something that is unclear or implicitly defined more explicit, can be used [100]. This process of explication is relevant to developing a theory about stakeholders in GCD as the knowledge held by researchers often includes how to do research, but not about what they are unaware that they are actually doing [101]. In this sense, researchers often have implicit knowledge about how they work, but they do not make their decisions explicit when conducting research. Accordingly, we employ the philosophy of science to reflect and make the implicit assumptions about GCD stakeholder knowledge and ways of thinking more explicit [101]. In addition, we also use explication to clarify theoretical concepts included in the hypotheses mentioned above. Love emphasizes that the terminology used in design research is often unhelpfully confusing and imprecise, and that clear terminology is essential [102]. For instance, one of the terms used to describe the way designers think is abductive reasoning, introduced by the philosopher Peirce [86]. However, as Roozenburg observes, this term has often been interpreted in design research as a form of explanatory reasoning, whereas one might expect this to be seen as a form of innovative abduction [103].

By bringing the implicit assumptions used in GCD practice and research to the fore and integrating them in a systematic way, we hope this thesis can contribute to GCD as a field of design science. A systematic GCD stakeholder theory could contribute to the development of a GCD design science by providing a description of the GCD process as a scientific activity amounting to an explicitly organized, rational, and systematic approach [57]. Here, explication can help to make stakeholder theory in GCD more scientific and, by extension, may further promote the development of GCD as field of design science. Nevertheless, as already noted, the development of design science remains a controversial movement [57,62]. As such, defining terms more precisely through explication can be considered an activity which aims to reduce design to a technical-rational activity, which would go against the broad understanding of design as a core human activity [78,96].

4.2. Developing theory using the philosophy of scientific discovery

To bring new theoretical insights, the philosophy of science sub-field known as the philosophy of scientific discovery is particularly relevant when aiming to develop a theory about stakeholders in GCD as it can provide the conceptual clarification needed in the explication process.

In the fields of both the philosophy of scientific discovery and design there is a similar interest in the process of developing new knowledge, but from different perspectives. Even though both fields seem to have started with similar goals they later diverged and evolved separately without learning from each other. For instance, both philosophers of scientific discovery and design theorists have been inspired by the work of Herbert Simon, who describes the design process as a rational problem-solving process [104]. This was a countermovement to the view in the philosophy of scientific discovery, popularized by Karl Popper, that there was no rational way to look at knowledge development[105]. Design theorists moved away from Simon's understanding of design, which was initially characterized as a purely analytical activity in a positivistic philosophy of science understanding [93], despite this being an extremely simplified understanding of science, as not all science activity is analytical. In fact, in the philosophy of science field, the countermovement against the Popperian view of scientific progress gave rise to the entire new field of scientific discovery, which embraces the non-traditional logic and creative processes in science that takes place in design [106–108]. Then again, the reference to positivism to describe design made design theorists lose interest in further developments in the philosophy of science field [93]. Consequently, they held on to their narrow viewpoint on science and the philosophy of science which they assumed focused only on this positivist understanding of science. This has created a false debate, which we alluded to in the sections above, between the rational-technical and therefore scientific understanding of design and a broader less stringent understanding of the design process [93].

In this thesis, we want to bridge design theory and the philosophy of scientific discovery believing that combining insights from both fields could be fruitful. In the field of scientific discovery, Ippoliti and Nickles characterized Simon's approach as an inferential approach to looking at scientific discovery, emphasizing the rational perspective [106]. In an inferential approach, one considers scientific innovation to be a problem-solving process, one that is highly content-specific and involving different ways of thinking [106,109]. The scientific discovery philosophers have also focused on how to describe creative scientific processes in a formal and logical way, which may be highly relevant for design theory [106,109–116]. In a similar way to scientific discovery philosophers, design theorists have tried to describe the design process. They describe the design process as a problem-solving process involving different ways of thinking [117,118]. Further, they have focused on how to describe this special type of knowledge as 'designerly knowledge', whereby design is characterized as both a practical and a reflective process, one that simultaneously produces new knowledge and artefacts [49,58,59,61,119–122].

However, design theorists lack a precise description of this process. As such, employing insights from the field of philosophy of scientific discovery seems very promising.

Even though, from a design science perspective, the field of scientific discovery may not be the obvious field from which to draw conceptual inspiration, the aim in this thesis is to use insights from the field of philosophy of scientific discovery to develop a sounder scientific theory about stakeholder knowledge and ways of thinking in GCD.

5. AIM AND RESEARCH QUESTIONS

The aim of this thesis is to explore and develop a GCD theory about stakeholder knowledge and ways of thinking for digital health development. The main research question is: What is the role of stakeholders in GCD for digital health?

From this, the following sub-questions can be developed:

- **How are stakeholders involved in GCD to develop digital health?**
- **What theory can be developed that incorporates current assumptions about stakeholders' knowledge and ways of thinking?**
- **How does this theory affect the GCD process for developing digital health?**

6. METHODOLOGICAL APPROACH

To address this research aim and these questions, we employ a 'research through design' approach [119]. The aim of research *through* design is to gain research knowledge while using a design way of working. We seek to answer the research questions through exploration, creation, and test phases, whereby each step builds upon and overlaps with each other. This is distinct from similarly named approaches, such as research *for* design where one uses research methods such as interviews as part of a design process. It is also different from the research *is* design approach where both research methods and design process are treated as the same.

Research *through* design approaches are not commonly used in health research. In this thesis, this approach serves the broader purpose of exploring how a design approach can help to further improve health services. As the focus lies on developing a prototype in the creation phase, our prototype is somewhat theoretical and research-driven, rather than a physical artefact as is typically the outcome of a design process. In the research through design approach, we use a three-phase design thinking cycle as described above (Figure 2). The key aims of the research through design phases are to address each of the research question as follows:

- **Exploration phase:**
  How are stakeholders involved in GCD to develop digital health?
  Overall aim: Develop a problem definition in order to focus the research
  Sub-aim 1: To gain an understanding of how stakeholders are currently involved in GCD science to develop digital health.
  Sub-aim 2: To understand how stakeholders are involved in GCD practice to develop digital health.

- **Creation phase:**
- **What theory can be developed that incorporates current assumptions about stakeholders' knowledge and ways of thinking?**
  Aim: Based on the insights from the exploration phase, to develop a GCD theory about stakeholders' knowledge and ways of thinking in GCD.

- **Testing phase:**
  How does this theory affect the GCD process for developing digital health?
  Aim: To test key hypotheses linked to the theory developed in the creation phase. In this way, the theory can be further adjusted to fit the needs of digital health practice.

7. FOCUS ON CARE FOR YOUNG ADULTS AND ADOLESCENTS WITH CANCER

The focus in this research is on the development of a GCD stakeholder theory for digital health in the field of cancer care for young adults and adolescents (AYA). AYA with cancer amount to a heterogenous group of people aged 15-39 [123]. Cancer is the fourth leading cause of death in adolescents and young adults globally and, worldwide, there were 1.19 million new AYA cases and 396,000 AYA deaths in 2019 [123]. Each year, about 3900 AYA aged 18-39 are diagnosed with cancer in the Netherlands [124].

AYA care was chosen for three reasons: first, this area of healthcare involves various stakeholders, second this is a young population who are interested in the use of digital health to improve their care process, and, third, the author was diagnosed with leukemia at the age of 14 and thus is an AYA himself.

Various stakeholders are involved in AYA cancer care since these patients are in the middle of a unique period in their life in which fundamental physical, emotional, and psychosocial aspects are changing [123,125–129]. Many are just beginning to become sexually active, some may want to or already have children, to advance their education and work and cope with financial struggles [123,130]. The care journey of AYA spans from their home to local community caregivers including physiotherapists and psychologists and involving one or more specialized hospital care centers, where some are treated in various outpatient or inpatient pediatric or adult wards. AYA patients are looking for traditional care, but also for complementary care services such as massage, music, acupuncture, and mindfulness [131]. In this process, they struggle to find appropriate care for their particular type of cancer, and their age and life style [123].

8. OUTLINE OF CHAPTERS

This thesis consists of three parts that reflect the research through design cycle. In PART I, we address the exploration phase with two sub-aims. In **Chapter 2**, we tackle the first sub-aim of the exploration phase and explore how stakeholders are involved in GCD science to develop digital health. In **Chapters 3 and 4**, we tackle the second sub-aim of the exploration phase to understand how stakeholders are involved in GCD practice to develop digital health and learn from the underlying assumptions. In PART II (**Chapter 5)**, we address the creation phase. Here we work towards the development of a theory about the knowledge and ways stakeholders think in GCD. In PART III (**Chapter 6**), we test key assumptions of this theory to assess how it affects GCD practice aiming to develop digital health.

In **Chapter 7**, the main findings of this thesis are summarized, discussed, and the implications are presented.

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CHAPTER 2

Generative Participatory Design Methodology to Develop Electronic Health Interventions: Systematic Literature Review

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ABSTRACT

Background

Generative participatory design (PD) may help in developing electronic health (eHealth) interventions. PD is characterized by the involvement of all stakeholders in creative activities. This is different from the traditional user-centered design, where users are less involved. When looking at PD from a *research through design* perspective, it is important to summarize the reasons for choosing a certain form of generative PD to further develop its methodology. However, the scientific literature is currently unclear about which forms of PD are used to develop eHealth and which arguments are used to substantiate the decision to use a certain form of generative PD.

Objective

This study aimed to explore the reporting and substantiation of generative PD methodologies in empirical eHealth studies published in scientific journals to further develop PD methodology in the field of eHealth.

Methods

A systematic literature review following the Cochrane guidelines was conducted in several databases (EMBASE, MEDLINE Ovid, Web of Science, and CINAHL EBSCOhost). Data were extracted on the recruitment and management of stakeholders, the use of tools, and the use of outcome measures.

Results

Of the 3131 studies initially identified, 69 were selected for qualitative synthesis. The reporting was very variable, depending to a large extent on whether the study stated that reporting on the PD process was a major aim. The different levels of reporting and substantiation of the choices of a recruitment strategy, stakeholder management, and tools and outcome measures are presented. Only a few authors explicitly used arguments directly related to PD guiding principles such as democratic, mutual learning, tacit and latent knowledge, and collective creativity. Even though PD principles were not always explicitly discussed in the method descriptions of the studies, they were implicitly present, mostly in the descriptions of the use of PD tools. The arguments used to substantiate the choices made in stakeholder management, PD tools, and the type of outcome measures adopted point to the involvement of PD principles.

Conclusions

Studies that have used a PD research methodology to develop eHealth primarily substantiate the choice of tools made and much less the use of stakeholders and outcome measures.

ABBREVIATIONS

CARD: Collaborative Analysis of Requirements and Design
eHealth: electronic health
mHealth: mobile health
PD: participatory design
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses

INTRODUCTION

Participatory Design Methodology

Stakeholder participation is considered to play an important role in developing electronic health interventions (eHealth) [1-4]. However, during the development of eHealth, challenges remain in gaining the trust of stakeholders, managing multiple stakeholders, and involving end users [1,5]. In contrast to more traditional forms of user-centered design, where stakeholders are less involved, generative participatory design (PD) focuses on including stakeholders in creative activities [3,4]. Therefore, PD is promising in that it could overcome the challenges seen in the development of eHealth [6-8].

PD is becoming increasingly intertwined with research and is therefore also considered to be a research methodology. Looking at PD from a research perspective, the methodological choices to be made are of particular interest. Methodological elements that play a key role in PD research are the recruitment and management of stakeholders [4], the use of outcome measures [4], and the use of tools [9,10]. The literature indicates that the application of each of these elements varies when PD is employed.

Looking at the literature on participatory methods to develop eHealth, a recent systematic literature review showed that 24 frameworks have been used [11]. However, as many studies do not refer to a framework, more attention is needed on the methodologies employed [11].

Methodological Elements

Turning to stakeholders, the varying involvement of patients as end users has been widely discussed in the literature [12,13]. Warnings have been given regarding the ability of users to express their needs and about the prejudices of PD practitioners regarding the participants [14], and the involvement of end users remains debated. When it comes to outcome measures, there is a wide variety that can be used to evaluate PD outputs related to the PD process itself and to the eHealth technology output [15,16]. Tools describe the actions that take place between participants [17], and PD scholars have categorized these tools into make, tell, and enact tools [3,10,17]. Make tools are material components such as a prototype to facilitate the embodiment of thoughts in physical artifacts [10]. Tell tools facilitate the telling of stories to capture implicit information about the use of a technology and how people may wish to use it in the future [10]. Enacting refers to the activities where one or more people act out possible futures by physically trying things out in settings that resemble the possible futures [10]. Finally, PD toolkits can involve make, tell, and enact tools and are used to push people to start thinking about their experiences so that using the tools in the PD process can yield better results.

How stakeholders, tools, and outcome measures are employed in the PD process depends on which PD methodology is followed. Furthermore, there is a lack of a strong methodological explanation that could help develop a more rigorous science of PD [2,4]. Using methodological arguments to make each methodological decision applied in studies employing PD more explicit could improve the scientific rigor of PD as a research methodology [18].

Guiding Principles

The PD literature encompasses various theories that form the foundations for methodologies [2-4,9,10]. Value-laden concepts such as democracy, participation, empowerment, and empathy [4,9] contain values such as inclusion and equality [9] and play a fundamental role in PD. On the basis of the work by Van der Velden and Mörtberg [9] and of Sanders and Stappers [3], four key guiding PD principles can be discerned:

- Democracy: In contrast to traditional design practices, the aim is to involve all stakeholders including nondesigners and future users who will be affected by new technologies. Users can become part of the design team as *experts of their experiences* given appropriate tools to express themselves [13]. The aim is to increase diversity of experience, values, and knowledge. This is believed to foster trust among those involved and to facilitate a learning process and a commitment to taking responsibility for each other and the design result.
- Mutual learning: Participants (both designers and nondesigners) learn from each other, but they also learn from themselves when reflecting on their own work.
- Tacit or latent knowledge: To assess the needs of people beyond the observable or easily detectable, that is, in the form of tacit needs. This deeper knowledge includes explicit and implicit day-to-day technological expertise from the present, future, and past [19]. Sanders has defined tacit needs as being conscious but not expressed and latent needs as subconscious needs that cannot be expressed in words [3,20].
- Collective creativity: PD is considered to be essentially a process of collective creativity [3]. Sanders and Stappers [3] refer to social creativity in which people follow a process referred to as the *path of expression*. Creativity facilitates a design process from which values emerge and become inscribed in the product or service [9]. Everyone is assumed to possess some creative ability, although a design role requires a certain level of creativity [13].

Given the developing nature of the PD methodology, the theoretical and empirical literature does not always incorporate these insights and the four guiding principles. In the theoretical design literature, the relationship between PD principles and the use of stakeholders, tools, and outcome measures is only implicitly suggested [2,4]. For instance, PD principles seem to be implicit in the description of make tools. The democratic principle is implicitly present as make tools include both designers and nondesigners in *making things* [10]. As such, make tools can be used to enhance the democratic involvement of stakeholders. In addition, the collective creativity principle is also implicitly present. Tools, depending on the aim, can be used within a PD project to (1) probe participants, (2) prime participants—to immerse them in a domain, (3) to gain a better understanding of their experiences, or (4) to generate new ideas [17]. Depending on the aim, make tools can be used as part of a probing approach (to inspire ideas), a participatory prototyping approach (stakeholders provide feedback on an existing prototype), or a generative approach (stakeholders give ideas a physical form) [10,19]. It has been suggested that the probing and generative approaches are better suited to early design, or the so-called fuzzy front end, and that prototyping is more useful in later, less fuzzy, design stages [19]. Therefore, the democratic principle and the creativity principles can be used to argue in favor of adopting make tools at different times in the design process.

Little has been reported on the specific arguments used to explain the choice of specific stakeholders, tools, and outcome measures. Although stakeholders can be involved in various ways in the development of gerontology [8], mobile health (mHealth) [7], and serious games [6,21], a discussion on the methodological considerations is missing. Second, various tools are described for developing health information technology [22], gerontology [8], and mHealth [7], but without methodological substantiation.

In addition, given the very limited presence of evaluations in the empirical literature, it is difficult to establish the outcome measures that are used, let alone the principles upon which they are selected. Eyles et al [7] failed to find any mHealth studies that reported outcome measures. Merkel and Kucharski [8] found a few studies that evaluated some eHealth results, for example, by testing a prototype. However, they did not report the results of the evaluations [8]. Merkel and Kucharski [8] also stated that there were no studies that had evaluated the process of PD itself. Exceptionally, DeSmet et al [21] did evaluate the effectiveness of PD in serious games. They expected that the use of PD in the development of serious games was less effective than when users were involved merely as testers in the game (albeit without taking sample size and strength of effect into account) [21].

Aim

Given these uncertainties, the aim of this study was to explore the substantiation behind the methodological choice to use a certain form of PD in developing eHealth. This paper was intended to be a start in looking at the state of reporting of PD research methodology and, therefore, used a systematic literature review to summarize the current status of reporting in peer-reviewed scientific journals. This research has the potential to guide researchers and practitioners to areas where greater substantiation is needed when using or reporting PD. By considering the current methodological choices, some recommendations are also provided that may also help researchers and practitioners select a method that helps them better achieve their aims.

METHODS

Systematic Literature Review

A systematic literature review with qualitative synthesis was conducted to summarize existing knowledge on PD methodology in the development of eHealth technology. In the medical field, the Cochrane review process is considered the gold standard. Given that this review is focused on eHealth, this systematic review follows the Cochrane guidelines [23]. To ensure completeness and transparency, a Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) reporting statement is included [24].

Given that PD methodology is developing, the focus was on the reported use and justification of the choices made in using PD tools, stakeholder management, stakeholder recruitment, and the outcome measures selected. The first research question focuses on the use of PD: "How is the use of PD, in particular the involvement of stakeholders, the use of tools, and the use of outcome measures described in the empirical literature about eHealth development?" The second research question focuses on the justification for a type of PD: "What reasons, related to the guiding principles of PD, are offered to substantiate the preference for a given use of stakeholders, tools, and outcome measures?"

Selection of Studies

Search queries were developed by an experienced medical information specialist (WB) and the searches used terms such as participatory design, co-design, cocreation, and collaborative design in the field of telehealth. In addition to these terms, we used a more descriptive approach where we combined human centeredness, patient involvement, etc, with shared decision making or doctor-patient relations in the field of telehealth. The term user involvement was also added to the search. The term participatory research was not used as the terms "co-creation," "co-design," and "participatory" were assumed to cover this field.

The search strategies for all the databases that were used can be found in online Multimedia Appendix 1. The following databases have been searched from their inception until November 12, 2019 (date last searched): EMBASE (1974-), MEDLINE ALL (Ovid, 1946-), Web of Science Core Collection (Web of Knowledge, 1900-), and CINAHL (EBSCOhost, 1937-). All the references from searches on electronic databases were exported and duplicates removed in Endnote X9 (Thompson Reuters Inc) software. The identified titles and abstracts were then screened for eligibility by two independent researchers.

The following working definition for PD was used: PD refers to the collective creative design process of designers and nondesigners, whereby users are considered partners during the design process. PD activities can generally be described as cocreation workshops or cocreation exercises, or they can be more specifically described by referring to make (ie, collage), tell (ie, cards), and act (ie, acting out) tools. Studies that used other terms were also included if they were described by the authors as co-design or PD-related activities [10,17]. Studies that used other popular terms such as cocreation were only included if, as part of the methodology, PD tools were described.

The selection criteria for inclusion and exclusion are shown in Textboxes 1 and 2.

Textbox 1. Inclusion criteria for screening.

- Language: English language
- Format: Full text available (including full conference papers)
- Study design: Empirical study describing the direct or indirect observation or experience of using participatory design (PD) to develop electronic health (eHealth) published in a peer-reviewed journal or conference proceedings. The aim of the paper was to report on the use of PD to develop eHealth.
- Product or service developed: eHealth related
- Method of development: PD as a collective creative design process of designers and nondesigners whereby users are considered to be partners in the process and the use of PD activities is described with this mindset (including participatory prototyping)
- Design development phases: All innovation phases included (predesign, early design [discover], and design and make)
- Setting: at least one of the PD tools used must be in a group setting (ie, more than one individual involved)

Textbox 2. Exclusion criteria for screening.

- Language: Other than English
- Format: Only abstract or full text unavailable
- Study design: Nonempirical studies (ie, reviews, editorials, discussion papers, methodological papers, papers reflecting on eHealth developed with PD), studies not peer reviewed (eg, dissertations)
- Product or service developed: Other than electronic health (eHealth
- Method of development: Nonparticipatory design, participatory design (PD) where users are considered as subjects in the design process (user-centered design), the use of PD is not described (ie, only qualitative research tools such as focus groups or interviews)
- Setting: All PD tools used only by individuals
- Design development phases: Value cocreation excluded (market phase and later marketing phases)

Studies that had as their main objective developing eHealth technology were included. Articles in conference proceedings were also included. Study protocols and conference abstracts were excluded as these included insufficient information about the execution of the PD study and its results. Non-English language publications were excluded.

All types of empirical study designs were included, and no restrictions were placed on the types of participants. For instance, studies involving only patients or only care professionals in PD were included. The presence of PD activities was chosen as the inclusion criterion rather than other features of PD because this area has the most clearly defined consensus in the literature. Other aspects of PD, such as stakeholder recruitment, stakeholder management, and PD outcome measures, were not used as the inclusion or exclusion criteria as these terms can be used in somewhat arbitrary ways.

The identification and selection of studies is summarized in Figure 1 according to the PRISMA guidelines [24]. Following the removal of duplicates, 3131 articles were identified through the search strategy, of which 3000 articles were then excluded based on the title and contents of the abstract. This left 131 unique full-text studies for review, of which 69 met the inclusion criteria (see online Multimedia Appendix 2 for full-text studies excluded). The main reasons for full-text exclusion were (1) not considered to be empirical studies or full-text peer-reviewed documents (eg, conference abstracts, protocols, and a PhD thesis; n=19), (2) mentioned PD-related activities, but no PD tools (n=7), (3) mentioned co-design but no PD tools (n=8), (4) mentioned cocreation but no PD tools (n=11), (5) mentioned user-centered design, but no PD tools (n=11), and (6) did not mention eHealth (n=6).

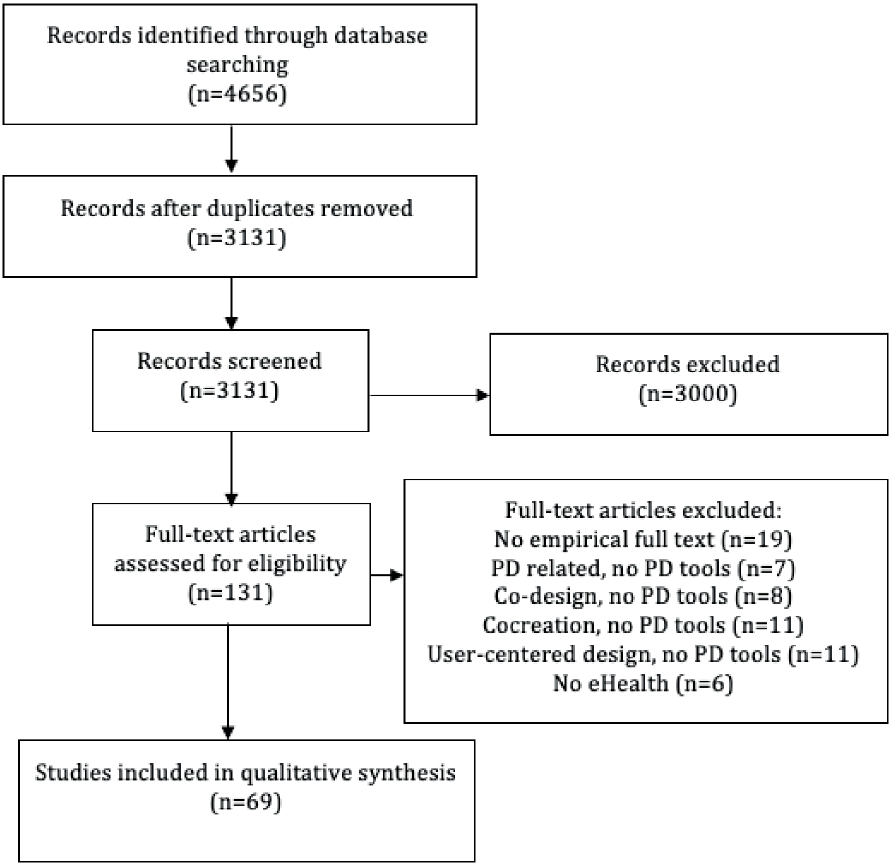

Figure 1. Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow diagram. eHealth: electronic health; PD: participatory design.

Data Extractions and Synthesis

To provide an overview of the general characteristics of the studies, the eHealth domain, the health domain, and the theoretical references used to refer to PD were summarized. In addition, the use of stakeholders, tools, and outcome measures was assessed as follows.

First, regarding the use of stakeholders, different strategies could be used depending on the interpretation of PD principles. Therefore, data were extracted related to the number and type of stakeholders, stakeholder recruitment, and stakeholder management. Second, regarding the use of tools, different tools can be used at different times depending on the PD principles. Therefore, the type of tool and the purpose in using the tool were extracted. Finally, the study was placed in a design phase depending on the stage in which the study started: predesign, early design, or post first prototype (Table 1).

Table 1. Description of design phases.

Design phase	Description
Predesign (including fuzzy front end)	Phase of understanding and defining the problem, often these studies would focus on the unmet need of a certain population.
Early design	In this phase, there is already some understanding of the problem and the aim is to develop a first concrete idea, often these studies would aim to develop or enhance a first idea or prototype.
Post first prototype	In this phase, there is already a first idea for a solution, which will be iterated or enhanced.

Third, as the use of outcome measures is influenced by the general methodological aim and the principles that are emphasized, the type of outcome measure that was used to evaluate eHealth and the PD itself was extracted.

Assessment of Sufficiency of Reporting

Owing to the variety of study designs, a quality assessment was not appropriate. Instead, an assessment of sufficiency of reporting was conducted, as used in a previous systematic review [7]. This was done with an 8-item checklist:

1. Setting: Is it clear where the PD development of the intervention took place?
2. Stakeholders: Is it clear who was involved in the PD, and does one know all that one needs to know about the participants?
3. Facilitators: Is it clear who facilitated the PD process?
4. Procedure: Is it clear what PD methods were used?
5. Materials: Are any physical materials used in the PD process adequately described?
6. Intensity: Is the length of the PD phase and individual sessions clear?
7. Schedule: Is the interval and frequency of the PD sessions clear?
8. Clarity: Is the description of the overall PD process clear?

RESULTS

Overall Findings

The general health and eHealth technology characteristics and the theoretical references used in the studies when referring to PD are described below. The year of publication ranged from 2006 to 2019. The 69 studies cover 65 unique eHealth technology products and services. The majority of these were either Web-based tools such as *online self-management tools* [25], *person-centered Web support* [26], or a *Web-based plan for integrated care* [27], or mHealth apps.

There is a large diversity in the health domains considered. The mental health domain was most often addressed by the eHealth technology. The most frequent aims of the eHealth were disease-specific interventions (weight loss, psychosocial care, and rehabilitation) and self-management. The prevalence of self-management aims could be expected because the PD democratic principle emphasizes the involvement of users, and this may help the later uptake by these users of eHealth focused on self-management.

In addition to the health and eHealth technology characteristics, the theoretical references of PD are presented here. Nearly all studies, 65, mentioned a theory of PD. Clemensen et al's description of the PD methodology [28,29] was referenced in 10 of the reviewed studies [30-39], and that by Sanders and Stappers [13] was referenced in 9 [27,30,31,40-45]. A handbook on PD by Simonsen et al [10] was referenced 7 times [27,31,36,46-49]. PD principles and practices [50,51] were also referenced on several occasions [38,47,52-54]. In addition, the methodology by Spinuzzi [2] was referenced in 4 papers [25,26,31,32]. References to other design theories were also used, such as experience-based design [55] in studies by Wherton et al [39] and Crosby [56], design thinking [57,58] in various studies [37,56,59-61], human-centered design [62] in the study by Das and Svanæs [63], and prototyping [64] in the study by Hetrick et al [65].

Reporting on Stakeholders, Tools, and Outcome Measures

The reporting on stakeholder recruitment, stakeholder management, PD tools (make, tell, or enact), and outcomes measures to evaluate eHealth and the PD process is presented in online Multimedia Appendix 3. The amount of reporting varied widely between 8 and 36 on a reporting scale of 40. All studies naturally reported on some kind of PD tools being used as this was an inclusion criterion.

Overall, 25 of the studies stated that an aim of the study was to describe the PD process or provide details of the PD process or of a design process similar to it (see gray-shaded rows in online Multimedia Appendix 3). These studies scored highest on the reporting scale, with 13 of the 17 studies scoring above 30 stating that describing the PD process was an aim.

Overall, 38 studies reported on stakeholder recruitment and 30 studies reported on stakeholder management. In addition, 23 studies reported outcome measures to evaluate the eHealth technology under development, and 3 studies reported outcomes to evaluate a PD process that was already employed.

Stakeholders

Types of Stakeholders

Overall, the number of participants taking part in the PD activities varied across studies. The number depended on the different types of stakeholders and the timing of the PD activities.

A total of 63 studies reported on the stakeholders involved. All of these studies involved the main intended user of the eHealth technology in the design process: the patient, the care professional, or both (see online Multimedia Appendix 4 and Table 2). Among the patient, or content expert, stakeholder group, young adults and children were involved in 17 studies. Many other stakeholder types were also involved in some studies. For instance, dieticians, psychologists, a social worker, and a journalist were all involved in 1 study [46], 1 study involved a business analyst [38], 1 study a pharmacist [66], and another involved government representatives [35]. In all, 3 studies also involved, alongside a core group of stakeholders, advisory groups to provide feedback at different times [25,67,68].

Table 2. Types of stakeholders included in the participatory design process (n=69).

Stakeholder	Studies
Patient or content expert	[25-27,30-35,37-40,42-46,49,52-54,56,59-61,63,65,68-93]
Care professional	[26,27,31,32,34,35,37,39,41,45,46,48,56,60,61,63,65,67,68,71,73,74,76,84,87,94-99]
Informal caregiver (ie, parent)	[32,35,46,60,65,68,78,87,97]
Designer	[25,26,42,46,52,65,71,76,98]
Software developer	[25-27,38,39,42,46,48,61,63,68,74,97]
Researcher	[25-27,32,37,41,42,52,54,61,63,65,68,98]

Stakeholder Recruitment

The reporting on recruitment was mostly about the patient or content experts and not the other stakeholders. For instance, no study clearly explained how they recruited designers or software developers. This may be because these stakeholders were not recruited but already part of the project team. The most common recruitment strategy was purposive or convenience sampling [30,31,33,37,42,46,52,63,70,71,80,83] followed by snowball or in-person recruitment [40,65,71,79]. One study used representative sampling to include all potential users [67]. In all, 5 studies aimed for diversity in recruitment [25,45,48,81,85].

Most studies that report recruitment criteria focused on age and health care exposure. A total of 7 studies also mentioned access to internet and basic knowledge in using phones or a computer and the internet. Overall, 4 studies also reported criteria related to personal traits such as social or communicative skills, creativity, motivation, and capabilities to engage actively [31,48,85,90]. Financial incentives were also often used in the recruitment process.

In general, there is a lack of methodological arguments provided for the recruitment choices. It is unclear why designers are involved in so few studies. The PD projects may have worked with researchers who were trained in design, or they may have consulted designers before or after the PD project. Furthermore, methodological argumentation is missing on how the recruitment criteria serve the PD process and PD design aims. For instance, arguments referring to PD principles could be used to substantiate the criteria chosen. As an example, the decision to use personal trait criteria could be substantiated by stating that people who are more communicative and motivated may share more relevant knowledge than others and help others to learn from each other. These arguments could refer to the PD principle of mutual learning. Optimizing mutual learning may be particularly relevant in a health care context, given health care professionals' limited available time.

Stakeholder Management

In terms of stakeholder management, creating a safe environment is important. Many approaches were reported, for example, a safe environment was sometimes fostered by creating small groups [37,63]. Sessions were deliberately shortened to reduce the burden on chronically ill patients and to give them time to reflect between sessions [49,91]. On other occasions, reassurance was provided by a researcher that no judgement was involved to avoid intimidation [40], or an explanation was provided that there was a flat communication structure [27,63].

Others mentioned the use of an icebreaker [80]. Introductions were given and sometimes also refreshments [85]. Games were used to establish the aims and rules of a workshop [71]. Others used a quick design exercise as an icebreaker, especially to get the participants used to participating in design activities [32].

Moderation was also used to reduce doubt and to seek consensus [65]. Field kits [41] or graphics [31] were used to clarify and explain concepts to clinicians and developers. Some reported that training sessions had been provided [32,47,85,92]. Information was provided using popular metaphors on key data points that were important in the design of the product or service [32]. Some studies helped children by explaining the interface and what was technically feasible during the exercises [75,89,90]. The expectations regarding a creative exploration component were clearly explained to nondesigners in one study. Elsewhere, it was made clear to the participants that the focus was on creativity and that they should not reflect on implementation at that stage [91,98]. One study [91] explicitly chose not to explain the existing technologies in order to not influence the participants and constrain their ideas.

Various approaches were taken toward the mixing of groups. Some studies chose to address the power imbalance between health professionals and patients by separating stakeholders [63,65]. Others wanted to mix stakeholders to cross-fertilize perspectives in some instances but keep subgroups by type to highlight the perceptions of a stakeholder group such as caregivers [67].

Some measures were also taken to stimulate creativity when tools were being used. To stimulate intuitive representations [32], participants were given blank cards and were invited to write on them directly [98]. Some facilitators also took an active role in helping participants suggest creative ideas but without trying to be dominant [80]. Another measure that was taken at the end of a PD session was to invite participants to walk around and look at the creations of other teams (world cafés) to increase the diversity of perspectives [32,93]. Consensus over a range of created ideas was moderated by inviting teams to evaluate the differences between ideas.

The reported facilitation varied between involving researchers and designers [42], a team of clinicians and designers [71], or a clinician and researchers [44]. Facilitation was intended to support creativity and hands-on exercises [37,48]. A mental health professional was also present during a workshop with participants who were at risk of psychological distress [73].

On some occasions, arguments related to PD principles are provided to substantiate the stakeholder management. For instance, when justifying exercises that are meant to stimulate creativity. However, further argumentation could have been provided about the relationship between creativity and the design goals.

Tools

A variety of PD tools are used in the studies that report the development of eHealth in the predesign, early design, and post first prototype phases (see Table 3).

Looking at all three phases, most combinations of tools are used in the predesign phase [31,37,39,44,97]. In this phase, 4 studies used combinations of three different types of PD tools (make, tell, and enact) [46,49,89,90]. The predesign phase is also characterized by mainly make tools that adopt a generative approach. Some studies also used a toolkit or field kit [41,47], which indicates the emphasis on helping people generate new ideas. This is different from the early design, and post first prototype phase, where fewer tools and fewer combinations of tools are used.

In all, 8 studies referred to specific techniques for a participatory prototyping approach such as *thinking aloud* [42,46,52,65,70,98], and 1 study referred to a card sorting technique for tell tools (Collaborative Analysis of Requirements and Design; CARD) [63]. Furthermore, methodological references were made to Design studio [65], Scaffold [41], the *good enough* model [71], and future workshops [80,91].

When looking at the substantiation offered for the PD tools used, different types of methodological arguments can be identified. Most studies argued that their main goal was to gather information or to develop, organize, or test new ideas to improve the product or service design (type 1). In many studies, an argument based on analogy is used to explain why they chose certain tools by referring to other PD literature where similar tools were used with similar design process aims (type 2).

Table 3. Tools (n=69).

Phase and tools	Studies
Predesign	
2D mapping, brainstorm, post-it, mind map, Chinese portrait [26]	[30,34,37,41,44-46,49,61,66,77,80,83-85,88,91,92,97-100]
Prototyping, 2D mockup, 2D design, sketch	[30,31,34,37,40,42-44,46,49,61,67,77,78,89-92,98,100,101]
Personas	[37,49,71,88]
Cards	[31,37,39,47,49,67,84,100]
Artifact for discussion	[85]
Storyboarding	[31,37,39,46]
Scenarios, customer journey	[44,66,89,90]
Service blueprint	[66]
Role-play	[46,49,82,89,97]
Design journal notebook	[91]
Early design	
2D mapping	[63,69]
2D mockups, sketch	[25,32,65,68-70,72-74]
Cards	[32,63]
Storyboarding	[26]
Scenarios	[56]
Post first prototype	
2D mapping, brainstorm, post-its	[36,52,59,76,79,81,93,96,102]
Prototyping, 2D or 3D mockup, sketch	[27,33,35,36,38,48,52-54,59,71,75,76,81,86,96]
Persona	[35,79,93]
Cards	[79,86]
Storyboarding	[53,76]
Scenarios, user journey	[35,54,81,93,102]
Role-play	[79]

Some authors specifically argued why they used certain generative tools by explaining the type of knowledge that they seek to capture (Type 3). Phillips et al [88] explained why they used empathy maps with people living with HIV was precisely because it is a good tool for exploring topics people feel shameful about. Ahmed et al [32] specifically highlighted their aim of using PD to visualize information in an actionable way. Some visualization tools, such as a timeline, were specifically used to capture hopes and beliefs about the future [59]. How et al stressed that their aim with PD was to merge different domains of knowledge brought together in the co-design process in their project [29]. In doing so, "the 'Technology Domain' comprises of selected emergent technologies that could inspire new design ideas, and the 'Health-care Domain' comprises of health areas that are of interest for developing new technological applications." The authors explained that the co-design tools were specifically chosen to bring these knowledge domains together and develop a solution in this knowledge-sharing process. One study also referred to the use of certain tools including storyboards to help stakeholders express their deeper tacit knowledge [31]. In all, 4 studies [30,41,69,91] used specific generative tools such as field kits, workbooks, and design journals without explicitly reporting why these specific tools were chosen. As implied by Peters et al [30], one might assume that they were used to sensitize in the sense that they can help stakeholders express their deeper or tacit knowledge.

Some studies also related the knowledge advantage of using tools to the stakeholders involved in the PD project (type 4). This type of study justifies identifying knowledge domains related to stakeholders and then choosing outcome measures to capture that knowledge. One study explicitly stated the value of having a design expert in the teams to help select appropriate tools [37]. Another study referred to PD principles in involving clinicians as nondesigners in the design decision-making process to enhance their views and facilitate insights of others in the design [75]. This suggests that the authors related their recruitment strategy and stakeholder management to the use of PD activities and tools.

Outcome Measures

Some of the studies evaluated the eHealth product or service output after the PD activities were concluded. The eHealth output varies depending on whether the development is in the predesign, early design, or post first prototype stage. Overall, 50 studies considered that the outputs of the PD process were in agreement with findings from similar studies or, in the case of an eHealth product, that after testing, they were effective. For instance, in an early design study, it was reported that "our design considerations show agreement with previous work related to human-factors for telerehabilitation technologies" [41]. A study where eHealth technology had been developed to a later stage reported that "we constructed an EHR-tethered PHR module named MyHealthKeeper and implemented this software in an EHR-friendly hospital" [74], which can be seen as indicating that the technology output was considered effective. Only 1 study [102] reported a negative experience: an app that had been developed for nurses did not improve the workflow, although important lessons were drawn.

Of these 50 studies that considered the outputs to be positive or effective, 22 studies reported outcome measures. These outcome measures concerned the development of the eHealth (ie, ideas developed), the quality of the eHealth (ie, usability), and the outcomes for the user (eg, body weight, managing medication, or education on health topics; see Table 4).

Most of the reported outcome measures were related to usability and user feedback. As an outcome of the idea generation process, 2 studies measured the number of ideas [90,96]. Another measured the quality of new ideas: they were grouped under labels and then rated by clinicians

[41]. 2 studies reported outcome measures based on clinical parameters and participation in activities for care transitioning, managing medication and education on topics such as health insurance [59,74]. There was another study reporting clinical outcome measures (not reported in Table 4); however, the authors did not make it clear whether they considered the eHealth to be effective [100].

Table 4. Outcome measures used when electronic health technology and the participatory design method were positively evaluated (n=69).

Outcomes measures	Studies
eHealth[a] evaluation	
eHealth development (number of ideas for development)	[41,90,96]
eHealth quality (usability, feasibility)	[30,35,46,52,53,56,63,66,68,69,71,72,75,84,90,92,96]
User outcome (effectiveness)	[59,74]
Participatory design method evaluation	
Quality of ideas (ie, unique ideas)	[41]
Understanding of new technology through co-design process	[41]
Enablement of clinical knowledge through co-design process	[41]
Overall experience	[45,93]
Workshop content in line with the aim	[45]
Voices heard (perception)	[45]
Balance between voiced patients and care professionals	[45]

[a]eHealth: electronic health.

In terms of substantiating the choices for certain outcome measures for evaluating eHealth, methodological arguments were generally missing. However, the outcome measures that How et al [41] used, such as idea grouping and the use of labels, suggest that their intention was to evaluate the knowledge development process. This could have been further substantiated by referring to PD principles related to the principles of mutual learning or creativity, for instance, to measure the impact of tools on ideas developed or shared.

Next to evaluating eHealth technology, some studies also evaluated the development process itself. Overall, 55 studies, based on the experience of the authors, considered the PD method to have successfully contributed to the eHealth development. For instance [41]:

> *Through a mediated exploration with clinicians and technology co-designers, we could broadly explore opportunity areas for new technologies within a healthcare domain and unravel initial design considerations related to this intersection.*

Of these 55 studies that considered the method to have effectively contributed to the eHealth development, 3 studies reported outcome measures [41,45,93] (see Table 4). Outcome measures were reported regarding the quality of the knowledge development process (ie, unique ideas) and stakeholder management (ie, voices heard [45]).

When it came to substantiating the outcome measures chosen for method evaluation, methodological argumentation was again generally missing. However, the outcome measures that How et al [41] used do suggest that the intention was to evaluate the knowledge development process. The authors measured how stakeholders rated the extent to which they had an understanding of the new technology and the extent to which the use of clinical knowledge was enabled in the co-design process. Similar arguments related to knowledge expression may have driven the choice of stakeholder management outcome measures made by Revenas et al [45].

DISCUSSION

Principal Findings

Overall, reporting on PD methods varied significantly in studies where PD is used to develop eHealth. The extent of the reporting depended on whether or not the aim of the study was to report on the PD process itself. When it came to substantiating the methodological choices made, the justification for the tools used tended to be given the most attention.

Only a few authors explicitly used arguments directly related to PD guiding principles such as democratic, mutual learning, tacit and latent knowledge, and collective creativity. Even though the PD principles were not explicitly discussed in the method of many studies, they were implicitly identified in some. The arguments used to substantiate the choices made in stakeholder management, PD tools, and the type of outcome measures point to these principles being considered. In this discussion, the results regarding the stakeholders, tools, and outcomes are discussed separately and considered alongside other literature.

A few studies had a clear recruitment strategy, and two studies aimed for diversity in recruitment. Purposive and convenience sampling were most often used. Some studies, when reporting on recruitment, gave the recruitment strategy or the recruitment criteria. However, it was often unclear why certain stakeholders were included or excluded or why certain recruitment criteria were used. For instance, in line with the mutual learning and creativity principle, it could be expected that the recruitment strategy would aim to include designers, and this was rarely the case.

The recruitment criteria that were mentioned included age, health care exposure, access to internet, knowledge of using phones and internet, communicative skills, motivation, and capabilities to engage actively. Few studies included criteria related to personal characteristics such as communication, motivation, and engagement. This is perhaps surprising given the importance of knowledge transmission in relation to the principles of mutual learning and collective creativity. Furthermore, some studies used financial incentives to recruit individuals.

In the PD literature, the levels of expertise, passion, and creativity are suggested to play important roles in the PD process [13]. Expertise has also been suggested by others as an important condition in enhancing the creative process [103]. A meta-analysis of the PD of serious games also mentioned expertise being included as a factor of interest, but it was not found in the included studies [21]. Diversity has also been stated to play an important role in the creativity process [3,104]. Considering these personal characteristics as a whole, diversity was only identified in the recruitment strategy of a few studies in this review. This is surprising, and we would have expected the assessment of personal traits to be more prominent in the recruitment strategies in the studies included in this review.

In terms of stakeholder management, the results of this study show that various actions were taken. Moderation was aimed at providing a safe environment for equal participation, and facilitation was adopted to enhance knowledge sharing between stakeholders and to enhance creativity. This shows that some studies did consider the democratic and creativity principles of PD. Consideration was given to managing the PD process by providing a presentation about its content. In line with the principles of mutual learning and collective creativity, it may be important to manage explanations, given the different levels of expertise of care professionals, software developers, and patients involved. Overall, we had the sense that there was an implicit emphasis on creativity and understanding in some studies, but it remained unclear why a certain form of stakeholder management was chosen.

As noted above, one study may have considered the cognitive abilities of the users involved. This was also suggested in a recent meta-analysis of PD used to develop serious games where it was stressed that one should facilitate the PD tools according to the users' cognitive abilities to increase the quality of idea generation [21]. In addition, others have also stressed that creativity can be managed on an individual level or on a group level [3,105]. Overall, it seems that adequate attention is being given to facilitating the creative process. On a personal level, creativity is correlated with a mental state of flow, and therefore, facilitating this state may play an important role in developing high-quality ideas in the PD process [16,103].

Various combinations of tools are used across the various design phases of eHealth. Some studies also described the use of toolkits, the scaffold method, the CARD technique, and the think aloud technique. The greater use of combinations of tools with a generative approach in the predesign phase may indicate that authors used these combinations to generate more new ideas. This is in line with the principles of collective creativity and tacit and latent knowledge.

When looking at the arguments used to select tools, the argumentation could be categorized into four types of arguments related to knowledge development: (1) tools are used to harvest ideas for the product or service development, (2) arguments in favor of the tools based on other literature, (3) arguments explaining the aim of the tools to retrieve specific type of knowledge, and (4) arguments explaining the aim of the tools in relation to the stakeholders involved.

This focus on knowledge arguments was expected as this is implied in other publications. However, it has not yet been explicitly summarized in terms of levels of argumentation. Others have stated the importance of recognizing the fundamental role of knowledge development in PD. Given the nature of PD, this implies gaining an understanding and a generative creativity that leads in itself to different ways of knowing [4]. In terms of epistemology, the field of knowledge development is closely related to creative processes. Sanders and Stappers [3] have hinted at using social creativity theory and a *path of expression.* Even though the knowledge development theory could be a building block in a methodological framework, it is remote from practical methodological guidelines on selecting between PD tools.

In terms of outcome measures, only a limited number of studies reported outcome measures to evaluate eHealth development and the use of the PD process itself. One study in this review described the outcome measures in considerable depth for the evaluation of both eHealth and the method [41]. Compared with the other studies reviewed, this study had a more rigorous methodological framework, which also substantiated the chosen tools. This study explicitly explained that the focus was on the development of ideas and the use of different fields of expertise and knowledge. It also hinted at considerations related to knowledge developments related to the chosen tools. Nevertheless, it remains challenging to propose appropriate outcome measures to capture the output of creativity given our current understanding of it. These methodological challenges may prevent reporting the use of certain epistemological argumentations.

The identified lack of outcome measures is in line with findings elsewhere. Previous systematic reviews have also highlighted the lack of transparency about the evaluations of PD [7,8]. However, depending on the methodology and design phase, different outcome measures are suggested to evaluate the method [15,106]. Three output domains have been suggested related to the stakeholders (ie, empowerment), to knowledge (ie, tacit, pragmatic, and technical), and to implementation (ie, ownership) [16].

Limitations

The results of this study are limited for several reasons. First, the search strategy for relevant research is limited by the focus on papers published in scientific journals. Given that many reports on PD in developing eHealth are not in scientific journals, the review only provides a partial view of the state of reporting PD methodology, namely only that in the empirical scientific literature.

The screening process is limited by the definitions applied for the terms used in the inclusion and exclusion criteria. As there is no universally agreed definition of PD, a working definition was chosen that focuses on one strand of PD research, namely where stakeholders are a partner in the process. Consequently, studies describing PD in a more user-centered way were excluded, and their inclusion may have led to different results.

Turning to the analysis and conclusions, the following limitations were identified. First, it is challenging to draw conclusions based on the reporting of the PD methods as described in the papers selected in the systematic literature review. The actual methodological intentions and considerations made during the PD project may differ from what is reported in the studies. The limited number of studies reporting outputs and outcome measures may be related to the recognized publication bias toward reporting positive results and eHealth products and services that are already fairly developed. In addition, the evaluation of the eHealth technology may have been reported in a separate publication; for example, in the paper by Waller et al [98] included in this review, it is noted that the results of the randomized controlled trial of the eHealth technology are reported elsewhere [107], and the latter paper did not meet the inclusion criteria for this review. This was because studies that focused on the outcome measures of the eHealth technology were excluded from this review.

Implications

The PD methodology is still under development [2,4,108]. Providing methodological reasoning in a transparent way about the choices of stakeholders, tools, and outcome measures employed is important for methodological progress. A clear PD methodology could well enhance the development of eHealth in practice as practitioners would then be able to argue more rigorously for a certain form of PD. A clear methodology may also improve the rigor and accountability of the science of PD. For instance, given a methodology, evaluation criteria could be used to evaluate the method, which can then inform other researchers about how it can be further improved. A clear methodology may also help to select an appropriate form of PD for a specific research design.

Reflection

The fact that the methodological reasonings behind the use of PD are not widely reported could be because of several reasons. From a scientific perspective, PD has mixed origins, ranging from social science through action research to the design sciences [3]. This may result in different scientific reporting styles appearing across the scientific literature; for example, the theoretical underpinnings of a methodology tend to be much less described in empirical literature in the health sciences than elsewhere.

The academic design culture is still developing alongside other different cultures such as engineering, the arts, and the social sciences [109]. Although classical research methods and design methods are closely related, they are different. In the PD science field, one sees many different crossovers; for example, one can involve research for a single aspect during a design project but also fully incorporate research methods at every design step. Depending on how research is used in a PD project, the reporting will differ. When the emphasis is on scientific reporting, the methodological steps tend to be explained, but when the emphasis is on design reporting, the design products will be more heavily emphasized. Looking at the results of our study from this perspective, one could argue that the majority of the authors have put the emphasis on design reporting and less on scientific reporting.

This observation can be further explained using the observations by Spinuzzi [2], who claimed that there is no strong methodological justification for PD in the first place. Although there are some principles, stated in this study, on how PD should be conducted, a methodological framework for PD is scarcely discussed [2,4]. This may leave researchers confused as to how to employ and report on PD methodology.

PD reporting could be improved if PD researchers were to adopt a more *scientific* attitude toward carrying out a PD project. Improving documentation on the choices of certain PD recruitment strategies, the use of certain tools, or the use of outcome measures could provide more information that could then be reported in scientific journals. Improving education about the scientific documentation of PD projects for designers and eHealth developers could help to improve future reporting. One key challenge here is to translate design terminology to scientific terminology and vice versa; for example, prototype testing in design might be translated as hypothesis testing in science.

Further Research

Further research can help improve the methodological framework for PD in eHealth. A particular focus on the knowledge development process, as a core aspect of PD, would greatly help in substantiating methodological choices and in measuring the outputs of a PD process, especially in eHealth given the various areas of technical knowledge involved. There is a growing interest in the methodology of design known as *Research through Design* [109], which could help foster the development of a methodological framework for PD that would help develop better eHealth.

Conclusions

Studies that use a PD research methodology to develop eHealth primarily substantiate the choice of tools and much less the selection of stakeholders and outcome measures.

CONFLICTS OF INTEREST

None declared.

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CHAPTER 3

Lessons for Employing Participatory Design When Developing Care for Young People with Cancer: A Qualitative Multiple-Case Study

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ABSTRACT

Purpose

Participatory design (PD) is a collective creative design process involving designers and non-designers. There is limited reporting on the experience of using PD for adolescent and young adult (AYA) care. This study summarizes lessons from employing PD to develop care for AYAs with cancer.

Methods

A qualitative multiple-case study method was conducted of three PD processes addressing food (FfC), intimacy and sexuality (I&S), and integrative medicine (IM) in caring for AYAs with cancer.

Results

Local key stakeholders, who were exposed to a problem and had not been successful at solving it individually, were recruited to "dream" together. Through this synergy, a shared understanding of the problem and a joint mission emerged to find a solution. PD tools were used to develop a problem definition. An open mind and explorative research helped to understand the problems, and stakeholders were managed such that idea-sharing and learning were enabled. Designers translated ideas into prototypes. The PD process was prolonged due to the hierarchical hospital environment, business considerations, and additionally required evidence. The FfC program produced an effective new food service for the whole hospital. The I&S initiative developed a podcast, two articles, and a prototype website. The IM project developed a pilot study.

Conclusions

For a PD process to successfully develop care for AYAs, one needs to use designers and skilled people, PD tools, and an open-ended approach to visualize and materialize new forms of care. Furthermore, recruitment and facilitation techniques help leverage knowledge and create a synergy in a democratic environment between stakeholders.

INTRODUCTION

Each year, about 2700 adolescents and young adults (AYAs) aged 18-35 are diagnosed with cancer in the Netherlands [1]. Since the Dutch AYA Care Network (AYA Care Network) was established in 2014, specific care for AYAs has been implemented in eight university hospitals and basic AYA care in a growing number of general hospitals across the Netherlands. However, there is still room for improvement in AYA care with many unmet needs during treatment, into adulthood, and beyond [1–5].

The AYA Care Network has always set out to harness collaboration between health care professionals, AYAs, and their relatives [1,6]. The AYA Care Network focuses strongly on AYA engagement with the vision "Nothing about AYAs without AYAs." Collaborative design methods, involving AYAs themselves, have been suggested to tackle the complex challenges in cancer care [7,8]. Participatory design (PD) is a collective creative design process involving three phases whereby designers and nondesigners are considered partners in the design process [9]. The three phases are exploration, creation, and testing [10–12]. The aim of the exploration phase is to clarify and define the problem by combining the perspectives of all the stakeholders. The creation phase is expected to develop prototypes of potential solutions. The evaluation phase should test these prototypes which, if successful, can be implemented in practice.

Designers, particularly, help to understand and integrate the perspective of different stakeholders, for example, AYAs, into physical solutions, called prototypes of a certain product or a service. These prototypes are initially simple and then further iterated. This iterative process involves creative tools.

In PD, one of the guiding principles is that every relevant stakeholder can and should be involved in the design process [9,13]. Examples of PD "make" tools, which can be utilized by designers, and also nondesigners are mind-maps, storyboards, and prototypes [14]. Such "make" tools help stakeholders express deeper lying knowledge such as complex emotions, dreams, or needs, which are hard to describe in words [15]. These insights are crucial to develop a successful service or product.

The use of PD to improve cancer care is seen as especially advantageous for AYAs for several reasons. First, AYAs receive treatments that have a life-changing impact as they go through important life events[16] and PD enables exploration of deeper levels of knowledge through these evolving phases. Second, the problems associated with caring for AYAs need to be explored with stakeholders beyond the medical paradigm, which is an inherent strength of PD. For example, not only physicians and specialized AYA nurses but also fertility and sex specialists, social workers, psychologists, and many more are involved [16]. The AYA population is also very active and open to innovation and collaboration[1] to harness their own experience for the common good, and this open mind-set can foster a successful PD project [12]. However, the implementation of AYA care services can be challenging for various reasons, including financial hurdles [16,17]. Actively involving stakeholders through all the PD design phases can facilitate implementation [9].

To date, researchers have described two other PD projects where AYAs were involved. They reported that there was good engagement with AYAs in designing a care pathway, [18] and an app was positively evaluated [19,20]. However, these studies did not provide in depth lessons about the use of PD as their main focus was on the developed products and services rather than evaluating the PD method.

The aim of this study is to summarize the lessons for employing PD when developing care services for AYAs. These insights may help health care professionals overcome the key challenges when employing PD to develop AYA care.

SCIENTIFIC BACKGROUND TO CASE STUDIES

Three case studies regarding food intake (Food for Care, FfC), intimacy and sexuality (I&S), and integrative medicine (IM) were identified by AYAs during an initial meeting organized by the AYA Care Network [21].

Food for care

The food intake of all oncology patients, including AYAs, tends to change substantially due to changes in taste, appetite, and experiencing pain when consuming food as a consequence of chemotherapy and radiotherapy [22]. Even though 40%–80% of all individuals, including AYAs, with cancer suffer from malnutrition and poorer treatment outcomes, this issue is often overlooked [22].

Sexuality & intimacy

One-third of AYAs experience sexual dissatisfaction and one-third of these desire supportive care in this area [23]. Cancer can interfere with normal sexual development [24–29]. A combination of physical [24,30] and psychological issues (body image) result in AYAs feeling less arousal, pleasure, and satisfaction[25] at the beginning of their sexual development phase.

Integrative medicine

AYAs not only find the use of complementary therapies such as massage, [31] music, [32] acupuncture,[33] and mindfulness[34] meaningful but also challenging. Patients are often unsupervised by physicians when using complementary therapies [35]. IM aims to combine mainstream medical and complementary therapies [35]. To avoid pitfalls of "alternative medicine," legal and ethical issues are addressed, for example, to cope with unsupervised administration of treatments, both patients and health care professionals need to be educated about drug interactions, product contaminants, other alternative therapies and evidence on effectiveness and safety using IM interventions [35].

METHOD

A qualitative multiple-case study method[36] was employed following the COREQ guidelines [37].

Methodological framework

A multiple-case study approach was used to explore how PD is used in real-world applications to develop AYA care [36]. Three case studies (FfC, I&S, and IM) were selected, in which PD meetings were held and PD tools used to develop AYA care. The PD projects were called "dream teams" by the stakeholders, emphasizing the collective creative aspect of developing better AYA care while daring to imagine completely new forms of care.

Study design

Data were collected and triangulated using documents, interviews with key stakeholders, and one observation. The data collection was conducted by the lead author (PV), who had experienced leukemia at a young age himself and was trained in qualitative research before this study. Face-to-face interviews of typically one hour duration were conducted (and audio recorded) at the workplace or by a video call (audio and video recording). The interview questions (see template in Appendix A1) were piloted and adapted if necessary. Introductions were made at the start of the interviews apart from with the director of the AYA Care Network who was already well acquainted with PV. At the end of each interview, a summary of the interview was discussed for comments or corrections.

The key stakeholders (age range 23–58) interviewed were all intensively involved in one of the three case studies: four FfC, five I&S, and three IM (Table 1). Other stakeholders, who were not involved throughout the entire process, were not interviewed. They were in the FfC case: four AYA and three partners, a clinical manager, a chef, a catering company, and the hospital board of directors; in the I&S case: the Director of the AYA Care Network, six AYAs, a sexologist, a journalist, and several MSc student designers; in the IM case: the Director of the AYA Care Network, four AYAs, a specialist AYA care nurse, a massage therapist, and other complementary care specialists. The AYAs were not reimbursed and received information before the PD process started by the Director of the AYA Care Network about how to leverage their story for the greater good of this project.

Even though the contribution of all stakeholders had equal weight, there were one or more facilitators in each PD project. FfC was directly facilitated by the Director of the AYA Care Network; in I&S, there was cofacilitation with the Director of the AYA Care Network and a sexologisturologist; and in IM, there was cofacilitation with the Director of the AYA Care Network, an oncologist and a pediatrician. The administration of the PD activities was supported by a secretarial assistant of the Director of the AYA Care Network.

Most of the documents studied (FfC: 100, I&S: 25) were collected through the director of the AYA Care network. No documents were available for IM. In each interview, stakeholders were asked if they could supply additional documents if they had any. The documents consisted of meeting notes, photographs or drawings of prototype ideas, presentations, and the master's dissertation of I&S Designer 1 [38]. Three further websites were consulted: of the AYA care network, [39] of FfC, [40] and of I&S. [41] Observational data were collected during the most recent national AYA congress on the March 7, 2019[42] where the I&S project presented and discussed their findings. The researchers discussed the moment of data saturation at the end of the data collection process.

Ethical approval was granted by Erasmus Medical Centre Ethics Committee, no. MEC-2019-0232. The research data were solely managed by the lead researcher (P.V.).

Table 1. Characteristics of Key Stakeholders Interviewed Per Case Study

Function	Education and background	Gender
Food for care (FfC)		
Director AYA Care Network and facilitator	PhD, involved in patient and health care organizations, cancer survivor	F
Dietician	25 years experience at oncology ward, including AYAs	F
AYA	Catering experience	M
Facility manager	Trained chef	M
Intimacy and sexuality (I&S)		
Sexologist-urologist and facilitator	MD, PhD, treating AYAs	M
Oncologist	MD, treating AYAs	F
AYA	MSc student medicine	F
Designer 1	MSc student industrial design	F
Designer 2	PhD student industrial design in health care	M
Integrative medicine (IM)		
Oncologist	MD, training integrative medicine, treating AYAs	F
Pediatrician	MD, training integrative medicine, manager integrative medicine in hospital	F
AYA	MSc law	F

AYA, adolescent and young adult.

Data analysis

A timeline and summary of the interviews and documents of each case study was developed and annotated. The data were iteratively coded and analyzed in Atlas.ti by the lead researcher (P.V.) (Appendix A2). Ambiguities were discussed and resolved with other researchers (M.d.D. and A.d.D.). First, the process of the PD projects was mapped over three PD phases: exploration; creation; test; and a fourth phase of implementation was added. Second, thematic and open codes were used to analyze the key events in each phase further. Given the large amount of data available, visualizations were made of the idea process development for FfC in Microsoft PowerPoint. Third, the most emphasized success factors of each case study were identified per PD phase and grouped in themes (Appendix A2). The variation between these themes was compared across case studies. Lessons were drawn from this comparison when success factors were present in all three case studies or if other case studies could benefit from applying insights from another case study.

RESULTS

The FfC, I&S, and IM PD processes were at different stages at the time of data collection and all projects were still developing. The FfC PD process resulted in a new implemented food service[40] for the entire hospital, reaching a much wider target audience than AYAs alone, potentially being implemented in other health care institutions. I&S had developed a podcast,[43] two research articles about communication[25,44] and a prototype website,[38] and IM developed a pilot study about communication about IM topics by caregivers. Across the case studies, seven themes were identified (Table 2).

Recruiting key local stakeholders directly exposed to the problem leads to synergy

The key stakeholders were interested in solving a problem that they had been previously exposed to. They were recruited in their local environment, where they were in contact with the problem, for example, at their workplace or where they studied, or at an event they attended. The dietician and the facility manager were recruited (FfC) at the hospital ward where the project was taking place. Designers were recruited (I&S) at a design school together with an AYA to present that project more vividly. AYAs were recruited (IM) through a national AYA conference[42] after a presentation on IM. During initial PD sessions, the "dreams" of each stakeholder to solve the problem were made explicit and each stakeholder was motivated to understand each other's dream. They therefore felt a shared experience of the problem and a joint mission to solve it together, as they realized that they could not solve the problem on their own. Joining all these stakeholders in this way leads to a "synergy." They were enthusiastic to contribute their extensive experience to solve the problems, and they were motivated to create solutions. They also had networks of people who made important contributions such as a food designer and chef in FfC and a journalist in I&S. In summary, a synergy emerged when stakeholders were recruited with relevant experience in places where they were directly exposed to the problem.

Table 2. Themes Identified Regarding the Use of Participatory Design to Develop Adolescent and Young Adult Care (Translated from Dutch)

Theme	Example interview quotes (function of key stakeholder, case study)
Recruiting key local stakeholders directly exposed to the problem leads to synergy	...at the end of the workshop there was a call, that they indeed wanted to start a dream team, and which AYAs would be interested to join, then I registered immediately with [Oncologist, IM], I talked with her and we were immediately enthusiastic, so we thought, we have to do this together... (AYA, IM)
	[AYA Care Network Director] came at a certain point around the corner, while I was a dietician at oncology and nephrology, and at some point she came to me and said. Can we have a chat? And what I really liked from the very start is that she always put the patient in the centre... (Dietician, FfC)
Using design tools helps to explore the problem from different angles	I can recall that in the first meeting we tried to map out the process for the coming 2 years. It started with surveys for AYAs and for care providers. That was the part that the researchers who were in the room were good at. And then, after that, we were kind of sketching out what should be the steps to take beyond those interviews and more sort of knowledge generation, and they kind of liked that. (Designer 1, I&S)
	Yes, what fascinates me is another look at things,... for example TU Delft, they are looking in a completely other way at different communications channels then us, and they are also looking in a different conceptual way at communication and that is very fascinating... I am very interested in how they look conceptually at the entire problem and how they would deal with the problem in a creative way (Sexologist-Urologist, I&S)
By listening and conducting research first a deeper shared understanding was created	I think it is good if you begin broadly and look what the needs are, and I think it is good we immediately sent out a questionnaire, because this allows you to take targeted action, instead of thinking what people want and make something nonsensical, I think this order in the process was important (AYA, I&S)
	At a conference in 2008,… experts said already 10 years we are trying to make sexuality a subject of conversation in the consultation room... and nothing changes... and now things are getting better, but let's say you need to change the structure and you need a kind of trial and error to research other things... from the medical profession we always think we know what's best for the patient... but in reality we are not listening to our patients to hear how they would their care services to be. (Sexologist-Urologist, I&S)
Taking small steps toward a vision facilitates imagination	I do not remember if (AYA Care Network Director) said it in exactly this way, but it was like, to have big dreams, but to do it in small steps. It is also really like that if you want to keep your feet on the ground, as I experienced myself (AYA, IM)
	Yes, that was one of the biggest challenges for me, because the enthusiasm was there, because we always got a lot of energy from it, but it all has to happen next to our normal job, which already took a lot of time (Oncologist, IM)

Table 2. Themes Identified Regarding the Use of Participatory Design to Develop Adolescent and Young Adult Care (Translated from Dutch) (*continued*)

Theme	Example interview quotes (function of key stakeholder, case study)
Respecting stakeholders in an equal collaborative environment fosters learning	Within my department, to my boss, I was the dietician and I remained the dietician. (Director AYA Care Network) saw that, and yes you should leave that to (Dietician). And she showed trust in me when I said, oh I will do that... yes, because when you collaborate you also get this feeling of each other. She really let me keep my own values. (Dietician, FfC)
	Yes we did that in fact all together, wat we want to achieve, as dream team, it was more like a presentation round, everyone is introducing himself or herself, [Oncologist] also presented a Powerpoint presentation... What is integrative medicine, what is integrative oncology... I really liked it that is was an equal group where everyone was sharing their stories (Pediatrician, IM)
Designers and skilled people help to translate ideas into prototypes	A group of design students suggested a few ideas as to how they could use their way of looking at things to design for this subject. So this was a kind of assignment, it was a lot of fun, and at a certain moment they gave presentations to us about different options, and they also had interviews with AYAs (Sexologist-Urologist, I&S)
	We involved a food designer, it all went very organically, when [Facility manager] heard from AYAs how they experienced the food and drinks, they said, let's go to the kitchen, So, what tastes so bad what food doesn't taste good? And then they tried all kinds of dishes. (Director AYA Care Network, FfC)
A hierarchical hospital environment, business considerations and additionally required evidence prolong the PD process	In hindsight, I think that in the second part, scaling up the pilot to multiple departments and the entire hospital, everyone started to get involved, because it was a very successful project. So, everyone was pursuing their own interests. ... Then a sort of hierarchy came into play about who will manage who. (Dietician) had nice beautiful ideas, which she could realize in the dream team and which she successfully concluded the first research pilot with. However, she could not express them adequately in the second research pilot, which no longer belonged to the dream team. (Director AYA Care Network, FfC)
	After it dissolved in Food for Care, let's say, actually in the period that the business case was made, ... in reality the catering company as a business, because they needed 600k food and drinks, nobody had the money, eventually we found the money with the catering company, so in that phase, it went pretty quickly, they were like thank you for the work… that is where the dream team stopped, because we knew what we wanted [AYA] and [Dietician] were there… but eventually you have to start looking at the business side of things to make it viable for the coming years and then the dreaming is over (Facility manager, FfC)

Using design tools helps to explore the problem from different angles

Design tools were used to visualize what was being discussed. Broadly framing a problem can prove challenging, as indeed the IM stakeholders experienced, and it can take considerable time to gather information. In the I&S case, the problem was framed more narrowly with the help of Designers 1 and 2 by visualizing the problem through a mindmap (Fig. 1) and a so-called customer journey, which visualizes the journey of the patient (Fig. 2). The mind-map helped them to more easily discuss both solvable problems, such as improving communication, and more difficult problems, such as a system-wide health care change. To get a better understanding of the place and time of the communication problem, Designer 1 developed a customer journey based on interviews with AYAs and other stakeholders. This helped to pin down the communication problem in the complex referral process (Fig. 2).

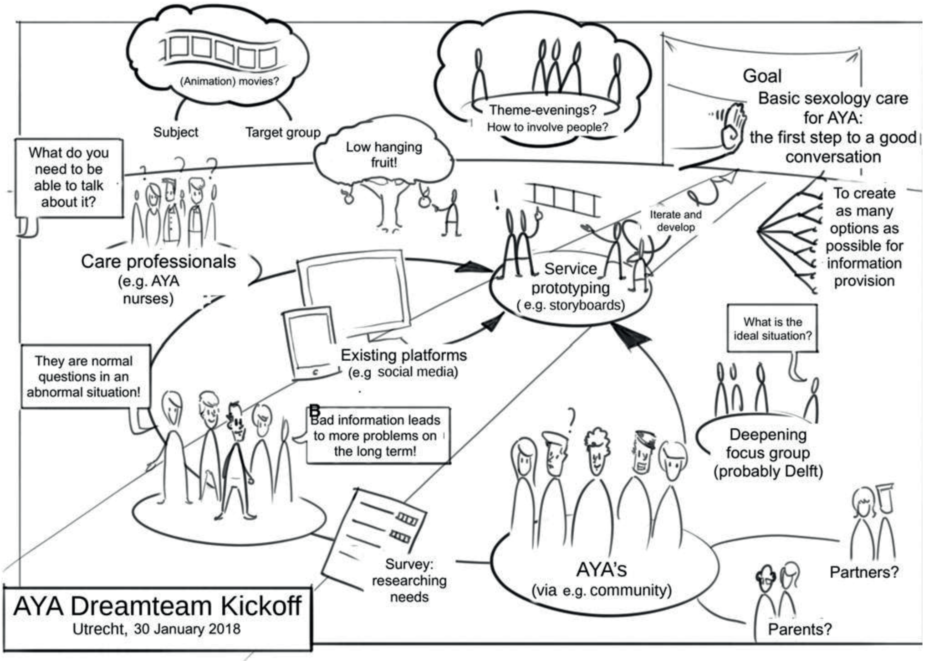

FIG. 1. Mind-map visualizing problems and solutions by Designer 2 for the Intimacy and Sexuality case.

By listening and conducting research, first a deeper shared understanding was created

The facilitators in each case explicitly invited everyone to share their own stories and dreams to improve care, and they actively sought AYA input. They facilitated an open and safe atmosphere that allowed empathy to grow between stakeholders and between the stakeholders and the problem. In doing so, the stakeholders became aware that their frustrations and dreams were similar and that connecting dreams worked synergistically. To further understand the communication problem identified in the I&S case, a survey was conducted [25]. The survey revealed that there was a misalignment in expectations about who should provide information, and that AYAs preferred to engage about this topic with nurses and sexologists. AYAs further indicated that the preferred mode of conversation was through a website, which contradicted the assumption made before the study that people would prefer an app.

Taking small steps toward a vision facilitates imagination

The Director of the AYA Care Network used particular wording to stimulate imagination and collaboration among stakeholders: “taking small steps” to make the progress achievable while holding on to “a vision on the horizon” to maintain a sense of direction. For example, the vision developed in the IM case included specialist nurses for complementary care, websites with reliable information, greater awareness, a referral network, and reimbursement structures.

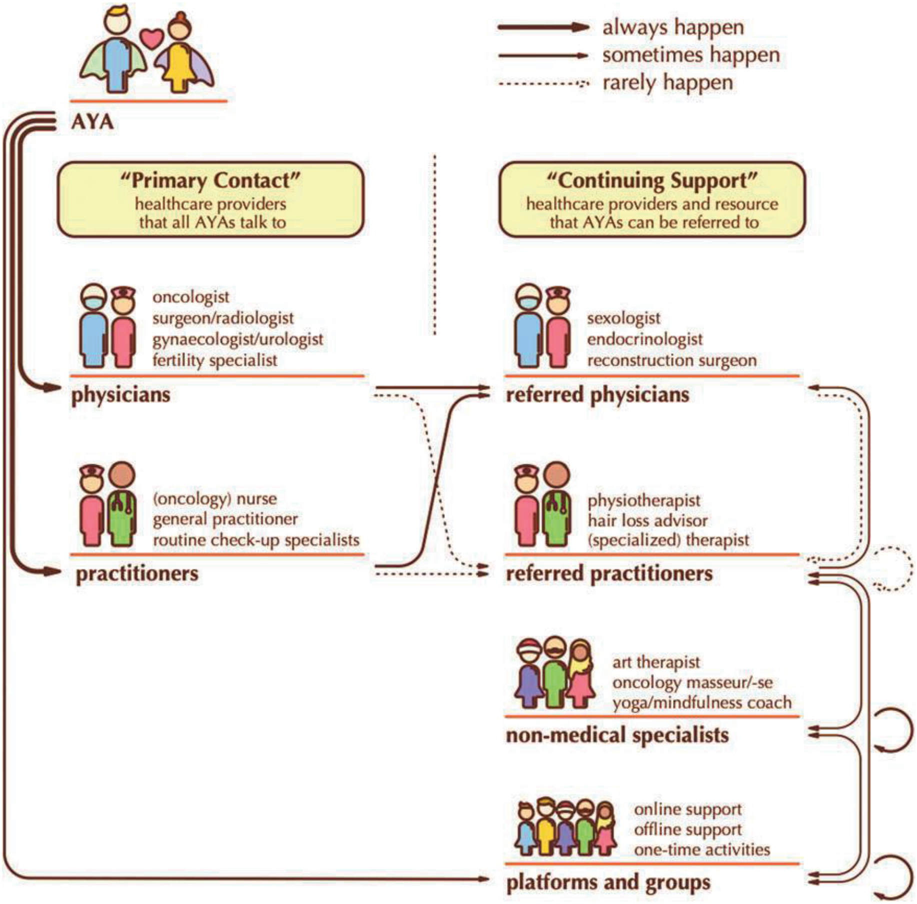

FIG. 2. Customer journey visualizing the journey of the patient by Designer 1 for the Intimacy and Sexuality case. see Wang R, Groeneveld B, Albers L, Desmet P. Designing sexuality and intimacy care for adolescents and young adults (AYAs) with cancer. In: Christer K, Claire Craig & Paul Chamberlain (Eds). Design 4 Health. Amsterdam, The Netherlands: Lab4Living, Sheffield Hallam University; 2020; pp. 85-92.

Combining an open approach with a sense of direction was crucial for some stakeholders, who felt that the problem was overwhelming. By having a direction, stakeholders could carry out activities outside the meetings and were seeking feedback in their own communities. A key challenge throughout the process was to keep that sense of direction, given that not everyone could attend every meeting. Health care professionals had conflicting agendas, and many had to combine what was voluntary work with their official job.

Respecting stakeholders in an equal collaborative environment fosters learning

Following the cocreation process of the AYA Care Network, the sharing of ideas and experiences was promoted by showing respect and empathy toward all stakeholders (Fig. 3). For instance, to emphasize that everyone would be involved equally in the process, the care professionals would not be allowed to wear white coats during the meeting and the Director of the AYA Care network, would use a virtual "eraser" at the start of meetings to emphasize the openness toward diverse backgrounds and cultures. This was important as the stakeholders were used to working in the hierarchical settings of health care institutions. The democratic environment that was created equalized the power relationships and stimulated knowledge sharing and knowledge integration, with each stakeholder contributing essential knowledge that others lacked.

Learning from each other about technical topics was important given the range of stakeholders. In the IM case, the oncologist presented an ethical framework (Appendix A3) that helped the other stakeholders understand how physicians define complementary care. In the FfC case, the idea was developed to use a "waiter" to encourage the patients, which was identified through a combination of patients' needs and the expertise of the Facility Manager (Fig. 4). Here, the knowledge of the Dietician also helped in sourcing ingredients to help patients recover. This was combined with the knowledge of the AYA cancer patients on what flavors and portions were desired.

FIG. 3. Cocreation process of the AYA Care Network "The AYA Network way of doing things."

FIG. 4. Presenting food to AYA cancer patients in the Food for Care project: a result of integrating experiences of different stakeholders. AYA, adolescent and young adult. Photo printed with permission.

Designers and skilled people help to translate ideas into prototypes

The involvement of people such as designers or journalists could be decisive in coming up with potential solutions because other stakeholders realized that they needed someone with more creative skills to help them visualize their ideas about a solution. In the I&S case, Master's student designers took on the challenge to develop solutions, which were further developed by Designer 1. This designer developed further prototypes for an app, which were turned into a website following the survey, to provide information and guidance for AYAs with questions about I&S (Appendix A4). In the FfC case, a designer helped visualize the food dishes (Fig. 5), and a highly rated chef gave crucial input for producing the prototypes. Research has shown that the FfC project did improve the experience and health of patients [45,46]. In the I&S case, a journalist experienced in sexuality communication helped to combine the knowledge of AYA cancer patients and sexologists in a podcast containing several episodes [43].

FIG. 5. Prototype food dishes in the Food for Care project.

A hierarchical hospital environment, business considerations, and additionally required evidence prolong the PD process

Due to the success of the initial pilot study of the FfC prototypes service, the board of directors was highly impressed and wanted to explore the possibility to provide FfC for the entire hospital. At this point, there was a long delay in the process for various reasons. First, two extra pilot studies had to be conducted for different patient groups and the results had to be included in a revised business case. Second, negotiations regarding the business case with the board of directors and the catering company took longer than expected. Third, there were additional bilateral discussions between the hospital and the catering company as the food could not be prepared in the hospital kitchen and food assistants would have to be contracted by the catering company to provide the innovative formula for the entire hospital.

To overcome these hurdles of FfC, crucial attributes required of the AYA Director were described by other FfC stakeholders as being solution-oriented, daring and strategic, and being able to connect people. Once the Director of the AYA Care Network could no longer take part in the project, the hierarchical hospital environment resurfaced. Only after 2 years of piloting with other patient groups, developing a business case for the whole hospital and negotiations, was the business case accepted and the FfC ideas embedded in several of the hospital's wards [40]. Notably, the Facility Manager stressed that upscaling this project only seemed to be successful in those wards where a PD approach was used to redesign the original FfC service to meet the needs of their patients and the setting. Even though I&S and IM were not at the implementation phase, the challenge of the hierarchical hospital environment also resonated with them as they were consciously looking for solutions outside of the hospital frame to experiment with new forms of care. In addition, IM suffers from the image of quackery of "alternative medicine," which meant that they had to be extra careful when starting a pilot study.

DISCUSSION

Table 3 presents the key lessons from the three case studies and makes practical recommendations on how to develop a successful service or product for AYA care.

Table 3. Lessons and Practical Implications to Employ Participatory Design to Develop Adolescent and Young Adult Care

Key lessons	Practical implications	PD reference
Recruiting key local stakeholders directly exposed to the problem leads to synergy	Identify locations where people are exposed to the problem and recruit those with relevant knowledge and motivated to solve it	Theory of knowledge in creative process[9]
Using design tools helps to explore the problem from different angles	Use mind-maps or customer journeys to explore problem	Mind-map,[10] journey,[12] other tools,[14] examples[9]
By listening and conducting research first a deeper shared understanding was created	Be empathic with stakeholders and be willing to change assumptions	Empathy,[9,12] beginner's mind-set[12]
Taking small steps toward a vision facilitates imagination	Use an open-ended approach without a specific goal to achieve	Open-ended approach[9]
Respecting stakeholders in an equal collaborative environment fosters learning	Create a safe space where input is equally respected by all stakeholders (nonhierarchical)	Principles of democracy and mutual learning[9,52]
Designers and skilled people help to translate ideas into prototypes	Involve designers and people who have skills to develop the product or service	Brainstorming and prototyping techniques[10,12]
A hierarchical hospital environment, business considerations and additionally required evidence prolong the PD process	Maintain the PD process by preserving democracy, consider involving implementation stakeholders early (i.e., financiers)	Testing,12 principle of democracy[9,52]

To employ PD to develop care for AYAs, one needs to involve designers and skilled people, PD tools, and an open-ended approach to visualize and materialize new forms of care. Through the initiative of a designer to use PD tools, the I&S stakeholders were able to quickly identify the problem. Furthermore, the designer's skills were instrumental in both the I&S and FfC projects quickly developing prototypes. Furthermore, the skills of the journalist (I&S) and a highly rated chef (FfC) were crucial in developing prototypes. Using the inputs of a designer and other skilled people, and employing the PD tools in an open-ended way, helped all stakeholders to develop novel solutions they would not have thought of on their own.

In addition, recruitment and facilitation techniques helped to leverage knowledge and cooperation among the stakeholders. Stakeholders were brought together who had been exposed to a particular problem and had relevant expertise in the area. Each stakeholder was limited by their own field of knowledge, and the integration of this knowledge proved essential later in the prototyping process. The knowledge integration process was facilitated by creating an openminded environment and equalizing power relationships by showing empathy and respect. Also, enabling the collaborative development of innovative care, participants found this approach to be highly satisfying and joyful.

Furthermore, the PD tools that the designers used helped to create a shared frame between stakeholders, in which new solutions could emerge. The mind-map in I&S, for example, set out the various ways in which one could frame the problem, that is, as an information "low hanging fruit" problem, as a conversational problem or as a service problem. The visualization of the food dishes in FfC helped the nondesigner stakeholders to frame the solutions as food dishes, rather than separate ingredients.

In line with earlier publications, the supportive role of design tools is highlighted as they help to share stories in a mutual language and build trust between staff and patients [11,47,48]. The findings favor the use of creative PD tools over a research-focused PD approach that had been used in a previous AYA PD project [18,48]. Involving a designer avoids "quick-fix" solutions – solutions which do not address the more fundamental underlying issues of a problem [48]. Furthermore, an open-ended approach is recommended in early design phases to enhance the creative process [9]. Similar to what this study highlights, others have also stressed the importance of recruitment[10,12] and of knowledge integration [49–51]. However, the relationship of recruitment and knowledge generation requires further examination. Facilitating a "beginner's mind set" is recommended as a way to overcome previous assumptions and iterate in the PD process [12]. To this end, stimulating a democratic environment and enabling mutual learning should be promoted as it is emphasized as a key aspect of PD [9,13,52].

Turning to the implications for the development of AYA care, the findings highlight the need to integrate tools and techniques from PD in health care innovation practices. The hierarchical and clinical research-focused approach to delivering and developing care, which emphasizes high-level evidence from randomized controlled trials, is in sharp contrast to employing an open-ended creative design mind-set. Even though health care institutions are increasing multidisciplinary activities, these are still far from creative PD practices. As the deeply rooted cultural differences pose challenges, special attention should be given to highlighting the value of PD to health care stakeholders [47,48].

Future recruitment strategies for using PD in an AYA setting could focus on identifying effective locations, where AYA care professionals, AYAs, and designers are based. In addition, financial and politically involved stakeholders could be approached at an early stage to hasten the implementation process [17]. To anticipate the implementation process, we would recommend engaging the manager of the cancer center and board members at an early stage. This may require some patience and slow the process down, but this patience may pay off later. The process may speed up due to their help to manage potential financial issues, building a robust business case, and advocating to other decisionmakers within the often complex hierarchical hospital management structure. Furthermore, considering their involvement, one should try to explicitly discuss the need to conduct pilot studies early on so that data can be collected to demonstrate the required clinical and organizational value. To secure the longevity of the project, one should make sure that when replacing team members, one should communicate the required competencies clearly to avoid a conflict of interest.

A range of creative tell, make, and enact tools[10,14] can be used to leverage the engagement of AYAs. Adopting an open-ended approach to manage these tools may be a significant contribution in the context of AYA care since this age group goes through a continuous identity construction process and a series of important life phases [2,16,53].

Facilitating the PD process should not be underestimated in the AYA context given the need and value in respecting the various stakeholders [17] Creating a safe and efficient process is perhaps even more crucial, given the limited time available to stakeholders employed in the health care sector. Elsewhere, it has been suggested that momentum in the PD process can be built through ownership and inclusion in ideation, setting expectations, and encouraging a critical attitude to constraints [48]. Furthermore, these facilitation techniques may be particularly crucial in sustaining the PD process when moving from a design testing phase[12] to an implementation phase, as was seen in the FfC project.

The main limitations of this study are related to the data collection process as only key stakeholders were interviewed and there were no direct observations of meetings. Interviewing more stakeholders of each type of stakeholder could enrich the findings and provide more interdisciplinary insights. Possible insights may have been missed due to recall bias, given that this was a complex interactive process. Nevertheless, a comprehensive image of events was reconstructed through triangulating a range of data sources. Although each case study was focused on a different problem, involving different stakeholders, one may still question the generalizability of the lessons drawn. Future research could validate the findings by examining PD applications in other, non-Dutch, AYA projects.

CONCLUSIONS

For a PD process to successfully develop care for AYAs, one needs to use designers and skilled people, PD tools, and an open-ended approach to visualize and materialize new forms of care. Furthermore, recruitment and facilitation techniques help leverage knowledge, raise awareness among stakeholders of different perspectives, and create a synergy in a democratic environment between stakeholders.

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CHAPTER 4

Leveraging User Experience to Improve Video Consultations in a Cardiology Practice During the COVID-19 Pandemic: Initial Insights

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ABSTRACT

During the coronavirus disease (COVID-19) pandemic, cardiologists have attempted to minimize risks to their patients by using telehealth to provide continuing care. Rapid implementation of video consultations in outpatient clinics for patients with heart disease can be challenging. We employed a design thinking tool called a customer journey to explore challenges and opportunities when using video communication software in the cardiology department of a regional hospital. Interviews were conducted with 5 patients with implanted devices, a nurse, an information technology manager and two cardiologists. Three lessons were identified based on these challenges and opportunities. Attention should be given to the ease of use of the technology, the meeting features, and the establishment of the connection between the cardiologist and the patient. Further, facilitating the role of an assistant (or virtual assistant) with the video consultation software who can manage the telehealth process may improve the success of video consultations. Employing design thinking to implement video consultations in cardiology and to further implement telehealth is crucial to build a resilient health care system that can address urgent needs beyond the COVID-19 pandemic.

ABBREVIATIONS

COVID-19: coronavirus disease
ECG: electrocardiogram
eHealth: electronic health
GDPR: General Data Protection Regulation
ICD: implanted cardioverter-defibrillator device
IT: information technology

INTRODUCTION

The coronavirus disease (COVID-19) crisis has challenged health care professionals to rapidly reduce face-to-face consultations. To ensure care continuity, the use of telehealth is recommended [1]. Telehealth refers to the use of electronic services to support a broad range of remote services, such as patient care, education, and monitoring [2]. Many health systems have already invested in telehealth, and some primary care practices in the United States have appeared to adopt telehealth almost instantly [3-5].

In Belgium, cardiologists remotely triaged patients who were originally scheduled for face-to-face consultations; however, many consultations were postponed during the lockdown period. Some patients are afraid to come to the hospital due to the risk of contracting COVID-19. This increases the likelihood that patients will stay at home or postpone consultations despite deteriorating symptoms. In fact, a declining incidence of acute myocardial infarction has been witnessed in the United States during the COVID-19 pandemic [6]. However, early detection of atrial fibrillation is crucial to prevent stroke, which is a leading cause of death globally [7,8]. In addition, early detection of heart failure is necessary to prevent hospitalization and death [9].

Telehealth can help mitigate these risks by enabling continued monitoring of patients. Various telehealth solutions can be leveraged for remote cardiology monitoring [1], such as video communication software and implanted devices. The adoption of these tools is now being facilitated because financial and reimbursement restrictions are being lifted; however, further measures are needed for wider adoption of telehealth [4,10,11]. Given that rapid acceptance of telehealth during COVID-19 is critical, telehealth technologies must be easy to implement and to scale up. To achieve this, we employed design thinking [12,13] to learn from the experiences of a cardiology practice in a regional Belgian hospital where video consultations are rapidly being implemented.

DESIGN THINKING

Design thinking aims to identify and solve problems in a systematic and collaborative way [12,13]. Collaborative design methods are widely used to improve electronic health (eHealth) [14], including the development of eHealth to assist heart patients with self-management [15-19]. However, design thinking research focusing on video communication software with heart patients is lacking. We used a design thinking tool called a customer journey to empathize with all stakeholders, identify the challenges facing each stakeholder, and identify opportunities to redesign the service [12]. To develop the customer journey, PV conducted telephone interviews to map the experience of the lead hospital information technology (IT) manager (who liaised with the legal team), a research nurse (KDJ), the treating cardiologist (YV), and the head of the Department of Cardiology (RT). Five patients with an implanted cardioverter-defibrillator device (ICD) were interviewed by a nurse (KDJ) shortly after the end of each video consultation about their experience. The data were analyzed in PowerPoint (Microsoft Corporation).

The treating cardiologist (YV) identified 13 patients with an ICD who were scheduled for face-to-face consultations in the outpatient clinic. The ICD patient population was prioritized because these patients could especially benefit from telehealth due to the opportunity to access their heart monitoring data remotely. These patients did not have any urgent needs, did not require a physical examination with hospital equipment, and had a telephone number on record. Of these 13 patients, 5 (38%, aged 43-64 years) were eligible for a video consultation. Of the 8 patients who were not eligible, 2 (25%) lacked a smartphone or computer, 2 (25%) were not reachable by telephone, 3 (38%) lacked the functionality for remote monitoring, and 1 (13%) had progressed to needing more urgent care.

CHALLENGES AND OPPORTUNITIES FOR STAKEHOLDERS

The customer journey (Figure 1) shows the actions taken by stakeholders in parallel rows and the touch points (blue and white circles) where the patient is in contact with health care professionals. Three areas of challenges (triangles) and opportunities (lightbulbs) are illustrated: the lower left area is related to the provision of technology, the center area is related to inviting the patient to the consultation, and the right area relates to when the patient joins the meeting and the video consultation starts.

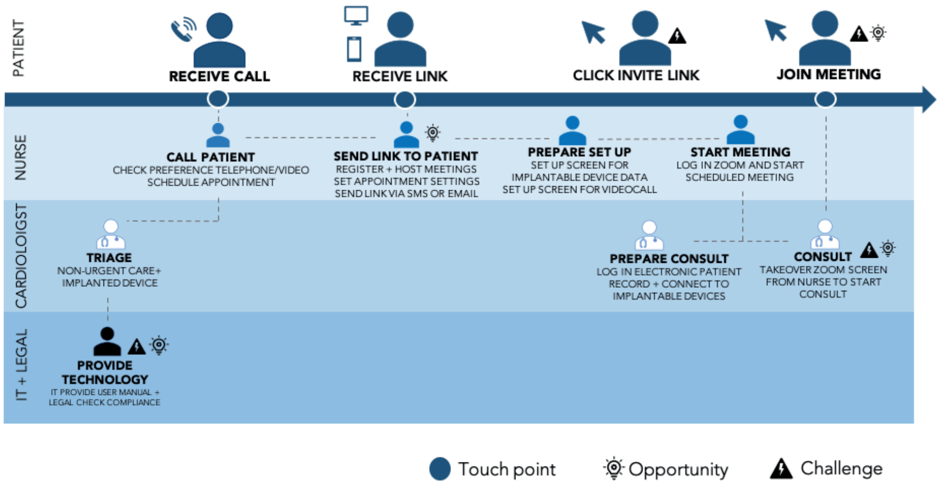

Figure 1. Customer journey of a video consultation for a patient with an implanted device. IT: information technology. SMS: short message service.

Video Consultation Technology: Need for Integration, Fewer Steps, and Long-Term Prospects

Available video consultation solutions were explored with the IT and legal teams based on ease of use and suitability for the patient group, short-term implementation for all stakeholders, adaptability, financial constraints, and compliance with the European Union General Data Protection Regulation (GDPR). Skype for Business (Microsoft Corporation) was accessible by all physicians, as it was installed across the hospital on desktop computers. Given its strong security, lack of additional cost, and availability in the hospital, this appeared to be a good option. However, Skype for Business is a rigid software package that will soon be replaced by Microsoft Teams. Eventually, video communication software will be integrated into the electronic patient record software, as is already the case in larger academic hospitals in Belgium. Therefore, Skype for Business demonstrated little adaptability and no long-term prospects. Given that it would still be necessary to provide training to health care professionals and patients, other software was considered. No solution could be identified that integrated video communication software with ICD monitoring, which would suit the patients best (challenge). However, other video communication software was tested, including Zoom (Basic account, Zoom Video Communications Inc). The cardiologist was given remote training on Zoom by the researchers while they simultaneously tested its functionalities compared to Skype for Business. They considered that Zoom was easier to use, as the patient would not need to install a software package on their computer and would need to complete fewer steps to use the desktop version or smartphone app (opportunity). The IT and legal teams had heavy workloads and were only able to provide limited technical support, such as a user manual.

Receiving the Meeting Invitation: Adapting the Settings

The nurse first called each patient to make an appointment for a consultation by telephone or video. If the patient preferred a video call, they were asked if they would like to receive the call through an app on their smartphone or on a desktop computer. Video consultation appointments were made using Zoom. To reduce the workload for the cardiologist, the nurse was responsible for making appointments and was then made the host of each meeting (opportunity). Here, opportunities were identified to improve safety by changing meeting settings with a password. Other settings were changed to reduce the number of steps the patient was required to take; immediate activation of the camera was enabled when joining a meeting, bypassing the waiting room function. After these steps were completed, a link with the invitation to the video consultation was sent to the patient. Here, another opportunity was identified to circumvent email use if the patient planned to use the app by sending them the link via SMS text message. However, this required the nurse to use an anonymous mobile phone number. Patients using the desktop version of Zoom were sent an invitation link via email.

Joining Meetings: Need for a Virtual Assistant

Before the start of a video consultation, the nurse prepared two screens (opportunity). On one screen, the cardiologist could log in to the patient's device, while the other screen was prepared to show the video communication software. For all the video consultations, a backup plan was established to switch to telephone and continue the consultation on an audio-only basis. The nurse was present throughout the entire VC process to help manage problems with communication connections and record the experiences of the patient and the cardiologist.

In 2 of the 5 video consultations, the patient and the cardiologist were connected with both audio and video via Zoom. In the four cases in which a video connection was established, even without audio (replaced by audio from a telephone), the patients were positive about the experience; however, for the one case in which the video connection could not be established, the patient was disappointed. Key challenges were identified due to failures of the video or audio on either the patient's or the cardiologist's side (3 times): in one case, the cardiologist's computer ran too slowly, in another case, the patient had not signed into the Zoom meeting, and in another case, the patient could not join the Zoom meeting. In addition, the patients were not always immediately in front of their devices at the start of the meeting. The nurse had to attempt to manage these problems in the moment on both the cardiologist and patient sides. However, connections could not always be established or re-established. This reveals the need for more advanced training on the use of video communication software before adopting video consultations, for both patients and health care professionals.

Opportunities were identified to improve the audio and video connections between the patient and the cardiologist. First, the nurse could test the Zoom video and audio links with the cardiologist's and patient's devices before the start of the consultation. This would require the nurse to be the host for all scheduled video consultations before the consultations start. For example, before the first consultation started, the nurse as the host could conduct a test conversation using the cardiologist's device to determine if the audio and video were functional and if the connection with the heart device was functioning. Following this, the cardiologist could take over the account from the nurse to start the consultation. The nurse could then prepare the next scheduled patient for their video consultation by starting the next meeting as the host and checking the audio and video connections between the patient's device and the local device by holding a test conversation.

Currently, there are technical challenges in implementing this workflow, as the meeting host cannot simultaneously start and manage multiple meetings [20]. No other video communication software could be immediately identified that would overcome this obstacle. It may be possible for a chatbot or similar automated diagnostic system to help the patient navigate the steps on their own to test the audio or video connection. All these potential solutions would require additional training for the patients and health care professionals.

LESSONS TO IMPROVE VIDEO CONSULTATIONS IN CARDIOLOGY

We employed a design thinking tool called a customer journey, which revealed several challenges and opportunities for stakeholders in a cardiology practice when testing video consultation software. Three lessons were identified to improve the experience for stakeholders:

Ease of Using the Technology

Attempt to reduce the number of clicks or screens that must be navigated to get to a meeting and preferably avoid downloading or registration of software and activation of a microphone or video camera (these appear to be easier to manage on a smartphone). Ideally, provide the ability to access data on implanted devices and video communication software in one integrated software solution.

Meeting Features

Ensure the video consultations are secure (ie, use a password and data encryption in line with the GDPR) and facilitate the establishment of video and audio connections by automatically starting microphone and video devices for both the health care professional and the patient. Use a convenient method to send information about the meeting to the patient, such as an SMS text message or email, depending on the wishes of the patient.

Management of Video and Audio Connections

Reduce the time spent preparing and managing connectivity. One option would be for a nurse to concurrently host multiple meetings to streamline the process of switching between consultations. If this option is not available or proves to be inadequate, it will be crucial to provide additional training for patients and health care professionals. It is therefore important to select a system that will not require time-consuming training, preferably one with an automated testing system (if available).

FUTURE CONSIDERATIONS

Looking toward the future, the population of heart patients in need of remote care is likely to grow given the prolongation of the COVID-19 pandemic. Using design thinking to improve telehealth for patients who are at risk of acute health problems, such as heart attack and atrial fibrillation, is therefore increasingly urgent. Remote diagnostic tools, such as remote electrocardiogram (ECG) technology, could be integrated into telehealth video communication software, as in smartphones [21]. Although there are some consumer devices on the market with up to six ECG leads [22,23], their use is still limited due to legal obstacles or financial concerns (linked to reimbursement).

LIMITATIONS

This short design thinking study was limited due to the physical constraints of COVID-19. The data collection would have benefited from more field observations. In addition, to prevent delays in the implementation process of the video consultation software, the traditional problem exploration process started immediately through testing existing software solutions. Therefore, some problems and solutions for the stakeholders may remain unexplored.

CONCLUSION

These initial insights highlight that even though financial regulations currently favor the use of video consultations [4,10,11], we identified many practical obstacles from a user perspective that have critical implications. Employing design thinking and involving all relevant stakeholders may help overcome these obstacles and aid further integration of telehealth and other medical device software. This further resonates with the call of the American Heart Association to conduct more human-centered research in this area [24]. In conclusion, employing design thinking to implement video consultations in cardiology and to further implement telehealth is crucial to build a resilient health care system that can address urgent needs beyond the COVID-19 pandemic.

CONFLICTS OF INTEREST

None declared.

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CHAPTER 5

The role of diverse knowledge and diverse ways of thinking in generative co-design: theoretical foundations for stakeholder selection

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ABSTRACT

Generative co-design (GCD) is a form of collaborative design characterized by a collective creative process in which knowledge is shared among stakeholders. A key hypothesis is that stakeholders with diverse knowledge and diverse ways of thinking improve the GCD process. However, this hypothesis has not been embedded and justified in a wider theoretical framework. A theory on the role of stakeholder knowledge in GCD could provide a more rigorous grounding to justify hypotheses supporting stakeholder involvement. To this end, in this study, we take the first theoretical step in developing a theory about stakeholder involvement in GCD. We use concepts from the philosophy of science to explicate diverse ways of stakeholder thinking involving four inference types and the diverse knowledge held by stakeholders based on three knowledge types. Here, we explain how stakeholders, depending on the use of a specific knowledge type, can significantly influence the GCD process when they use various inference types. When stakeholders use the inference type, specified as abduction-2, driven by the knowledge type labelled contextual certainties, they could significantly change the course of the GCD process. Based on the fuller description of the roles of diverse stakeholder knowledge and inferences in the GCD processes, arguments are developed to justify the involvement of stakeholders. Finally, recommendations are made for selecting stakeholders for a role in a GCD project.

INTRODUCTION

The involvement of design and non-design stakeholders[4] is key to generative co-design (GCD)[5] as they all contribute to a knowledge development process. Yet, even though GCD is increasingly applied,[6] we found[7] that a justification for including specific stakeholders seems to be lacking in GCD research seeking to develop digital health[8].

In the literature, a key hypothesis has been suggested by Sanders and Stappers[9] that could be used to justify the involvement of specific stakeholders in a GCD project. They claim that, when stakeholders with diverse knowledge, and different ways of processing knowledge, are brought together that this will improve the GCD process. However, this argument has not been further integrated in a broader theory about the role of stakeholders in GCD and it is not convincingly justified.

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4 Stakeholders are more actively involved in GCD as partners than in the more classic user-centered design processes whereby people are more passively involved. See Elizabeth Sanders and Pieter Jan Stappers, *Convivial Design Toolbox : Generative Research for the Front End of Design* (BIS, 2012).

5 GCD is characterized by a collective creative process whereby knowledge is shared and developed among stakeholders, seeMaaike Kleinsmann et al., "Development of Design Collaboration Skills," *Journal of Engineering Design* 23, no. 7 (2012): 485–506, https://doi.org/10.1080/09544828.2011.619499; Elizabeth Sanders and Pieter Jan Stappers, "Probes, Toolkits and Prototypes: Three Approaches to Making in Codesigning," *CoDesign* 10, no. 1 (January 2, 2014): 5–14, https://doi.org/10.1080/15710882.2014.888183; Elizabeth Sanders and Pieter Jan Stappers, "Co-Creation and the New Landscapes of Design," *CoDesign* 4, no. March (2008): 1–16, http://journalsonline.tandf.co.uk; Sanders and Stappers, *Convivial Design Toolbox : Generative Research for the Front End of Design*; A. van Boeijen, J. Daalhuizen, and J. Zijlstra, *Delft Design Guide*, vol. 53 (BIS Publishers, 2020), https://www.bispublishers.com/delft-design-guide-revised.html; Joe Langley, Daniel Wolstenholme, and Jo Cooke, "'Collective Making' as Knowledge Mobilisation: The Contribution of Participatory Design in the Co-Creation of Knowledge in Healthcare," *BMC Health Services Research* 18, no. 1 (December 25, 2018): 585, https://doi.org/10.1186/s12913-018-3397-y.

6 M. Bird et al., "A Generative Co-Design Framework for Healthcare Innovation: Development and Application of an End-User Engagement Framework," *Research Involvement and Engagement* 7, no. 1 (December 1, 2021): 1–12, https://doi.org/10.1186/S40900-021-00252-7/FIGURES/1; Pieter Vandekerckhove et al., "Generative Participatory Design Methodology to Develop Electronic Health Interventions: Systematic Literature Review," *Journal of Medical Internet Research* 22, no. 4 (April 27, 2020): e13780, https://doi.org/10.2196/13780; Langley, Wolstenholme, and Cooke, "'Collective Making' as Knowledge Mobilisation: The Contribution of Participatory Design in the Co-Creation of Knowledge in Healthcare."

7 Vandekerckhove et al., "Generative Participatory Design Methodology to Develop Electronic Health Interventions: Systematic Literature Review."

8 The term digital health refers to the development and use of digital technologies such as the Internet of Things, advanced computing, artificial intelligence including machine learning, and robotics to improve health, see World Health Organization, "Global Strategy on Digital Health 2020-2025" (Geneva, Switzerland, 2021), http://apps.who.int/bookorders.

9 Sanders and Stappers, *Convivial Design Toolbox : Generative Research for the Front End of Design*.

A well-founded theory on the role of stakeholder knowledge in GCD could provide a more rigorous grounding to justify hypotheses linked to stakeholder involvement. This theory should describe in a systematic way how knowledge is brought in by different stakeholders and how knowledge is further developed by these stakeholders in a GCD process.[10]

Philosophical concepts can be of great value when seeking to clarify how knowledge influences the design process, and the design process has indeed been described with philosophy in mind.[11] Concepts from the philosophy of science[12] such as Peirce's reasoning typology (induction, deduction, and abduction) have already been used in design theory to describe the design process.[13] However, these concepts are generally not incorporated in a larger theory that describes the role of stakeholder knowledge.

The philosophy of scientific discovery field is particularly relevant because both design processes and discovery processes are similarly described. Both scientific discovery philosophers and design theorists have been inspired by the work of Herbert Simon who described the design process as a rational problem-solving process.[14] This was a countermovement to the philosophy of scientific discovery view, popularized by Karl Popper, that there is no rational way

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10 This theory could provide the basis for a GCD methodology by providing a coherent set of assumptions and arguments describing the knowledge process in a systematic way. Developing a GCD methodology would be useful given that it is unclear precisely how stakeholders should be involved as there are no validated guidelines provided in design practice manuals. As such, a methodology could provide recommendations on how to involve stakeholders. For design methodology see Dina Wahyuni, "The Research Design Maze: Understanding Paradigms, Cases, Methods and Methodologies," *Journal of Applied Management Accounting Research*, June 26, 2012; Lisa M. Given, *The Sage Encyclopedia of Qualitative Research Methods* (Sage Publications, 2008), https://us.sagepub.com/en-us/nam/the-sage-encyclopedia-of-qualitative-research-methods/book229805; Nigel Cross, *Development in Design Methodology* (John Wiley & Sons Ltd., 1984); Frithjof E. Wegener and Philip Cash, "The Future of Design Process Research? Exploring Process Theory and Methodology," in *DRS2020: Synergy*, vol. 5 (Design Research Society, 2020), https://doi.org/10.21606/drs.2020.132.

11 Ann Heylighen, Humberto Cavallin, and Matteo Bianchin, "Design in Mind," *Design Issues* 25, no. 1 (January 1, 2009): 94–105, https://doi.org/10.1162/DESI.2009.25.1.94.

12 The field of philosophy of science focuses on how science and scientific methodologies develop and how knowledge is developed more broadly.

13 Claus L. Cramer-Petersen, Bo T. Christensen, and Saeema Ahmed-Kristensen, "Empirically Analysing Design Reasoning Patterns: Abductive-Deductive Reasoning Patterns Dominate Design Idea Generation," *Design Studies* 60 (January 1, 2019): 39–70, https://doi.org/10.1016/j.destud.2018.10.001; Kees Dorst, "The Core of 'design Thinking' and Its Application," *Design Studies* 32, no. 6 (November 1, 2011): 521–32, https://doi.org/10.1016/j.destud.2011.07.006.

14 Herbert Simon, *Models of Discovery*, vol. 54, Boston Studies in the Philosophy of Science (Dordrecht: Springer Netherlands, 1977), https://doi.org/10.1007/978-94-010-9521-1.

to look at knowledge development.[15] Ippoliti and Nickles characterized Simon's approach as an inferential approach of looking at scientific discovery and emphasizing the rational perspective. In the inferential approach, one considers scientific innovation as a problem-solving process that is highly content-specific and involves different ways of thinking.[16] Scientific discovery philosophers have further focused on how to describe creative scientific processes in a formal and logical way, and this may be highly relevant to design theory.[17] Design theorists have also described the design process as a problem -solving process involving different ways of thinking.[18] Here, similarly, a countermovement was led against the characterization of design by Rittel as rational problem-solving, who describes design problems as wicked problems that are too complex to truly solve.[19] As such, design should not be considered as a simple problem-solving practice but as a rhetorical process geared towards what 'ought to be' in the future.[20] Design theorists have further focused on how to describe this special type of knowledge, 'designerly knowledge', whereby design is characterized as both a practical and reflective

15 Karl Popper, "The Logic of Scientific Discovery," 1961, 480, https://books.google.com/books/about/The_Logic_of_Scientific_Discovery.html?id=Yq6xeupNStMC.

16 Emiliano Ippoliti and Tom Nickles, "Introduction: Scientific Discovery and Inference," *Topoi* (Springer, September 1, 2020), https://doi.org/10.1007/s11245-019-09673-2; Emiliano Ippoliti, "Scientific Discovery Reloaded," *Topoi* 39, no. 4 (September 1, 2020): 847–56, https://doi.org/10.1007/s11245-017-9531-3.

17 Ippoliti and Nickles, "Introduction: Scientific Discovery and Inference"; Ippoliti, "Scientific Discovery Reloaded"; Joke Meheus and Thomas Nickles, *Models of Discovery and Creativity*, ed. Joke Meheus and Thomas Nickles, *Models of Discovery and Creativity* (Springer Netherlands, 2009), https://doi.org/10.1007/978-90-481-3421-2; Joke Meheus and Diderik Batens, "A Formal Logic for Abductive Reasoning," in *Logic Journal of the IGPL*, vol. 14, 2006, 221–36, https://doi.org/10.1093/jigpal/jzk015; Diderik Batens, "The Need for Adaptive Logics In Epistemology," in *Logic, Epistemology, and the Unity of Science* (Dordrecht: Springer Netherlands, 2009), 459–85, https://doi.org/10.1007/978-1-4020-2808-3_22; Joke Meheus et al., "Ampliative Adaptive Logics and the Foundation of Logic-Based Approaches to Abduction *," 2001; Dagmar Provijn, "The Generation of Abductive Explanations from Inconsistent Theories," *Logic Journal of the IGPL* 20, no. 2 (April 2012): 400–416, https://doi.org/10.1093/jigpal/jzq056; Diderik Batens, "Adaptive Fregean Set Theory," *Studia Logica* 108, no. 5 (October 1, 2020): 903–39, https://doi.org/10.1007/s11225-019-09882-1; Graham Priest and Richard Routley, "Introduction: Paraconsistent Logics," *Studia Logica*, 1984, https://doi.org/10.1007/BF00935736.

18 Kees Dorst, "Co-Evolution and Emergence in Design," *Design Studies* 65 (November 1, 2019): 60–77, https://doi.org/10.1016/j.destud.2019.10.005; Wolfgang Jonas, "Design as Problem-Solving? Or: Here Is the Solution -What Was the Problem?," *Design Studies* 14, no. 2 (1993): 157–70, https://doi.org/10.1016/0142-694X(93)80045-E.

19 Horst Rittel, *On the Planning Crisis: Systems Analysis of the "First and Second Generations"* (Institute of Urban & Regional Development, University of California, 1972), https://books.google.be/books/about/On_the_Planning_Crisis.html?id=fAgvtAEACAAJ&redir_esc=y; Thomas Wendt, "Arational Design," in *Advancements in the Philosophy of Design*, ed. Pieter Vermaas and Stéphane Vial (Springer, Cham, 2018), 101 20, https://doi.org/10.1007/978-3-319-73302-9_6.

20 Wendt, "Arational Design."

process that produces new knowledge and artefacts simultaneously.[21] As such, the philosophy of scientific discovery and design theory look at the development of knowledge from different perspectives. Further, they seem to have evolved in parallel without learning from each other and. Therefore, in this paper we integrate concepts from both fields and critically assess their relevance. To identify concepts we used an integrative literature review approach[22] to identify relevant concepts and then further develop the description of the knowledge process in GCD by using a philosophical method of explication[23]. This allows us to describe the knowledge process in GCD more precisely whereby we can clarify the roles of diverse knowledge and ways of thinking in this process.

First, we explicate the role of stakeholder knowledge in relation to the design aims and the design process in general. Afterwards we specify the role of stakeholder knowledge and ways of thinking in a GCD process. Finally, we demonstrate how this theoretical clarification can help to describe the role of stakeholder in a GCD process and we provide recommendations to select stakeholders.

21 P Stappers and E Giaccardi, "Research through Design," in *The Encyclopedia of Human-Computer Interaction. Soegaard, M. & Friis-Dam, R. (Eds.)*, 2017, http://www.interaction-design.org/literature/book/the-encyclopedia-of-human-computer-interaction-2nd-ed/research-through-design; Heylighen, Cavallin, and Bianchin, "Design in Mind"; Jon. Kolko, *Exposing the Magic of Design : A Practitioner's Guide to the Methods and Theory of Synthesis* (Oxford University Press, 2011); Donald Schön, *The Reflective Practitioner: How Professionals Think In Action*, 1st ed. (Basic Books, 1984); J. Christopher Jones, *Design Methods: Seeds of Human Futures* (J. Wiley, 1981), https://doi.org/10.2307/2581920; Derek Jones et al., "Introduction: Design Epistemology," 2016, 27–30, https://doi.org/10.21606/drs.2016.619; Nigel Cross, "Designerly Ways of Knowing: Design Discipline Versus Design Science," *Design Issues* 17, no. 3 (July 13, 2001): 49–55, https://doi.org/10.1162/074793601750357196; Nigel Cross, "A Brief History of the Design Thinking Research Symposium Series," in *Design Studies*, vol. 57, 2018, 160–64, https://doi.org/10.1016/j.destud.2018.03.007.

22 Richard J. Torraco, "Writing Integrative Literature Reviews: Guidelines and Examples:," *Http://Dx.Doi.Org/10.1177/1534484305278283* 4, no. 3 (July 24, 2016): 356–67, https://doi.org/10.1177/1534484305278283.

23 Explication is a philosophical method to make something that is unclear or implicitly defined more explicit. See Moritz Cordes and Geo Siegwart, "Explication," in Internet Encyclopedia of Philosophy, 2021, https://iep.utm.edu/explicat/.

IN THE GCD PROCESS, STAKEHOLDERS AIM TO UNDERSTAND AND CREATE

We start by explicating stakeholder knowledge in the GCD process as it is the output of how stakeholders think. However, given that few authors have specified the role of knowledge in the GCD literature we draw on two models from design literature more broadly.[24]

Hatchuel and Weil[25] developed the Concept-Knowledge model that explicitly states the knowledge aim of design. They describe design as an iterative process of knowledge activities whereby concepts are transformed into true knowledge: propositions that are true in the relevant knowledge space of the design process. Concepts are indeterminable, partially unknown, objects whose existence is not guaranteed in the targeted space of all true knowledge. Second, the reflective practitioner model[26] implicitly sees knowledge as the object of the design process in achieving a desired design aim. He describes the process of design as a converging cyclical process involving different steps of naming, framing, moving, and reflecting on knowledge. The aim of this knowledge process is to understand a problem and move towards a solution. Moreover, how this happens is described as concurrent evolution (see next section).

Based on the above summary of these two models (drawing on[27]), we extracted two distinct knowledge aims for a GCD project. One aim is to reach a better understanding through a new perspective (also referred to as a perception, name, composition, or frame) on a design issue. The other aim is to describe, predict, or move towards new knowledge to achieve the aspired value of a design project. Further, the design process can be characterized as a cyclical iterative

24 Nigel Cross, *Development in Design Methodology* (John Wiley & Sons Ltd., 1984); Cross, "A Brief History of the Design Thinking Research Symposium Series"; Cross, "Designerly Ways of Knowing: Design Discipline Versus Design Science"; Herbert Simon, *The Sciences of the Artificial*, 3rd editio (London: MIT Press, 1996), https://books.google.nl/books?hl=en&lr=&id=k5Sr0nFw7psC&oi=fnd&pg=PR9&dq=sciences+of+the+artificial&ots=-w0GoJHNIC&sig=dY_ZQ6hNpdhlmEcVjCpyBqSDh7A&redir_esc=y#v=onepage&q=sciences of the artificial&f=false; Jonas, "Design as Problem-Solving? Or: Here Is the Solution -What Was the Problem?"; Lieven de Couvreur and Richard Goossens, "Design for (Every)One: Co-Creation as a Bridge between Universal Design and Rehabilitation Engineering," *Https://Doi.Org/10.1080/15710882.2011.609890* 7, no. 2 (June 2011): 107–21, https://doi.org/10.1080/15710882.2011.609890; Heylighen, Cavallin, and Bianchin, "Design in Mind."

25 (2008)

26 Schön, *The Reflective Practitioner: How Professionals Think In Action*.

27 Cramer-Petersen et al., 2019)

process.[28] As such, it could be argued that, in design practice, the two design aims are cyclically alternated.

These two design aims can be further explicated by referring to two streams of thought in the philosophy of science.[29] The scientific realists, following Dunhem[30], claim that science provides theories that are attempts to describe reality that even go beyond the realm of observable things. The instrumentalists, following both Peirce and Popper[31], claim that science aims to provide theories that amount to functional tools to classify and predict observations or even solve problems.[32] In this way, an instrumentalist could view progress in science as occurring when more useful research problems and their solutions are proposed.[33] As such, scientific progress involves problem defining and problem solving.

Using these concepts, we can explicate the two design aims as follows. From a scientific realist perspective, the first aim in design is to understand reality to define a problem. From an instrumentalist view, the second aim in design is to create new ideas that can serve as solutions to solve problems. On this basis, one should select stakeholders in a GCD project who can help achieve these two aims: understanding the problem or generating ideas for a solution. Now, we further consider how to satisfy these two aims to define which stakeholders are most appropriate.

STAKEHOLDERS USE KNOWLEDGE AND INFERENCES IN A PROBLEM-SOLVING PROCESS

Both design aims can be pursued in an iterative design process, described as co-evolution between problem and solution.[34] As such, the knowledge in a GCD process can be considered to evolve through problem and solution phases. However, when considering the two design aims in conjunction with co-evolution theory, it becomes clear that there is not a one-to-one

28 Schön, *The Reflective Practitioner: How Professionals Think In Action*; Dorst, "The Core of 'design Thinking' and Its Application"; Dorst, "Co-Evolution and Emergence in Design"; Cramer-Petersen, Christensen, and Ahmed-Kristensen, "Empirically Analysing Design Reasoning Patterns: Abductive-Deductive Reasoning Patterns Dominate Design Idea Generation."

29 Ilkka Niiniluoto, "Scientific Progress," in *Stanford Encyclopedia of Philosophy*, ed. Edward N. Zalta, 2019, https://plato.stanford.edu/archives/win2019/entries/scientific-progress/.

30 Pierre Maurice Marie Duhem, *The Aim and Structure of Physical Theory* (Princeton University Press, 1954).

31 Popper, "The Logic of Scientific Discovery."

32 Tom Nickles, "Scientific Discovery as a Topic for Philosophy of Science: Some Personal Reflections," *Topoi* 39, no. 4 (September 1, 2020): 841–45, https://doi.org/10.1007/s11245-018-9566-0.

33 Yafeng Shan, "A New Functional Approach to Scientific Progress," *Https://Doi.Org/10.1086/704980* 86, no. 4 (September 18, 2019): 739–58, https://doi.org/10.1086/704980.

34 Dorst, "Co-Evolution and Emergence in Design"; Jonas, "Design as Problem-Solving? Or: Here Is the Solution -What Was the Problem?"

relationship between a design aim and a design phase. That is, both design aims could be achieved in a single design phase or, depending on the project, a design phase need not include both design aims. For instance, in the problem phase there could be a cyclical process of design activities to achieve the aims of (1) understanding different aspects of the stakeholders' problems and (2) generating a new problem statement based on those insights that may lead to a general problem definition. Here, Dorst[35] has stressed that, in this respect, there is a lack of a broader framework to explain the non-linear jumps between problem and solution.

Turning to design practice methods, the design phases are first aimed at understanding the problem (empathize, understand, explore) and afterwards at developing a solution to generate knowledge to achieve the aspired value (creating, prototyping).[36] Others claim there is also a test phase, although it can be argued that an evaluative or test phase is not unique or distinct from the other design phases.[37]

Now, we further explore the knowledge process with both design aims in an iterative process. Here we must further explicate how both design aims are achieved: how does one understand and generate ideas in a co-evolution process? To clarify the problem-solving process, we draw on the philosophy of scientific discovery. Here, Nickles[38] describes, not dissimilar to the ideas of co-evolution, the theory of evolutionary computation as a way of viewing innovation in scientific knowledge. This theory describes the creative process, based on the theory of natural selection, as a process of blind variation plus selective retention.[39] Problems and solutions evolve together, rather than the problems needing to be solved analytically. In this sense, scientific discovery is a problem-solving process that involves stakeholders from various disciplines using

35 (2019)

36 S Doorley et al., "Bootcamp Bootleg," 2018, https://s3.xopic.de/openhpi-public/courses/1NcWQVnyTA0dLYw9kHLs4e/rtfiles/35m0Q8qXYjvHO7FHuwgVgg/bootcampbootleg2010.pdf; Michael G. Luchs, K. Scott Swan, and Abbie. Griffin, *Design Thinking: New Product Development Essentials from the PDMA*, *Design Thinking: New Product Development Essentials from the PDMA*, 2015, https://doi.org/10.1002/9781119154273; P. Badke-Schaub and E. Voute, "Design Methodology: Where Do You Go?," *Proceedings of International Design Conference, DESIGN* 1 (2018): 25–32, https://doi.org/10.21278/IDC.2018.0550.

37 The test phase in these methods can be seen as activities containing elements related to problem understanding, redefined as a hypothesis to be tested with a certain product or service representing the solution (see also the next section on inference types). Accepting this view, the iterative design process can be fully described by the two explicated aims, which can be subdivided into various phases without the need to create a third design test knowledge process. See Cramer-Petersen, Christensen, and Ahmed-Kristensen, "Empirically Analysing Design Reasoning Patterns: Abductive-Deductive Reasoning Patterns Dominate Design Idea Generation"; L Koskela, S Paavola, and E Kroll, "The Role of Abduction in Production of New Ideas in Design," 2018, 153–83.

38 Thomas Nickles, "Scientific Discovery," in *The Routledge Companion to Philosophy of Science*, ed. Martin Curd and Stathis Psillos (Routledge, 2013), 529–38, https://doi.org/10.7551/mitpress/3729.003.0013.

39 Nickles.

different problem formulation and problem-solving techniques and cultures or disciplines.[40] These problem formulation and problem-solving techniques and cultures are types of inferences. An inference, as with reasoning, describes a train of thought but covers more than the classical forms of reasoning by including, for instance, heuristics.[41] Heuristics are specific forms of problem-solving activity.[42] Therefore, we can further add that each stakeholder may bring different or specific inferences to address the problem-solving process. In addition, Batens[43] further specified that knowledge develops in a specific knowledge context.[44] We can add here that this knowledge context will vary depending on the knowledge of the different stakeholders.

Therefore, we can state that stakeholders with diverse knowledge and inferences take part in a problem-solving evolutionary process that may include non-linear jumps. In this process, a wide variety of inferences are combined with a broad range of knowledge to achieve the design aims. This statement essentially provides a broad description of the scene in which stakeholders share and process knowledge. To be able to justify why one needs diverse stakeholders with diverse inferences we need to investigate the process further. In the following sections, we explicate the role of diverse knowledge and inferences in a GCD process. Based on this description we provide a justification for involving specific stakeholders in a GCD project.

THE ROLE OF DIVERSE STAKEHOLDER INFERENCE-TYPES IN GCD

Four inference types: induction, deduction, abduction-1, abduction-2

Following Peirce's typology of inferences[45], design theorists use these four types of inferences to describe how stakeholders process knowledge in a design process.[46] Inference amounts to:

40 Ippoliti and Nickles, "Introduction: Scientific Discovery and Inference."

41 Robert Burch, "Charles Sanders Peirce," in *Stanford Encyclopedia of Philosophy*, 2021, https://plato.stanford.edu/entries/peirce/#dia.

42 Jutta Schickore, "Scientific Discovery," in *Stanford Encyclopedia of Philosophy*, 2018, https://plato.stanford.edu/entries/scientific-discovery/.

43 Diderik Batens, "Adaptive Logics as a Necessary Tool for Relative Rationality: Including a Section on Logical Pluralism," in *Logic, Reasoning, and Rationality*, 2014, 1–25, https://doi.org/10.1007/978-94-017-9011-6_1.

44 Batens (2014) states that knowledge develops in a specific knowledge context. In these contexts, all meaning is defeasible and therefore contextual. Moreover, the contexts are all part of a system that is dynamic and open, and not hierarchical. See Thomas Nickles, "What Is a Problem That We May Solve It?," *Synthese* 47, no. 1 (1981): 85–118, https://doi.org/10.1007/BF01064267; Batens, "Adaptive Logics as a Necessary Tool for Relative Rationality: Including a Section on Logical Pluralism."

45 Burch, "Charles Sanders Peirce."

46 Cramer-Petersen, Christensen, and Ahmed-Kristensen, "Empirically Analysing Design Reasoning Patterns: Abductive-Deductive Reasoning Patterns Dominate Design Idea Generation"; Dorst, "The Core of 'design Thinking' and Its Application."

a generalization of knowledge (induction), a conclusion (deduction), or a new explanation or idea (abduction). Further, two sub-types of abduction have been proposed in design theory.[47] The abduction-1 type is used in generating a new object or service when a working principle is known and there is knowledge about the aspired value. The abduction-2 approach is used to generate knowledge about a working principle and an object or service to achieve the aspired value when only the aspired value is known.[48] The abduction-2 type of inference is particularly emphasized for playing a key role in design due to its extraordinary power to generate new knowledge, while abduction-1 inferences are more commonly used in other activities.

Turning to the roles and the order of inferences in the design process, the production-deduction-induction model of March[49] explicitly describes the design process as an iterative process of inferences.[50] First knowledge is produced through abduction, then deduction is used to analyze the performance and, finally, induction is used to accumulate the knowledge from the previous steps.[51] However, this model had been criticized for overemphasizing induction, or the evaluative phase[52] and for too rigidly following the classical hypothesis and deductive process of scientific discovery.[53]

As more research has been conducted into the use of inferences, design scholars have increasingly challenged the role and definition of the inference types. Empirical studies have found that abduction and deduction play significant roles in design practice, and the role of induction in early design stages is less evident.[54]

Moreover, the ways that deduction and abduction are used in design practice do not match the formal definitions. Deduction can introduce new knowledge[55] beyond the classical understanding of merely combining existing knowledge. Abduction can be used to create new

47 Dorst, "The Core of 'design Thinking' and Its Application"; N.F.M. and Eekels, J. Roozenburg, "Product Design: Fundamentals and Methods," *John Wiley & Son Ltd., Chichester*, 1995.

48 Cramer-Petersen, Christensen, and Ahmed-Kristensen, "Empirically Analysing Design Reasoning Patterns: Abductive-Deductive Reasoning Patterns Dominate Design Idea Generation"; Dorst, "The Core of 'design Thinking' and Its Application."

49 (1976)

50 Cramer-Petersen, Christensen, and Ahmed-Kristensen, "Empirically Analysing Design Reasoning Patterns: Abductive-Deductive Reasoning Patterns Dominate Design Idea Generation."

51 March, "The Logic of Design and the Question of Value."

52 Koskela, Paavola, and Kroll, "The Role of Abduction in Production of New Ideas in Design."

53 Cramer-Petersen, Christensen, and Ahmed-Kristensen, "Empirically Analysing Design Reasoning Patterns: Abductive-Deductive Reasoning Patterns Dominate Design Idea Generation."

54 Cramer-Petersen, Christensen, and Ahmed-Kristensen.

55 Per Galle, "Design Rationalization and the Logic of Design: A Case Study," *Design Studies* 17, no. 3 (July 1, 1996): 253–75, https://doi.org/10.1016/0142-694X(96)00004-X.

frames of understanding by combining existing knowledge or, by adding new knowledge, new ways of reaching conclusions.[56] As such, both deduction and abduction are emphasized as they can add new knowledge or combine existing knowledge and create a divergent effect. However, given the potential of induction to generate new knowledge, which is also labelled as ampliative inference[57] in the philosophy of discovery, we would caution against too easily dismissing induction.

Considering the various inference types, abduction would seem to be the most powerful for GCD. However, it remains somewhat vague how it works exactly, and we therefore now attempt to clarify abduction further.

Abduction in the GCD process can be described in more detail by using generative heuristics from the philosophy of scientific discovery field.[58] Generative heuristics are either primitive or derived heuristics[59] that can be used separately or in combination.[60] Primitive heuristics cover analogies, disanalogies, inductions, and metaphors.[61] Derived heuristics are developed from these primitive ones (such as inversion heuristics by reframing the problem in terms of the opposite), by switching heuristics (changing the level of analysis), by the use of figures and diagrams, scenario building, thought experiments, the analysis of extreme cases, and the analysis of a deviant case.[62]

56 Andy Dong, Massimo Garbuio, and Dan Lovallo, "Generative Sensing in Design Evaluation," *Design Studies* 45 (July 1, 2016): 68–91, https://doi.org/10.1016/J.DESTUD.2016.01.003.

57 Igor Douven, "Abduction," in *The Stanford Encyclopedia of Philosohpy*, ed. Edward Zalta N., 2021, https://plato.stanford.edu/cgi-bin/encyclopedia/archinfo.cgi?entry=abduction.

58 Thomas Nickles, "Scientific Discovery as a Topic for Philosophy of Science: Some Personal Reflections," *Topoi* 39, no. 4 (September 1, 2020): 841–45, https://doi.org/10.1007/s11245-018-9566-0; Jutta Schickore, "Scientific Discovery," 2018, https://plato.stanford.edu/archives/sum2018/entries/scientific-discovery/.

59 Emiliano Ippoliti, "Heuristic Logic. A Kernel," in *Building Theories*, vol. 41 (Springer International Publishing, 2018), 191–211, https://doi.org/10.1007/978-3-319-72787-5_10.

60 Ippoliti, "Scientific Discovery Reloaded."

61 Ippoliti, "Heuristic Logic. A Kernel."

62 James Jaccard and Jacob Jacoby, *Theory Construction and Model-Building Skills: Second Edition: A Practical Guide for Social Scientists* (The Guildford Press, 2010), https://www.guilford.com/books/Theory-Construction-and-Model-Building-Skills/Jaccard-Jacoby/9781462542437; Ippoliti, "Heuristic Logic. A Kernel."

As such, the abduction-2 type of inference contains a form of generative heuristics[63] and it may even contain steps involving induction and deduction.[64] This explains why other design theories have emphasized the role of analogy[65] or metaphors[66] in the design process. Given the wide range of ways that abduction-2 inferences can be used by stakeholders in GCD, a more specific definition is required to describe how they impact on knowledge dynamics. That is, we need to be more specific about the use of abduction-2 inferences on the knowledge level (see Section 4).

Justification to involve stakeholders with specific inference types

The inference types can provide arguments to substantiate the inclusion of certain stakeholders. Stakeholders can employ specific inference types such as induction or abduction-2, and their experience with drawing inferences to solve a problem is therefore important. It could therefore be argued that those stakeholders who have the most experience in drawing inferences should be involved in a GCD project.[67] These stakeholders may well be professional designers, but others such as experienced users, engineers, managers, or analytical philosophers may also have relevant problem-solving experience.[68]

Having described the various inference types in GCD, it is apparent that inferences can be applied in many ways to achieve a design aim. To explain how the use of different inference types impacts the knowledge output in the design process we first need to explicate the diverse stakeholder knowledge in GCD.

63 Koskela, Paavola, and Kroll, "The Role of Abduction in Production of New Ideas in Design."

64 For instance, Dorst (2011, 2015) appears to describe, in the design framing process, a form of abduction-2 that includes an analogy: a metaphor combined with induction. This analogical reasoning process, which produces a new working principle, has been implicitly described elsewhere in P. Vermaas, K. Dorst, and C. Thurgood, "Framing in Design: A Formal Analysis and Failure Modes," in *Proceedings of the International Conference on Engineering Design, ICED*, vol. 3, 2015, http://www.designingoutcrime.com/.

65 Linden J Ball and Bo T Christensen, "Analogical Reasoning and Mental Simulation in Design: Two Strategies Linked to Uncertainty Resolution," *Design Studies* 30, no. 2 (2009): 169–86, https://doi.org/https://doi.org/10.1016/j.destud.2008.12.005.

66 Paul Hekkert and Nazli Cila, "Handle with Care! Why and How Designers Make Use of Product Metaphors," *Design Studies* 40 (September 1, 2015): 196–217, https://doi.org/10.1016/j.destud.2015.06.007.

67 The more that a stakeholder has experienced a problem, the more likely that they will have used heuristics to solve the problem. Experienced stakeholders may also provide knowledge about successful or failed heuristics, such as analogies that lead to a new frame or working approach.

68 Seifert et al. (2015) identified 77 different heuristics used by designers and the choice may depend on the mindset of the designer. Here, it should be noted that the heuristics described in the philosophy literature refer to reasoning steps on a more abstract level, such as analogies, than those described by Seifert et al.. As such, each stakeholder may have a different set of heuristic skills based on the problem-solving tradition of their discipline

THE ROLE OF DIVERSE STAKEHOLDER KNOWLEDGE IN GCD

Three knowledge types: relevant statements, methodological instructions, and contextual certainties

Dorst[69] described a design process using a formula in which three different kinds of knowledge are used: "If knowledge about the form of an object (What) and a working principle (How) are combined, the aspired value (Value) can be achieved". Dorst's knowledge description of the working principle (the How) is similar to the description by Schön[70] as a form of "If…then…", which Schön argued plays a key role in the design process. With his description of the three kinds of knowledge and their relationship, Dorst describes a formal solution statement, or an outcome of a design thinking process.

Further, design theorists have claimed that stakeholders use knowledge on different levels: the readily available level, and a tacit or latent level such as feelings and dreams.[71] Tacit knowledge, such as implicit memory events, has a significant impact on the knowledge process in design by, for instance, influencing how one understands a problem through automatic priming and stereotypes.[72]

To further define the three types of knowledge that Dorst described and the differences in knowledge levels, we further draw on concepts from the philosophy of science. The first type of knowledge can be labelled contextual certainties.[73] These determine the meaning of the problem and can be seen as more distant theories that play a background role. These can include the laws of nature, characteristics of measurement tools, the theory of evolution, and fundamental characteristics of a product or service. They are taken as always valid in that the truth of these statements is not in question for the problem. They are part of the knowledge one

69 (2011)

70 (1984)

71 Claudia Mareis, "The Epistemology of the Unspoken: On the Concept of Tacit Knowledge in Contemporary Design Research," *Design Issues* 28, no. 2 (2012): 61–71, https://doi.org/10.1162/DESI_a_00143; Sanders and Stappers, *Convivial Design Toolbox : Generative Research for the Front End of Design*; Sanders and Stappers, "Probes, Toolkits and Prototypes: Three Approaches to Making in Codesigning."

72 John A. Bargh, Mark Chen, and Lara Burrows, "Automaticity of Social Behavior: Direct Effects of Trait Construct and Stereotype Activation on Action," *Journal of Personality and Social Psychology* 71, no. 2 (1996): 230–44, https://doi.org/10.1037/0022-3514.71.2.230; Daniel Kahneman and Gary Klein, "Conditions for Intuitive Expertise: A Failure to Disagree," *American Psychologist* 64, no. 6 (September 2009): 515–26, https://doi.org/10.1037/A0016755; Carey K. Morewedge and Daniel Kahneman, "Associative Processes in Intuitive Judgment," *Trends in Cognitive Sciences* 14, no. 10 (October 1, 2010): 435–40, https://doi.org/10.1016/J.TICS.2010.07.004; Sanders and Stappers, *Convivial Design Toolbox : Generative Research for the Front End of Design*.

73 Diderik Batens, "Contextual Problem Solving and Adaptive Logics in Creative Processes," *Philosophica* 64, no. 2 (1999): 7–31, http://www.philosophica.ugent.be/fulltexts/64-2.pdf.

holds about the wider context of the problem, or the world in general, and are often implicitly present in the thought process. One cannot derive a fact from a contextual certainty, contextual certainties are true in every case, although they also provide meaning to the other two types of knowledge.

Next, there are relevant statements. They can help define the knowledge of the 'What' of a product or service, and of the 'Value' of the aspired value.[74] Batens[75] uses the term 'relevant statements' as they impose conditions on the solution but do not determine the possible solutions to a problem. Relevant statements may allow one, given the certainties, to derive a solution as the correct answer to the problem, or at least to eliminate some possible solutions since the most appropriate solution needs to be compatible with the statements. The statements are considered to be true and relevant facts in the specific context, although they could be false, and tell us something about the problem and the solution. These statements are often explicitly discussed and shared with others as they are seen as relevant to the problem statement. For instance, the effectiveness of different active bio-chemical components is a relevant statement to a caregiver as this imposes conditions on the treatment the doctor will prescribe. In comparison, where they have parked their bicycle is not a relevant condition for this problem.

Finally, there are methodological instructions that can help define the 'How' knowledge defined as a working principle in an "If…then…" form.[76] Methodological instructions are sets of approaches, specified within a problem context, that one can follow to solve a problem. They are referred to as instructions as they are often in the form of "if … is present, then do …". They are sets of do's and don'ts to come to a solution. For example, if a patient experiences discomfort in the hospital room when there are children around, then several types of furniture can be used that have various functions and ways of changing shapes to tackle this problem. As such, many methodological instructions can be used to tackle a problem, and these can be subdivided into classes for the specific problem context.

To further explicate how the diverse knowledge of various stakeholders contributes to the GCD process we need to further explore how this knowledge is used with different inference types. Therefore, in the next section, we explicate how the three knowledge types function within the four inference types.

74 Dorst, "The Core of 'design Thinking' and Its Application."

75 Batens, "Contextual Problem Solving and Adaptive Logics in Creative Processes."

76 Schön, *The Reflective Practitioner: How Professionals Think In Action*; Dorst, "The Core of 'design Thinking' and Its Application."

Explicating the use of knowledge types with inferences

Although inference types are broadly applied in design practice, and there are considerable varieties within the abduction-2 type, the roles of different kinds of knowledge within the inference types, and especially in abduction-2, remain unclear. What is required is a more granular description of how different types of knowledge are generated through the various inference types.

For instance, induction can be used to generalize any type of knowledge as contextual certainties, relevant statements, or methodological instructions. As such, induction can take various forms depending on the type of knowledge sought. For instance, when stakeholders share relevant statements about aspects of a problem, these can be combined in an overarching relevant statement. Deduction could similarly result in various knowledge types. For instance, deduction could be used to check whether a methodological instruction would work given relevant statements on the problem at hand.

Abduction-1 and abduction-2 types of inference can be used for various ends. Abduction-1 can be used to develop relevant statements about a form of a product or service (the What) where a methodological instruction (working principle) and relevant statements about possible solutions in the solution phase are already present. As such, abduction-1 inference is based on previous experience and provides contextual certainties to the usual, or commonly used, knowledge context.

Abduction-2 types of inference can be used to come up with methodological instructions that originate from a different problem context. The new knowledge context may be closely related to the existing knowledge context or entirely different. Therefore, the use of abduction-2 type as an overarching inference containing various combinations of inferences and generative heuristics can have a key function in knowledge dynamics by producing an important new design direction.[77]

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77 Given that there are many different routes to abduction-2 inferences, depending on the heuristics and the way the knowledge types are used, it would be an oversimplification to consider abduction-2 inferencing as involving merely the three distinct steps proposed by Dorst (2011): (1) identifying themes with induction; (2) establishing working principles with metaphors; and (3) select a working principle through analogy. An example of a knowledge generation pattern using an abduction-2 type inference is: (1) a set of relevant statements is identified from different scenarios with different contextual certainties about the problem; (2) some key relevant statements are summarized through redefining the problem; (3) a large set of methodological instructions is identified through abduction-1 type inference based on previous experience of using these methodological instructions to produce relevant statements regarding the aspired value to solve a similar problem using analogies; (4) several methodological instructions are identified through redefining the previous ones using metaphors; and (5) a methodological instruction is selected through an analogy with a problem context where it has been successfully used before.

The generation and identification of contextual certainties plays a key role in the abduction-2 process and, by extension, the entire GCD process. However, identifying a new problem context, with new contextual certainties, during the design process with other stakeholders may not be sufficient. Although a contextual certainty could be adopted by the other stakeholders, it may also give rise to a new contextual constraint together with a new methodological instruction, possibly in the form of a metaphor. Whether a methodological instruction is adopted by other stakeholders in a GCD activity may depend on whether it is intuitively considered compelling[78] and may also depend on a negotiation process [79]. Therefore, it should be noted that even though involving stakeholders with diverse knowledge can play an essential role in the design process to develop new methodological instructions, it does not necessarily achieve the aspired value.

The process of shifting contextual constraints, as elements of different problem contexts, in various ways through abduction-2 inferencing also highlights that knowledge is dynamic in GCD. It explains why there could be unusual shifts between problem phases (from solution back to problem) or why there might be jumps back and forth in the design process.[80]

Justification for involving stakeholders with specific knowledge types

The claim that the diversity and the different levels of knowledge are important in the GCD process can be substantiated given the different knowledge types. A diversity of knowledge types, such as contextual certainties, relevant statements, and methodological instructions, from different stakeholders relevant to the context of the problem is important in the GCD process. Similarly, the claim that knowledge on different levels plays a role can also be substantiated by the different knowledge types. The meaning of relevant statements and methodological instructions is determined by contextual certainties. While contextual certainties are on a more abstract ontological level, relevant statements and methodological instructions are on a more factual level. In this way, we can explain that the function of the deeper lying knowledge is to provide meaning to other knowledge being used in GCD. For instance, although information about the problems of a stakeholder can be shared on a factual level as relevant statements, these are influenced by deeper lying contextual certainties. As such, it is important to take deeper lying knowledge into account in the GCD process.

78 Dorst, *Frame Innovation*.

79 Jonathan H G Hey, Caneel K Joyce, and Sara L Beckman, "Framing Innovation: Negotiating Shared Frames during Early Design Phases," *Journal of Design Research*, vol. 6, 2007, https://www.inderscienceonline.com/doi/abs/10.1504/JDR.2007.015564.

80 Dorst, "Co-Evolution and Emergence in Design."

EXAMPLE TO DESCRIBE DIVERSE STAKEHOLDER KNOLWEDGE AND WAYS OF THINKING

In this section, we demonstrate how the explicated description of diverse stakeholder knowledge can help to describe the various knowledge contributions of stakeholders in a GCD project.[81] Through the GCD process different stakeholders introduced new relevant statements and a new methodological instruction was developed (Table 1). Initially, some of the stakeholders' relevant statements were conflicting. For instance, the dietician did not want to give in to demands by the facility manager for easy "industrially-produced" food, which the dietician considered over-cooked and less nutritious. Nor did the dietician want to provide fast food, as suggested by the patient, as this did not contain sufficient nutrients. In addition, the wishes of the patient to have food provided when they had an appetite was inconsistent with the regular schedules of the facility manager's staff. Tests (deduction) were carried out to see if the food could be kept fresh in refrigerators on the ward to avoid the need for irregular shifts, but this proved too difficult in practice, so this solution was abandoned.

Table 1: Explicated knowledge of stakeholders in a GCD project

	Relevant statements	Methodological instruction	Metaphor (abduction-2)	Solution
1	Some mixed and prepared food is healthy, fast food is to be avoided	Forms of food that are easier to digest will provide more nutrients	Personal room service	Food assistants will present small, pleasant smelling food portions based on new recipes to the patients six times per day
2	Staff have limited working hours; food cannot be kept fresh for long in the department	If there is on-demand self-service on the ward, more food will be eaten		
3	Availability of variety of odorless food dishes (particularly avoiding strong scents), vibrant colors	If a greater variety of delicious food is provided when patients are hungry, they will eat something		

A new common methodological instruction was paraphrased with analogies (abduction-2 inference) related to personal room service. The redefined aspects of the service were given in the form of relevant statements. The dishes, the timing of serving, the serving procedure, and the working scheme were reviewed in a different way. Patients had to be "seduced" with a customer service approach. A food designer helped to develop the "look and feel" of these food dishes. The food designer's suggestions helped the other stakeholders to think beyond their previous methodological instructions, which could be related to the views of the hierarchical hospital management. The solution included a proactive food assistant presenting smaller portions of

81 See the GCD project described elsewhere (Vandekerckhove, de Mul, de Groot et al., 2020), whereby the aim was to help young adults with cancer suffer less from malnutrition since this affects their wellbeing. The key stakeholders were a dietician, a food facility manager, and an adolescent and young adult (AYA) patient.

food on a more frequent basis. The food would be pleasantly smelling, nutritious, look fresh and have a soft texture.

RECOMMENDATIONS FOR SELECTING STAKEHOLDERS IN A GCD PROJECT

Following the justification provided above for including specific stakeholders, one can develop recommendations to select specific stakeholders. The selected stakeholders should collectively have relevant knowledge types and inferences that are diverse and complementary when brought together. The individual stakeholders do not each need to have all the knowledge types on a particular topic or be able to use all the inference types. These criteria can be further specified and, depending on the approach, other criteria could be added to include for instance personality traits.[82]

DISCUSSION

We provided a detailed and explicit description of the role of diverse knowledge and of diverse ways of thinking in a GCD process. We explained that, in a GCD project, stakeholders aim to understand design problems and to create solutions. That these two aims can be interchangeably present in the design process was seen in terms of the co-evolution of problems and solutions. This process involves four inference types and three knowledge types that can be used in various ways depending on the stakeholders' knowledge and inference experiences.

Through this explication, it becomes clear that stakeholders with diverse background knowledge and extensive experience in drawing inferences play essential roles in the knowledge component of the GCD process. This is due to the important role played by abduction-2 type variations that are driven by diverse contextual certainties. This description can be used to justify the involvement of specific stakeholders. The main recommendation of our study is to select stakeholders with complementary knowledge types and inference experience, who can be identified using a selection procedure of stakeholders.

The important role of contextual certainties in the GCD may also explain why, in design theory and in the philosophy of discovery, the way in which a problem or solution is perceived

82 Badke-Schaub and Voute, "Design Methodology: Where Do You Go?"

(or framed) is viewed as a key step in the process of developing a solution.[83] Furthermore, we believe that the shifts between different contextual certainties, inference types as abducution-2, and design phases are related, and that this can explain the non-linear jumps in the design process[84].

By providing an explicit description of the diverse knowledge and inference skills of stakeholders in a GCD process, and by providing explicit justifications to involve specific stakeholders, we hope to intensify the discussion on reporting standards in GCD research. For instance, a minimum level of transparency in reporting the stakeholder selection process in GCD research could be promoted. This could help researchers improve the rationale for their approach and it may help others to evaluate the appropriateness of the stakeholders involved.

Limitations

There are various definitions and labels attached to GCD, such as collaborative design and participatory design, often with different perspectives on the collaboration or design element. In this paper, we have considered GCD as an active exchange of knowledge between stakeholders[85] In focusing on the knowledge perspective, we have not addressed other aspects of collaboration, such as the social perspective[86] or the value-driven or political perspective [87], which have historically played a critical role in co-design. This limits the applicability of our proposed theory to the co-design field as a whole. Nevertheless, by focusing on knowledge

83 The role of perception, also called a frame or perspective, has been widely discussed. However, it is unclear whether a frame refers to a specific type of knowledge, or to a type of inference as a design activity, or a combination of both. Perception also depends on what many authors call a mental model. However, it does seem that the mental model concept refers to a much larger definition of the design knowledge context than the definition we employ. For the role of mental models in design see Cramer-Petersen, Christensen, and Ahmed-Kristensen, "Empirically Analysing Design Reasoning Patterns: Abductive-Deductive Reasoning Patterns Dominate Design Idea Generation"; Heylighen, Cavallin, and Bianchin, "Design in Mind."

84 Dorst, "The Core of 'design Thinking' and Its Application"; Dorst, "Co-Evolution and Emergence in Design."

85 Kleinsmann et al., "Development of Design Collaboration Skills"; Sanders and Stappers, "Probes, Toolkits and Prototypes: Three Approaches to Making in Codesigning"; Elizabeth Sanders and Pieter Jan Stappers, "Co-Creation and the New Landscapes of Design," *CoDesign* 4, no. 1 (March 2008): 5–18, https://doi.org/10.1080/15710880701875068; Sanders and Stappers, *Convivial Design Toolbox : Generative Research for the Front End of Design*; van Boeijen, Daalhuizen, and Zijlstra, *Delft Design Guide*.

86 Lars Bo Andersen et al., "Participation as a Matter of Concern in Participatory Design," *Https://Doi.Org/10.1080/15710882.2015.1081246* 11, no. 3–4 (October 2, 2015): 250–61, https://doi.org/10.1080/15710882.2015.1081246.

87 Andrea Botero et al., "Getting Participatory Design Done: From Methods and Choices to Translation Work across Constituent Domains," *International Journal of Design* 14, no. 2 (2020): 17–34, http://www.ijdesign.org/index.php/IJDesign/article/view/3781; Rachel Charlotte Smith and Ole Sejer Iversen, "Participatory Design for Sustainable Social Change," *Design Studies* 59 (November 1, 2018): 9–36, https://doi.org/10.1016/j.destud.2018.05.005.

interaction in developing a GCD theory, we have addressed an essential dimension of creative collaboration among stakeholders.

In addressing the philosophical explication process, we focused heavily on Batens' contextual knowledge theory and on heuristics as applied in the philosophy of scientific discovery. However, the concepts we considered do not reflect the entire field of the philosophy of scientific discovery as this is an entire discipline in its own right. Moreover, there are ongoing advances in the field of scientific discovery related to epistemology, adaptive logics, and the philosophy of science, each a research area in themselves. We selected those concepts that we considered most useful in developing a GCD stakeholder theory. Given the progress made, we hope to inspire other researchers to further explore the combination of GCD theory and the philosophy of scientific discovery.

Throughout the paper, we have briefly touched upon pivotal concepts of design theory to demonstrate the added value of a GCD stakeholder theory. Although we have nuanced our approach where possible, we have not addressed the much wider debate surrounding the use and value of concepts such as design aims[88], design phases[89], co-evolution[90], and framing [91]. Even though we have not contributed directly to these theoretical debates, we have utilized pivotal concepts to demonstrate the reach of this GCD stakeholder theory. Further research is needed to integrate these other concepts in a more detailed way.

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88 Cross, *Development in Design Methodology*; Cross, "A Brief History of the Design Thinking Research Symposium Series"; Cross, "Designerly Ways of Knowing: Design Discipline Versus Design Science"; Simon, *The Sciences of the Artificial*; Jonas, "Design as Problem-Solving? Or: Here Is the Solution -What Was the Problem?"; de Couvreur and Goossens, "Design for (Every)One: Co-Creation as a Bridge between Universal Design and Rehabilitation Engineering."

89 Jones, *Design Methods: Seeds of Human Futures*; van Boeijen, Daalhuizen, and Zijlstra, *Delft Design Guide*; Cramer-Petersen, Christensen, and Ahmed-Kristensen, "Empirically Analysing Design Reasoning Patterns: Abductive-Deductive Reasoning Patterns Dominate Design Idea Generation."

90 Dorst, "Co-Evolution and Emergence in Design"; Nigel Cross, "Developing Design as a Discipline," *Journal of Engineering Design* 29, no. 12 (December 2, 2018): 691–708, https://doi.org/10.1080/09544828.2018.1537481; Stefan Wiltschnig, Bo T Christensen, and Linden J Ball, "Collaborative Problem–Solution Co-Evolution in Creative Design," *Design Studies* 34, no. 5 (2013): 515–42, https://doi.org/https://doi.org/10.1016/j.destud.2013.01.002.

91 Erving Goffman, *Frame Analysis: An Essay on the Organization of Experience* (Northeastern University Press, 1986); Dorst, "Co-Evolution and Emergence in Design"; Vermaas, Dorst, and Thurgood, Framing in Design: A Formal Analysis and Failure Modes ; Donald A. Schön, Problems, Frames and Perspectives on Designing, *Design Studies* 5, no. 3 (July 1, 1984): 132–36, https://doi.org/10.1016/0142-694X(84)90002-4; Milene Gonçalves and Philip Cash, The Life Cycle of Creative Ideas: Towards a Dual-Process Theory of Ideation, *Design Studies* 72 (January 1, 2021): 100988, https://doi.org/10.1016/J.DESTUD.2020.100988.

Further research

Overall, we would see this paper as an initial theoretical step in an iterative process to apply stakeholder knowledge in GCD.[92] The next step could further develop the theory by testing the descriptions of stakeholder knowledge and inferences in GCD or by testing the stakeholder selection recommendations. Based on the insights acquired, the theory would be further enriched.

Further, one could expand the scope of the knowledge interaction considered beyond the stakeholders and examine the relationship between stakeholders' knowledge development and design environments[93], or new types of digital knowledge aids in the design process[94]. For instance, where there is a set of relevant methodological instructions and inferences from which knowledge can be derived to solve a specific design problem, it would be valuable to assemble this knowledge in a library. Natural language processing algorithms could then be used to analyze this database and offer recommendations such as relevant methodological instructions to solve new problems. These algorithms could become the next generation of stakeholders in the design process.

CONCLUSIONS

We have explicated the roles of diverse knowledge and diverse stakeholder inferences in GCD by describing how and why stakeholders can combine three types of stakeholder knowledge and four types of inferences. Based on this description, we justify involving specific stakehold-

92 Philip J. Cash, "Developing Theory-Driven Design Research," *Design Studies* 56 (May 1, 2018): 84–119, https://doi.org/10.1016/j.destud.2018.03.002.

93 Katja Thoring et al., "The Architecture of Creativity : Toward a Causal Theory of Creative Workspace Design," *International Journal of Design* 15, no. 2 (2021): 17–36, http://www.ijdesign.org/index.php/IJDesign/article/view/4061.

94 Peter Kun, Ingrid Mulder, and Gerd Kortuem, "Data Exploration for Generative Design Research," in *DRS2018: Catalyst*, vol. 4 (Design Research Society, 2018), https://doi.org/10.21606/drs.2018.565; Rens van de Schoot et al., "An Open Source Machine Learning Framework for Efficient and Transparent Systematic Reviews," *Nature Machine Intelligence 2021 3:2* 3, no. 2 (February 1, 2021): 125–33, https://doi.org/10.1038/s42256-020-00287-7; Xiaoyu Zhang et al., "A Visual Analytics Approach for the Diagnosis of Heterogeneous and Multidimensional Machine Maintenance Data," in *IEEE Pacific Visualization Symposium*, vol. 2021-April, 2021, 196–205, https://doi.org/10.1109/PacificVis52677.2021.00033; Xiaoyu Zhang, Senthil Chandrasegaran, and Kwan Liu Ma, "Conceptscope: Organizing and Visualizing Knowledge in Documents Based on Domain Ontology," in *Conference on Human Factors in Computing Systems - Proceedings* (arXiv, 2021), https://doi.org/10.1145/3411764.3445396; Suyun Sandra Bae et al., "Spinneret: Aiding Creative Ideation through Non-Obvious Concept Associations," in *Conference on Human Factors in Computing Systems - Proceedings* (Association for Computing Machinery, 2020), https://doi.org/10.1145/3313831.3376746.

ers who we identify as essential in a GCD process and recommendations are made on how to select them.

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DECLARATION OF COMPETING INTERESTS

None

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CHAPTER 6

Diversity in stakeholder groups in generative co-design for digital health: assembly procedure and preliminary assessment

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ABSTRACT

Background

Diverse knowledge and ways of thinking are claimed to be important when involving stakeholders such as patients, care professionals, and care managers in a generative co-design (GCD) process. However, this claim is rather general and has not been operationalized; therefore, the influence of various stakeholders on the GCD process has not been empirically tested.

Objective

In this study, we aimed to take the first step in assessing stakeholder diversity by formulating a procedure to assemble a group of diverse stakeholders and test its influence in a GCD process.

Methods

To test the procedure and assess its influence on the GCD process, a case was selected involving a foundation that planned to develop a serious game to help people with cancer return to work. The procedure for assembling a stakeholder group involves snowball sampling and individual interviews, leading to the formation of 2 groups of stakeholders. Thirteen people were identified through snowball sampling, and they were briefly interviewed to assess their knowledge, inference experience, and communication skills. Two diverse stakeholder groups were formed, with one more potent than the other. The influence of both stakeholder groups on the GCD process was qualitatively assessed by comparing the knowledge output and related knowledge processing in 2 identical GCD workshops.

Results

Our hypothesis on diverse stakeholders was confirmed, although it also appeared that merely assessing the professional background of stakeholders was not sufficient to reach the full potential of the GCD process. The more potently diverse group had a stronger influence on knowledge output and knowledge processing, resulting in a more comprehensive problem definition and more precisely described solutions. In the less potently diverse group, none of the stakeholders had experience with abduction-2 inferencing, and this did not emerge in the GCD process, suggesting that at least one stakeholder should have previous abduction-2 experience.

Conclusions

A procedure to assemble a stakeholder group with specific criteria to assess the diversity of knowledge, ways of thinking, and communication can improve the potential of the GCD process and the resulting digital health.

INTRODUCTION

Background

Stakeholders such as patients, care professionals, and care managers are considered to play an important role in designing and creating digital health [1-4]. A widely used form of co-design that can involve a group of people to develop a digital health product is generative co-design (GCD) [5,6]. GCD is characterized by a collective creative process whereby knowledge is shared by stakeholders to develop a product or service, such as digital health [7-12]. In a GCD process, stakeholders are more actively involved in the creative design process than in a more classical design process [10].

A wide variety of people who do not necessarily have a design background, such as patients, care professionals, and health policy makers, can be GCD stakeholders in a digital health project. For instance, content experts such as patients (often referred to as "users") may improve the uptake of the output, as their needs regarding user guidance, specific reminders, and personal tracking will likely be better addressed [13]. Health policy experts may also contribute to digital health development. For instance, it has been suggested that their involvement during the COVID-19 pandemic has led to improved alignment between payers and care professionals, which may have contributed to the rapid uptake of digital health [14,15].

There are both theoretical and practical issues when involving different stakeholders in GCD. From a theoretical standpoint, GCD scholars hypothesize that the more the diverse stakeholders involve in a group in terms of diverse knowledge and ways of thinking, the better the GCD process [10]. However, this claim is not clearly explicated, which may be due to the conceptual challenges present, such as the lack of consensus on the definition of "stakeholder" and "involvement" [16]. For instance, how one defines involvement depends on how one views stakeholder representation, the time involved in the project, and whether the scope focuses on the project or a wider cultural change [16-18]. In addition, GCD is part of a larger research field known as participatory design (PD) [10]. In PD, specific values are upheld, including democracy, equalized power relations, mutual learning, and situation-based actions [16,19]. However, these values are not currently applied explicitly in the GCD stakeholder selection procedure. For instance, adhering to a democratic principle could mean that not only a hospital manager but also current and future users should be involved in the development process of digital health. However, criteria have not been proposed to justify the selection of ideal participants.

From a practical point of view, assembling a diverse stakeholder group to design digital technology may require more deliberation in the health care field than in other sectors because the interests of the diverse stakeholders may not be aligned. This may lead to practical challenges for stakeholders in gaining trust and managing multiple stakeholders and time pressure when involving patients and physicians [20-25]. However, design practice manuals do not address how to overcome these additional challenges when using GCD to develop digital health [11,26,27].

When tackling these theoretical and practical issues and involving stakeholders in the GCD process to develop digital health, there is little scientific guidance to help select the best stakeholders. No study has evaluated the performance of different stakeholder groups when using GCD to develop digital health. A meta-review, albeit limited to the development of serious games, has highlighted the need for this research, as the effect of involving some users as stakeholders in PD studies is unclear [28].

Objective

To provide further scientific guidance on the involvement of stakeholders, we tested the hypothesis that stakeholders with more diverse knowledge and ways of thinking would improve the GCD process. To satisfy this aim, we operationalized the hypothesis through a procedure to assemble distinct stakeholder groups and assess their influence on the GCD process and output. As such, the research question is as follows: *Do stakeholders with diverse knowledge and diverse ways of thinking improve the GCD process for digital health?* The study's goal is to conduct a preliminary assessment of diverse stakeholder groups assembled through a prescribed procedure in the early stages of a GCD process of a digital health project. This assessment will hopefully provide deeper insights that other researchers and practitioners can consider when deciding the most appropriate stakeholder to involve in their GCD project. With time, this could lead to a validated GCD stakeholder involvement procedure for digital health.

METHODS

Procedure to Assemble Diverse Stakeholder Groups

The stakeholder group assembly procedure amounts to the operationalization of the Sanders and Stappers [10] hypothesis that stakeholders with more diverse knowledge and ways of thinking could improve the GCD process. To involve stakeholders who meet these requirements in a GCD process, a procedure containing 3 steps was followed: snowball sampling, interviews, and assemblage of stakeholders (Figure 1).

First, to recruit people, one needs to identify those who are committed to addressing the problem at hand. It can be useful to sample stakeholders through relevant organizations, associations, or events [25,29]. This should help ensure their commitment to solving problems, as these people have directly or indirectly been exposed to the problems and are logically more motivated to develop a solution.

Second, individual interviews can be conducted to qualitatively assess the diversity of knowledge and ways of thinking of the potential members. To operationalize the term "knowledge," we define 3 types of knowledge (Textbox 1) based on the work of Batens [30-32]. One key form of knowledge that is also defined in GCD research is the deeper-lying tacit knowledge [10], which we measure here as contextual certainties. In addition, there are methodological instructions and relevant statements. Each of these 3 types of knowledge was assessed during an interview on a scale of 0 to 3 (Table 1). Stakeholders with extensive knowledge regarding the relevant statements and contextual certainties will be given the maximum score (3); stakeholders who are uncertain are given a score of 2 and those who seemed to have little knowledge, or did not provide relevant information in the interview, were awarded lower scores (1 and 0, respectively).

To operationalize the other component, "thinking," we define 4 types of inferences, namely, induction, deduction, abduction-1, and abduction-2 (Textbox 1), as categorized initially by Peirce [33,37,38]. In particular, abduction-2 inferencing is expected to play an important role in the design process [33,38] and is typically attributed to how designers think. Previous experience with these types of inferences can be assessed during an interview by counting the number of times an inference is used (Table 1). Abduction-1 can be scored as the number of methodological instructions formulated as concrete solutions (eg, having an overview of one's energy capacity after cancer treatment to continue work). Abduction-2 can be scored by looking at the use of generative heuristics as analogies or metaphors.

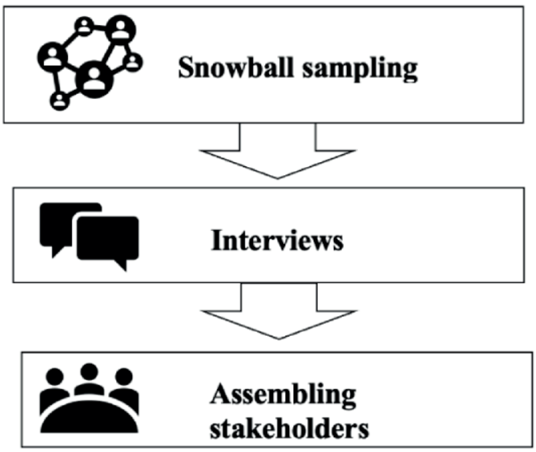

Figure 1. Stakeholder group assembly procedure.

Textbox 1. Working definitions of knowledge and inference types used for assessment.

Knowledge types

- Contextual certainties
  a. Knowledge containing a deeper-lying perspective or philosophical principle
- Methodological instructions
  a. An approach to solve a problem or subproblem such as a procedure for operations, instruments, or tools
- Relevant statements
  a. Factual knowledge about the problem or the solution

Inference types

- Induction
  a. A sequence of reasoning steps leading to a generalization, whereby several similar utterances are grouped under a new term or name, often in the form of a remark or conclusion following the utterances of others [33]
- Deduction
  a. A sequence of reasoning steps leading to a conclusion based on several previous utterances [33]
- Abduction-1
  a. A sequence of reasoning steps leading to the suggestion of a solution in the form of a methodological instruction
- Abduction-2
  a. A sequence of reasoning steps leading to the suggestion of a solution in the form of a methodological instruction whereby induction, deduction, abduction-1 and generative heuristics can be used, for example, a metaphor [34,35] or analogy [36]

Table 1. Criteria used for stakeholder selection.

Assessment aims and criteria	Example interview questions and assessment	
Assess knowledge diversity and depth		
	Professional background	What is your job?
Relevant statements	What, in your view, is the core of the problem about cancer and work? (0-3 score)	
Contextual certainties	Why is this an important problem? (0-3 score)	
Assess inference experience		

Table 1. Criteria used for stakeholder selection. (*continued*)

Assessment aims and criteria	Example interview questions and assessment	
	Induction	How did you come upon this problem, through direct or indirect experience? (0-3 score)
	Deduction	Have you previously tested solutions regarding work and cancer? (0-3 score)
	Abduction-1 (methodological instructions)	What inspiring solutions arise in your mind to address the work and cancer challenge? (count number of occurrences)
	Abduction-2	Abduction-1 with generative heuristics as analogies or metaphors (count number of occurrences)
Assess communication abilities		
	Self- assessment	Choice between 3 suggested answers: "OK, but sometimes challenging," "good," or "very good"

In addition, communication skills can be assessed to determine whether potential stakeholders can effectively communicate their ideas to others in a group. For instance, we can assess whether a patient has the appropriate content expert background with various relevant statements that they feel confident to share during a GCD process with other stakeholders by asking the respondent for a self-evaluation.

Third, after conducting the interviews and scoring the responses, a diverse stakeholder group can be assembled based on 3 criteria. One can start by combining people from different professional backgrounds. Next, one can ensure that those stakeholders with the highest knowledge scores are included as they have more knowledge. In other words, if there are 2 stakeholders with the same professional background, the one with the highest score is included. Finally, the diversity of inferencing experience can be assessed. Here, one should ensure that a stakeholder group covers all inference types. Once one is satisfied that the stakeholder group covers all inference types, one can seek out the stakeholders with the greatest inference experience. For instance, if there are 2 stakeholders with abduction-2 experience, the one with the most experience (highest score) can be selected.

Action Research Approach

To assess the stakeholder group assembly procedure, an action research approach [39] was used to guide the practitioners of a GCD project while adding the stakeholder group assembly procedure to simultaneously gain research insights.

Hypothesis to Test

The aim was to test how a stakeholder group, assembled using the stakeholder group assembly procedure described in the aforementioned section, would influence the GCD process. We expected that this stakeholder group assembly procedure would produce a group with diverse knowledge and ways and that this would have a positive influence on the GCD process and output. We also expected that, in such a group, the "contextual certainties" knowledge type would be expressed more often by all stakeholders and the "abduction-2" inference type would be more often used specifically by the stakeholders with design expertise than in our less-experienced comparison group.

Digital Health Project

A digital health development project in which multiple stakeholders could be involved in the GCD process was sought, and we could test the stakeholder assembly procedure to determine if it could make the GCD process more methodologically sound. Given the expertise of the first author (PV) with the problems faced by patients with cancer, a related project was identified and initiated by a Dutch cancer foundation called oPuce (The Foundation). The Foundation aims to create awareness of the stigmatization of cancer and supports initiatives to help people with cancer continue working during and after the illness and promote their return to paid work [40]. The Foundation had planned to start the development of a serious game to help people with cancer address their work-related needs. Although the actual development process had not yet started, The Foundation was interested in using a co-design process to develop the serious game. Because The Foundation had a large network of people who could potentially be involved as stakeholders in the design process to develop the serious game, we chose to add the stakeholder group assembly procedure as a first step in this process and help them with the first GCD activity.

Ethics Approval

Ethics approval was granted by Erasmus Medical Centre's Ethics Committee (MEC-2021-0231).

Assembled Stakeholder Group

Overview

The stakeholder group assembly procedure described in the aforementioned section was followed in this study. The research data were solely managed by the first author (PV). The stakeholders received no financial compensation to participate in this study.

Here, we describe how snowball sampling, interviews, and group assembly were carried out. The first author initiated the snowball sampling [41] by approaching people at The Foundation via email and phone to identify stakeholders. At the end of this process, 13 potential stakeholders who had been involved in the initial conversations over the development of a serious game were identified (Table 2).

The 13 potential stakeholders were each assessed through 45-minute interviews, except for the network coordinator with COVID-19. Before the interviews, the participants were informed about the research and asked for informed consent. The web-based audio and video recorded

Table 2. Number of potential stakeholders identified through snowball sampling per professional background (N=13).

Background	Stakeholder, n (%)
Game developer and designer	1 (8)
Employer (employing people with cancer)	3 (23)
Employer network	2 (15)
Employed cancer survivor	1 (8)
Occupational physician	1 (8)
Researcher	3 (23)
Network coordinator and patient with a previous history of cancer	1 (8)
IT manager	1 (8)

interviews were carried out by PV and facilitated by creative exercises on Miro's web-based collaborative whiteboard platform (Miro Corp; online Multimedia Appendix 1). The creative exercises helped the interviewees gain a visual understanding of their ideas and become accustomed to the web-based creative software they would use during the GCD workshop.

Given that there were multiple stakeholders with similar backgrounds but scored differently in terms of knowledge and inference, the stakeholders could be divided into 2 groups (Tables 3 and 4). A more potent stakeholder group was formed of stakeholders with diverse backgrounds who scored highly on the knowledge and inference criteria. These stakeholders scored high in terms of providing more relevant statements and contextual certainties. This group had experience with all the inference types. A less potent stakeholder group was formed of the remaining stakeholders who still met the desired range of diverse backgrounds but scored less on the knowledge and inference criteria by showing less extensive knowledge and less inferencing experience during the interviews. Notably, none of the stakeholders in this group had experience with abduction-2 inferencing.

The stakeholders in both groups were unaware of this selection procedure, or why they were placed in which group, and the detailed aims of the study.

Table 3. Scores of stakeholders in the more potent diverse group.

Background	Score[a]
Game developer and designer	11
Employer (employing people with cancer in company A) and facilitator	11
Employer (employing people with cancer in company B)	9
Employer network	9
Employed cancer survivor	9.5
Occupational physician	10
Researcher	11.5

[a]Average score per stakeholder is 10 (SD 0.95).

Table 4. Sores of stakeholders in the less potent diverse group.

Background	Score[a]
Researcher 1	5
Researcher 2	3.5
IT manager	2.5
Employer network	3.5
Employer and facilitator	6
Network coordinator and cancer survivor[b]	10
Ecosystem expert[c]	—[d]

[a]Average score per stakeholder is 5 (SD 2.47).
[b]No formal interview was conducted; information was gathered through informal conversations.
[c]No interview was conducted because this stakeholder only joined as an observer at the start of the generative co-design workshop.
[d]Not available.

Data Collection

Data were collected during individual interviews as part of the stakeholder assessment procedure. In addition, data were collected in 2 identical parallel workshops that were part of a larger web-based event organized by The Foundation regarding the working of their organization. Before the workshops, all the stakeholders were given information about the aim of the identical parallel-running workshops, and a link was provided to familiarize themselves with the web-based Miro platform. GCD workshops are social activities in which stakeholders can share knowledge and work with creative exercises toward achieving the purpose of the design project [10,42,43]. Web-based workshops were considered the best option given the COVID-19 pandemic restrictions. The 30-minute web-based GCD workshops were audio and video recorded.

To provide a focus for the assessments, the GCD workshops were slightly artificially divided into 2 phases: the problem phase with the aim to understand the issues to formulate a problem definition and the solution phase to create ideas for a solution. The materials used in the 2 parallel-running GCD workshops were identical and organized specifically to focus on the interactions among stakeholders in both phases. Both groups received 5 identical instructions with a hexagon template delineating both the problem and solution phases, and sticky notes were provided (online Multimedia Appendix 1).

In terms of roles, PV similarly facilitated both workshops and switched between them to ensure that the instructions were clear while consciously avoiding steering the content development process. Each stakeholder participated in the respective workshops as a co-designer. In addition, before the workshops, 2 stakeholders were asked if they would take on the double role of a participant and an assistant facilitator. All participants, including the assistant facilitators, were blinded to the hypotheses and aims of the study.

Qualitative Analysis

The data from the interviews and workshops were iteratively coded and analyzed using ATLAS.ti (Mac Version 22.1.0; Scientific Software Development GmbH). The influences of the 2 diverse stakeholder groups on the GCD process were assessed in terms of knowledge changes (knowledge output) and how the stakeholders processed the knowledge (the use of inferences). Given this focus, the changes in knowledge were assessed by comparing the knowledge displayed during the initial interviews with that developed during the workshop within both groups.

To compare the 2 workshops, we coded each set of interactions between stakeholders in the problem and solution phases about a certain topic as a sequence in each workshop. In each sequence, we used the deductive and inductive codes described in the following section to be able to compare the knowledge processing of both stakeholder groups in each sequence and phase. We separately compared the sequences of both groups in the problem and solution phases because the knowledge outputs in the problem phase (the problem statement) and solution phase (forms of methodological instructions) were different.

Thematic and inductive codes were used to assess changes in the knowledge from that revealed in the interviews to that in the workshops. The thematic codes were based on the definitions in Textbox 1, using 3 types of knowledge and 4 inference types to assess the knowledge processing and output. Using the same definitions of the assessment criteria during the stakeholder group assembly procedure and workshop analysis ensured that we could compare at the level of knowledge and inference types. The interview data can show that an individual stakeholder mentioned a certain fact (relevant statement type) or a certain approach to finding a solution (methodological instruction type) before joining the GCD process. To evaluate the changes in knowledge possessed by the stakeholders over time, that is, interview through workshop, we used codes such as "repetition from interview" if the knowledge generated in a workshop had already been mentioned by one of its members in their interviews. If the knowledge did change during the workshop, we assessed how it had changed in a particular sequence of interactions between stakeholders.

Thematic inference type codes were used to code group interactions during the GCD workshops. We followed a coding approach similar to that by Cramer-Petersen et al [33], whereby inferences were coded and analyzed in an empirical design setting. As such, utterances that bore similarities to the logical inference forms were coded according to the appropriate inference type (Textbox 1).

To further qualify the knowledge processing and knowledge output identified with the above-described deductive codes, 17 inductive codes (online Multimedia Appendix 2) were used to identify stakeholder behaviors (eg, suggest a new idea or a reformulation; Table 5). These were used to understand why certain knowledge or inference types were used in each sequence.

Table 5. Examples of inductive code names and definitions to assess changes of knowledge within the workshops (see online Multimedia Appendix 2 for complete list).

Code name	Definition
Introduce	Utterance whereby a new idea is proposed
Reformulate	Utterance whereby a previous idea is expressed using different words
Add	Utterance whereby aspects are added to a new idea

Inductive codes to code the knowledge changes: on x-axis from abstract to concrete and on y-axis from general to specific.

To assess the knowledge output in a sequence during the solution phase, 4 inductive codes were used to code knowledge changes through stakeholder interactions (Figure 2): concrete specific (eg, proposing to use a coach), concrete general (eg, proposing to use artificial intelligence), abstract specific (eg, a virtual angel—a specific object or artifact), and abstract general (eg, an empowering journey—a general image that may contain several specific solutions).

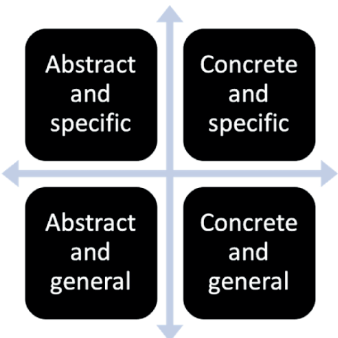

Figure 2. Inductive codes to code the knowledge changes: on x-axis from abstract to concrete and on y-axis from general to specific.

Examples of inductive code names and definitions to assess changes of knowledge within the workshops (see online Multimedia Appendix 2 for complete list).

RESULTS

Main Findings

Our hypothesis on diverse stakeholders was confirmed, as the more potent stakeholder group had a relatively larger influence on the GCD workshop process and output in the problem phase (see *Greater Processing of Relevant Statements Increased Knowledge About the Problem*) and solution phase (see *Greater Use of Abduction-2 Inferencing Improves the Concreteness and Specificity of Solutions*) than the less potent group (Table 6). Regarding the problem phase, in terms of influence on the process, the more potent stakeholders built on each other's relevant statements, some of which had already been mentioned in the interviews before the workshop. Here, we noticed a dual movement. On the one hand, there was an expansive movement of diverse knowledge as the varied stakeholders shared their knowledge about the problem, and on the other hand, there was a narrowing integrative movement in which the content of ideas changed, and this changed the course of the discussion. In terms of *output*, the more potent group developed a more comprehensive problem definition.

Table 6. Frequency of codes in interactions in the more potent and less potent stakeholder groups

Code group and code	Frequency in more potent group	Frequency in less potent group			
Inference type					
	Induction[a]	*10*	0	*0*	2
	Deduction	*9*	6	*4*	5
	Abduction-1	0	2	0	5
	Abduction-2	0	*13*	0	*0*
Knowledge type					
	Relevant statements	*14*	4	*10*	6
	Methodological instructions	0	24	0	*8*
	Contextual certainties	1	0	0	0

[a]Key differences have been highlighted in italics.

Regarding the solution phase, in terms of influence on the *process*, the more potent group used more abduction-2 inferences, leading to a greater variety of methodological instructions (Table 6). In addition, the more potent diverse stakeholder groups, as in the problem phase, developed each other's methodological instructions. This made the solutions more concrete and specific. Therefore, in terms of GCD *output* in the solution phase, the more potent stakeholders had a greater influence, as this group produced more precisely described solutions.

The other 2 subhypotheses were not supported. Only once, and only implicitly, contextual certainties were identified in the GCD workshop (Table 6). This was true only among the more potent stakeholder groups. As such, there seems to be no substantial difference between the 2 groups in terms of explicitly sharing more tacit deeper-lying knowledge. Furthermore, although we had expected abduction-2 type inferencing to be applied by stakeholders with a design background, it was not used by the game developer who was the only participant with this background in the more potent diverse stakeholder group. Rather, abduction-2 inferences were made by the nondesigners in this group, which is contrary to our expectations.

The Greater Processing of Relevant Statements Increased Knowledge About the Problem

In terms of interactions about the problem, the stakeholders in the more potent group shared a greater diversity of relevant statements (14 vs 10), which were processed using more induction (10 vs 0) and deduction inferences (9 vs 4) than the less potent diverse stakeholder group did (Table 6). Furthermore, the stakeholders in the first group built on each other's relevant statements, some of which had already been mentioned in the interviews before the workshop. These interactions were related to focusing on the discussion, asking questions, explaining ideas, introducing new ideas, and reformulating old ones, which occurred more frequently in the more potent group.

How stakeholders in the more potent stakeholder group developed each other's knowledge about the problem is clearly demonstrated in the examples of the more potent group (Table 7). The employer expanded the discussion concerning the self-management of cancer survivors and added that one should consider the resilience of these people and avoid putting them into a victim role. Although he had already mentioned the need for a bespoke resilient solution in the individual interview, this was not in relation to considering the victim role of a patient or in relation to self-management. The employer and facilitator reformulated these points slightly and responded that this comment was related to developing the content of the serious game rather than its implementation. The game developer specified (relevant statement) that these aspects concern the content and didactics behind the content of the serious game. This probably follows from a more abstract principle that the game designers believe in, that "the content of a serious game always has a didactic aim behind it" (contextual certainty). The employed cancer survivor returned to what the employer had mentioned earlier and questioned whether there was a victim role at all. Finally, the employer and facilitator attempted to integrate the different points and reformulate this as a new question.

Thus, in the more potent group, the stakeholders such as employers and a patient shared their views on the problem by asking questions, reformulating points, and trying to draw connections. They shared their different ways of viewing self-management for people with cancer

Table 7. Sequence with codes from more potent diverse stakeholder group (translated into English for reporting purposes).

Stakeholder and sequence of utterances (order of conversation)	Behavior code	Inference-type code	Knowledge-type code	Repetition code	
Employer					
	1. It feels to me that a user-centered bespoke solution is very general. I mean, doesn't that apply to any situation?	Focus	Deduction	—[a]	—
Employer and facilitator					
	2. How would you make it more concrete?	Focus and ask	Deduction	—	—
Employer					
	3. For example, coming back to what was said previously, how can we facilitate self-management? How can we avoid creating a victim role?	Introduce	—	—	—
	Because we want to make something bespoke. For example, how can you contribute to the resilience of the candidates looking for work or those who want to maintain work?	Explain	Deduction	Relevant statement	From interview
	It's in line with self-management, but a bit more.	Reformulate	Induction	—	—
Employer and facilitator					
	4. How can you connect that to a serious game? It's obviously also a general problem.	Ask	Deduction	—	—
	How do you maintain self-management? How do you prevent the victim role? Then, you are in the development process of the serious game.	Reformulate	Induction	—	—
Game developer and designer					
	5. But more content, the didactics behind it.	Introduce	Induction	Relevant statement and contextual certainty	From interview
Employer					
	6. The content	Reformulate	Induction	—	—

Table 7. Sequence with codes from more potent diverse stakeholder group (translated into English for reporting purposes). (*continued*)

Stakeholder and sequence of utterances (order of conversation)	Behavior code	Inference-type code	Knowledge-type code	Repetition code	
Game developer and designer					
	7. Yes, indeed	Agree	—	—	—
Employed cancer survivor					
	8. If there would be a victim role?	Ask	—	Relevant statement	—
Employer and facilitator					
	9. I am thinking about the last point of (employer) and from (researcher) to keep it concrete and small and still also connect it with the piece on implementation.	Focus	Induce	—	—
Then we arrive again at the point of how do we make sure that the serious game offers added value for individual employees with cancer, but then we still remain with a big problem.	Reformulate	Deduce	—	—	

[a]Not available.

looking forward to returning to work. As a stakeholder, the technological background of the game developer enabled him to quickly point out how this could be accommodated in a serious game through the underlying didactics. This shows how each of the different stakeholders in the GCD process can rapidly interject useful information to define the problem based on the actual needs while conforming to what is technically needed and possible.

The interaction between stakeholders in the less potent group (Table 8) was more a group conversation without people building on each other's knowledge (relevant statements). This led to less integration of the knowledge that was being shared. Even though they seemed to make a start to focus on the aspect of the problem as "the barriers preventing people with cancer to resume work," they did not ask each other what that means or attempted to define the barriers. In the more potent stakeholder group, we observed more concentrated attention on the content of the problem, which led to more integration of knowledge about the problem, for example, the concepts of self-management, the victim role, and serious game development were rapidly connected to a problem definition.

Table 8. Sequence with codes from less potent diverse stakeholder group (translated into English for reporting purposes).

Stakeholder and sequence of utterances (order of conversation)	Behavior code	Inference-type code	Knowledge-type code	Repetition code	
Researcher 1					
	1. If I am now looking. I am focusing on the serious game. That seems to be the starting point. Then, I think a central problem is that we see that the current ways of people getting back to work are not successful. And we want to improve that. Improve self-management. Well, let's continue here, I am sure you can add to this.	Introduce	Deduction	Relevant statement	From interview
Employer and facilitator					
	2. Does everyone agree?	Ask	—[a]	—	—
Network coordinator and cancer survivor					
	3. I think also, how can you improve the collaboration? How can you, with each other? Perhaps intercompany or inter-academic? Perhaps, this has nothing to do with…	Introduce and ask	—	—	—
Ecosystem expert					
	4. What I thought is that solution-oriented thinking is more on the outside of the hexagon (exercise template). I think that the word removing barriers to resume work, that is for example a problem related to the content. I don't know how others are looking at this?	Introduce, reformulate, and ask	—	—	—
Researcher 2					
	5. I agree with that.	Agree	—	—	—
Network coordinator and cancer survivor					
	6. This is about keeping your work?	Ask and reformulate	Deduction	—	—
Ecosystem expert					
	7. Keeping your work.	Agree	—	—	—

[a]Not available.

Over time, the interactions about the problem in the GCD workshop with the more potent stakeholders showed a dual movement that was not present in the less potent group. On the one hand, there was an expansive movement of diverse knowledge as the stakeholders shared more knowledge about the problem and on the other hand, there was a narrowing integration movement whereby the content of ideas changed, which changed the course of the discussion. For example, initially, there was an expansive diverse knowledge movement as various stakeholders discussed the broad theme of user-centeredness. Then, there was a narrowing integration discussion about the definition of the user, whereby the question was raised as to whether one should focus on the development or implementation aspects. Some aspects were considered together, as it was mentioned that self-management was important for users. Here, the initial ideas changed as this was rephrased to clarify that some aspects are relevant during the development phase of the serious game and others during its implementation. Other elements that were discussed concerned resilience and the victim roles to be considered (Table 8), although these were not integrated into the problem definition. This dual movement may have contributed to the more potent diverse stakeholder group having a more comprehensive problem definition (Textbox 2) than the less potent group. In the problem definition phase, the less potent stakeholder group seemed to have brought together ideas in an expansive movement; however, there was no subsequent integration of or change in the content that formed the problem definition. The more potent group's more elaborate problem definition seems to have provided a better-founded basis on which to develop solutions.

Textbox 2. Problem definitions.

Problem definition of the more potent diverse stakeholder group

- How do we realize a bespoke approach and self-management during the implementation of the serious game (whilst taking this into account during development of the serious game)?

Problem definition of the less potent diverse stakeholder group

- Maintaining work during and after cancer

Greater Use of Abduction-2 Inferencing Improves the Concreteness and Specificity of Solutions

In the solution phase, the more potent group of diverse stakeholders used more abduction-2 inferences (13 vs 0), which led to a greater variety of methodological instructions (24 vs 8) than those observed in the less potent group (Table 6). In addition, similar to what the stakeholders did in the problem phase, the more potent diverse stakeholder group developed each other's methodological instructions in the solution phase. This resulted in more concrete and specific solutions. Furthermore, abduction-2 inferencing was used by nondesigners, which was less anticipated because inferencing is typically attributed to designers.

How stakeholders developed ideas based on each other's methodological instructions and how this made the solution more concrete and precise are clearly demonstrated in the example of the more potent group (Table 9). The researcher suggested a solution that he explained as being a tool for a social network, using a Star Trek metaphor by referring to The Borg. This is an abstract solution, characterized by a metaphor, yet sufficiently specific, as it is further described as a social network. Next, other suggestions, each using a different metaphor, were used as analogies to highlight different features or aspects of the social network. Thus, the solution became more concrete and specific. The occupational physician suggested a buddy system; the researcher suggested a similar swipe function as in a Tinder app; and the employer and facilitator suggested offering personal suggestions based on an artificial intelligence algorithm. The metaphors that were used seem to have come from popular culture or daily use, which may have made them immediately clear to all stakeholders. As such, the solution-related knowledge of the various stakeholders started on an abstract-specific level and moved toward a more concrete and specific level (Figure 3). Overall, the more potent diverse stakeholder group had a strong influence on the quality of the knowledge output regarding the solution.

Table 9. Example sequence utterances from the more potent diverse stakeholder group in the generative co-design workshop with codes (translated into English for reporting purposes).

Stakeholder and sequence of utterances (order of conversation)	Behavior code	Inference-type code	Knowledge-type code	Repetition code	
Researcher					
	1. You are not as an individual… because in such a game you are addressed as an individual, so how do we keep the social element and your environment? As an image I have The Borg[a], that's from Star Trek, and you are being assimilated in a very large network of other individuals.	Introduce	Abduction-2	Methodological instruction	From interview
Game developer and designer					
	2. I didn't know you were a Trekkie.	Joke	—[b]	—	—
Researcher					
	3. Wait until you see my costume, ha-ha.	Laugh	—	—	—
Occupational physician					

Stakeholder and sequence of utterances (order of conversation)	Behavior code	Inference-type code	Knowledge-type code	Repetition code	
	4. I am thinking about a sort of buddy system[c], rather than peers with similar experience, use buddy's to play together.	Introduce	Abduction-2	Methodological instruction	—
Researcher					
	5. Yes, and maybe we can therefore also connect that with a Tinder app[d], because which buddy would you like?	Introduce	Abduction-2	Methodological instruction	—
Occupational physician					
	6. Ha-ha.	Laugh	—	—	—
Employer and facilitator					
	7. And, there, the artificial intelligence rises to the surface again? So that you can see on the basis of your use of the game with who you have the best connection[e]?	Introduce	Deduction and abduction-2	Methodological instruction	—
Occupational physician					
	8. Exactly.	Agree	—	—	—
Employer and facilitator					
	9. That you are not only swiping, but also get a suggestion, like Hi, this person could fit with you.	Explain	—	—	—

[a]First visual image.
[b]Not available.
[c]Second visual image.
[d]Third visual image.
[e]Fourth visual image.

The interaction in the less potent group was more on the level of sharing relevant statements about a solution, for example, improving the skills of people with cancer (Table 10). They did not discuss in more detail how skills training could be implemented with, for instance, visual images (abduction-2). Therefore, the solutions did not change from abstract to concrete; instead, they remained relatively the same at a concrete level.

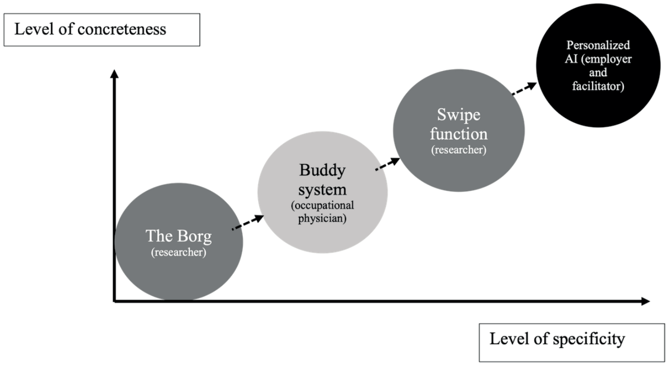

Figure 3. Visualization of iteration of solutions (bubbles) suggested by different stakeholders in terms of specificity and concreteness (different shading for each stakeholder). AI: artificial intelligence.

Table 10. Example sequence utterances from the less potent diverse stakeholder group in the generative co-design workshop with codes (translated into English for reporting purposes).

Stakeholder and sequence of utterances (order of conversation)	Behavior code	Inference-type code	Knowledge-type code	Repetition code	
Employer network					
	1. I am still thinking about an approach including skills, how that would enable people. I put it left under (in Miro), I lost it…	Introduce	Abduction-1	Methodological instruction and relevant statement	From interview
Network coordinator and cancer survivor					
	2. No, but skills are really important. Here, you have to do something completely different, and you are looking at work differently.	Agree and add	—[a]	Relevant statement	—
Ecosystem expert					
	3. But I think that next to the work environment also, if you assume that that was the work environment where you were, the other one could then call a different work environment. Then those skills arise again, because you can perhaps get the possibilities to develop yourself differently.	Add	Deduction	—	—
Employer network					
	4. Yes, and when one conquers cancer, for example you have certain perseverance, that you are resilient. And when you focus on that, your employer can you help you realise this.	Add	Conclude	Relevant statement	—

[a]Not available.

DISCUSSION

Principal Findings

This study aimed to answer the following research question: *Do stakeholders with diverse knowledge and diverse ways of thinking improve the GCD process for digital health?* As a first step in attempting to answer this research question, we assessed how a diverse stakeholder group, put together using the proposed stakeholder group assembly procedure, would influence the GCD process. We also established a second stakeholder group consisting of individuals who scored less well in the preliminary interviews held to assess the required competencies.

Our preliminary findings confirm Sanders and Stappers' main hypothesis that a group of stakeholders with diverse knowledge and ways of thinking has a positive influence on GCD. The more potent of the 2 diverse stakeholder groups had a relatively larger influence on the GCD workshop process and output. The stakeholders in the more potent group built more on each other's knowledge, which led to a more comprehensive problem definition and more precisely described solutions. In the problem phase, the stakeholders in the more potent group shared a greater diversity of relevant statements (14 vs 10), which were processed using more induction (10 vs 0) and deduction inferences (9 vs 4) than the ones in the less potent diverse stakeholder group. Furthermore, the stakeholders in the first group built on each other's relevant statements, some of which had already been mentioned in the interviews before the workshop. This resulted through a dual movement toward a more comprehensive problem definition. In the solution phase, the more potent group of diverse stakeholders used more abduction-2 inferences (13 vs 0), which led to a greater variety of methodological instructions (24 vs 8) than those observed in the less potent group. In addition, similar to what the stakeholders did in the problem phase, the more potent diverse stakeholder groups developed each other's methodological instructions in the solution phase. This resulted in solutions that were developed from a more abstract and general level toward a more concrete and specific level.

The other 2 subhypotheses were not supported. First, there was no substantial difference between the 2 groups in terms of explicitly sharing deeper-lying knowledge (contextual certainties). One contextual certainty was used implicitly in the more potent group. Second, abduction-2 inferences were used 13 times by nondesigners in the more potent group but not by the game designer in the more potent group. This result was contrary to our expectations.

Using a person's professional background as the sole criterion for group member selection as, for example, done by Trischler et al [44], may not deliver the full potential of a GCD session. Rather, it is the combination of stakeholders with diverse and complementary knowledge in terms of 3 knowledge types (relevant statements, methodological instructions, and contextual certainties) and the most diverse and complementary inference experience in terms of 4 complementary inference skills (deduction, induction, abduction-1, and abduction-2) that enhances the GCD process and its output. Moreover, abduction-2 inferencing did not occur spontaneously in our study in the less potent diverse stakeholder group. Therefore, the involvement of at least one stakeholder with abduction-2 experience (not limited to professional designers) could be critical when using GCD in hierarchical hospital settings [25], with stakeholders who are not naturally involved in creative activities.

Furthermore, the speed brought about by the dual movement of divergence and convergence [45] in the problem phase could be due to the diversity of knowledge and thinking among the stakeholders, as each one has the potential to convergence or diverge. Here, each has knowledge that others lack and cannot think in ways that others can. In the problem phase, the example provided was about an idea that was rapidly considered from a patient experience and from the employer and technical development perspectives. This led to reformulations and the raising of new questions, which steered the process in a new direction. This could be viewed as a change of frame, or perspective, brought about through the interaction of different stakeholders. Although there is extensive literature on the framing process [46-49], the interactions of diverse stakeholders in the framing process have not yet been explicitly described. The example we provided in the solution phase suggests that framing involving diverse stakeholders can be viewed as a knowledge process that looks for a solution from different knowledge contexts that provide different perspectives when looking at a possible solution. During this process, we observed an implicit negotiation process, which has been mentioned by other researchers [47,50], in the sense that the stakeholders' responses to the proposed solutions varied. On some occasions, stakeholders laughed, which may signify acceptance of a solution. This was surprising and unexpected given that it did not relate to their own knowledge context. As such, a stakeholder group with diverse knowledge and ways of thinking may be the most effective when it can reframe ideas rapidly.

The framing process may be accelerated when stakeholders share more contextual certainties. However, we observed only 1 event in the problem phase that demonstrated how a contextual certainty can rapidly bring a new perspective to a discussion; in this case, a didactic perspective that is essential when developing serious games [51,52]. This emphasizes the need to share deeper-lying knowledge in the GCD process [10] and the need to explicate how they are used by different stakeholders in design theory more broadly [53]. The limited expression of contextual certainties in our study may be due to the lack of priming exercises [8] ahead of our workshops, coupled with the time pressure and workload of participants. This may have suppressed the participants' awareness of deeper-lying ideas. This suggests that there may be a minimum critical time before people can share such deeper-lying knowledge that our workshops failed to exceed.

Implications

Finally, we reflect on our stakeholder group assembly procedure in light of the normative values present in the GCD that originate in the PD field [10]. In PD, broadly defined values are upheld such as democracy, equalized power relations, mutual learning, and situation-based actions [16,19]. Given the lack of theoretical consensus, there are no solid normative grounds on which to judge our stakeholder selection procedure. For instance, the democratic principle might imply that one should involve people who are affected by the design decisions made or the end product [19]. In addition, it is emphasized that power relations should be equalized by giving voice to those who may be invisible or weaker [16]. In terms of digital health, this could imply that patients and informal caregivers should be involved. As it is often difficult to get involved in a health care setting [21], we considered the use of a snowball sampling method. This is potentially more inclusive and faster than a widely advertised recruitment strategy that may not attract susceptible groups. As such, in the protocol, we tried to cast a wide net of possible participants through snowball sampling to include people and other vulnerable populations. However, to participate in and contribute to the GCD process, individuals should be able to bring new or complementary knowledge and inferencing experience to the stakeholder group. On the basis that they lacked these assets, we did not include cancer survivors in the more potent diverse stakeholder group, even though they were in a susceptible position. Furthermore, it is argued that democracy requires educated and engaged people acting in their own interests and in the interest of the common good [54,55]. Kensing and Greenbaum [55] state that, when necessary, this should involve educating people in terms of the required technical jargon and engaging them in the process, an aspect related to the principle of mutual learning [16,19,55]. In this respect, Kleinsmann argues that in collaborative activities, there should be minimal shared understanding [56]. In our protocol, we tried to ensure this by looking for people with a basic interest in the topic through snowball sampling and then using self-assessment to evaluate group communication abilities. In this sense, we believe that the stakeholder group assembly procedure that we used can serve as an example of how these values can be respected while improving the GCD process and output.

Limitations

The designed stakeholder group assembly procedure was operationalized in a minimally viable form to meet the aim and scope of this study. Although the assessment process was intended to accurately score the knowledge, inference skills, and communication skills of potential group members, there may be a built-in bias in the questions. Although we attempted to limit this by discussing the formation of the groups within the research team, there may still be some errors in allocating individuals to one of the 2 groups.

Indeed, not all the criteria were sufficiently sensitive to differentiate between the experiences of some stakeholders to ensure robust selection. For instance, all the stakeholders scored similarly on the criteria addressing induction and deduction inference types and communication abilities. This could be due to the snowball sampling that preselected stakeholders who were already part of The Foundation's network with a certain level of educational training and communication abilities. Even though all the stakeholders showed a similar ability to use induction and deduction inference types in their interviews, the stakeholders in the less potent group used these less often during their workshop, which affected their knowledge output and knowledge processing. It is possible that the stakeholders in this group were less inclined to use these inference types because of a lack of interaction.

The case was selected based on the background of the lead researcher and the fact that it was a project that had momentum, was about to start, and had good potential to involve various stakeholders. However, the selected case also raised concerns, as it took longer than expected to gain approval to start the stakeholder selection procedure from the project manager. One reason for this could be that GCD is often used as an informal design practice rather than as a formal scientific approach with formal stakeholder selection.

We would caution readers against drawing any causal relationships based on our study about the influence of the stakeholder groups on the GCD process. To maintain focus in our analysis, back-and-forth interactions between the problem and solution phases, which might occur when addressing a real issue, were not considered. Furthermore, given the exploratory purpose of this study, various variables were ignored, including content-related facilitation, interpersonal relationships [57], the creative environment [58], mutual learning over time, and the higher-level strategy of the project and host organization [56,59]. Nevertheless, even without these aspects, this study was still able to provide initial insights into the role of stakeholder diversity in GCD. To ensure this, reflection meetings were organized between the lead researcher and coauthors to identify and avoid any potential biases in the study design and interpretation of the results.

Further Research

We would recommend further exploring how to strike a balance between the time and resources spent on snowball sampling and the number of stakeholder assessment criteria (knowledge, inference experience, and communication abilities) used. One option would be to ignore induction and deduction and focus on abduction-1 and abduction-2 inference experiences. One could also ignore communication abilities if the organization under consideration is a hospital that already requires interdisciplinary collaboration and focus instead on visual communication skills and open-mindedness as an indication of creative thinking. Next, to further assess the influence of the selected stakeholders on the knowledge processing component, the role of metaphors (in abduction-2 inferencing) and contextual certainties could be explored. For instance, one could link the dual-processing theory of reasoning, which involves deeper unconscious knowledge processing based on intuition and experience, and the more conscious deliberated processing with different knowledge and inference types [60]. Finally, the knowledge processing and knowledge output could, over time, be further assessed in the GCD process, in which the expression of contextual certainties is considered alongside stakeholders' learning processes.

Conclusions

A procedure to assess the diversity of knowledge, diversity of ways of thinking, and communication skills in assembling a stakeholder group that meets specific criteria may improve the potential of the GCD process and the resulting digital health. We would encourage the validation of our preliminary findings. Ultimately, this will help researchers make methodologically more robust decisions about stakeholder involvement and report them in an appropriate way, which will improve the scientific rigor of GCD science for digital health.

CONFLICTS OF INTEREST

None declared.

Abbreviations

GCD

generative co-design

PD

participatory design

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CHAPTER 7

Conclusions and discussion

1. INTRODUCTION

Digital health has proven itself essential in rapidly transforming care since the onset of the Covid-19 pandemic but has had a troublesome history as evidence for the long-term benefits are lacking. Generative co-design (GCD) has been put forward as a promising method to improve digital health by including both designers and non-designers as stakeholders. As GCD is an iterative, front-end creative process in which stakeholders actively participate, it is expected that the resulting digital health will better cater for the needs of the stakeholders.

Even though stakeholders play an important role in developing better digital health in GCD, their role remains unclear. Design researchers have claimed that designers have a distinct way of thinking, such as abductive-2 reasoning [3]. GCD researchers [1,2] have hypothesized that stakeholders with diverse knowledge and diverse ways of thinking can improve the GCD process. In addition, there is also a strong role for the deep-lying knowledge of stakeholders in the GCD process [1,2]. However, it remains unclear what precisely these hypotheses are claiming. In addition, they are not embedded in a coherent theory.

In this thesis, I set out to define the role of stakeholders more clearly and to develop a GCD stakeholder theory. The hope is that this theoretical foundation can eventually serve to further develop a GCD methodology for stakeholder involvement. This chapter answers the research questions, provides reflections, and offers suggestions for future research.

2. MAIN FINDINGS

A *research through design* approach was followed to answer the research questions [4]. Below, the main findings are presented related to the research questions in each phase of the GCD approach.

2.1. PART I: Exploration phase

In the exploration phase, we attempted to find out how stakeholders were involved in the use of GCD to develop digital health in reports in scientific publications (Chapter 2) and by reviewing how stakeholders were involved in GCD practice (Chapters 3 and 4). We found that even though the decisions to involve certain stakeholders in a GCD process are among the first choices to be made, the underlying reasons for identifying and selecting stakeholders were mostly not provided or not well founded.

We identified recruitment approaches through a systematic literature review (Chapter 2). The most often reported recruitment strategy in the reviewed studies was purposive or convenience sampling in combination with snowball sampling. When adopting these recruitment approaches, five studies also aimed for diversity. However, it was not clear what diversity precisely meant, or why it was considered important in those studies. As such, the underlying assumptions behind the recruitment approaches were either unreported or not fully explained.

By studying GCD inpractice in three case studies on AYA care (Chapter 3), we uncovered some potentially underlying reasons for using snowball sampling. Snowball sampling strategies helped to identify people who were affected by the problem or engaged in improving the care process. For instance, motivated patients were found at a patient conference, and a designer through the network of other stakeholders. Further, during the GCD process itself, there was no formally identified and stable stakeholder group. Rather, through the network of stakeholders already involved in the project, other stakeholders were invited to join. This suggests that there was an ongoing process of stakeholder recruitment during the GCD process. Therefore, the underlying reason why a snowball strategy was used seemed to be that it allows one to continuously recruit stakeholders who are engaged and have relevant knowledge. This explains why, in the case studies reported in Chapters 2 and 3, after snowball sampling, no further stakeholder selection was made on a more granular basis.

The stakeholders who were involved in the case studies in Chapter 2 and Chapter 3 had a range of backgrounds. However, in the research for these chapters, no explicit reasons were given to justify why a particular mix of stakeholders was considered an appropriate stakeholder group. In Chapter 2, we saw that all the studies involved the intended users, in the form of patients, care professionals, or both. Out of 63 studies a designer was involved in nine studies but only a few studies involved a software developer or a researcher, and only once was a business analyst involved. No studies involved stakeholders with wider hospital management, logistics, or infrastructural expertise, which would be relevant skills for in-hospital implementation. Even though, in each case, particular stakeholders were involved, while others were not, there were no reasons given to justify involvement in the GCD process. Where a justification was offered, this mostly concerned only specific individual stakeholders. For example, a patient or content expert was involved because of their experience and age, while it was unclear why other stakeholders were involved.

We found potentially underlying reasons that could have been used to justify the involvement of certain stakeholders in a stakeholder group when adopting GCD practices. Often, each stakeholder seemed to have different knowledge to contribute, which the others were lacking. For example, in Chapter 3, the AYA patients shared their experiences and care providers talked about the research. The designer helped to visualize the information in a visual roadmap that highlighted the information they shared, and also raised new questions that led to a new shared way of looking at the problem and the solution. All the stakeholders contributed to the process and together they generated new knowledge and questions, which aided the GCD process. Similarly, in Chapter 4, the care professionals, the patients, the IT and legal department all provided different perspectives on the problems and possible solutions. When pulling together the information from all stakeholders, it appeared that some key issues, which none of them had explicitly mentioned, were missing. For instance, the care professionals and patients would have benefited from a virtual waiting room with a virtual assistant to provide structure and ease to the video consultation workflow.

Turning specifically to the involvement of designers, which was unclear in Chapter 2, we identified in Chapters 3 and 4 some underlying reasons why designers could be involved. The involvement of designers with design tools seemed to reveal deeper-lying knowledge. For instance, a designer who facilitated the roadmap process (Chapter 3) generated new questions about the needs of patients. Even using a patient journey map without a designer (Chapter 4), helped to map the inputs of the different stakeholders and made the deeper needs of various stakeholders in a care path more explicit. This shows that a designer using design tools in the GCD process can expose deeper-lying knowledge and that design tools, even without a designer's direct input, can offer significant advantages over more traditional research methods.

The decisions made to involve particular stakeholders also depend on the phase of the project. In Chapter 3 we found that the involvement of people with either business startup or research expertise are crucial to move from the design phase towards a successful implementation in a hospital. For instance, in one project, we saw that there were significant delays due to the lack of a stakeholder with business expertise. In addition, the approach adopted towards communication about the GCD project needs to be carefully considered in advance given that care professionals and businesspeople on the board of directors of a hospital have different evidence requirements. As such, a single, narrow snowball sampling strategy that seeks to recruit care professionals or patients is insufficient to identify people with all the relevant knowledge background.

PROBLEM DEFINITION: *The decisions concerning stakeholder involvement are the first choices to be made in the GCD process, and these can have a significant impact on the GCD process.* However, t*here is a lack of clarity about the justification used to involve stakeholders in GCD research and GCD practice to develop digital health. For instance, it is not clear how stakeholders are recruited and why stakeholders are involved, or why business managers and designers or design tools have a strong impact on the GCD process. Consequently, there is a need to develop a theory to help understand the roles of stakeholders in GCD.*

2.2. PART II: Creation phase

Based on the insights from the exploration phase, we developed a GCD stakeholder theory (Chapter 5). The isolated hypotheses about stakeholders (Chapter 1) were embedded and justified in this GCD stakeholder theory. These key hypotheses are about diverse ways of thinking, diverse knowledge, deeper knowledge in GCD, and the special role of designers.

We described the interaction of stakeholders in GCD as a dynamic process whereby stakeholders use four types of thinking (inferences) to process three types of knowledge (including deeper knowledge), and so generate new knowledge. A combination of stakeholders with specific inferencing experiences and specific knowledge backgrounds can be justified on the grounds that they each add to the dynamic of other stakeholders. On this basis, GCD researchers can justify why a certain group of stakeholders should be involved in GCD, and how this will improve the GCD process and lead to better digital health.

The involvement of stakeholders with diverse ways of thinking can be described and justified based on the four inference types. These inference types had already have been introduced in design theory through the work of the philosopher Charles Peirce [5]. *Induction* is used when a stakeholder generalizes knowledge shared in the GCD process. *Deduction* is used when a stakeholder draws a conclusion from knowledge shared in the GCD process. *Abduction-1* is used when a stakeholder proposes a new explanation. *Abduction-2* occurs when a stakeholder proposes a new idea. This inference type is typically attributed to designers.

Contrary to how inferences are traditionally categorized in this way, we claim that all inferences can have multiple functions and that they can play important roles when used by designers and non-designers. That is, the complexity of these inferences can depend on the length and depth of the interaction among stakeholders, which can lead to various outputs. Deduction will not always lead to a factual summary of previous facts, as is classically believed. Since stakeholders look at 'the facts' from different perspectives through the creative exercises in a GCD process, this leads to a whole new way of viewing the facts. For instance, when a non-designer such as a care professional uses deduction to combine knowledge from other stakeholders such as patients or IT professionals, they could change their perception of the problem and their thinking about the problem and the solution. As such, deduction can sometimes provide a similar output as abduction-2 in the form of a new idea.

The involvement of stakeholders with diverse knowledge can be described and justified in terms of three knowledge types: contextual certainties, relevant statements and methodological instructions, and. First, contextual certainties determine the meaning of the problem and can be viewed as deeper-lying theories that play a background role. These are considered to be always valid as the truth of these statements is not in question in relation to the problem as they are often abstract core philosophical beliefs about the world. This is the most fundamental basis on how one looks at a problem or a solution, and are often not part of daily discussions about problems or solutions. In this way, contextual certainties, as a type of knowledge, describe how tacit and latent knowledge more precisely function in GCD, and highlight the potentially important role of deeper knowledge as hypothesized by Sanders and Stappers [1]. Since contextual certainties can also influence the use of abduction-2, the use of different contextual certainties by different stakeholders can influence the GCD process. Relevant statements also impose conditions on the solution but do not determine the possible solutions to a problem. Finally, methodological instructions are sets of do's and don'ts to come to a solution.

The special role attributed to designers in design research due to their use of abduction-2 reasoning [3,6] can be more fully described in terms of these inferences and knowledge types. Abduction-2 can be used as primitive heuristics, e.g., drawing analogies, and derived heuristics, e.g., reframing the problem. Therefore, we further refine the claim that specific forms of abduction-2 (e.g., derived heuristics) can be typically attributed to designers by adding that they can, in theory, also be used by non-designers in GCD. However, this does not refute the claim that designers, as stakeholders, have a unique role to play in GCD compared to other stakeholders. On the contrary, as already highlighted above in the Exploration Phase, designers bring a range of relevant statements based on their design experience and they are more skilled than other stakeholders at visual communication and in the use of some forms of abduction-2 inferencing such as derived heuristics.

In this way, the proposed GCD stakeholder theory clarifies what the initially stated hypotheses refer to, what their functions are, and how they can be used to justify the involvement of stakeholders in a GCD process. Assembling a particular stakeholder group, with complementary knowledge backgrounds and inference skills, can significantly influence the GCD process. For instance, the theory highlights the role of contextual certainties (deeper knowledge). A range of contextual certainties can be expected in a stakeholder group that involves stakeholders with different knowledge backgrounds. Stakeholders who are able to use abduction-2 inferencing, can use these contextual certainties to suggest a new way of looking at a problem or a solution, and this can significantly change the course of the GCD process.

PROTOTYPE: We describe the interaction of stakeholders in GCD as a dynamic process whereby stakeholders use four types of thinking (inferences) to process three types of knowledge (including deeper knowledge), which generates new knowledge. A combination of stakeholders with specific inference experiences and specific knowledge backgrounds can be justified on the grounds that they each add to the dynamic with the other stakeholders.

2.3. PART III: Testing phase

In the testing phase (Chapter 6), the aim was to test the key hypotheses included in the GCD stakeholder theory (Chapter 5). The main hypothesis was that a stakeholder group containing stakeholders with diverse knowledge and ways of thinking would improve the GCD process. We used a stakeholder group assembly procedure to form two distinct groups based on the different types of knowledge and inference types specified in Chapter 5. We compared these two groups and assessed their influences on the GCD process. We adopted a case study approach for this assessment of an organization (The Foundation) that was about to develop a serious game to help get cancer patients back into work. Here, the stakeholder group assembly procedure provided a more solid methodological approach for selecting various potential stakeholders who could be involved in the project.

The procedure consisted of three steps. First, a snowball strategy identified potential stakeholders, then qualitative interviews assessed each stakeholder separately, and finally two stakeholder groups were assembled. Through the snowball strategy, thirteen people were identified through The Foundation's network. Each person was interviewed separately and then qualitatively scored according to three criteria: background knowledge diversity, inference experience, and confidence in group communication. The highest scoring individuals were assembled in one group, which was assumed to be a more potent and diverse stakeholder group. The other individuals formed a second group, which was assumed to be less potent, to see if the outputs of the two groups differed as anticipated.

We hypothesized that the more potent stakeholder group, with more comprehensive diverse knowledge across the three knowledge types and more experience with all four inference types, would have a greater potential to influence the GCD process. This hypothesis was confirmed. The more potent diverse group had a stronger influence on the knowledge output and knowledge processing, which resulted in a more comprehensive problem definition and more precisely described solutions. Stakeholders in the higher performing group more often processed relevant statements, which increased the knowledge about the problem. For instance, the relevant statements shared by the employer, the patient, the employer/facilitator, and the game developer were frequently processed as a sequence of interactions, which helped to define the problem. In addition, various non-designer stakeholders from the high performing group often used abduction-2 inferencing, which enhanced the development of a greater range of visually described solutions. This confirmed the hypothesis that abduction-2, when used by non-designer stakeholders, can play an important role in the GCD process. Further, in the less potent stakeholder group, none of the stakeholders had abduction-2 experience, and this inference type was not used during the GCD workshop. As such, it seems that this type of reasoning does not spontaneously arise in a GCD workshop. This suggests that there is a need to include at least one stakeholder with previous experience of abduction-2 inferencing, which is not easily found in a medical hospital setting. Deepening the understanding of how abduction-2 inferencing is used by designers and non-designers as patients and care professionals will help to address this challenge to developing digital health.

TEST: The hypothesis on the positive influence of a diverse stakeholder group on the GCD process was confirmed. The stakeholder group assembly procedure whereby criteria established in Chapter 5 were used to assess diversity of knowledge and diversity of thinking enabled us to assemble a more diverse stakeholder group that had a greater influence on the GCD process than a less potent stakeholder group.

3. DISCUSSION

Here, we will first reflect on how this thesis can be positioned in the overarching discussion concerning cross-disciplinarity. Following this, we will discuss the main findings.

3.1 Reflection on cross-disciplinarity

In two ways, cross-disciplinarity, as the collaboration of people from different backgrounds, is the abstract overarching theme of this thesis. First, in the *research through design* process, I collaborated with people from different disciplines and, second, the topic of my research concerned collaboration among people with different backgrounds.

Here I reflect on the lessons learnt from this thesis's research process regarding cross-disciplinarity and, in a more abstract way, on the main findings regarding the interaction of different stakeholders. Here, the definitions of cross-disciplinary activities proposed by Eigenbode et al. [7] are adopted. They describe a continuum of cross-disciplinary interaction that are typically classified as follows: multidisciplinary activities that involve insights from different disciplines while the focus lies on addressing a question or problem in a single system. Interdisciplinary collaboration requires considerable coordination so that methods and analytical approaches can be combined, which can then lead to new questions and new methodologies. Transdisciplinary approaches are uniquely formulated and are not tied to existing disciplinary domains. As such, multidisciplinary activities sit towards one end of the continuum, with less interaction, and transdisciplinary activities at the other end with more interaction.

3.1.1. Cross-disciplinary process

In tackling the research questions, we critically analyzed and integrated concepts from design, from health sciences, and from philosophy. Based on the definitions of Eigenbrode et al. [7], I started with a multidisciplinary approach in which I used design science to answer research questions regarding digital health in health sciences in Part I. In Part II, I took an interdisciplinary approach, in which the philosophy of scientific discovery gave rise to new questions related to design and digital health such as questions about the knowledge and inference interactions between stakeholders. As the primary audience for the intended theory was GCD researchers, I did not attempt to surmount the design field itself. However, I did try to extend all three fields in Part III. I used a hybrid evaluative study design by operationalizing the stakeholder group assembly procedure and testing this with a qualitative comparative analysis. This could perhaps be seen as an example of transdisciplinary research on stakeholder involvement when using GCD for digital health.

During the research process, I experienced the same challenges that Eigenbrode et al. [7] highlighted: finding the appropriate level of integration, linguistic divides, validation of evidence, societal context of the research, perceived nature of the world, and reductionistic versus holistic science. I concur with Eigenbrode et al. that these challenges fundamentally arise out of conflicting assumptions about the nature of the world [8], the development of knowledge, and the role of values in the scientific process.

We drew lessons on cross-disciplinary collaboration from a historical debate in the philosophy of science field initiated by Feyerabend and by Kuhn about whether it is even possible to communicate effectively in science [9]. Following Kuhn, when working with concepts from different disciplines, one should be aware that they could require translation. Reflecting on my cross-disciplinary process, I found that considerable 'translation' work is needed if design researchers, philosophers, and health services researchers are to benefit from insights from each other's disciplines. In the long-term, this would require a space where transdisciplinary research about stakeholder research is promoted so that cross-disciplinary collaborations can flourish.

To ensure effective communication to enable a fruitful collaboration, we continuously employed a philosophical analysis to identify the conceptual roots of the cross-disciplinary challenges. We used explication (see Introduction) through which we drew out the underlying assumptions of each discipline, and made the assumptions that researchers make about the discipline more explicit. For instance, in Part II, we understood that key terms used in philosophy of science, such as logic and epistemology, would be received as controversial or would be confusing for design researchers. Even though key terms from the philosophy of science were already being used by several authors in design research [3,6,10–12], we expected that there could be resistance to terms related to logic or logical proofs, which could be interpreted as an overly mechanical approach to the intuitive design process. In addition, terms such as logic and epistemology were defined differently in design research publications than in philosophy of science publications. From a philosophy of science perspective, one could consider the process through which stakeholders develop knowledge together as an epistemological issue whereas, in design research, the knowledge questions often seem related to the knowledge a designer uses in a design process. As such, epistemological questions in the field of design seemed to be restricted to design epistemology in the strictest sense. In design research, the term logic often refers to a specific type of simple formal logic, perceived as a rational process. However, in the philosophy of science and logic, various types of much more complex and relevant logics have been described, such as paraconsistent logic and, specifically, adaptive logic [13–15]. On this basis, we concluded that design researchers use a narrow definition of logic, and one which we found too narrow to describe the complex GCD process with its rational and intuitive dynamics. Design researchers therefore seemed to be missing out on insights from a large field of research that occupies itself with the logic of creative processes and could be relevant to GCD [16].

3.1.2. GCD stakeholder interaction: implications for cross-disciplinary research

In cross-disciplinary research, the most intense form of collaboration between researchers from different disciplines is traditionally termed transdisciplinary collaboration [7]. A transdisciplinary collaboration, according to Eigenbrode et al., occurs "when the collaborators accept and adopt epistemological perspectives unique to the collaborative effort and distinct from those of any of the cooperating disciplines." Considering the interaction of stakeholders in GCD, the aim of GCD is to help express the deep-lying knowledge, which involves what Eigenbrode et al. label epistemological perspectives about the nature of the world, the development of knowledge, and the role of values in the scientific process. In Chapter 5, we observed that contextual certainties play a crucial role in the use of abduction-2 inferencing, which can strongly steer the GCD process. Therefore, an aim should be to promote transdisciplinary interaction among stakeholders in a GCD process. However, these interactions can also be monodisciplinary, multidisciplinary, and interdisciplinary.

Further, there are various other kinds of deep-lying knowledge which GCD aims to use and develop that are not explicitly mentioned in the definition of transdisciplinary collaboration. For instance, deep-lying knowledge, which does not necessarily have a traditional-rational origin as is often assumed in a scientific process, could include knowledge from other origins concerning practical procedures, sensory knowledge, knowledge from dreams or memories [1]. The interactions of these different types of knowledge have been proposed as part of social creativity [1,17–19]. Increasingly in the field of creativity research, more attention is being given to the process of collaboration between different stakeholders. Psychology researchers are also increasingly focusing on the collaborative aspects of creativity [17,18]. For instance, Okaka and Simon further developed a theory on the psychology of scientific discovery; where they claim that paired discovery is better than single discovery [20]. In this respect, the philosophy of scientific discovery had previously focused heavily on discoveries by individuals rather than collaborative discoveries [16,21,22]. Here, the developing areas in the philosophy of scientific discovery, about inferences [23,24] and imaginative processes [25], could increase interest in the creative collaboration between different people.

Finally, considering that, in science, the collaboration between scientists from different disciplines, genders, and backgrounds is increasingly stimulated [26–29], perhaps more attention should be given to the theoretical and practical challenges of involving diverse stakeholders, including researchers, in a GCD process. This will help us understand when certain types of collaboration are needed, and how intense the interaction between diverse people should be for a specific GCD project.

3.2 Reflection on the main findings:

3.2.1. Differences between health and design research

An early finding was that there was a lack of explicitly justified recruitment strategies and stakeholder group assembly procedures described in GCD research publications (Chapter 2) and employed in GCD practice (Chapter 3). This is perhaps not that surprising given the differences in the scientific cultures of health researchers and design researchers. Health researchers expect stakeholder involvement to be transparently reported and justified by referring to a validated method that justifies how stakeholders were found and how they were selected. For example, in randomized controlled trials (RCTs), considered the gold standard for evaluating effectiveness and safety of healthcare interventions, there is a standardized methodology: patients should adequately represent the target population, and there are reporting standards about how patients are recruited and who participates [30]. More generally in quantitative research, and often adopted in health research, one refers to the representativeness of the subjects using statistical terms. However, when considering GCD as a qualitative research approach, the representativeness of the stakeholders would be addressed differently in terms of data triangulation or member checks [31]. Therefore, from a quantitative methods perspective, it is understandable that justifying the representativeness of the stakeholder selection method is less of a focus in GCD research. However, this does not mean, from a qualitative methods perspective, that one should only address stakeholder involvement implicitly in GCD. In our proposed GCD stakeholder theory, we explain how different stakeholders can influence the GCD process, which makes it relevant to justify and evaluate why a stakeholder group and its individual members were involved.

Next, the distinct ways to validate findings in health research and in design research form another hurdle when communicating progress with a GCD project (Chapter 3). To convey our findings to both health and design researchers and to care managers we used a hybrid study design in Chapter 5. We iterated and implemented the GCD theory in an operationalized procedure as part of a GCD process, which is often reported in terms of a case study in design research. To test it, we used a form of comparative evaluation, which is more common in health research. In this way, we tried to combine the evaluative perspectives of both design research and health researchers.

However, one could also consider other study designs. For instance, given that the number of stakeholders involved varies over time, other study designs could be used to evaluate the design output at different points along the process according to the stakeholders involved [32,33]. In addition, increasingly other forms of evidence are being considered apart from RCTs and systematic literature reviews, and the need for design research is increasingly recognized [34–39]. To understand better how the stakeholder selection affects the underlying mechanism of a design process one could use realist evaluations, which are more fequently being used in healthcare research [40,41].

More broadly, the value of GCD can be seen differently by health researchers and design researchers. Design researchers have highlighted that these different perspectives can make it more challenging to employ co-design approaches in a hospital setting [42–44]. For instance, Pirinen found that hospital staff consider design as something related to superficial decoration, while designers doubt the ability of patients to provide useful input [43]. Further, in line with what Pirinen [43] found, it seems that care professionals are used to receiving finished products and they find the process of open solution development uncomfortable. This could explain why it is challenging to find a variety of motivated stakeholders in a hospital setting to use GCD in an early phase of the digital health development process. For instance, when care managers view Covid-19 as an operational problem since patients cannot visit the hospital, decisions are made to implement video consultation software already available on the non-healthcare-specific market (Chapter 4). However, simply implementing a finished solution avoids the initial question of what the problem is precisely. Consequently, the imposed solution did not address the various needs of the different stakeholders related to video consultation software. In a different approach, GCD researchers would instead depart from a problem-in-practice, where there are diverse stakeholders with underlying needs. This is what design researchers have called a phenomenological process [45–47]. Therefore, if the implementation process for digital health is considered differently by health care professionals and by designers, we would recommend that it is ensured that their expectations are aligned.

Finally, given the differences between health research and design research, it is not always evident to health researchers why designers should be involved in a GCD project, and for designers why stakeholders, beyond immediate ‘users’, such as patients and care professionals, should be involved in a GCD project [43,48]. However, a designer with design tools (Chapter 3) (or even just design tools (Chapter 4)) can help non-designers with healthcare backgrounds to express their deeper knowledge. Helping to express this deeper knowledge could also help soften underlying tensions or conflicts. Designers and healthcare stakeholders are not always aware of the tensions and often conflicting interests between healthcare stakeholders [49]. For instance, a patient may want to feel more involved whereas a care professional may want to protect patients by involving them less explicitly. Another example would be a care professional wanting to provide the best possible care for each individual patient whereas a care manager wants to control the department budget. Therefore, the involvement of designers with other healthcare stakeholders in a GCD process can benefit all stakeholders by bringing deep-lying knowledge to the fore, leading to better alignment. This is perhaps why in other PD approaches, such as Experience-based co-design (EBCD), there is also a strong emphasis on using design tools. Further, as EBCD has been criticized for not always involving a designer [44,50], it is important to involve a designer or at least someone with abduction-2 experience to fully take advantage of the co-design process (Chapter 6).

3.2.1 Using a situation-based approach as a GCD methodology

The endeavor to develop a GCD stakeholder theory (Chapter 5) within the broader field of design science could be seen as controversial. Design has strong origins in practice and is situation-based [51–53]. Further, in design, one employs intuitive design knowledge [54], which can also include intuitive approaches to involve stakeholders. Therefore, design researchers can be wary of a theoretical technical-rational approach to stakeholder involvement in GCD. Perhaps even more so when one uses the philosophy of science, which can be considered an additional threat to transform the intuitive craft of design into a logical mechanism.

However, I would disagree with the argument that because GCD is situated and intuitive, and therefore does not need an explicit stakeholder process, there is no need to justify stakeholders' involvement and to transparently report on this. In an analogy, scientific experimental research also varies by default, and there are significant struggles to reproduce scientific studies, and, because of this, transparency is seen as an important value in science [55]. A fully fledged GCD methodology could help to explicitly strike a balance between GCD's normative values such as democracy, which would allow many people to be involved, and selecting specific stakeholders. At least it would help researchers reflect more thoroughly on their use of a GCD approach, which for instance refers to values such as democracy, and define more clearly how it is used in their stakeholder group assembly procedure. In this way, a stakeholder group assembly procedure would feel less uncomfortable when it embeds GCD's normative values. Therefore, discussing a stakeholder group assembly procedure alongside GCD's normative values would facilitate transparent scientific reporting including a rational justification for a specific stakeholder group.

In time, a GCD stakeholder methodology would help to explain design processes and help to further build GCD theory based on previous insights about the GCD process. For instance, Dorst found it theoretically challenging to describe and explain why, in a design process, one moves from the solution back to the problem, which Dorst described as non-linear jumps [56]. Dorst claimed that one might interpret this as an emergent process and warned against the misuse of 'emergence' as a process for finding something that already exists. In this sense, I conclude that Dorst suggests that, when we start considering a design process as a passive activity, we fall back on the perspective of intuitive design which, due to its unclear description, seems to be a black box [57]. The complex dynamics in GCD can easily be explained using a general intuition argument. This revamps Rittel's thinking that emphasized the fuzzy or wicked nature of design, one that cannot be described with a rational scientific framework [58,59]. This would deny the need for any further theoretical development towards a more formal GCD methodology. I would see the tendency to explain design processes as intuitive processes without a theoretical justification as intuitive relativism since it reduces complex theoretical questions to a general concept of intuition without providing further explanation. To help avoid intuitive relativism, our GCD stakeholder theory should perhaps be able to theoretically explain the GCD process more clearly. For instance, the solution–problem move could be described as a suggested methodological instruction about a solution in the form of metaphor, which is developed through abduction-2 inferencing involving a contextual certainty and relevant statements. Subsequently, another stakeholder can share other relevant statements and a different contextual certainty to trigger a new metaphor and add a new perspective to the problem.

Finally, GCD, as a field with a situation-based approach and its normative history, will not immediately shift towards a theoretical debate about stakeholder group assembly. To move towards a more theoretical–empirical cycle [51] about stakeholders will probably also require a cultural shift for GCD practitioners and researchers to be more methodologically rigorous in their stakeholder approach. Eventually, this will promote methodological reflection about stakeholder involvement in the design-thinking cycle, both in research [60,61] and in practice [62,63].

4. FURTHER RESEARCH

In this thesis, we have focused our investigation of stakeholder interaction in a GCD process on cognitive knowledge shared between humans during GCD activities. However, there are other types of knowledge beyond cognitive knowledge with different origins such as experiential knowledge and practice-based knowledge, which are also claimed to play a role in the design process [64,65]. This opens the wider debate about what type of knowledge ontologies are relevant in a GCD process. This is important to consider for instance in GCD projects, when considering which stakeholders have appropriate knowledge regarding problems for people with sensory impairments. This raises further questions about the implications for a stakeholder group assembly procedure. For instance, knowledge from deep-lying emotions and memories could be assessed after meditation exercises [66]. Meditative exercises can help a stakeholder experience meta-awareness [67], which can help them express more latent forms of experience.

In addition to human cognitive stakeholder knowledge, one could also explore the use of non-human knowledge in a design process [68]. Increasingly, researchers are focusing on the use of data to support the design process. As Kun [69] proposes, an algorithm could be used during the design process to provide input knowledge, and it can also help to visualize ideas and knowledge during the design process [70,71]. For example, semi-automated systematic literature searches can be carried out using ASReview [72], which could provide up-to-date insights about a problem and potential tested solutions.

Further, in this thesis, we focused on stakeholder interaction during the early development process of digital health. However, stakeholder interaction can be defined in diverse ways which determines the scope of the research [73,74]. Interaction can be a single event (e.g., the development of a prototype) or an ever-present part of all elements of an innovation project and even a cultural change regarding digital health. Beyond the design process, when the market process starts, collaboration still plays a role in value co-creation [75]. In this phase, consumers have an active role and together create value with a business through stages of production and consumption. Further research could explore the roles of stakeholders along the entire design process and how these stakeholders differ from the consumers in the market process. In Chapter 3, through my research, I made the borders of GCD more explicit and recommended also considering the market process as part of the GCD process and therefore involving business-minded people as stakeholders. Further research could help clarify when a crucial turning point occurs: when the early GCD process turns into a startup process in terms of managing a product for the market. In terms of content, both processes can run in parallel since, the earlier one starts using GCD to develop an idea in a better way, the greater the relevance of the resulting value proposition will be on the market.

Related to digital health innovation, further research could clarify what business knowledge would be relevant in the GCD process. For instance, when a product is intended to improve the life of a patient and one first has to go through the national regulatory bodies, one would need someone with expertise on early Health Technology Assessment, which is used to explore the value and cost of a product for different stakeholders such as both patients and funders [76]. When a product will not be reimbursed but sold to care managers or hospitals one would need additional business expertise with broader skills related to marketing and hospital finance.

More broadly, alongside further developing GCD stakeholder theory, one can improve other areas of GCD theory and this would make the stakeholder justification more rounded in a fully-fledged GCD methodology. For instance, one could relate stakeholder theory to a theory on the use of specific tools and outcomes [77]. When reviewing the use of tools and outcomes in GCD research in Chapter 1, we found that the use of tools was much better justified than the outcomes used in GCD research. In design thinking more broadly, it seems that the most popular tools are largely creative exercises that originated from design practice [63,78] although a number of exercises are being continuously developed and experimented with. One large area to further explore would be exercises that can help bring deeper knowledge to the fore. For instance, one could experiment with using philosophy exercises or experience-altering exercises such as meditation, or virtual reality with stakeholders with some experience with these tools who could help facilitate these sessions. Next, the theory concerning outcomes needs to be further developed and related to the stakeholders involved. Here one can draw inspiration from clinical outcomes. However, referring back to the discussion about the tension between health research and design research, one needs to appropriately translate these concepts. New outcomes could be clinical outcomes with a stronger focus on user experience, and more measurable quantitative and qualitative design process measures.

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Epilogue

Looking back on my PhD journey I learned so much more about myself, project management and the fun of science. On a personal level I realized that science is a never ending process, which may well be a metaphor for many activities in our life. Therefore, one of the hardest lessons I learned was how to let go of assumptions, have patience, learn to look at the positive side of hard reviewers. I realized that the speed of my research output is less relevant if the process is not diligently followed. I realized that doing a PhD does not mean being alone in a dark room in front of your PC (all the time). It feels like scientific activities for me are more about the open-minded mindset, which is fundamental to make progress.

I also truly enjoyed helping students going through the process of personal growth and development. Even though teaching students can be challenging given that they are all different young adults with their own busy lives, I believe that it is my mission to help them think about more grand-scale global solutions to the complex problems in healthcare.

I really got a lot of fulfillment when I was helping to improve the care for young adults and adolescents with cancer (AYA) through my research. The biggest physical contribution was the project I did to help to create a space for AYA, who had a family and young children to find peace and enjoy being together in cozy places, which were different from the typical cold hospital setting. In this project I used generative co-design (GCD) to develop the interior of a room at the oncology ward of the University Hospital of Antwerp (Appendix 1). Eventually I hope my focus on the role of stakeholders in GCD has helped to strengthen GCD as a science which will improve the lives of AYA and all other stakeholders.

To further test and evaluate the stakeholder selection procedure (Part III), I am leading an ongoing study where we focus on improving the care for AYA with breast cancer with digital health in the Franciscus & Vlietland hospital in Rotterdam. Next to this ongoing study, I am part of a Convergence flagship called I-Cell. Here I am planning to apply the stakeholder group assembly procedure starting from fundamental science insights.

PhD portfolio

Research

Conference: Global Adolescent and Young Adult Cancer Congress (Atlanta) (2017)		1.00
Basic didactics & course dynamics (2018)		0.80
Erasmus MC - Reviews: project management, other databases and EndNote (2018)	Medical Library	0.20
Erasmus MC - Systematic literature retrieval in Embase (2018)	Medical Library	0.20
Erasmus MC - Systematic literature retrieval in PubMed (2018)	Medical Library	0.40
Co-creation and creativity seminar (2018)		0.20
Conference: Medical Informatics Europe Conference (2018)		1.00
Conference: Global Adolescent and Young Adult Cancer Congress (Sydney) (2018)		1.00
Conference: Space 4 AYA: Nationale AYA 'JONG & Kanker' (2019)		1.00
Conference: Experienced based co-design sharing experiences and co-designing new applications (2019)		0.50
Qualitative interviewing and focus groups (2019)	Evers Consulting	0.20
Qualitative analysis (2019)	Evers Consulting	0.20
Ethical Research Dilemma Game (2019)		0.20
Global Design thinking week (2019)	Hasso Plattner Institute	3.00
Digital Health 2020 (KAUST, Saudi-Arabia) (2020)		1.00
Review JMIR paper 1 (2020)		0.20
Podcast: Co-design Health (2020)		1.00
NRC Live event: Future of healthcare for health professionals (2020)		0.20
Review JMIR paper 2 (2021)		0.20
Member Working group Kom Op Tegen Kanker: AYA care (2021)		2.50
Visual thinking (2021)		0.20
Review BMJ paper (2021)		0.20
Design Thinking Fundamentals (2021)		0.40
Conference: Global Adolescent and Young Adult Cancer Congress (Online) (2021)		1.00
University Teaching Qualification (2021)	RISBO	10.00
Professionalism and integrity in research (2022)		0.40
Academic Visit at Politecnico Milano: Department of Healthcare Design (2022)		10.00
Science Club (2022)		1.00

Teaching

Supervision Bachelor thesis students (2019)		1.50
Supervision Master thesis students (2021)		6.00
Lecturing: Technology & Innovation (2021)		4.00
Tutor: Advanced Research Methods, Technology and Innovation, Critical Studies of Healthcare Innovation Management (2017)		2.50

Total EC		52.20

Summary

Even though digital health, since the Covid-19 pandemic, has proven itself essential in rapidly transforming care, it continues to have a troublesome legacy. In this thesis, we focus on the challenges involving the roles of various stakeholders who are directly and indirectly involved in digital health development.

The World Health Organization promotes digital health, defining it as the development and use of digital technologies such as the Internet of Things, advanced computing, artificial intelligence including machine learning, and robotics to improve health. Digital health is considered to be promising to improve healthcare systems in various ways. This has led to a rush to pluck these technologies from the market and implement them in care practice. However, the evidence is lacking behind the promises and there have even been negative effects reported regarding the implementation of large-scale costly technologies such as electronic medical records. This raises questions about the promised benefits of digital health in healthcare and how it can be implemented so that all stakeholders would benefit.

Researchers have therefore become increasingly interested in involving patients and care professionals in the development of digital health. In the field of human-centered design, Generative co-design (GCD) has been advanced as a promising method to improve digital health by including not only designers but also non-designers as stakeholders. GCD therefore includes stakeholders as patients, care professionals, policymakers, managers, technology developers and many more. Since GCD is an iterative, front-end creative process in which stakeholders actively participate, it is expected that the resulting digital health will cater better for the needs of the various stakeholders. Even though stakeholders play an important role in GCD to develop better digital health, their role remains unclear. In this thesis, we take this first step by exploring the importance of stakeholders' GCD contributions in developing digital health. We wanted to define the role of stakeholders more clearly and develop a GCD stakeholder theory. Establishing such a theoretical foundation could eventually serve to further develop a GCD methodology about stakeholder involvement in GCD activities for digital health. The main research question was:

What is the role of stakeholders in GCD for digital health?

We answered this question in three parts. In PART I, we explored how stakeholders are involved in GCD science and GCD practice to develop digital health. In PART II, we worked towards the development of a theory about the knowledge of stakeholders and ways stakeholders think in GCD. In PART III, we tested key assumptions of this theory to assess how it affects GCD practice aiming to develop digital health. Finally, we discussed the main findings and the implications for GCD research and practice.

Part I: Exploration phase: How are stakeholders involved in GCD to develop digital health?

In the exploration phase, we explored how stakeholders are involved in GCD science and practice. In **Chapter 2**, we wanted to gain an understanding of how stakeholders are involved in GCD science to develop digital health. Through a systematic literature review, 69 studies (of 3131) were selected for qualitative synthesis. We found that the reporting was very variable regarding choices of a recruitment strategy, stakeholder management, tools and outcome measures. Only a few authors explicitly used arguments directly related to participatory design (PD), which are fundamental in GCD, such as democratic, mutual learning, tacit and latent knowledge, and collective creativity. However, regarding stakeholder involvement, most authors did not justify the recruitment of stakeholders and therefore it was unclear why certain stakeholders were involved.

In Chapter 3 and Chapter 4, we reviewed and explored the role of stakeholders in PD practices. In **Chapter 3** we reviewed the PD process in three case studies about food, intimacy and sexuality, and integrative medicine in caring for adolescents and young adults (AYAs) with cancer. Local key stakeholders were recruited with an open mindset to "dream" together about a potential solution. Through this synergy, a shared understanding of the problem and a joint mission emerged to find a solution for the identified problems. Participatory design tools were used to develop a problem definition and designers translated ideas into prototypes. The PD process was prolonged due to the hierarchical hospital environment, business considerations, and additionally required evidence. We concluded that for a PD process to successfully develop care for AYAs, one needs to use designers and skilled people, PD tools, and an open-ended approach to visualize and materialize new forms of care. Furthermore, the recruitment of stakeholders was important to leverage knowledge and create synergy in a democratic environment between stakeholders.

In **Chapter 4**, we employed a design thinking tool (customer journey) to explore challenges and opportunities when using video communication software in the cardiology department of a regional hospital. Interviews were conducted with 5 patients with implanted devices, a nurse, an information technology manager and two cardiologists. We found that the knowledge of each of these stakeholders contributed in an important way to the implementation of video consultations in cardiology. This emphasizes the importance to involve appropriate stakeholders to develop more resilient care as the combined knowledge of these stakeholders matters.

Part II: Creation phase: What theory can be developed that incorporates current assumptions about stakeholders' knowledge and ways of thinking?

Based on the insights from the exploration phase, the creation phase aimed to develop a GCD theory about stakeholders' knowledge and ways of thinking in GCD. Therefore, in **Chapter 5** we took the first theoretical step in developing a coherent theory about stakeholder involvement in GCD to incorporate three key hypotheses:

1. GCD researchers have hypothesized that involving stakeholders with diverse knowledge and diverse ways of thinking can improve the GCD process.
2. Design researchers have claimed that designers have a distinct way of thinking, such as abductive-2 reasoning.
3. Deep-lying knowledge of stakeholders is important in the GCD process.

To develop this theory we used concepts from the philosophy of science to explicate (1) diverse ways of thinking with four inference types and (2) the diverse knowledge with three knowledge types to explain how stakeholders influence the GCD process. We explained how stakeholders, depending on the use of these knowledge types: relevant statement, methodological instruction and contextual certainties. We explicated diverse ways of thinking with four inference types: induction, deduction, abduction-1 and abduction-2. For instance, when stakeholders use the inference type abduction-2, driven by the knowledge type contextual certainties, they can significantly change the course of the GCD process. Based on the fuller description of the roles of diverse stakeholder knowledge and inferences in the GCD processes, we developed arguments to justify the involvement of stakeholders.

Part III: Testing phase: How does this theory affect the GCD process for developing digital health?

In the testing phase, **Chapter 6**, we tested the first hypothesis stated above (Chapter 5) as a main hypothesis and the other two as sub-hypotheses. Initially, we operationalized the first hypothesis into the following procedure. We assembled two groups of diverse stakeholders and tested their influence on a GCD process. First, we used a snowball strategy to identify potential stakeholders. Then qualitative interviews were used to assess the potential contribution of each stakeholder separately with the knowledge and inference types (Chapter 5) and a communication criterion. Finally, two stakeholder groups were assembled to compare their performance. As the more potent and diverse group performed better, the diversity hypothesis was confirmed. Although, the sub-hypotheses about abductive-2 reasoning and deep-lying knowledge were not confirmed. We see that the more potent diverse group has a stronger influence on the knowledge output and knowledge processing. Therefore, merely assessing the professional background of stakeholders is not sufficient to reach the full potential of a GCD process. As a consequence, a procedure to assemble a stakeholder group with specific criteria to assess the diversity of knowledge, ways of thinking and communication can improve the potential of the GCD process and improve the resulting digital health.

In **Chapter 7** we presented the main findings of this thesis. According to the research through design approach, we present them here in the format of a problem definition (Part I), theoretical prototype (Part II) and test (Part III). Firstly, in the exploration phase (Part I), our findings mounted to this problem definition:

PROBLEM DEFINITION: The decisions concerning stakeholder involvement are the first choices to be made in the GCD process, and these can have a significant impact on the GCD process. However, there is a lack of clarity about the justification used to involve stakeholders in GCD research and GCD practice to develop digital health. For instance, it is not clear how stakeholders are recruited and why stakeholders are involved, or why business managers and designers or design tools have a strong impact on the GCD process. Consequently, there is a need to develop a theory to help understand the roles of stakeholders in GCD.

In the creation phase (Part II), we developed this GCD stakeholder theory:

PROTOTYPE: We describe the interaction of stakeholders in GCD as a dynamic process whereby stakeholders use four types of thinking (inferences) to process three types of knowledge (including deeper knowledge), which generates new knowledge. A combination of stakeholders with specific inference experiences and specific knowledge backgrounds can be justified because they each add to the dynamic with the other stakeholders.

In the testing phase (Part III), we tested the theory about stakeholder diversity. This led us to the following insight into the testing phase:

TEST: The hypothesis on the positive influence of a diverse stakeholder group on the GCD process was confirmed. The stakeholder group assembly procedure whereby criteria established in Chapter 5 were used to assess diverse knowledge and diversity of thinking enabled us to assemble a more diverse stakeholder group that had a greater influence on the GCD process.

Strikingly, in Chapter 6, various non-designer stakeholders in the high-performing group often used abduction-2 inferences, which enhanced the development of a greater range of visually described solutions. This confirmed what we proposed in the theory: abduction-2 can play a crucial role in a group of different stakeholders. This suggests that there is a need to include at least one stakeholder with previous abduction-2 experience, which may not be easily found in a medical hospital setting.

Further, we reflected on how this thesis can be positioned in the overarching discussion concerning cross-disciplinarity. I found that considerable ‘translation’ work is needed if design researchers, philosophers, and health services researchers are to benefit from insights from each other’s disciplines. In the long term, this would require a space where transdisciplinary research can flourish. In cross-disciplinary research, research should especially be promoted about transdisciplinary interaction among stakeholders in a GCD process. The developing areas in the philosophy of scientific discovery, about inferences and imagination, could increase interest in this collaborative creative process.

Finally, we concluded that even though there are important differences between the research traditions from where GCD was born, that should not be a reason to overlook the process of stakeholder involvement in GCD for digital health. When developing digital health, one should use a stakeholder group assembly procedure which takes into account the diverse knowledge and ways of thinking alongside GCD’s normative values such as democracy. This would facilitate transparent scientific reporting and offer a rational justification to involve a specific stakeholder group such as patients in digital health development. This way this thesis contributes to the first methodological step to make sure the appropriate stakeholders are involved in GCD to improve digital health, which eventually could improve healthcare for all.

Samenvatting

De Covid-19-pandemie heeft de nood tot een snellere implementatie van digitale zorg duidelijk gemaakt. We constateren echter dat het succesvol implementeren van digitale zorg op lange termijn problematisch blijft. In dit proefschrift richten we ons op de uitdagingen die ontstaan wanneer belanghebbenden direct of indirect betrokken worden bij de ontwikkeling van digitale zorg.

De Wereldgezondheidsorganisatie promoot digitale zorg en definieert het als: de ontwikkeling en het gebruik van digitale technologieën zoals 'The Internet of Things', artificiële intelligentie en robotica om de gezondheid te verbeteren. Er worden veel beloften gemaakt over hoe digitale zorg het zorg systeem kan verbeteren. Dit heeft geleid tot een stormloop om deze technologieën in de zorgpraktijk te implementeren. Het bewijs achter de grote beloften ontbreekt echter vaak. Bovendien zijn er zelfs onvoorziene negatieve effecten zoals de onvrede bij de gebruikers van elektronische medische dossiers. Dit roept vragen op over hoe digitale zorg kan worden geïmplementeerd zodat alle belanghebbenden er baat bij hebben.

Onderzoekers zijn daarom steeds meer geïnteresseerd geraakt in het betrekken van patiënten en zorgprofessionals bij de ontwikkeling van digitale zorg. Zoals het onderzoek waarbij de ontwerpbenadering 'human-centered design' wordt gebruikt, waarbij belanghebbenden een belangrijke rol hebben tijdens de ontwikkeling van digitale zorg. Zo is 'Generative co-design' (GCD), een vorm van 'human-centered design', naar voor geschoven als een geschikte methode om digitale zorg te verbeteren. Dit kan in GCD door belanghebbenden, zoals ontwerpers en niet-ontwerpers, samen actief te betrekken bij de ontwikkeling. Hierbij gaat het over een breed scala aan belanghebbenden zoals patienten, zorg professionals, beleidsmakers, managers, ontwikkelaars en nog veel meer.

GCD staat voor een iteratief proces tijdens de vroege innovatiestadia van digitale zorg ontwikkeling, waarbij belanghebbenden creatieve activiteiten doorlopen om een product of service vorm te geven. Omdat belanghebbenden hierbij actief participeren wordt verwacht dat de resulterende digitale zorg beter tegemoet zal komen aan hun eisen. Ondanks dat belanghebbenden een heel belangrijke rol spelen in GCD voor betere digitale zorg, blijft hun rol in dat proces onduidelijk. Het betrekken van belanghebbenden blijft dus ook vaag voor onderzoekers en ontwikkelaars van digitale zorg.

In dit proefschrift zetten we een eerste stap om de bijdrage van belanghebbenden bij de ontwikkeling van digitale zorg in GCD beter te begrijpen. Daartoe willen we de rol van belanghebbenden duidelijker definiëren en een GCD-theorie hierover ontwikkelen. Het opzetten van de theoretische basis zou uiteindelijk kunnen leiden tot een GCD-methodologie om de juiste belanghebbenden te betrekken bij GCD-activiteiten voor digitale zorg. De centrale onderzoeksvraag luidt:

Wat is de rol van belanghebbenden in GCD voor digitale zorg?

We beantwoorden deze vraag in drie delen. In Deel I onderzoeken we hoe belanghebbenden betrokken zijn bij GCD in de wetenschap en in de praktijk om digitale zorg te ontwikkelen. In Deel II ontwikkelen we een theorie over de kennis en manieren van denken van belanghebbenden in GCD. In Deel III testen we de belangrijkste aannames van deze theorie (Deel II) om te beoordelen hoe die de GCD-praktijk en de ontwikkeling van digitale zorg beïnvloeden. Ten slotte stellen we de belangrijkste bevindingen en de implicaties voor GCD-onderzoek en -praktijk voor.

Deel I: Verkenningsfase: hoe worden belanghebbenden betrokken bij GCD om digitale zorg te ontwikkelen?

In deze fase onderzoeken we hoe belanghebbenden betrokken worden bij GCD in de wetenschap en de praktijk. Wat betreft het gebruik van GCD in de wetenschap, willen we in **Hoofdstuk 2** inzicht krijgen in de betrokkenheid van belanghebbenden bij het ontwikkelen van digitale zorg. Via een systematisch literatuuronderzoek werden 69 studies (van 3131) geselecteerd voor kwalitatieve synthese. We stelden vast dat de onderbouwing van keuzes betreffende rekruteringsstrategie, het managen van belanghebbenden, 'tools' en het meten van uitkomsten zeer variabel was. Slechts enkele auteurs gebruikten expliciete argumenten gerelateerd aan de principes van 'participatory design' (PD), die fundamenteel waren voor GCD, zoals democratie, wederzijds leren, impliciete en latente kennis en collectieve creativiteit ter onderbouwing van hun keuzes. We besluiten dat de meeste auteurs de rekrutering van belanghebbenden niet onderbouwen, waardoor het onduidelijk blijft waarom ze betrokken zijn.

In Hoofdstuk 3 en Hoofdstuk 4 onderzoeken we de rol van belanghebbenden in PD-praktijken. In **Hoofdstuk 3** evalueren we het PD-proces in drie casestudy's: over voeding, intimiteit en seksualiteit, en integrale geneeskunde bij de zorg voor adolescenten en jongvolwassenen (AYA's) met kanker. Lokale belanghebbenden werden gerekruteerd met een open mind-set om samen te "dromen" over een oplossing. Door deze synergie ontstond er een gedeeld begrip van het probleem en een gezamenlijke missie om een oplossing te vinden. Participatieve ontwerptools werden gebruikt om een probleemdefinitie te ontwikkelen en ontwerpers vertaalden ideeën in prototypes. Het PD-proces duurde langer dan verwacht vanwege de hiërarchische ziekenhuisomgeving, zakelijke overwegingen en de vraag naar aanvullend wetenschappelijk bewijs. We concluderen dat bij het gebruik van een PD-proces om nieuwe vormen van AYA zorg te visualiseren en te materialiseren bepaalde elementen essentieel zijn. Er is nood aan ontwerpers en bekwame mensen, samen met PD-tools, en een open benadering. De rekrutering van belanghebbenden blijkt belangrijk te zijn om kennis te benutten en een synergie te creëren in een democratische omgeving tussen belanghebbenden.

In **Hoofdstuk 4** gebruikten we een design thinking-tool (customer journey) om uitdagingen en kansen te verkennen bij het gebruik van videocommunicatiesoftware op de cardiologieafdeling van een regionaal ziekenhuis. Interviews werden gehouden met 5 patiënten met geïmplanteerde apparaten, een verpleegkundige, een IT-manager en twee cardiologen. Hier stellen we opnieuw vast dat de kennis van elk van deze belanghebbenden in belangrijke mate heeft bijgedragen aan de implementatie van videoconsulten in de cardiologie. Het betrekken van de juiste belanghebbenden zou dus uiteindelijk kunnen helpen om meer veerkrachtige zorg te ontwikkelen.

Deel II: Creatiefase: Welke theorie kan worden ontwikkeld waarin de aannames over de kennis en denkwijzen van belanghebbenden zijn verwerkt?

Het doel van de creatiefase is om op basis van de inzichten uit de verkenningsfase een GCD-theorie te ontwikkelen over de kennis en denkwijzen van belanghebbenden in GCD. Daarom zetten we in **Hoofdstuk 5** de eerste theoretische stap naar een coherente theorie over belanghebbenden bij GCD, waarbij we drie kernhypothesen integreren:

1. GCD-onderzoekers stellen de hypothese dat het betrekken van belanghebbenden met uiteenlopende kennis en verschillende denkwijzen het GCD-proces kan verbeteren.
2. Ontwerponderzoekers beweren dat ontwerpers een aparte manier van denken hebben, zoals bijvoorbeeld abductief-2 redeneren.
3. Diepgaande kennis van belanghebbenden is belangrijk in het GCD-proces.

Om deze theorie te ontwikkelen, gebruikten we concepten uit de wetenschapsfilosofie om verschillende manieren van denken te expliciteren aan de hand van vier inferentietypes: inductie, deductie, abductie-1 en abductie-2. De uiteenlopende kennis wordt geëxpliciteerd met drie kennistypes: relevante kennis, methodologische instructies, contextuele zekerheden. We leggen uit hoe belanghebbenden, afhankelijk van het gebruik van inferentietypes en kennistypes het GCD-proces kunnen beïnvloeden. Wanneer belanghebbenden bijvoorbeeld het inferentietype abductie-2 gebruiken, aangedreven door het kennistype contextuele zekerheden, veranderen ze de loop van het GCD-proces aanzienlijk. Op basis van de uitgebreide beschrijving van de rol van uiteenlopende kennis en verschillende inferenties van belanghebbenden in het GCD-proces, ontwikkelen we argumenten om de betrokkenheid van belanghebbenden te rechtvaardigen.

DEEL III: Testfase: hoe beïnvloedt deze theorie het GCD-proces voor het ontwikkelen van digitale zorg?

In de testfase, **Hoofdstuk 6**, toetsen we de eerst hierboven genoemde hypothese (Hoofdstuk 5) als hoofdhypothese en de andere twee als sub-hypothesen. We hebben de hypothese eerst geoperationaliseerd in de volgende procedure. We brachten twee groepen van verschillende belanghebbenden samen en testten hun invloed op een GCD-proces. Eerst gebruikten we 'snowball sampling' om potentiële belanghebbenden te identificeren. Vervolgens werden kwalitatieve interviews gebruikt om elke belanghebbende afzonderlijk te beoordelen op hun mogelijke bijdrage met de kennis- en inferentietypes, en een communicatiecriterium (Hoofdstuk 5). Ten slotte werden er twee groepen belanghebbenden samengesteld om die met elkaar te vergelijken. De hoofdhypothese werd bevestigd, omdat de meer heterogene groep een groetere invloed had op het proces en de uitkomst. Echter, de sub-hypothesen over abductief-2 redeneren en diepliggende kennis werden niet bevestigd. We besluiten dat, indien we het volledige potentieel van een GCD-proces wensen te benutten, het onvoldoende is om alleen de professionele achtergrond van belanghebbenden te beoordelen. Daarom kan onze voorgestelde procedure waarbij de uiteenlopende kennis- en denkwijzen, en communicatievaardigheden worden gebruikt om een groep belanghebbenden samen te stellen, het GCD-proces verbeteren en de resulterende digitale zorg.

In hoofdstuk 7 stellen we de belangrijkste bevindingen voor van het proefschrift om de onderzoeksvraag te beantwoorden. Omdat we een ‘research-through-design’ aanpak volgen, geven we de bevindingen in het formaat van probleemstelling (Deel I), theoretisch prototype (Deel II) en test (Deel III). Ten eerste, in de verkenningsfase (Deel I) komen we tot deze probleemstelling:

PROBLEEMSTELLING: Beslissingen over de rol van belanghebbenden zijn de eerste keuzes die moeten gemaakt worden in het GCD-proces. Deze kunnen een aanzienlijke impact hebben op het GCD-proces. De keuzes over het betrekken van belanghebbenden bij GCD-onderzoek en GCD-praktijk om digitale zorg te ontwikkelen worden echter niet voldoende onderbouwd. Het is bijvoorbeeld niet duidelijk hoe belanghebbenden worden gerekruteerd en waarom ze worden betrokken, of waarom bedrijfsmanagers en ontwerpers of ontwerptools een sterke invloed hebben op het GCD-proces. Daarom is er behoefte aan het ontwikkelen van een theorie over de rol van belanghebbenden in GCD.

In de creatiefase (Deel II) komen we tot dit theoretisch prototype over de rol van belanghebbenden in GCD:

PROTOTYPE: We beschrijven de interactie van belanghebbenden in GCD als een dynamisch proces waarbij ze vier soorten denken (inferentietypes) gebruiken om drie types kennis te verwerken (inclusief diepere kennis), wat nieuwe kennis genereert. Een combinatie van belanghebbenden met specifieke inferentie-ervaringen en specifieke kennisachtergronden kan worden verantwoord omdat ze elk bijdragen aan de dynamiek met de andere belanghebbenden.

In de testfase (Deel III) toetsen we de stelling over de rol van verschillende belanghebbenden:

TEST: De hypothese over de positieve invloed van een heterogene groep belanghebbenden op het GCD-proces werd bevestigd. De procedure voor het samenstellen van de stakeholdergroep, waarbij de in Hoofdstuk 5 vastgestelde criteria werden gebruikt, om de uiteenlopende kennis en verschillende manieren van denken te beoordelen, stelde ons in staat om een meer heterogene stakeholdergroep samen te stellen, die een grotere invloed had op het GCD-proces.

Het valt op in Hoofdstuk 6, dat verschillende niet-ontwerpers in de goed presterende groep vaak abductie-2-conclusies gebruikten, wat de ontwikkeling van een groter scala aan visueel beschreven oplossingen bevorderde. Dit bevestigt wat we stellen in de theorie (Hoofdstuk 5): abductie-2 kan een cruciale rol spelen in een groep van verschillende belanghebbenden. Dit suggereert dat het nodig is om ten minste één belanghebbende te hebben met abductie-2 ervaring. De kans is echter reëel dat dit type belanghebbenden niet gemakkelijk te vinden zijn in een medische ziekenhuisomgeving.

Verder positioneren we dit proefschrift in de overkoepelende discussie over de intersectie tussen verschillende disciplines. Om ontwerponderzoekers, filosofen en onderzoekers in de gezondheidszorg te laten profiteren van elkaars inzichten is er meer werk nodig om inzichten te "vertalen" tussen elkaars disciplines. Op de lange termijn zou hiertoe de ruimte moeten worden geboden waar transdisciplinair onderzoek kan floreren. Bij onderzoek tussen verschillende disciplines moet vooral onderzoek worden gestimuleerd naar transdisciplinaire interactie tussen belanghebbenden in een GCD-proces. Nieuwe inzichten uit de wetenschapsfilosofie en wetenschappelijke ontdekking over inferenties en verbeelding, zouden de interesse voor dit collaboratieve creatieve proces kunnen vergroten.

Tot slot concluderen we dat hoewel er belangrijke verschillen zijn tussen de onderzoekstradities waaruit GCD voorkomt, dit geen reden mag zijn om het proces van betrokkenheid van belanghebbenden bij GCD in digitale zorg over het hoofd te zien. Bij de ontwikkeling van digitale zorg zou men een rekruteringsprocedure voor een groep belanghebbenden moeten hanteren waarbij men rekening houdt met de uiteenlopende kennis en verschillende manieren van denken naast de normatieve GCD-waarden zoals democratie. Dit zou ook de transparante wetenschappelijke rapportage faciliteren, en een rationele onderbouwing zijn om een specifieke stakeholdergroep, zoals patiënten, te betrekken in digital zorgontwikkeling. Op deze manier draagt dit proefschrift bij aan de eerste methodologische stap, zodat men de juiste belanghebbenden kan betrekken bij GCD, wat kan leiden tot de ontwikkeling van betere digitale zorg en uiteindelijk betere zorg voor iedereen.

Appendix 1

Abstract and poster presented at 4th Global Adolescent and Young Adult (AYA) Cancer Congress 2021 (online)

Title: Incorporating family needs in an AYA space in a Belgian hospital

Abstract: The physical structure of hospital wards does not often accommodate AYA social and affectional needs to spend time with friends and family in a non-clinical setting. There have been inpatient AYA spaces developed in hospitals across several countries, however the needs of young parents were not addressed. This study describes the first development (2019-2021) of an AYA space on a hematology ward in a Belgian hospital, which incorporates the needs of AYA parents.

Co-design, a qualitative design research methodology, is an iterative collective creative process with active involvement of designers and nondesigners. An audio and video-recorded focus group (76 minutes) was used to explore the problem with a partner of an AYA patient, an AYA treating hematologist, a designer, and a psychologist (age 25-55). A semi-structured interview guide was used. An audio and video-recorded co-design workshop (130 minutes) was organized to create a design of a family room, with 4 AYA, 2 parents of AYA, an AYA treating hematologist and two designers (age 21-56). Co-design tools such as a mindmap, persona, customer journey and prototype were used. Stakeholders in both sessions were carefully selected based on their relevant expertise. Both sessions were transcribed and coded using thematic content analysis. To evaluate the final design two semi-structured qualitative interviews were conducted with two nurses and an online survey was sent out to three patients on the ward.

Three key themes for young AYA parents were identified in the focus group: emotional exhaustion from uncertainty of disease; parent-child relationship and the need for clear communication; generalization is difficult. Five key themes were identified in the co-design workshop: coziness, social interaction, serenity, multifunctionality and space for parents and children. These were implemented through a multifunctional bench close to the window, a dining table, an electrical fireplace and a small kitchenette. The co-design process was prolonged due to the administrative process of the hospital. The room was positively evaluated by two nurses and three patients.

Co-design is an appropriate method to develop an AYA family room. Initial insights show a positive evaluation of the AYA family room by the users.


Incorporating family needs in an AYA space in a Belgian hospital
Pieter Vandekerckhove (Msc), Marleen de Mul (PhD), Antoinette de Bont (PhD)
Hospital wards lack AYA accommodation in a non-clinical setting. A co-design method with patients, designers, parents, physicans and a psychologist was used to develop an AYA space for AYA and their kids.
Services included (theme addressed)*:
+ Electrical fireplace (coziness)
+ Dining table (social, coziness, multi-functional)
+ Seats/couch (social, coziness, multi-functional)
+ Window bench/bed (multi-functionality, serenity)
+ Kitchenette (social, coziness, multi-functionality)
+ Kids toys/books (AYA and kids)
+ TV/Wifi (Coziness, AYA and kids)
* Themes identified through co-design research, products and services are approved with high hospital standers for hygiene, fire safety and cleaning comfort
1. Focus group
2. Co-design workshop
3. Prototype
Vandekerckhove@eshpm.eur.nl
Watch video here:
https://surfdrive.surf.nl/files/index.php/s/
UZA' foundation
This room is dedicated to Eva Sturtewagen and realised with the Eva-Ida fund

About the author

Pieter Vandekerckhove is Assistant Professor Healthcare Entrepreneurship (tenure track) at Delft Centre for Entrepreneurship. He completed his PhD at Erasmus University Rotterdam, Erasmus School of Health Policy & Management. His research and education have focused on the development of generative co-design methodology for digital health at an early stage. He developed a stakeholder involvement method to assemble a group of diverse stakeholders as patients, care professionals, managers, technical people, fundamental researchers and designers in generative co-design to develop digital health. He aims to use this as a scientifically robust method to effectively use generative co-design for digital health. Pieter has published in scientific journals and has reviewed papers for JMIR and BMJ Open.

Pieter is involved in a flagship project called iCell in the health and technology convergence programme of TU Delft, Erasmus MC and Erasmus University Rotterdam. iCell aims to develop new technologies based on insights from fundamental biology and genetic research to improve cancer care. He is also involved in a NWO granted research project called My Smart Family Buddy to improve the health of impoverished families in Rotterdam.

Pieter's main interest lies in improving cancer care, recently he published a book based on his experience with cancer as an adolescent "The Self Hologram: Awakening a philosophy of life". His mission is to improve cancer care from a patient perspective so that one can go through the same experience as he did and live a fulfilling life during and after a cancer diagnosis.