Ethics of User Involvement in Sensitive Design Situations

Susanne Lindberg
"I think I'll try defying gravity"
Elphaba, *Wicked*
Abstract

While this era of digital technology brings great possibilities for improving the lives of many people with digital healthcare services, the design of these services in turn present challenges that are ethical in nature. Participatory Design (PD) values user involvement in design from a democratic, empowerment and ethical perspective. However, the design of digital healthcare services constitutes sensitive design situations, that is, situations that have the potential to negatively impact the participants. As a consequence, participation in these design situations involves risks, causing ethical dilemmas. The ethical dilemmas that designers face in sensitive design situations are situated, dynamic, diverse, unpredictable, and occur in-action. Yet, it is a complex field with little in situ support for designers who intend to involve users in sensitive design situations, and high complexity and risk increase the need to understand ethics in these situations. Consequently, this thesis intends to answer the question: How can users be involved in sensitive design situations?

The research question has emerged from the study of two design projects and is addressed through a Design Research (DR) approach. Both projects aimed at designing Digital Peer Support (DPS); one designs DPS for children between 8-12 cured from cancer, and the other designs DPS for people diagnosed with schizophrenia. The DR approach enables the study of de facto design situations in the two design projects. The thesis consists of a collection of five papers and a cover paper.

The results show that, in sensitive design situations it can be challenging to uphold the fundamental ethical commitments of PD: that participation is a democratic right, the user is the expert, design should enhance, and design is situated. Based on the empirical study, I propose four principles for ethics in sensitive design situations that aim to support the upholding of these ethical commitments: (I) the principle of enhancement; (II) the principle of acknowledgement; (III) the principle of advocacy; and (IV) the principle of accommodation.

The research contributes to the discourse on ethics in PD by expanding the understanding of ethical values of user involvement. Ethical guidelines must be dynamic and responsive, and participation should be carried out using methods for continuous critical reflection. The research contributes to practice by providing practical guidance for those who intend to involve users in sensitive design situations, ethical review boards who review PD, and for training of future PD researchers.
Acknowledgements

I’ve been writing these acknowledgements in my head for so long, it almost feels surreal to sit down and actually write them. Putting them to paper makes this – more than anything else – seem real. I have been told that this is the most read section of any PhD thesis, and therefore hope I can do all the people who have been part of my journey justice. I fear words may not be enough.

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This almost feels like a goodbye. In a sense it is – it puts an end to nearly five years of work. But instead it’s the start of something new and exciting. I can’t wait to see what it is.

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## Abbreviations

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<th>Description</th>
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<tbody>
<tr>
<td>CHIPS</td>
<td>Child Health Interactive Peer Support (project)</td>
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<td>DPS</td>
<td>Digital Peer Support</td>
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<td>DR</td>
<td>Design Research</td>
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<td>LiwS</td>
<td>Living with Schizophrenia (project)</td>
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<td>PD</td>
<td>Participatory Design</td>
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<td>UGC</td>
<td>User Generated Content</td>
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CHAPTER 1

Introduction

Involving users in design is complex and ethically challenging. It entails sharing power of design decisions with non-designers, handling unexpected events, dealing with conflict, and supporting the participants in design activities by providing familiar and easy-to-learn design techniques. As digital technology now reaches into most of our lives, there are possibilities for providing access to different kinds of digital services, in contexts and ways that have not been feasible before. There are great opportunities for social innovation supporting and improving the lives of many with the use of digital healthcare services; smart homes can for example monitor the health status of elderly in their own homes (see e.g. Liu, Stroulia, Nikolaidis, Miguel-Cruz, & Rios Rincon, 2016), digital healthcare applications can give access to medical professionals anywhere (Watson et al., 2016), and social networking can provide social support for mental health care (O'Leary, Bhattacharya, Munson, Wobbrock, & Pratt, 2017). However, involving users in the design of these types of digital services also presents ethical challenges.

The design of digital healthcare services necessitates designing for a sensitive design situation; this is a situation in which the private life, emotions and experiences of an individual are involved, which can potentially have adverse consequences for the participant or community. Failure to meet the requirements of the users can lead to a negative impact on the users' health and wellbeing. It can inadvertently contribute to stigmatisation of individuals or the user community, and involvement in sensitive design situations can cause distress, unintentionally make private concerns public, and possibly result in the
relapse of symptoms. Furthermore, techniques for user involvement may need to be adapted to the physical or cognitive abilities of the participants. Yet, user involvement in design supports the possibilities for digital services to be relevant to the community and meet user requirements by dealing with the complexity of the design problem from a user point of view (Bødker & Pekkola, 2010). Designing digital healthcare services is particularly complex, and involving users in the design process is one way to handle this complexity.

User involvement in design has a long history. It has been linked to benefits such as increased user satisfaction (McKeen, Guimaraes, & Wetherbe, 1994), accuracy of requirement specification, acceptance, understanding and cost avoidance (Kujala, 2003). Furthermore, users are sometimes involved for other values not directly related to product quality; the so called Scandinavian tradition of Participatory Design (PD) has its ties in political values, highlighting democracy, empowerment and ethics as reasons for involving users in design (Bjerknes & Bratteteig, 1995). These values stem from the approach’s early roots in the Scandinavian union movement in the 70’s and early 80’s (Bannon & Ehn, 2012; Bødker & Pekkola, 2010).

With a history of focusing on design for the workplace, the past decade has seen a shift in the focus of PD to an increased interest in the individual, experience and culture (Frauenberger, Rauhala, & Fitzpatrick, 2017). PD is no longer solely concerned with workplace and democratic values, but also on the values that emerge throughout each collaborative design process (Iversen, Halskov, & Leong, 2012). The focus on design techniques for collaboration, conflict management and equalisation of power between stakeholders (Bødker, Grønbæk, & Kyng, 1993) has also shifted towards an increased focus on design techniques for involving users with a spectrum of physical and cognitive abilities (Börjesson, Barendregt, Eriksson, & Torgersson, 2015; Waycott, Wadley, Schutt, Stabolidis, & Lederman, 2015). PD techniques are particularly useful for understanding the users and the use context (Bødker & Pekkola, 2010), and PD is thereby notably suitable for approaching the challenges of designing digital healthcare services. The shift in focus has indeed opened up for PD to be carried out in previously unexplored design situations with users that have not traditionally been included in design (Bødker, 2015; Nathan, Thieme, Tatar, & Branham, 2017).

Involving users as agents with decisive power equal to that of the designer is a foundation of PD (Bratteteig & Wagner, 2012; Nelson & Stolterman, 2003). The user is respected and valued as an expert of the use situation, and from an ethical standpoint the design process should serve to empower the user
(Robertson & Wagner, 2012). Involvement is also ethically important. Excluding users from the design process is considered unethical as the users miss out on benefits they could have had; the final design can even be harmful to the users if they are not involved in the design process (Bravo, 1993).

However, being involved in design in a sensitive design situation also constitutes a risk to the participants and is thus ethically challenging (Waycott, Wadley, et al., 2015). The plethora of PD research in sensitive design situations includes design with vulnerable users such as children (see e.g. Ruland, Starren, & Vatne, 2008), refugees (Nielsen, 2014), people with cognitive limitations (Hendriks, Slegers, & Duysburgh, 2015), and people with mental illness (Wadley, Lederman, Gleeson, & Alvarez-Jimenez, 2013). These examples demonstrate the types of complexities and ethical challenges that designers meet when designing digital healthcare services, including unpredictable challenges, variety of user ability and limited access to users. Ethical dilemmas are not only contingent on the vulnerability of the users – they can also be caused by the performance of the research (Vines et al., 2017), as there are risks of contributing to stigmatisation or increasing the vulnerability of a user group through participation.

Ethical challenges in PD are situated, dynamic, unpredictable, and arise in situ (Frauenberger et al., 2017; Munteanu et al., 2015; Waycott, Wadley, et al., 2015). Meanwhile, ethical models for research are often static and anticipatory (Ferguson, Crist, & Moffatt, 2017). Due to the nature of ethics in PD, anticipatory models of ethics cannot provide the ethical support necessary for carrying out PD in sensitive design situations; it is impossible to avoid, anticipate, or prepare for all ethical dilemmas in advance. Understanding and supporting how ethical challenges in sensitive design situations are handled is therefore essential (Frauenberger et al., 2017; Munteanu et al., 2015; Nathan et al., 2017; Robertson & Wagner, 2012; Waycott, Davis, et al., 2015).

Several authors have attempted to tackle the ethics of user involvement in sensitive design situations. Munteanu et al. (2015) provide recommendations for what they call situational ethics, claiming that ethics in a design process is unpredictable and dynamic. Frauenberger et al. (2017) develop this concept further, presenting what they call In-Action Ethics as a framework for bridging anticipatory ethics with the reality of PD research. Malinverni and Pares (2017) take a different approach to ethics in PD by focusing on critical reflection, and suggest an autoethnographic approach to making ethical decisions in design. Lastly, Ferguson et al. (2017) analyse existing codes of ethics by hospice organisations, from which they develop a framework for ethical reflection in
sensitive design situations. The framework is used retroactively to understand experienced ethical concerns, and enables planning of future research (Ferguson et al., 2017).

Recent years have seen an increased interest in ethics in PD, possibly because of the increase of PD in sensitive design situations. Yet, it is a complex field, and there is currently little *in situ* ethical support for designers who want to involve users in sensitive design situations. While PD values user involvement as ethically important, there are many ethical challenges to involving users in design, and this ethical contradiction becomes particularly prevalent in sensitive design situations where the risks of participation are higher. In the light of this, I seek to answer the question:

*How can users be involved in sensitive design situations?*

This research question stems from the study of two design projects aimed at designing Digital Peer Support (DPS). Peer support is a form of social support (Solomon, 2004) that connects people with shared experiences in mutual support based on shared understanding and empathy (Mead, Hilton, & Curtis, 2001). A well-known example in the form of a self-help group is Alcoholics Anonymous, but there are many others, including peer support for cancer survivors (Campbell, Phaneuf, & Deane, 2004; Docherty, 2004) or people with mental illness (Chinman et al., 2014). Peer support has shown benefits for self-esteem and self-efficacy (Turner, 1999), knowledge sharing (Munn-Giddings & McVicar, 2007), daily function, and increased perception of one's own health (Solomon, 2004). Peer support can benefit society at large by reducing hospitalisations (Solomon, 2004), and can reach individuals who are opposed to or unable to access regular healthcare systems (Segal, Gomory, & Silverman, 1998). DPS has also been shown to overcome some of the impediments of the traditional healthcare systems, for example in the treatment of mental health (O'Leary et al., 2017). Technical developments in later years further extend the possibilities by enhancing accessibility (O'Leary et al., 2017) and social interaction afforded by social media (Obar & Wildman, 2015).

The two design projects that make up the empirical context for this study present design situations with particular challenges due to the target user groups being established on common, difficult life experiences. The focus on ethics developed gradually throughout the span of the research, as it became clear that ethical dilemmas were not only complex but also particularly important to handle because of the high risk of harm.
Due to the explorative nature of this research question, and the focus on *de facto* design, the research question is addressed through a Design Research (DR) approach (Koskinen, Zimmerman, Binder, Redstrom, & Wensveen, 2011; Zimmerman, Forlizzi, & Evenson, 2007) by means of qualitative data collection methods suitable for the study of complex, social contexts (Myers, 1997b). DR posits that knowledge is created through the act of design (Zimmerman et al., 2007). The aim of this research is to provide *in situ* ethical guidance for involving users in sensitive design situations.

This thesis consists of a cover paper and five individual papers. The cover paper is structured as follows. The next chapter, chapter 2, outlines PD, identifying distinctive features of ethics in PD and focusing on PD in sensitive design situations. Chapter 3 describes the research approach and method, while chapter 4 outlines the details of the design study and the empirical cases. Chapter 5 then summarises the contributions from the individual papers, and chapter 6 outlines the contribution of the research, contextualising four principles for ethics of user involvement. Lastly, chapter 7 presents some concluding remarks. After the cover paper, each of the five individual papers are included, and are presented in the following order:


1.1 Key Concepts

Some of the key concepts used in this cover paper require a brief introduction as to how they are used in this text: design, design process, designer, design situation, sensitive and vulnerable. Finally, I will present a definition of sensitive design situation, which will be used throughout this cover paper.

*Design* refers to both the act of creating something and the something that has been created. In this thesis, the subject is always *digital* design, that is, the design of digital artefacts. Design usually happens through a structured and creative design process.

The *design process* extends from the first steps of ideation and concept creation, to the creation of a final specification that is intended for development. The outcome of the design process can be the same as the final developed artefact, or at a higher level of abstraction.

The *designer* in this text is considered to be a PD researcher or someone carrying out a PD process. Therefore, the term designer is not used to refer to design practitioners carrying out so-called routine design. In this text, the designer and the PD researcher are used synonymously.

All design activities are carried out within a *design situation*. It is not always evident what constitutes a design situation, as this can be subject to interpretation; it includes the factors that affect the use of the final outcome, and also the factors that affect the possibility of carrying out the design process, for example ethical limitations or workplace conflicts.

All design that carries a potential cost to its participants can be defined as *sensitive*. Topics that can be considered sensitive include, for example personal, traumatic experiences, religious beliefs, social control or deviance (Liamputtong, 2006).

Furthermore, an individual can be *vulnerable* in different ways. Vulnerability is a socially constructed concept and includes physical, cognitive, emotional and social vulnerability (Vines et al., 2017) that affect the individual's ability to participate in design. Vulnerability can be temporary, due to for example an illness (Culén & van der Velden, 2013), or more permanent due to for example age, physical or cognitive disability, life situation or stigmatisation (Liamputtong, 2006). Someone who is vulnerable is also at risk.
On the basis of these concepts, this thesis defines a *sensitive design situation* as a combination of factors with potential for negatively impacting the participants' wellbeing, affecting the design process as a whole, or separate design activities. In a sensitive design situation, it is necessary for the designer to enter the private space of an individual, and require that the designer is careful not to distress an already vulnerable individual. There is always a risk of causing distress or affecting the wellbeing of users who participate in sensitive design situations, and thus it is particularly important to consider the lives and wellbeing of the involved individuals.
CHAPTER 2

Ethics in Participatory Design

This research focuses on user involvement in sensitive design situations. This chapter provides an overview of the state of the art in ethics in Participatory Design (PD), beginning by outlining the background and development of PD. I then move on to delineate related research done in sensitive design situations. The chapter concludes by focusing on ethics, and summarises distinctive features of ethics in PD.

2.1 Historical Overview of Participatory Design

The Scandinavian approach to PD has its roots in the 1970's political and civil rights movements (Bødker et al., 1993). The approach was a response to the expansion of digital technology in the workplace, and experiences of that technology having a negative effect on the work environment (Robertson & Simonsen, 2012). The values that were important then are still emphasised today, though in different contexts.

PD roots foundational values in such perspectives as democracy, feminism and phenomenology (Bødker et al., 1993; Kensing & Greenbaum, 2012). The foundation in democracy is expressed in the value of bottom-up design as a way to give the users a voice and decision making power (Kensing & Greenbaum, 2012), highlighting Marxist emancipatory practice. The foundation in feminism is expressed in the valuing of personal experience and empowerment goal of PD (Kensing & Greenbaum, 2012). The foundation in phenomenology is
expressed in the focus on the use situation and on breakdowns in use, that is, when something is not working (Ehn, 1988). Moreover, PD as a research approach has roots in action research, as the designer is seen as an active change agent. In accordance with action research, the designer should also consider the users' needs, as well as create value for the participants through the design process (Bannon & Ehn, 2012).

Active participation and equalising of power is fundamental in PD, as is the view of design as being situated (Greenbaum & Kyng, 1991). As such, design techniques that are primarily used are those that enable users to express their everyday experiences and act in an equal capacity to designers (Bødker et al., 1993). As an example of this, working with prototypes is central to PD (Bødker et al., 1993).

Today, PD faces new challenges. As the boundaries between work and private life are blurring, and digital technology spreads from the workplace to the home, a different assortment of challenges than those that PD has previously faced are created. Bødker (2006) and Harrison, Tatar, and Sengers (2007) describe what they call three waves or paradigms of design. The first wave was influenced by cognitive science and human factors, promoting scientific studies using formal methods for systematic testing. PD emerged during the second wave, which focused on work settings and established communities of practice (Bødker, 2006). The third wave is, in contrast, characterised by a broadened context of use, a view of interaction as socially situated, and a focus on culture and emotion (Bødker, 2006; Harrison et al., 2007). Approaches such as PD, that are active and situated, are suitable for handling the challenges of the third wave (Frauenberger, Good, Fitzpatrick, & Iversen, 2015).

As digital technology is being designed for new contexts, PD is recognised in a wide range of disciplines. There are examples where PD is carried out in research on education (see e.g. Casanova, Di Napoli, & Leijon, 2017; Könings & McKenney, 2017) and health science (see e.g. Al-Itejawi et al., 2016; Noergaard et al., 2017), as well as many other fields. The many strengths of PD are increasingly becoming acknowledged.

Nevertheless, PD is also challenged by the emerging contexts of use outside of the workplace (Bødker & Pekkola, 2010) and changing work practices (Bratteteig, Bødker, Dittrich, Mogensen, & Simonsen, 2012). Challenges that PD as an approach is currently facing include how to design for a variety of contexts of use, how to learn about these contexts, how to design for mixed
reality environments, and how to design for a market that increasingly focuses on first impressions (Bratteteig et al., 2012).

Regardless of the context in which PD is carried out today, there are a number of pervasive, underlying ethical commitments to the approach:

• *Participation is a right.* Participation is a basic right for all individuals (Robertson & Wagner, 2012). This ethical commitment is rooted in democracy, and historically was expressed as a worker's right to participate in the development of technology for their workplace (Bjerknes & Bratteteig, 1995). In acknowledging the right to participate, PD also acknowledges that participation should not be solely tokenism, but genuine with decisive power (Greenbaum & Kyng, 1991). This ethical commitment has encouraged PD researchers to design with marginalised and vulnerable groups (Robertson & Wagner, 2012).

• *The user is an expert.* Mutual learning should occur throughout a design process (Kensing & Greenbaum, 2012). The user is considered the expert of his or her own work or life situation, while the designer is the expert of the design tools and techniques (Robertson & Wagner, 2012). In a design process, many stakeholders should be involved, and each one of them should learn from the others. This means that a design process will include conflict and different power relations (Kensing & Greenbaum, 2012), and dealing with conflict is inherent in design (Greenbaum & Kyng, 1991).

• *Design enhances.* Design should improve a situation (Greenbaum & Kyng, 1991). As such, digital technology should serve to enhance and better a situation, instead of hindering or making it more rigid (Bødker et al., 1993). Because the introduction of digital technology creates change, it is the designer's responsibility to improve the quality of life for the users (Greenbaum, 1993).

• *Design is situated.* Design is emergent from use (Henderson & Kyng, 1991). As such, design should be carried out in use-like settings, utilising prototyping to evaluate the technology in a use situation (Bødker & Grønbæk, 1991). The context of use should be the starting point for the design process (Greenbaum & Kyng, 1991), and since design is situated and the use situation changes over time, the design process must then be able to change (Henderson & Kyng, 1991). Using techniques such as cooperative prototyping, where users have an active role in creating prototypes, enables communication between users and designers (Bødker & Grønbæk, 1991). This commitment has contributed to a focus of research on tools and techniques for carrying out PD (Kensing & Blomberg, 1998).
2.2 Challenges of Participatory Design in Sensitive Design Situations

A sensitive design situation is defined as the entirety of factors affecting the design process that can potentially negatively impact the participants. Within PD and related approaches, there is a growing interest in design for sensitive design situations (Culén & van der Velden, 2013; Herron, Andalibi, Haimson, Moncur, & van den Hoven, 2016; Waycott, Wadley, et al., 2015). However, carrying out PD in a sensitive design situation with vulnerable users entails unique challenges for the designer. Due to the design situation being complex, with an increased risk of harming or stigmatising participants, the designer must be particularly cautious (Waycott, Wadley, et al., 2015). It can be more difficult for the designer to empathise with vulnerable users groups (Culén & van der Velden, 2013) and labelling someone as vulnerable can further serve to enhance their vulnerability or increase stigmatisation (Waycott, Wadley, et al., 2015). There are fewer suitable design techniques adapted to the vulnerabilities of the users (Culén & van der Velden, 2013), and PD techniques typically presuppose that participants are cognitively, physically and emotionally able to describe current and future technology needs (Hendriks, Truyen, & Duval, 2013); this requires ability for abstract thinking and clear communication.

Due to the complexities and heterogeneity of stakeholders in some sensitive design situations, it may sometimes be impossible to carry out a PD process, despite the potential. Healthcare is one such area where some argue that PD may be incompatible with the in situ design challenges (Mønsted & Onarheim, 2010). Challenges to PD in healthcare include the complexity of existing systems, stakeholders and practices, the geographical distribution and high workload of healthcare professionals, and the physical and cognitive limitations that patient groups may experience (Mønsted & Onarheim, 2010). Nevertheless, PD can also bring additional value in sensitive design situations because there is more at stake for the participants (Frauenberger, Good, & Keay-Bright, 2011) and there is more potential for empowerment of disempowered groups (Nathan et al., 2017).

In conclusion, despite the long and successful history of PD, new challenges emerge with the development of digital technology. The remainder of this section will present a select number of representative examples of PD being carried out in sensitive design situations in order to highlight the different challenges inherent in this type of research. These examples present diverse design situations, with different kinds of sensitivity, and involve people with a range of health and social difficulties.
Waycott, Wadley, et al. (2015) present several design projects that involve user groups considered to be vulnerable: socially isolated adults are involved in the design of a social networking tool; young adults with mental illness are involved in the design of an online tool for social and therapeutic support; children with high functioning autism are involved in the evaluation of a digital technology based social club; children patients are involved in the design of digital technology for social connectivity; and women with chronic pelvic pain are involved in the design of a therapeutic mobile application. The authors identify five key issues for designing in sensitive design situations: (1) the challenges that emerge are situationally dependent and therefore impossible to fully predict; (2) there is a risk of exposing participants and by aiming the designed digital technology towards user groups with specific vulnerabilities, there is a risk of disempowering instead of empowering with the technology; (3) because designers lack the training that some other professions have for encountering sensitive situations it may be necessary to include medically trained personnel; (4) design is fundamentally a social practice, but due to the vulnerability of the participants this can cause them discomfort; and (5) participants may be more invested in the results and thus also more disappointed if the results do not meet their expectations, making expectation management particularly important.

Culén and van der Velden (2013) involve three user groups considered to be vulnerable: young learners with special needs are involved in the design of a learning application; teenage patients are involved in the design of support for voicing their needs; and elderly living alone are involved in the design of communication technologies. They identify practical, methodological and ethical challenges to PD in sensitive design situations. Practical challenges include how to understand the needs of the users, for example when they are unable to express their technology needs. Methodological challenges include how to adapt and develop new design techniques suitable to the participants' prerequisites. This necessitates a flexibility and ability to improvise, supported by a methodological sensitivity. Ethical challenges include handling consent on a continuous basis throughout the design process and not as a singular instance at the beginning of the process. Additionally, the authors experienced that involving different stakeholders in a group setting, which is a typical PD constellation, was not possible when the users were vulnerable. Instead, it was necessary to work one-on-one with the participants.

Hendriks et al. (2013) formulate and evaluate guidelines for PD with people with dementia. Their user group presents cognitive, physical and emotional
challenges that prevent them from being involved in design using traditional PD techniques. The guidelines relate to: preparation, such as to communicate clearly with stakeholders in order to manage expectations; the design techniques used, such as to avoid too many options; approaching the participants, such as to enclose personal information to create rapport; and the analysis of the outcome, such as involving caregivers to establish feasibility of interpretations. The guidelines highlight that care to accommodate the prerequisites of the participants must be taken, and that the interpretation of the activities may be difficult.

Frauenberger et al. (2011) involve children with special needs in a PD project to design a technologically enhanced learning environment for developing social skills. They adapt several PD techniques to the abilities of the children, and their findings include the following difficulties in comparison to design involving children without special needs: (1) there were more practical difficulties of organisation, relating to number of participants and restriction of access; (2) more potential impact from the designed technology and thus more at stake; and (3) that building a relationship and gaining the participants' trust is more complex but also more important.

Gaudion, Hall, Myerson, and Pellicano (2015) involve people with autism, learning disabilities and limited speech in PD activities. They note that while children with autism have been included in design before, involving adults with autism is more rare. In order to involve people with autism, Gaudion et al. (2015) develop highly individualised design techniques suited to each participant in order to build trust and familiarity. They involve both the autistic adult and their carer in participatory activities, and involve them in three stages that serve to validate observations and interpretations from previous stages. They conclude that the designer's ability to empathise is the most important; because their interpretations from the previous stage influenced the next stage, the accuracy of that interpretation was paramount, yet also the most complex.

Table 1 summarises complications of carrying out PD in sensitive design situations as described in the literature. The complications have primarily been identified from PD in sensitive design situations, but may also be relevant in design situations that are not apparently sensitive. These complications contribute to making PD in sensitive design situations particularly complex.
Table 1. Overview of complications of PD in sensitive design situations identified from literature

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<th>Complication</th>
<th>Description</th>
<th>Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unpredictability of challenges</td>
<td>Challenges that may occur during the design process are varied and unique to each situation, and therefore cannot all be predicted.</td>
<td>Waycott, Wadley, et al. (2015)</td>
</tr>
<tr>
<td>Diversity of stakeholders</td>
<td>When users are vulnerable, there are typically a greater number of stakeholders, such as carers, parents and medical personnel. Stakeholders also have greater investment in the cause because of the possibility of greater impact on the wellbeing of the users. Triangulation of different stakeholders may be necessary, e.g. when users have limited communication skills.</td>
<td>Frauenberger et al. (2011); Gaudion et al. (2015); Monsted and Onarheim (2010); Waycott, Wadley, et al. (2015)</td>
</tr>
<tr>
<td>Variety of user ability</td>
<td>Traditional PD design techniques are not suitable for users with varied abilities and need to be adapted, e.g. to meet difficulties with motor skills, social skills or difficulties communicating.</td>
<td>Culén and van der Velden (2013); Frauenberger et al. (2011); Gaudion et al. (2015); Hendriks et al. (2013)</td>
</tr>
<tr>
<td>Risk of harm</td>
<td>Participation in design activities can increase the vulnerability and stigmatisation of the user group. It is necessary to maintain a balance of risks and benefits.</td>
<td>Waycott, Wadley, et al. (2015)</td>
</tr>
<tr>
<td>Difficulty empathising</td>
<td>It is difficult for a designer without the users' background to empathise with their unique and difficult experiences. Yet empathy is essential for the adaptation and interpretation of the outcome of the design activities.</td>
<td>Culén and van der Velden (2013); Gaudion et al. (2015); Hendriks et al. (2013)</td>
</tr>
<tr>
<td>Limited access to user group</td>
<td>Vulnerable user groups can be difficult to access due to size, anonymity in society, or due to a complex stakeholder relationship where guardians or medical personnel also need to be involved. There may be a limit to how often users or stakeholders can meet.</td>
<td>Frauenberger et al. (2011); Hendriks et al. (2013)</td>
</tr>
<tr>
<td>Difficulty interpreting</td>
<td>There is a risk of over interpreting participants. It may be necessary to involve users or stakeholders to validate interpretations.</td>
<td>Frauenberger et al. (2011); Gaudion et al. (2015); Hendriks et al. (2013)</td>
</tr>
<tr>
<td>Level of expectations</td>
<td>Since the users are vulnerable, and the outcome of the design process may serve to alleviate a difficult situation, the stakes are high for all parties involved. This may increase expectations and subsequent feelings of disappointment if the technology does not meet these expectations.</td>
<td>Frauenberger et al. (2011); Waycott, Wadley, et al. (2015)</td>
</tr>
</tbody>
</table>
There are fewer suitable design methods adapted to the vulnerabilities of the users (Culén & van der Velden, 2013), and PD techniques tend to assume that participants are cognitively, physically and emotionally able to describe current and future technology needs (Hendriks et al., 2013); this requires the ability to think abstractly and communicate clearly. PD is to a great extent carried out in a social setting, yet social interaction can create unpredictable ethical dilemmas (Waycott, Wadley, et al., 2015) where there is no clear correct choice. Labeling someone as vulnerable can further serve to enhance their vulnerability or increase stigmatisation (Waycott, Wadley, et al., 2015).

2.3 Features of Ethics in Participatory Design

Ethics is the branch of philosophy that deals with moral reasoning, that is, one's principles of what is right and wrong. Four principles are fundamental to all research ethics: non-maleficence (to do no harm), beneficence (to do good and benefit the individual), autonomy (the individual's right to make choices) and justice (to treat each individual equally) (Beauchamp & Childress, 1994, as cited in Mingers & Walsham, 2010). Most research involving people goes through an ethical review or evaluation. In Sweden, this is done by a central, or one of six regional, ethical vetting boards. Similar ethical regulatory bodies exist around the world. While such anticipatory ethical reviews are important, sometimes they do not provide adequate support for researchers who carry out sensitive and complex research (Ferguson et al., 2017; Munteanu et al., 2015).

With the third wave of design research, and its associated shift of focus to new use contexts and user groups, previously inapplicable ethical challenges emerge. Designers who carry out approaches such as PD, which is pragmatic and builds on user involvement, face ethical challenges that emerge dynamically in situ, and cannot be handled only by anticipatory ethical guidelines (Munteanu et al., 2015).

There is an underlying ethical stance in PD that users have the right to participate as equals in the design process (Bravo, 1993; Carroll & Rosson, 2007). In sensitive design situations, where there is risk of harming participants, this ethical stance gives rise to an ethical contradiction: while excluding users is unethical, participation can potentially cause the participants harm, which would also be unethical. There are potential benefits to involving vulnerable users in PD processes, such as empowerment of disempowered groups (Nathan
Due to users being seen as equal participants and not as research subjects, there is a clash with the anticipatory ethical regulations enforced by ethical reviews; these reviews focus on protecting and anonymising participants, while PD strives to empower and provide participants with a voice (Frauenberger et al., 2017). Indeed, it is possible to identify distinctive features of ethics in PD that together contribute to making it particularly complex. The features are summarised from literature in table 2.

**Table 2. Summary of the distinctive features of ethics in PD**

<table>
<thead>
<tr>
<th>Feature</th>
<th>Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Situated: embedded in the design situation</td>
<td>Frauenberger et al. (2017); Malinverni and Pares (2017); Munteanu et al. (2015); Nathan et al. (2017); Robertson and Wagner (2012)</td>
</tr>
<tr>
<td>In-action: emerges in action</td>
<td>Frauenberger et al. (2017); Steen (2011)</td>
</tr>
<tr>
<td>Dynamic: changes over time</td>
<td>Culén and van der Velden (2013); Frauenberger et al. (2017); Munteanu et al. (2015)</td>
</tr>
<tr>
<td>Diverse: varies in nature and severity</td>
<td>Ferguson et al. (2017); Waycott, Wadley, et al. (2015)</td>
</tr>
<tr>
<td>Unpredictable: impossible to anticipate in advance</td>
<td>Munteanu et al. (2015); Nathan et al. (2017); Waycott, Wadley, et al. (2015)</td>
</tr>
</tbody>
</table>

Due to the complexity of carrying out PD in sensitive design situations, each situation involves a unique set of ethical considerations. Ethics in PD is *situated*, that is, dependent on the nature of the situation in which the design activities are carried out (Frauenberger et al., 2017; Munteanu et al., 2015). PD is social and pragmatic, which in itself gives rise to ethical challenges. Further, PD in sensitive design situations involves different ethical challenges and requires greater sensitivity (Munteanu et al., 2015). As a result, the designer needs to be flexible and able to adapt to the prerequisites of the users (Munteanu et al., 2015).

Ethical challenges in PD emerge *in-action*. Because PD is pragmatic and focuses on action together with participants, many ethical dilemmas do not emerge until that action is performed (Frauenberger et al., 2017). Ethics in PD is expressed in the cooperation and dialogue with users and stakeholders that is at the heart of the approach (Steen, 2011). This requires that the designer has an awareness of and reflects on ethics throughout the design process (Ferguson et al., 2017; Frauenberger et al., 2017; Malinverni & Pares, 2017).
Ethics in PD is also *dynamic*, and changes over time. The situation in which the design activities are carried out is constantly changing, which also changes the ethical challenges. The participants' health and wellbeing can for instance change over time, which affects the ethical circumstances. For example, while informed consent is typically considered static, there are complications in sensitive design situations that can change how voluntary participation is during and between activities (Munteanu et al., 2015). Participants may be unable to express their change in consent, may be physically unable to leave, or may be in a position of power where they experience that they cannot end their participation (Culén & van der Velden, 2013). As such, ethics in PD in sensitive design situations is an on-going process and ethics needs to be pervasive throughout the entire design process (Frauenberger et al., 2017).

Ethics in PD is *diverse*. The ethical challenges in sensitive design situations can vary in nature and severity. They can for example relate to the abilities of the participants, the complexity of the context of use, or stakeholder complexity. Ferguson et al. (2017) identify a framework of seven ethical themes for reflecting on and articulating ethical dilemmas; we can also see the diversity in the varying cases and examples used to explore ethics in PD by Frauenberger et al. (2017), Munteanu et al. (2015) and Waycott, Wadley, et al. (2015).

Any research carried out in the field is invariably impossible to predict; ethics in PD is therefore *unpredictable*. Designers will encounter ethical dilemmas (Waycott, Davis, et al., 2015) where they face choices that seem to have no right or wrong answer. The nature of these dilemmas arise from the situation in which the design is carried out (Munteanu et al., 2015; Waycott, Davis, et al., 2015).
CHAPTER 3

Research Methodology

This chapter describes the research approach used to answer the research question: *How can users be involved in sensitive design situations?* This chapter describes Design Research (DR), the main research approach for this thesis, and how the research process was carried out. Lastly, I reflect upon quality criteria for DR, ethics, and the transferability of the results from this study.

3.1 Design Research

Design Research is an approach to research that sees knowledge as the product of the design and evaluation of artefacts, and where the researcher is simultaneously a researcher as well as a designer. Design is used as a way to do more than just solve problems; it is about reaching a preferred future state (Nelson & Stolterman, 2003), and produce knowledge through constructing artefacts (Zimmerman et al., 2007). The focus of DR is not primarily to create artefacts for a consumer market, but instead to further knowledge through design (Zimmerman et al., 2007).

It is possible to distinguish different discourses within DR. One discourse originates in Information Systems, also referred to as design science or design science research (see e.g. Pries-Heje & Baskerville, 2008; Vaishnavi & Kuechler, 2004). Another originates in Human-Computer Interaction, also referred to as research through design or constructive design research (see e.g.
Fallman, 2008; Koskinen et al., 2011; Zimmerman et al., 2007). Common in these discourses is the furthering of knowledge through design, with a focus on the future and what will be. DR roots its philosophical underpinnings in the writings of Herbert Simon in the 1960's (see e.g. Simon, 1996) and Nigel Cross (see e.g. Cross, 2001), with important influences from for example Donald Schön and the concept of the reflective practitioner (see e.g. Schön, 1984).

There were several reasons for using DR to conduct this research. For one, DR resonates well with the challenges of the third wave of design (Durrant et al., 2017). A goal of DR is to create a transformation, and the aim of this research is to aid designers and better understand ethics of user involvement in sensitive design situations; as such, it was considered important to actually carry out design in such a situation. Being close to the object under study would arguably lead to a better understanding of it, and DR can serve to contextualise research (Keinonen, 2010).

DR as a research approach is still taking shape (Fallman, 2008; Koskinen et al., 2011; Roth, 1999). Yet, it is possible to distinguish distinctive assumptions and positions inherent in the approach. First, knowledge is created through the design and evaluation of artefacts (Koskinen et al., 2011). The artefact serves not only as a knowledge creation tool, but also as a demonstrator of the research contribution (Zimmerman et al., 2007). It can serve as a way to both reach the solution to a problem, as well as the intended future state. The artefact can also inform future research in the sense that it makes the knowledge transferable. In order to drive knowledge creation, theory is built into the artefact; artefacts are considered embodiments of theory (Zimmerman et al., 2007). This study consists of two design projects with the purpose of designing Digital Peer Support (DPS): CHIPS, a project aimed at designing DPS for children between 8-12 cured from cancer; and LiwS, a project aimed at designing DPS for people diagnosed with schizophrenia. Though both projects were aimed at designing DPS, the DPS artefacts are not the focus here; the design of DPS is inherently sensitive, which means that both design projects involved handling sensitive design situations. In this research, the artefacts are the instances of user involvement in both projects, and by communicating the knowledge as principles, it is possible to transfer to other situations.

Secondly, DR should be relevant in practice and drive change (Zimmerman, Stolterman, & Forlizzi, 2010). The topic of this research, the ethics of PD in sensitive design situations, is highly relevant; there is a contradiction in the ethical practice of PD when it is considered unethical to exclude users from the design process (Bravo, 1993), despite the high risk of harm that comes with
involving users in sensitive design situations. Meanwhile, the involvement of vulnerable user groups is valued in terms of inclusivity and carries the potential for empowerment, so it is important to support PD researchers in ethical practice to enable that involvement.

Thirdly, the inherent reliance on creativity as part of the research process separates DR from other paradigms (Koskinen et al., 2011). It is never possible to reproduce the outcome of a DR process, because each process is contextual and dependent on the creativity and imagination of the researchers (Zimmerman & Forlizzi, 2014). Instead, since theory is built into the artefact, the artefact can be used to critically evaluate the knowledge, and the artefact can communicate the transferability of this knowledge in the sense that it can serve as an allegory. In this research that studies user involvement in sensitive design situations, the users were involved in ways adapted to each design situation, and this adaptation was done based on an understanding gained from related literature, empirical studies, as well as creative choice. In this way, creativity played a part in this research. Further reflections on the transferability of this research can be found in the end of this chapter, and in chapter 6.

Lastly, DR is iterative, where each iteration tests an alternative solution in order to create knowledge (Koskinen et al., 2011). The iterations that make up this research are described in depth in chapter 4, which also describes the design projects in more detail. In summary, this research began with the intent of studying the design of DPS but early iterations already indicated the importance of ethics, which gradually led to a shift in focus. Evaluations have been iteratively done through reflection, summatively after each design process, and finally through an additional summative study of both finalised design projects. Each paper included in this thesis presents one iteration.

DR differs from non-research design practice, or routine design. There is a difference in intent; the focus is on producing knowledge, not creating products for a market (Zimmerman et al., 2007). Throughout this research, the intent has been to better understand user involvement in design in a sensitive design situation. This is the key that differs a design researcher from a routine designer; that there is an underlying research question to the design work (Fallman, 2008).
3.2 Research Process and Method

This research consists of the study of two design projects aimed at designing DPS. My role has been that of an involved researcher (Walsham, 1995b) as an active agent in both project teams. The focus on ethics emerged through an iterative research process centred on activities involving users in sensitive design situations. Each iteration developed my insights into the importance of ethics in sensitive design situations. Table 3 provides an overview of the research process, while the research iterations and the outcome of each iteration is described in more detail in chapter 4.

Table 3. Overview of the research process

<table>
<thead>
<tr>
<th>Year</th>
<th>2012</th>
<th>2013</th>
<th>2014</th>
<th>2015</th>
<th>2016</th>
<th>2017</th>
<th>2018</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• Joined the CHIPS project in the spring</td>
<td>• Personas and scenarios in CHIPS</td>
<td>• Paper 1 published</td>
<td>• Evaluations in CHIPS</td>
<td>• Future workshops in LiwS</td>
<td>• Paper 2 published</td>
<td>• Paper 3 submitted for second round</td>
</tr>
<tr>
<td></td>
<td>• Literature review on PD with children</td>
<td>• Feedback workshop in CHIPS</td>
<td>• Literature review on evaluations with children</td>
<td>• Literature review on design with people diagnosed with schizophrenia</td>
<td>• Future workshops in LiwS</td>
<td>• Paper 4 accepted for publication</td>
<td>• Paper 5 submitted</td>
</tr>
<tr>
<td></td>
<td>• Design workshops in CHIPS</td>
<td>• LiwS project initiated</td>
<td>• Stakeholder interviews in LiwS</td>
<td>• Literature review on ethics in design</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Through my involvement in the two design projects, I have been able to first-hand experience ethical dilemmas in sensitive design situations. For a qualitative researcher, having access to real-world situations is crucial, and I have been directly involved in two design projects in sensitive design situations. The remainder of this section will describe the research activities in more detail.

This research was conducted using a broad selection of qualitative data collection methods such as design workshops, interviews, a diary study, and qualitative usability tests. A variety of methods are used within DR (Roth, 1999; Zimmerman et al., 2010), but the focus on creating a preferred future state and the complexity of the problems addressed through DR indicate the suitability of qualitative methods (Roth, 1999). While qualitative and quantitative methods can be used irrespective of research paradigm (Guba & Lincoln, 1994), qualitative methods are especially suited for DR (Roth, 1999).

Qualitative methods enable the study of social and cultural phenomena (Myers, 1997a) and are suitable for understanding contexts and processes (Walsham, 1995a). In comparison to quantitative methods that look for cause-effect relationships through structured observation, qualitative methods are more
suitable for dealing with wicked problems (Walsham, 1995a); that is, problems that are constantly changing, contradictory and complex (Rittel & Webber, 1973). Since the aim of this research was to study how users can be involved in sensitive design situations, which presents many ethical challenges, the phenomenon under study was not only complex but also required flexibility and critical reflection. Table 4 summarises the data collection activities included in this research.

Table 4. Summary of data collection activities

<table>
<thead>
<tr>
<th>Year</th>
<th>Project</th>
<th>Activity</th>
<th>Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>2012</td>
<td>CHIPS</td>
<td>Design workshops</td>
<td>5 children aged 11-13 with a history of cancer</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Persona development</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>Scenario development</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Iterative design and prototyping</td>
<td></td>
</tr>
<tr>
<td>2013</td>
<td>CHIPS</td>
<td>Feedback workshop</td>
<td>7 children aged 10-12 without a history of cancer</td>
</tr>
<tr>
<td>2014</td>
<td>LiwS</td>
<td>Stakeholder interviews</td>
<td>4 parents of people diagnosed with schizophrenia, 1 activity coordinator, 1 psychiatric nurse, 1 housing support</td>
</tr>
<tr>
<td>2015</td>
<td>CHIPS</td>
<td>Evaluation: usability tests</td>
<td>6 children aged 10-12 without a history of cancer</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Evaluation: diary study</td>
<td>10 children aged 10-12 without a history of cancer</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Evaluation: focus group interview</td>
<td>7 children aged 10-12 without a history of cancer</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Evaluation: survey</td>
<td>7 children aged 11-16 with a history of cancer</td>
</tr>
<tr>
<td></td>
<td>LiwS</td>
<td>Future Workshop</td>
<td>2 people diagnosed with schizophrenia</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Iterative design and prototyping</td>
<td></td>
</tr>
<tr>
<td>2016</td>
<td>LiwS</td>
<td>Future Workshop</td>
<td>2 people diagnosed with schizophrenia (1 quit after the first workshop)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Iterative design and prototyping</td>
<td></td>
</tr>
<tr>
<td>2017</td>
<td>LiwS</td>
<td>Prototype development and evaluation</td>
<td>2 people diagnosed with schizophrenia</td>
</tr>
</tbody>
</table>

*Design workshops* were used as a primary source to involve users. Workshops were conducted in the CHIPS project with children between the ages 10-13, both with and without a history of cancer, and in the LiwS project with people diagnosed with schizophrenia.
In the CHIPS project, users were involved in usability tests, a diary study and a qualitative survey study. The usability tests involved six children without a history of cancer, and served to evaluate the ease of use and learnability of the digital artefact that had been designed in the project. The diary study evaluated the use of the digital artefact over two weeks with ten children participating. The survey study evaluated the concept for the digital artefact, and was filled out by seven children and young adults with a history of cancer.

Interviews were used to gain a situational understanding as well as for evaluative purposes. Individual interviews with stakeholders in the LiwS project served to further the understanding of the design situation and possibilities for people diagnosed with schizophrenia to participate in design. Focus group interviews were used in the CHIPS project as part of the evaluation of the digital artefact, and in the LiwS project as part of the design workshops.

Some design activities were also carried out without including users, such as persona and scenario development, and iterative design. In both design projects it proved impossible to involve users in all design activities for various reasons, such as user access, cognitive ability, risk of over use, and issues of wellbeing. However, all interpretations and design decisions made during these activities were later presented to the users in various ways, for feedback and verification.

The data has been analysed using different approaches depending on the aim of the analysis and the nature of the data. I performed the majority of the transcription and analysis, which created a familiarity with the material. In two of the papers, software specifically designed for qualitative analysis was used. Table 5 summarises the data collection and analysis of the individual papers. Paper 1 performed abductive thematic coding with the aim to understand how literature on ethics had driven the design choices; Paper 2 performed a deductive thematic analysis on the basis of literature on involving children in evaluations, with the aim to understand how to handle the challenges that emerged; Paper 3 performed a grounded theory analysis with the aim to understand the complexity of the design situation; Paper 4 performed an inductive thematic analysis to understand the challenges and success factors for involvement of vulnerable users; and Paper 5 performed a variation of the Critical Incident Technique to identify ethical dilemmas when involving users in sensitive design situations, and resolving actions taken to handle them. The dilemmas were conceptualised to actionable guidelines on the basis of a systematic literature review. The individual papers take a practice-oriented perspective on the research contribution, while this cover paper provides a
perspective on a principle level through conceptualisation using the state of the art literature presented in chapter 2.

Table 5. Summary of adopted research methods in the individual papers

<table>
<thead>
<tr>
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</thead>
<tbody>
<tr>
<td>CHIPS</td>
<td>CHIPS</td>
<td>LiwS</td>
<td>LiwS</td>
<td>CHIPS and LiwS</td>
<td></td>
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<tr>
<td>In situ guidance for ethics in sensitive design situations</td>
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<td></td>
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<tr>
<td>Proactively adapting design activities to ethical considerations</td>
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<tr>
<td>Involving children in the evaluation of DPS</td>
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<tr>
<td>Understand the wickedness in the design of DPS for people diagnosed with schizophrenia</td>
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<tr>
<td>Involving people diagnosed with schizophrenia in the design of digital technology</td>
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<tr>
<td>Participatory design with children</td>
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<tr>
<td>Ethics in design with children</td>
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<tr>
<td>Involving children in evaluations</td>
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<tr>
<td>Research with vulnerable children</td>
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<tr>
<td>Schizophrenia Wicked problems</td>
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<tr>
<td>Schizophrenia User participation in design</td>
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<tr>
<td>Ethics in design</td>
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<tr>
<td>Design workshops</td>
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<tr>
<td>Usability test</td>
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<tr>
<td>Diary study</td>
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<tr>
<td>Focus group interview</td>
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<tr>
<td>Survey</td>
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<tr>
<td>Interviews</td>
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<tr>
<td>Focus group interviews</td>
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<tr>
<td>Design workshops</td>
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<tr>
<td>All data from CHIPS and LiwS</td>
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<tr>
<td>Abductive thematic coding</td>
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<tr>
<td>Deductive thematic analysis</td>
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<td>Grounded theory analysis</td>
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<tr>
<td>Inductive thematic analysis</td>
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<tr>
<td>Variation of Critical Incident Technique</td>
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</tbody>
</table>

As this thesis consists of this cover paper and five individual research papers, table 6 summarises my contributions to the individual papers. I am the first author of all the papers, with an active part in all data collection. Further, I took the lead in the data analysis in four papers, with an equal share of the analysis in the fifth (Paper 1). One paper is a single authored paper (Paper 3).
Table 6. My contributions to the included papers

<table>
<thead>
<tr>
<th>Paper</th>
<th>My contribution</th>
</tr>
</thead>
</table>

3.3 Quality Criteria for Design Research

Zimmerman et al. (2007) present four quality criteria for evaluating the research contribution of DR. I will here reflect briefly on this research in relation to the four criteria, in order to evaluate the quality of this research.
Process
It has to be possible to evaluate the rationale behind the choice of the applied research methods, and the rigor with which they have been applied (Zimmerman et al., 2007). Since creativity is a fundamental part of design (Nelson & Stolterman, 2003), transparency is particularly important. Methods appropriate for the research purpose have been used; qualitative methods were found suitable due to the explorative nature of researching a scarcely researched sociotechnical phenomena (Myers, 1997b). Papers 1 and 2 describe the theoretical foundations for the methodological choices made in the CHIPS project; the papers describe in detail how the children were involved in the different stages of the design and evaluation processes. Papers 3 and 4 do the same for the LiwS project. In both projects, the choice of design techniques used was grounded in the literature and empirical studies, previous experience, along with a level of creativity. In the interest of methodological transparency, the two design projects are also described in more detail in chapter 4 of this thesis.

Invention
The contribution from DR must be novel in the sense that it should advance the current state of the art (Zimmerman et al., 2007); in chapter 2 the current state of the art on ethics in PD is detailed, summarising distinctive features of ethics in sensitive design situations. This research contributes to the state of the art by providing not only a practice-oriented approach to ethics in design in the individual papers, but also by furthering the understanding of design situations as being sensitive, and emphasising ethical values of importance for user involvement in sensitive design situations. This cover paper proposes principles for ethical user involvement, and as such, makes ethical values explicit.

Relevance
While validity is often the focus of other research paradigms, DR values relevance; DR contributions should be articulated in relation to a preferred state, with motivation of why this should be preferred (Zimmerman et al., 2007). As society becomes more inclusive, and digital technology more widespread, ethical issues will only become increasingly important. The growing body of literature on ethics in design and PD in sensitive design situations shows the pertinence of this research. The increase of PD in previously unexplored, sensitive design situations has served to raise the demand for research on ethics in PD. Furthermore, the previously mentioned complications of user involvement in sensitive design situations, and the high risk of harm to participants, show the necessity of the research.
Extensibility

It should be possible to further develop the contribution from DR (Zimmerman et al., 2007). A key ability of a design researcher is the ability to communicate a preferred state – something that does not yet exist – and thus enable it to be attained (Nelson & Stolterman, 2003). The communicated knowledge should be possible to use by the community; it should drive further research and practice (Zimmerman et al., 2007). By formulating the contribution as principles, the contribution is intended to be concrete and practicable by the PD community. The research findings have been communicated to both audiences at international conferences and international journals, at seminars and local conferences for both researchers and practitioners, and as part of presentations to various audiences at national conferences. The language in all publications is, to the best of my ability, easy and concise.

3.4 Ethical Considerations

All research must follow basic research ethical principles; these typically include questions of autonomy, beneficence, justice and non-maleficence (Mingers & Walsham, 2010). Due to the sensitive nature of this research, it is particularly important to emphasise that the research has been conducted in an ethical manner. Therefore, this section will reflect upon the ethics of this research following the ethical framework for qualitative research presented by Tracy (2010). As the framework is specifically adapted to qualitative research, it is suitable as a foundation for this reflection.

Research ethics can be separated into four kinds: procedural ethics, situational ethics, relational ethics and exiting ethics (Tracy, 2010). Procedural ethics contain the ethical principles that are determined by organisations or institutions (Tracy, 2010) and highlight ethical standards that all research should live up to. In this research, I have followed the ethical recommendations by the Swedish Research Council (see Hermerén, 2011). It is important to ensure that the research is ethically responsible by attaining informed consent, during the conduct of the research by avoiding risk of harm to participants, and after the research has been conducted when publishing the results (Hermerén, 2011). Both projects included in this research have been subject to an ethical review by the regional ethical review board.
Situational ethics is unique to each research situation and can only be ascertained through critical reflection by the researcher (Tracy, 2010). Since the research in this thesis involves the exploration of sensitive design situations, it has been of utmost importance to grant the participants anonymity and handle the data confidentially. This was also stressed by some of the participating stakeholders in the LiwS project who were concerned that their participation could hurt their relatives. As such, all information that may lead to the identification of the participants has been excluded, and the data is stored on encrypted servers, or on external hard drives in restricted locations.

Additionally, important ethical questions in this research do not only include the handling of the participants' information. There was a risk to the participants' wellbeing; the subject matter in both projects was sensitive and could cause harm. In the CHIPS project, at least one of the researchers who participated in all activities had a background in nursing, and in the LiwS project one of the researchers also had a background in nursing, with extensive experience from caring for people diagnosed with schizophrenia. They could use their expertise to reduce risks to the participants' wellbeing, and if anything occurred to negatively affect the participants, they had knowledge on the best course of action to minimise that effect.

Relational ethics implies that researchers should take care how they affect others, and to respect the participants in the conduct of the research (Tracy, 2010). This can be done for example by giving the participants a say in how the research is conducted, and to ensure that open and honest communication exists between participant and researcher (Tracy, 2010). This research has been conducted closely together with users, and users have to a great extent driven design decisions. There has been a focus on empowerment of the participants, and on helping them communicate their design needs. Both projects took the view of the user as an expert on their own situation, and therefore it was necessary as part of the research, and not only from an ethical standpoint, to create a reciprocal process.

Lastly, exiting ethics relates to how the research is presented and understood; researchers should not highlight only the "great stories", but give an unbiased picture of the research (Tracy, 2010). There is also a risk that research can do harm if it leads to further stigmatisation of already stigmatised groups, or if marginalised groups are portrayed negatively (Tracy, 2010). This is highly relevant to this research; it is possible that by highlighting the challenges that were encountered in this work I have boosted existing prejudice. I have endeavoured to tackle this risk by focusing on the major contribution of the
participants in this research. Further, I have been careful to use terms that do not equate the participants with their diagnoses. For example, while the LiwS project involved people diagnosed with schizophrenia, it does not mean that their diagnosis defines who they are. Schizophrenia is a diagnosis that cannot be made using an objective test, but rather through the elimination of other diagnoses. Meanwhile, it is associated with a greater degree of stigma. Therefore, I considered it important to not suggest that someone diagnosed with schizophrenia is defined by it. Simply by showing that it is possible to involve vulnerable users in PD, and in that process attempt to empower them, goes against established discourses about what vulnerable users, such as people diagnosed with schizophrenia and children with a history of cancer, can do.

3.5 Reflections on Limitations and Transferability

In simple terms, one can separate a design process into three parts: before, during and after design. This research does not take into account the third and final part, what happens after the design process is complete and the digital technology has been introduced. It is important to be aware that this also raises ethical challenges related to the digital artefact, such as acceptance, risk of stigmatisation, and privacy. However, this is out of scope for this research.

It is possible to produce an intermediate kind of generalisation through qualitative research (Payne & Williams, 2005); it is also common to discuss transferability rather than generalizability in relation to qualitative research. Transferability is a judgement made regarding the degree of which the findings could be transferred to another situation; this judgement can only be made by someone who has knowledge of both the sending and receiving situation, and thus it is important to provide a thick, detailed description of the research and the research context (Lincoln & Guba, 1985). A thick description in this context involves the appropriate amount and type of information necessary to make a judgement of transferability (Lincoln & Guba, 2000). I have attempted to incorporate the relevant information throughout this cover paper and the included research papers. The outcome is formulated as principles for user involvement in sensitive design situations, formulated to enable transferability to other relevant situations. In an interest of transparency, I also reflect on the transferability of the research in chapter 6.
This thesis presents a DR study of two design projects. This chapter describes the design study and the context for the research in more detail. The chapter also presents the two design projects: CHIPS and LiwS, and how each iteration of the design study contributes to the outcome of the research.

4.1 Digital Peer Support

The goal of both design projects that constitute the empirical material was to design Digital Peer Support (DPS). In order to expand on the sensitivity of the two design projects, I describe DPS in more detail. In order to define DPS, I draw on literature on peer support (mutual support groups, group support) and social media (social networking, blogs, virtual social worlds).

Peer support is social support based on a reciprocal process of peers with shared experiences providing each other with social support (Barak, Boniel-Nissim, & Suler, 2008; Klemm & Hardie, 2002). Peer support can help reduce some of the participants' symptoms, extend their social networks, increase their social interaction and positively affect their quality of life (Solomon, 2004). Peer support can further reduce symptoms of depression and improve the emotional state and sense of self-worth (Barak et al., 2008; Schwartz & Sendor, 1999).

The aim of peer support is to improve or maintain the wellbeing of the participants (Solomon, 2004). Wellbeing is a subjective concept; Dodge, Daly,
Huyton, and Sanders (2012) define it as a balance between an individual's psychological, social and physical resources to handle challenges on one side, and the challenges they face on the other. The perception of wellbeing and balance can vary by situation and individual (Dodge et al., 2012).

Engagement in peer support, since it leads to improved wellbeing, can also lead to fewer hospitalisations and thus potential cost savings (Solomon, 2004). Furthermore, some peer support can reach those who require, but may not trust or be able to access health services (Solomon, 2004), for example the homeless (Segal et al., 1998). Also, benefits do not only lie in the received support, but also in the providing of support (Schwartz & Sender, 1999; Solomon, 2004). Peer support is sometimes referred to as mutual support (e.g. Munn-Giddings & McVicar, 2007), highlighting the reciprocity of the support. The nature of peer support interaction varies; it can be provided between two people (one-to-one) or in groups (many-to-many), in different milieus, and be professionally moderated or peer-led (Dennis, 2003).

Social media is defined as Web 2.0 Internet based applications that are made up of user-generated content (UGC) and are built around the concept of user profiles to create networks and relationships between users and groups (Obar & Wildman, 2015). Examples of social media include social networking sites (e.g. Facebook), blogs, collaborative projects (e.g. Wikipedia), content communities (e.g. YouTube) and virtual social worlds (e.g. Second Life); these differ as to richness in social presence and self-presentation (Kaplan & Haenlein, 2010).

Since the key content of social media is UGC, and its function is to create networks of users, it is an ideal platform for DPS, that is, peer support provided through digital technology. There are many examples of DPS being carried out using social media, for example using Facebook groups (Oh, Lauckner, Boehner, Fewins-Bliss, & Li, 2013). A unique feature of DPS is that the provided support is available around the clock (Niela-Vilén, Axelin, Salanterä, & Melender, 2014; Setoyama, Yamazaki, & Namayama, 2011). However, in some cases it is not possible to use existing social media structures; for example when the users are too young to use social networking sites that often have age limitations, when requirements of privacy or privilege are higher than normal, when users need more support or better accessibility for their interaction than what is typically provided in social media applications, or when the risk of misinformation is high. Studies have for example shown risks of manipulation and security (Househ, Borycki, & Kushniruk, 2014) and risks of being identified and exposed to associated stigmatisation (Naslund, Grande,
Aschbrenner, & Elwyn, 2014). Compared to social media, DPS often has higher requirements regarding privacy, accuracy of information, and security.

In contrast, social media has been dedicated to peer support (e.g. online.supportgroups.org or The Experience Project). These are unrelated to general social media, such as Facebook or YouTube, in the sense that it is not connected to a public profile, which gives users more control over their privacy. This dedicated DPS goes under many names, for example "online support group" (e.g. Barak et al., 2008; Khair, Holland, & Carrington, 2012; Klemm et al., 2003), "online self-help group" (e.g. Hsiung, 2000), "online peer support" (e.g. Ali, Farrer, Gulliver, & Griffiths, 2015; Masuda, Anderson, Letourneau, Morgan, & Stewart, 2013; Melling & Houguet-Pincham, 2011), or "patient communities" (e.g. Josefsson, 2005; Leimeister, Ebner, & Krcmar, 2005). Since DPS is more specialised than typical social media, it can be designed to not only connect users through a shared background, but also through aspects such as age, interests and preferences, while simultaneously meeting the users' accessibility needs (O'Leary et al., 2017).

Similar benefits of peer support engagement have been found for DPS (Melling & Houguet-Pincham, 2011). However, there are few studies that validate the benefits (Melling & Houguet-Pincham, 2011), possibly because the subjects are so diverse (Barak et al., 2008). There are indications that benefits of DPS engagement include empowerment (Barak et al., 2008), improved coping strategies (Tanis, 2007), reduction of self-stigma (Lawlor & Kirakowski, 2014), and comfort (Setoyama et al., 2011). Nevertheless, it is suggested that the users' activity level is a significant factor for the amount of experienced benefits from DPS; several studies have found that while active users experienced benefits, the so called "lurkers" – the users who only read but do not contribute themselves – did not experience the same benefits (Lawlor & Kirakowski, 2014; Setoyama et al., 2011).

Based on the presented literature, this thesis defines DPS as a reciprocal process of social support provided by peers, with the aim to improve or maintain wellbeing, conducted using digital technology. Because the users of DPS engage in these support channels as a means of dealing with having difficult experiences, there is a built-in sensitivity.

In addition to the built-in sensitivity, the design of DPS aimed towards vulnerable user groups is complicated further. It is not uncommon that DPS is aimed at physical (e.g. Klemm et al., 2003; Nicholas et al., 2009) and mental health related issues (e.g. Kaplan, Salzer, Solomon, Brusilovsky, & Cousounis,
2011; Melling & Houguet-Pincham, 2011), or other stigmatised or sensitive topics (e.g. Tixier & Lewkowicz, 2011). Since each individual case of design of DPS involves different subjects, user groups, and is thusly made up of different combinations of challenges, each case of design of DPS will invariably be unique, sensitive and complex.

4.2 Designing Digital Peer Support

Two design projects make up the empirical material for this thesis: CHIPS and LiwS. Both projects were aimed at designing DPS and involved users and other stakeholders in participatory activities. Here I describe the projects in detail.

4.2.1 CHIPS

The Child Health Interactive Peer Support (CHIPS) project was initiated in 2011, and it was in early 2012 that I joined. The goal of the project was to design DPS for children between 8-12 who have survived cancer. Adolescents who have gone through the experience of cancer treatment as children can experience feelings of being different from their friends (Enskär & Berterö, 2010). Therefore, the aim of the project was to connect children with peers who shared their experience of cancer treatment before they reached an age when these relationships would be decisive for their wellbeing. Focus group interviews with children who had gone through cancer treatment, as well as individual interviews with stakeholders such as doctors, nurses and support staff, had already been conducted by the time I entered the project.

Children are considered vulnerable in all research, due to their relative lack of power in society (Liamputtong, 2006). Additionally, this context relates to the experience of cancer treatment, a process that can be painful and traumatic (Stuber, Christakis, Houskamp, & Kazak, 1996). Because cancer is common (in 2015, 65,000 cases of cancer were diagnosed (Cancerfonden, 2017) in Sweden, in a population of approximately 9,800,000), even children who have not experienced cancer treatment themselves are likely to know of someone who has. Furthermore, children who have gone through cancer treatment can have cognitive limitations, such as difficulty concentrating (Moore, Hockenberry, & Krull, 2013), or physical limitations (Rueegg et al., 2012).
The regional ethical review board reviewed the project. The focus of the activities involving children was specified as salutogenic (health related), in contrast to a pathogenic (disease related), which would have focused on the cancer experience. As a result, many common techniques for involving children in design could not be used, as they focus directly on the subject for the design; instead it was necessary to devise design techniques that allowed the exploration of the children's experiences, without speaking directly of them. A literature review led to the conclusion that proxies could be used in order to speak about the subject of being unwell, without focusing on the children's own experiences. The concept of comicboarding (see Moraveji, Li, Ding, O'Kelley, & Woolf, 2007) was influential in the choice of setup for the two rounds of three workshops that were conducted initially. Characters were used as proxies, and comics were used to create scenarios. We worked in pairs with the children to ensure their wellbeing and to help them maintain focus. More details on how the workshops were conducted are described in Papers 1, 2, 5 in this thesis, and in Lindberg (2013).

Some dilemmas further complicated the design process. One such dilemma was user access; after the initial design workshops and a follow-up meeting, some of the children had aged out of the 8-12 age span, and all the children had spent a great deal of time on the design activities. The choice was made to not involve the same users further. However, recruiting more children with a history of cancer proved impossible. This was primarily due to gatekeeper complexity, as
it was not possible to recruit children directly. We attempted recruitment through a child oncology ward, but the staff was too busy to aid in recruitment, and recruitment via parents using social media yielded nothing.

Instead of excluding users completely, children without a history of cancer treatment were involved as representatives in the remainder of the design activities, including a feedback workshop and evaluations. This limited the possibilities for feedback on specific issues relating to the possibilities for engaging in peer support, but allowed for feedback on usability, user experience, and the possibility of making friends.

Based primarily on the design workshops, iterative design work and the feedback workshop, a final design concept and high-fidelity prototype was developed. This concept was named Give Me a Break\(^1\), and the prototype was developed by a game development firm. It focused on the social experience of having breaks between classes at school – breaks that children who undergo cancer treatment tend to miss and are essential for the children's social

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\(^1\) For more information on the prototype, see http://givemeabreak.se/
development; one consequence of having cancer as a child is missing out on activities with friends (Pöder, Ljungman, & von Essen, 2010). The design concept involved three categories of users: the children between 8-12 who were the main target group; alumni who were older but wanted to support the younger children; and adult pedagogues who created activities, ensured the children's wellbeing, and moderated the interaction. Figure 2 shows screenshots from the four areas in the Give Me a Break prototype.

The CHIPS project ended in 2015. The results of the evaluations were promising, and there was potential for Give Me a Break to be useful for the children as support, and to create the contacts with peers with shared experiences that might become vital as they grow older.

4.2.2 LiwS

The Living with Schizophrenia (LiwS) project was initiated in 2014 as a small part of a larger project that aimed to improve the wellbeing of people diagnosed with schizophrenia. The project was specifically aimed at designing DPS for people diagnosed with schizophrenia. Schizophrenia is an illness that is often misunderstood and socially stigmatised (Campellone, Caponigro, & Kring, 2014). Schizophrenia is characterised by psychotic symptoms, apathy, withdrawal and cognitive impairment (Frangou, 2008). This implies mostly cognitive symptoms, such as deficits in memory, attention, verbal ability, and illogical thinking (Schuldberg, 2001; Wilder-Willis, Shear, Steffen, & Borkin, 2002), often combined with depression and lethargy (Kay, 1991).

Schizophrenia is primarily treated using anti-psychotic medication, which treats the most acute symptoms but tends to have a limited effect on cognitive symptoms (Wilder-Willis et al., 2002). The target user group for the LiwS project were those diagnosed with schizophrenia who have not been able to return to a normal life after the onset of the illness; about 10% of those affected by schizophrenia never recover (Frangou, 2008) and require support with everyday tasks.

Symptoms of the illness, combined with possible, severe side effects from the medication (DiBonaventura, Gabriel, Dupclay, Gupta, & Kim, 2012), social isolation (Castelein, Bruggeman, Davidson, & van der Gaag, 2015) and social stigmatisation (Campellone et al., 2014), make it difficult for users to participate in design. Further, many people with schizophrenia in Sweden are on disability pension, and therefore do not have the economic circumstances to purchase digital technology. Paired with the common symptom of paranoia
(Kay, 1991) aimed towards technology, and having experienced negative consequences of naïve technology use in the past, this can result in users lacking experience with digital technology.

Due to the target user group being considered particularly vulnerable, it was thought advisable to initiate the project with stakeholder interviews to gain as complete of an understanding of the challenges for user involvement as possible. Relatives of people diagnosed with schizophrenia as well as medical personnel were interviewed. The outcomes of the interviews are described in more detail in Papers 3 and 4. The interviews concluded that the stakeholders viewed it as potentially difficult to work together with the target user group to design DPS, and that there was a risk of the DPS not being used, due to lack of digital technology use. Despite this, the stakeholders all agreed that there was a great need for anything that could improve the everyday lives and wellbeing of their sons, daughters, and patients, which motivated the continued work on the design of the DPS.

Due to the vulnerability of the target user group and their inexperience with digital technology, the choice was made to adapt the format of Future Workshops (see e.g. Denvall & Salonen, 2000; Müllert & Jungk, 1987; Vidal, 2005) to involve the users in design activities. All four people who participated in the workshops had had their diagnosis for more than 10 years and lived with varying support from healthcare providers. Despite careful planning and discussion about the setup of the workshops, some unforeseen issues occurred. Most were minor and could be handled by simply being flexible in the setup of the workshops, for example by working together in one group instead of splitting into smaller constellations. I, myself, consider one event that occurred to be major, and that was when one of our questions unexpectedly led one of the participants to talk about the voices that he heard, which made him visibly uncomfortable. The question was changed for the second round of workshops to avoid the possibility of this happening again. One of the other researchers in the project was also a nurse and maintained contact with the participants between the workshops to ensure that they were not harmed.

Another dilemma during the design workshops was that due to the users' inexperience with digital technology, it was difficult for them to communicate their technology needs. The participants had varying experience with digital technology, and while they all owned smartphones, some were more frequent users than others. The low-fi prototypes that we created together had to be adapted in order to be realistic. It was, for example necessary to break some ideas down into separate concepts after the workshops. Further, one of the
participants ended his participation after the first workshop because he, as he described it, was going through a period when he did not want to do anything.

After the two rounds of workshops we had developed four low-fi prototypes, but lacked the possibility of developing them further, which halted the process. It was not until the spring of 2017 that the possibility of involving a group of four students in the development of a mixed-fidelity prototype presented itself. The students developed the prototype as part of one of their bachelor level courses in the program Digital Design and Innovation. They were given access to the project's articles and anonymised material from the workshops. I supervised their work and joined them in two meetings with two participants, in which we involved the participants for feedback on and evaluations of the prototype. The outcome of the students' project was a mixed-fidelity prototype, and although the functionality was limited to a specified scenario, it granted us the possibility to test and evaluate. The feedback from the two participants was positive as to both its functionality and use.

Figure 3 shows screenshots from the prototype. The prototype is a mobile application, which involves the use of anonymous posts to express feelings and connect with others. Through anonymous user profiles and a high level of profile access control, managing who can see and interact with one's profile, the intent was to create a feeling of trust between the users and the application. Posts are organised using simple tags in order to facilitate easy lookup and connectivity between users; users choose the posts that they are interested in and can contact the author anonymously to initiate a conversation.

The LiwS project ended in 2017 after the development of the prototype. There is still hope to develop the prototype further based on the positive feedback from the participants, and the need for support expressed by the stakeholders.
Figure 3. Screenshots from the LiwS prototype
4.3 Design Iterations

This research has been a process of exploration. The process has been iterative, reflexive, and grounded in the problem relevance. Each iteration has served to further my understanding of the complexity of user involvement in sensitive design situations, and has contributed to my understanding of the relevance and outcome of this research. Figure 4 illustrates and summarises the iterations.

Iteration 1 consists of exploring and ideating design activities from the CHIPS project, including design workshops, persona and scenario creation, and a feedback workshop. This iteration is communicated in Paper 1, and ethics in already here highlighted as being particularly important for user involvement. The iteration contributes with a perspective of how design activities can be adapted from an ethical point of view. Yet, at this stage the extent of the importance of ethics was not clear to me.
Iteration 2 consists of evaluating activities from the CHIPS project, including usability tests, a diary study and a survey. This iteration is communicated in Paper 2, and identified challenges for user involvement and strategies for handling these challenges.

Iteration 3 consists of exploring activities from the LiwS project, including stakeholder interviews and focus group interviews. The iteration is communicated in Paper 3, and provided and in-depth perspective on the complexity of user involvement in sensitive design situations, and also showed the importance of a grounded understanding of the design situation.

Iteration 4 consists of exploring and ideating activities from the LiwS project, including the stakeholder interviews and future workshops. The iteration is communicated in Paper 4, and identified challenges for user involvement and strategies for handling these challenges and unlocking the design potential of the participants. Together, iteration 2 and 4 emphasise the complexity of user involvement in sensitive design situations.

Iteration 5 provides an ethical perspective on the activities of both projects. This iteration showed that there is a need for literature on ethics of user involvement, and that ethics is imperative when users are involved in sensitive design situations. The iteration is communicated in Paper 5, and contributed with guidelines for ethical user involvement in design. The guidelines are oriented to practice, and intended to be applicable by designers who intend to involve users in sensitive design situations. As such, iteration 5 provides a practical perspective on this research.

In the two projects, I encountered two different kinds of sensitivity in the design situations. The CHIPS project was complicated from a design technique perspective, and there was a deep sense of need to protect the children. In this project, the question of ethics became one of method. The LiwS project was complicated from a user vulnerability perspective. Because little design research has been done involving people diagnosed with schizophrenia, and because symptoms can vary greatly, it was difficult to predict how the users could best be involved. The early interview study gave invaluable insights, but also showed a pessimistic view from the stakeholders; it made me question whether it would be possible to design digital technology with and for people diagnosed with schizophrenia at all. The later work showed that it was possible. In this project, the question of ethics became one of involvement.
When I started the research in 2012, my intent was to study the design of DPS. However, it quickly became apparent to me that what was actually complex was not the design of DPS, but the user involvement, and focus gradually shifted to ethical issues. Through the research process, ethics progressively emerged as the key question of user involvement in sensitive design situations. My research journey from design of a DPS artefact thus led me to ethics of user involvement in sensitive design situations.
This thesis consists of a collection of five individual conference and journal papers that have been internationally peer-reviewed. Three papers are published: two in international journals and one in an international PD conference. One of the papers has been submitted to an international journal, and another one of the papers is in the second round of review in another international journal. This chapter summarises each paper and gives an overview of how the papers relate to the contribution of this thesis. The papers are organised by project in order to maintain a clear structure: Papers 1 and 2 are from the CHIPS project, and Papers 3 and 4 are from the LiwS project. Paper 5 consolidates both projects. Papers 1 and 5 explicitly deal with ethics of PD in sensitive design situations, while Papers 2, 3 and 4 deal with different aspects of the complexities of user involvement in sensitive design situations. At the end of this chapter, I list published research papers that communicate results from the two projects, but to a lesser extent explicate results that support the research question of the thesis.

5.1 Role of the Research Papers

Each paper has contributed to the outcome of this research. As mentioned above, Papers 1-4 each highlight different aspects of PD in sensitive design situations. Paper 5 serves as a consolidator, which brings together the two projects with the perspective of ethics. This cover paper then serves to place
Paper 5 into perspective in relation to ethics in PD in sensitive design situations. Figure 5 illustrates the role of the papers in relation to the cover paper.

5.2 Paper 1: Ethics of Involving Children in PD in a Sensitive Design Situation


This paper addresses the ethical challenges situated in the particular design situation of involving children cured from cancer in the design of DPS. The paper concludes lessons learned from handling these ethical challenges. The design activities of the CHIPS project up to the date of publication (including stakeholder interviews, design workshops with children cured from cancer, and iterative design and persona development) were thematically coded using an abductive approach to identify ethical themes. The analysis highlights how the design process was adapted to handle the ethical challenges.
Paper 1 shows how design activities can be adapted to handle ethical challenges when involving children in sensitive design situations, and presents lessons learned. These include: using activities familiar to the children, using personas when users cannot be accessed, being flexible in the design activities, working in pairs with the children, using proxies to distance sensitive subjects, and including healthy children instead of children with a history of cancer when possible. Further, Paper 1 reflects on the need to proactively design an ethical perspective into the entire design process, due to the situated, diverse, dynamic and unpredictable nature of ethics in PD in sensitive design situations.

Paper 1 contributes to this thesis by providing an ethical perspective on how design activities can be adapted, exploring the nature of ethics in PD in sensitive design situations, depicting the ethical challenges that were experienced in the CHIPS project, and by highlighting the importance of ethical reflection as an on-going process. The paper emphasises that ethics is a primary value when the design situation is sensitive.

5.3 Paper 2: Challenges of User Participation in a Sensitive Design Situation


This paper addresses the challenges of user involvement in design evaluation in sensitive design situations. The paper provides insights into key strategies for handling the complexity and sensitivity of the design situation by presenting a case study of the prototype evaluation in the CHIPS project. The evaluation process was primarily analysed using top-down thematic analyses; each step was coded on the basis of relevant literature for that particular activity.

Paper 2 concludes that there were three key strategies to handling the complexities and sensitivity of the design situation: progression, proxies and reflection. Progression implies that the evaluation process was designed to incrementally increase the sensitive questions of the evaluation in relationship with the increase in familiarity with the children. Proxies imply that users without the specific background of the target user group, in this case children without a history of cancer, can be involved as representatives in some
activities without jeopardising the validity of the evaluation outcomes. Reflection implies that the researcher should invoke proactive critical reflection in relation to each step of the evaluation process as a means to handle the challenges that emerge in situ.

Paper 2 contributes to this thesis by exploring the challenges that can emerge from user involvement in sensitive design situations, and strategies for how to handle these challenges. Paper 2 particularly highlights reflection as a crucial strategy due to the situated, dynamic and unpredictable nature of the emerging challenges. In doing so, the paper accentuates that reflection is a central activity when involving users in sensitive design situations, and that ethics is an essential value in that process.

5.4 Paper 3: Complexity of a Sensitive Design Situation


This paper addresses the complex and contradictory nature of the design situation in the LiwS project, which involves people diagnosed with schizophrenia in the design process. In order to understand the challenges faced in the design process and attempt to anticipate what design techniques would be appropriate to carry out, this paper seeks to gain an in-depth understanding of the design situation.

Paper 3 performs a grounded theory analysis of the stakeholder interviews and the first workshops of each workshop round in the LiwS project. Through the analysis, four wicked problems are identified: struggle of dependence, contradiction of social interaction, contradiction of trust, and counteracting improvement behaviour. It is necessary to handle these wicked problems in the design for and involvement of people diagnosed with schizophrenia. On the basis of these wicked problems, Paper 3 discusses consequences for user involvement and the design, acceptance and use of digital technology aimed at people diagnosed with schizophrenia. Paper 3 further shows the viability of using a grounded theory approach to understanding wickedness of a design situation.
Paper 3 contributes to this thesis by showing the complexity of involving vulnerable users in sensitive design situations – a complexity that will affect the users' prerequisites for being involved in a PD process. Paper 3 further shows the importance of having an in-depth and empirically grounded understanding of the design situation prior to involving users in design when they are vulnerable. The contradictions in the identified wicked problems serve to highlight that PD in sensitive design situations must take the situated nature of the challenges into account.

5.5 Paper 4: Challenges of User Participation in a Sensitive Design Situation


This paper addresses the challenges of involving vulnerable users with lowered cognitive and social abilities in design. The paper presents a case study of the LiwS project. By using a bottom-up thematic analysis, the paper is able to study the stakeholder interviews. Likewise, a top-down thematic analysis, based on the themes that were identified from the stakeholder interviews, is used to study the design workshops with users. Paper 4 illustrates the challenges and opportunities of user involvement that emerged from designing together with people diagnosed with schizophrenia.

The analysis of the stakeholder interviews indicated four areas that were particularly challenging for user involvement in this case: social interaction, technical experience, cognitive ability and loss of individuality. The analysis of the design workshops identified five strategies for handling these challenges: working together with concrete materials and examples; maintaining a positive focus; accepting all ideas; maintaining and requiring realism; and using previous interaction. The strategies are specifically aimed at handling the dynamic and unpredictable nature of the challenges that occur in-action. Paper 4 further reflects on the value of involving users in sensitive design situations, and argues that it would not have been possible to carry out the design process if only stakeholders were involved.
Paper 4 contributes to this thesis by identifying challenges for user involvement and addressing how these challenges can be handled. The users' prerequisites made it necessary to adapt the design activities. As such, the paper also recognises that the designer has a responsibility to be solicitous when users are vulnerable, while understanding that vulnerable users are capable of participating in design activities adapted to their abilities, and that the value of this involvement is high. Paper 4 establishes the value of user involvement in sensitive design situations.

5.6 Paper 5: Ethics in Design


This paper addresses the ethical dilemmas of involving vulnerable users in sensitive design situations. A systematic literature review shows that the literature on ethics in design is scarce and spread over several fields. It highlights that much of the ethical support provided by literature and ethical guidelines is too abstract or general to be helpful when facing a sensitive design situation.

Paper 5 applies a variation of the Critical Incident Technique to analyse both the CHIPS and the LiwS projects. Critical incidents are defined as ethical triggers, or a situation that can evoke an ethical dilemma. Ethical dilemmas consist of a choice between two morally challenging courses of action. Resolving actions for the critical incidents consist of the actions taken to deal with the ethical dilemma.

The analysis in Paper 5 identifies eight critical incidents. The outcome of the empirical study is contextualised with the outcome of the literature review, from which three guidelines for ethical user involvement in sensitive design situations are proposed: (I) anticipation, (II) attentiveness and (III) critical self-awareness. The anticipation guideline is to, as far as possible, attempt to foresee ethical dilemmas that may occur, and attempt to reduce possible risks. The attentiveness guideline is to be watchful of the vulnerability, integrity and wellbeing of each participant in order to minimise possible harm. The critical self-awareness guideline is to be critically vigilant both in situ, and of one's own interpretations and actions.
The three guidelines proposed in Paper 5 presuppose an underlying ethical conduct based on established research ethical guidelines and principles. As such, they are intended to provide additional ethical support for the designers who intend to involve users in sensitive design situations. Furthermore, the paper emphasises reflection as a key element to ethics in design, but argues that the three guidelines add additional guidance for designers.

Paper 5 contributes to this thesis by bringing the two design projects together from an ethical perspective, and as such, it provides an overall perspective that adds a dimension to the other papers. It emphasizes the situated and unpredictable nature of ethics in design. Paper 5 not only provides an overview of existing support for ethics in design, but also provides actionable guidelines for ethics in sensitive design situations. The guidelines have significant influence for the contribution of this cover paper; they are material in the conceptualisation of the ethical principles for user involvement in the following chapter.

5.7 Related Research Papers

In addition to the papers included in this thesis, I have contributed to several other papers. Some are earlier versions of included papers: the 2017 SCIS paper is an earlier version of Paper 3, and the 2012 IRIS paper is an earlier version of Paper 1. The other papers to a lesser extent explicate results that support the research question of the thesis. However, they contribute to showing my research journey.


CHAPTER 6

Discussion

The starting point for this research was the identified ethical contradiction of PD in sensitive design situations. This chapter will conceptualise the research contributions from the individual papers using the state of the art of ethics in PD, in order to chisel out the contribution from this cover paper. The outcome of this research is intended to provide ethical support for user involvement in sensitive design situations, and by doing so, support the enforcement of the underlying ethical commitments of PD.

This chapter is divided into three sections. The first section presents four proposed principles for supporting the ethical commitments of PD in sensitive design situations. The second section delineates the implications for theory and practice. Together these two sections address the research question on how users can be involved in sensitive design situations. The final section reflects on the limitations and transferability of the research contributions.

6.1 Principles for Ethics in Participatory Design

At its core, PD makes the ethical commitment that participation is a right, the user is the expert, design should enhance, and design is situated; these have been described in detail in chapter 2. However, as we have seen, these ethical commitments are challenged when PD is carried out in sensitive design situations. On the basis of the research in this thesis, I propose four principles for ethical user involvement in sensitive design situations, intended to be of
support for upholding the ethical commitments of PD. As such, they are not intended to replace the ethical commitments, but to be complementary.

I. The Principle of Enhancement

While participation is considered a right, and users should be given a voice in the design of digital technology (Bjerknes & Bratteteig, 1995; Greenbaum & Kyng, 1991), users are not always able to participate under equal conditions. Cognitive limitations, power imbalances and institutionalisation are examples of variables that can limit the possibility for equal participation.

The principle of enhancement supports equal participation, in order to enable all users to participate with decisive power in the design process. Since users may have physical or cognitive limitations that affect their ability to participate, and may require adapted design activities and personalised design processes, a high degree of flexibility may be required from the designer. The principle highlights that PD ought to enhance the users' abilities and possibilities; this can be done if there is an in-depth understanding of the users' prerequisites to participate and by using both creativity and rigor in the choice of design activities.

The groundwork for this principle is developed and demonstrated in Papers 1, 2 and 4, which describe the adaptations that were made to the design activities in both projects. In the CHIPS project, the design activities were made to both suit the salutogenic (health related) focus required by the ethical review, and were tailored to the abilities of the children whose health changed the requirements on the activities, all while maintaining a playful and fun atmosphere. This was done based on a review of related literature and by making creative choices. In the LiwS project, adaptations were also made to suit the abilities of the participants. Papers 3 and 4 describe the empirical studies that grounded the understanding of the abilities and needs of the users, which was the foundation for the adaptations. Nevertheless, some adaptations were more successful than others. For example, Paper 4 describes how the design activities were supposed to be carried out in designer-user pairs. However, the participants were visibly uncomfortable working in pairs, so the activities were adapted in situ to suit working as a group.

Furthermore, the principle of enhancement is reflected in Paper 2, which describes that it was of importance to show restraint in the involvement of the target user group in some of the activities. Instead of only involving children with a history of cancer, children within the age range but without a history of cancer were also involved. This may seem controversial in a PD context, but it is not a claim that users can be easily replaced. The argument here is that it is
better to involve representatives than not carrying out the research at all. It is a more critical view than cursory acceptance of participation as always positive; in some situations participation can cause more harm than good. Nevertheless, the balance between the risk and the benefits must be judged based on each design situation. By also emphasising that it is possible to show restraint in the involvement of users, this principle underscores that there is a limit for participation in PD in sensitive design situations.

The principle of enhancement builds on the guidelines of anticipation and attentiveness presented in Paper 5. The guidelines emphasise the situatedness of adaptations, and that the needs and wellbeing of the participants transcend the research goals.

Much of the literature on PD in sensitive design situations focuses on the creation or adaptation of design activities to suit the abilities of the users. Extant PD techniques tend to be incompatible with the abilities of vulnerable users (Culén & van der Velden, 2013; Hendriks et al., 2013), and consequences of choosing improper techniques go beyond simply having an effect on the research outcome; they can affect people's lives. Yet, participation also has the potential to improve and empower the lives of vulnerable users (Nathan et al., 2017). Through the use of suitable design techniques, it is possible to enhance participation.

II. The Principle of Acknowledgement

While users are considered to be experts (Robertson & Wagner, 2012), it can be more difficult to understand and empathise with users in a sensitive design situation. There may also be a large number of stakeholders involved, and some may function as gatekeepers to accessing the users, complicating recruitment and stakeholder involvement.

The principle of acknowledgement supports the assertion of the users' abilities and limitations, in order to enable the user to function as the expert of their life situation. Since it can be more difficult to understand and empathise with users, it is of importance to verify interpretations with the users, and to break the design process down into separate, aggregating activities. The principle highlights that PD ought to acknowledge both the users' abilities and their limitations; this can be done through the accumulation of understanding over time. One way of achieving this is to initiate with explorative activities before entering into design activities. In order to handle the complexity, it may be beneficial to involve different users and stakeholders at different times, in different ways.
The principle is reflected in Papers 1, 2 and 4, which describe how stakeholders and users were involved in the different stages of the design processes. In the prototype evaluation process in the CHIPS project, it proved necessary to show restraint in the involvement of children from the target user group. Children without a history of cancer were involved in several evaluative activities, while children from the target user group were involved in a survey. By separating the evaluation process into activities with and without the target user group, it was possible to evaluate the prototype and achieve target group involvement. Similarly, Paper 4 presents two separate analyses: one of stakeholder interviews and one of design workshops with people diagnosed with schizophrenia. The first served to explore the possibilities for involving people diagnosed with schizophrenia, in order to enable the second. In both design processes it was important to validate our interpretations with the participants; both Paper 1 and 4 describe how the users added to and adapted the conclusions drawn from the previous activities.

Furthermore, the principle of acknowledgment is reflected in Paper 3, which explores the complex and challenging nature of designing for people diagnosed with schizophrenia. The paper constitutes an attempt to understand and anticipate some of the risks in the LiwS project, identifying four wicked problems related to the struggle between dependence and independence, contradictions in social interaction, contradiction in trust behaviour, and counteracting improvement behaviour. Paper 3 shows how grounding in the empirical situation can lead to an improvement in the understanding of the design situation.

The principle of acknowledgment builds on the guidelines of anticipation and critical self-awareness presented in Paper 5. The guidelines emphasise that grounding in the design situation enables the anticipation of ethical dilemmas, and that being critical and reflective enables empathy.

Carrying out PD in sensitive design situations involves facing a variety of complications: there is a high diversity and number of stakeholders (Mønsted & Onarheim, 2010), users can be difficult to access (Frauenberger et al., 2011), and it can be difficult to empathise with and understand the users (Culén & van der Velden, 2013). Yet, the user is considered the expert of their own life situation (Robertson & Wagner, 2012), and it is vital to learn from them. By acknowledging the users' abilities as well as their limitations, it is possible to verify and aggregate learning from the users as experts of their own life situations.
III. The Principle of Advocacy

The purpose of design is to enhance a situation (Greenbaum & Kyng, 1991), however, in sensitive design situations participation in design can in itself cause harm and contribute to stigmatisation, while misaligned expectations can cause disappointment in an already difficult situation.

The principle of advocacy supports the promotion of users, to enable the enhancement of sensitive design situations. Since participation in a sensitive design situation can harm an individual or user group, it is the responsibility of the designer to be vigilant, critical and reflecting in practice. The principle highlights that PD ought to advocate the users; this responsibility does not end when the design project ends, but in a sensitive design situation it may be necessary to ensure the continuation of the digital technology that has been introduced during the project. On an individual level, the principle further emphasises the responsibility for the participants' wellbeing, both during and after design activities.

The groundwork for this principle is demonstrated in Paper 4, which describes how risks to the participants in the LiwS project were anticipated and handled. In the project, one of the researchers in the project maintained contact with the participants between the workshops; this was particularly necessary when anticipation failed to prevent distress for one of the participants. One of the seemingly harmless questions in the first workshop led one of the participants to discuss the auditory hallucinations that he experienced, which made him visibly uncomfortable. Between the activities, the researcher with nursing training communicated with the participant, to ensure his wellbeing.

The principle of advocacy is further reflected in Papers 1, 2, 3 and 4. Papers 1 and 2 describe how risks to the participants were anticipated in the CHIPS project by performing literature reviews, and Papers 3 and 4 describe how empirical studies informed the design activities. Paper 4 also delineates a difference in attitude between the interviewed stakeholders and participating users; the first was challenge-oriented, implying that digital technology was unlikely to be beneficial for the target user group, and that the challenges for involving people diagnosed with schizophrenia in design activities would be great. In contrast, the design workshops involving users showed the use of digital technology as very promising, and demonstrated that people diagnosed with schizophrenia are able to participate in design activities when the activities have been adapted to their abilities. The outcome of the stakeholder interviews was in fact challenge-oriented to such a degree that it almost led to the
cancellation of the project, which would have lessened our understanding of how to involve people diagnosed with schizophrenia in design.

The principle of *advocacy* builds on the guidelines of attentiveness and critical self-awareness presented in Paper 5. The guidelines emphasise a high level of watchfulness for the vulnerability, integrity and wellbeing of the participants, and accountability for critically evaluating actions and assumptions throughout the design process.

When involving users in PD in sensitive design situations, it is not certain that the participants themselves will ask to stop the activity (Culén & van der Velden, 2013). Harm can also occur between activities or after the project has ended. Advocacy and responsibility for the users thus extends beyond the limits of the design project, as well as beyond the design activities. Furthermore, in sensitive design situations there is more at stake for the participants (Frauenberger et al., 2011; Waycott, Wadley, et al., 2015) which can create unrealistic expectations and false hope, and lead to disappointment (Vines et al., 2017). From an ethical perspective, this makes PD in sensitive design situations a major commitment. Ethics in PD in sensitive design situations is unpredictable (Nathan et al., 2017), making it impossible to specifically know what kind of risks to watch for. By advocating the users and taking responsibility beyond the design project, it is possible to enhance a sensitive design situation.

*IV. The Principle of Accommodation*

Since design emerges from use, PD must be situated and dynamic (Bødker & Grønbæk, 1991; Henderson & Kyng, 1991). In sensitive design situations, it is not always possible to access the context of use, and the design situation may be unpredictable and change drastically even between design activities (Waycott, Wadley, et al., 2015). Furthermore, each user may have a unique use context, making it necessary to not only be situated, but to personalise each design process, which in turn increases complexity.

The principle of *accommodation* supports the modification of the design process to the users, to enable PD to be situated in the sensitive design situation. Since sensitive design situations complicate the possibilities for accessing the use context, it is of importance to be ready to respond to changes and be flexible in the conduct of the design activities. The principle highlights the accommodation of users; while the ethical commitments of PD are fundamental, they are not more important than the wellbeing of the participants.
As such, if the risks to the participants are too high, it may be necessary to compromise some aspects of the design process.

This principle is demonstrated in Papers 1, 2 and 4, which describe the level of flexibility required in situ. In the CHIPS project, the children worked in adult-child pairs to ensure the children's wellbeing. By working closely with each child, it was possible to ensure that they were not harmed. However, as in the LiwS project, while the intent was to work in similar constellations, it instead caused the participants to express discomfort, and this was then changed in situ. To discern the participants’ discomfort in this instance required sensitivity and empathy.

Furthermore, the LiwS project demonstrates that in sensitive design situations, it may not always be possible to achieve the mutual learning that is essential to PD. There was a major difference in power relation between the target user group (people diagnosed with schizophrenia) and the stakeholders (relatives and health care personnel), which when combined with the incompatible views of the abilities of the user group made it appear impossible to bring the different stakeholders together in a mutual learning situation. The compromise thus had to be made to involve users irrespective of stakeholders.

The principle of accommodation builds on the guidelines of anticipation and attentiveness presented in Paper 5. The guidelines emphasise risk reduction by adaptation to foreseen dilemmas, and a readiness to act on ethical dilemmas in situ.

This research indicates that it is of importance to be guided by the values that arise from the sensitive design situation, rather than by the ethical commitments of PD. Culén and van der Velden (2013) reflect that it was impossible to create a full PD process with mutual learning in their work with vulnerable participants. Similarly, Hendriks et al. (2013) involve stakeholders in the analysis in order to improve the accuracy of their interpretations, since cognitive limitations restricted communication with the users. By accommodating the users and maintaining versatility in the design process, it is possible to be situated in the sensitive design situation.
6.2 Reflections on the Principles

It is clear that PD is challenged to uphold its underlying ethical commitments when the design situation is sensitive. The contribution of this cover paper is formulated as principles for ethical user involvement in sensitive design situations. The principles are interrelated and presuppose an underlying ethical ethos; they do not replace basic ethical principles, such as non-maleficence, beneficence, respect for autonomy, and justice. The purpose of the principles is to support ethical user involvement in sensitive design situations, and uphold the ethical commitments of PD. The four principles, described in the previous section, are summarised in Table 7.

<table>
<thead>
<tr>
<th>Principle</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>I. The Principle of Enhancement</td>
<td>This principle promotes the enhancement of users through personalisation of the design activities to the abilities of the users, and through flexibility and restraint in favour of the wellbeing of the users.</td>
</tr>
<tr>
<td>II. The Principle of Acknowledgement</td>
<td>This principle promotes the acknowledgement of user abilities and limitations through stepwise grounding, verification of interpretations and breaking down of the design process into accumulating steps.</td>
</tr>
<tr>
<td>III. The Principle of Advocacy</td>
<td>This principle promotes the advocacy of users through respect and responsibility between design activities and outside of the project boundaries. On an individual level, through vigilance of the participant's integrity and wellbeing.</td>
</tr>
<tr>
<td>IV. The Principle of Accommodation</td>
<td>This principle promotes the accommodation of users through a versatility in situ, and readiness to compromise prior ethical commitments in favour of ethical values arising from the project.</td>
</tr>
</tbody>
</table>

This research also emphasises reflection as a key element to ethics in PD. This is particularly stressed in Papers 1, 2 and 5, as well as in the literature (Ferguson et al., 2017; Frauenberger et al., 2017; Munteanu et al., 2015). It is the responsibility of the individual designer to judge if the four principles are pertinent in the design situation. It is also of importance to realise that participation in itself can be a source of harm to the participants. Due to the
dynamic nature of ethics in PD, reflection is an iterative process; in this, ethics and design are inseparable (Frauenberger et al., 2017). Likewise, the four proposed principles are also inseparable, as they each are part of the ethical reflection.

It is possible to pinpoint an implicit ethical commitment for PD in sensitive design situations in the set of principles proposed in this thesis; tacit in each principle is the commitment that it is better to err on the side of caution rather than uncritically enforce equal participation as a fundamental right. As such, the principles address the contradiction of ethics in PD; participation is seen as a democratic right (Robertson & Wagner, 2012) and excluding users is considered unethical (Bravo, 1993). Yet, in sensitive design situations, there is an increased risk of harm to participants (Waycott, Wadley, et al., 2015). In this, critical reflection is crucial as a driver to understand when to show restraint.

Lastly, this research demonstrates the value of involving users, even though involvement can make the design situation sensitive. The goal of this research is to encourage participation, despite maintaining that it is complex and challenging. From my experiences, nothing can replace the design input provided by users, and there is additional value in the empowerment of those who are disempowered.

6.3 Contributions

This research intended to answer how users can be involved in sensitive design situations and this section will summarise the contributions for theory and practice. As this research was carried out over several years and two design projects, it is challenging to comprehensively summarise all the insights that were gained during this time. Much of this is presented in detail in the included papers.

6.3.1 Contribution for Theory

This research contributes to the discourse on ethics in PD in sensitive design situations by providing a deeper understanding of the ethical values involved in sensitive design situations. By defining what a sensitive design situation is, and understanding the features of ethics in sensitive design situations as situated,
dynamic, diverse and unpredictable and occurring in-action, it is possible to understand material challenges faced by PD researchers.

Moreover, understanding ethics as situated helps us understand that ethical guidelines cannot be solely prescriptive and static. The research serves to further that which has been done by for example Munteanu et al. (2015), Frauenberger et al. (2017), and Malinverni and Pares (2017). The four principles proposed in this thesis reflect the values that are ethically important for user involvement in sensitive design situations, and are of importance for guiding future research.

Finally, this research supports the upholding of the ethical commitments of PD, which are challenging to maintain in sensitive design situations. This is of importance as PD is being increasingly carried out in sensitive design situations. By emphasising important ethical values of user involvement in sensitive design situations, this research also contributes to PD as approach.

6.3.2 Contribution for Practice
This research contributes to practice in several ways. By illustrating in the included papers how the four principles can be expressed in practice, it provides practical support for designers who intend to involve users in sensitive design situations. By emphasising ethical values emerging from the design process, the focus of is on how to safeguard the users in sensitive design situations.

Moreover, the outcome of this research can be used for ethical training and for preparing, carrying out and evaluating PD projects in sensitive design situations. Understanding ethics in sensitive design situations as situated can help ethical review boards and other ethical bodies to evaluate design projects.

6.4 Reflections on Limitations and Transferability
This research proposes four principles for ethics in PD in sensitive design situations, and provides practice-oriented support for ethical user involvement. The research is based on a DR study of two design projects. The two projects present examples of specific sensitive design situations and offer unique challenges. Nevertheless, it is reasonable to assume that the contribution is relevant to PD in design situations that are not apparently sensitive; as such, it
can be relevant to all PD. Design situations that do not appear to be sensitive may prove to be so when critically examined.

It is up to the judgement of each individual designer to determine whether or not the principles are relevant. I have attempted to provide a rich description of the research in order to enable such reasoning. However, based on this research, it is my belief that the four principles are relevant to PD in design situations relating to sensitive subjects or involving vulnerable users.
This research intended to answer the question: How can users be involved in sensitive design situations? PD takes the ethical stance that users should be involved in design; yet, when the design situation is sensitive, there is an increased risk of the users being harmed by participating. This research has attempted to better understand ethics of user involvement, in order to ensure the safeguarding of participants. The four proposed principles for ethical user involvement presented in this cover paper express how this can be done on a level of principle. The included papers provide practical guidance for how these principles can be applied.

This thesis presents several contributions. First, Paper 1 provides an ethical perspective on how design activities can be adapted to the prerequisites of vulnerable users. Secondly, Paper 2 explores challenges emerging from user involvement in sensitive design situations, and proposes strategies for handling these challenges. Thirdly, Paper 3 shows the importance of a grounded understanding of the design situation prior to involving vulnerable users. Fourthly, Paper 4 explores and addresses challenges for involving vulnerable users in design. Fifthly, Paper 5 gives an overview of existing support for ethics in design and provides three actionable guidelines for ethics in sensitive design situations. These guidelines make up concrete support for designers who intend to involve users in sensitive design situations.

Lastly, this cover paper summarises distinctive features of ethics in PD, arguing that these features create a need for a different approach to research ethics other
than the traditional static, anticipatory ethics that are so often applied. The cover paper also presents underlying ethical commitments of PD, which can be difficult to uphold in sensitive design situations, due to the added complexity and ethical challenges. I propose four principles for ethics in sensitive design situations to support the upholding of these ethical commitments: (I) the principle of *enhancement*; (II) the principle of *acknowledgement*; (III) the principle of *advocacy*; and (IV) the principle of *accommodation*.

It is the hope that this research can inspire others to involve users in sensitive design situations despite the risks, by making it more approachable to do so in an ethical way. The spread of digital technology in society brings great potential, but also great responsibility. There is much promise in the design of digital technology for vulnerable user groups. I cherish a humble ambition that this research, by furthering the understanding of the ethics of user involvement, can help overcome some of the challenges.
CHAPTER 8

References


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Ethics in Health Promoting PD: Designing Digital Peer Support with Children Cured from Cancer

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Abstract
Innovative design targets new user groups and application areas. One example is health promoting digital services. In such design contexts it is essential to take social and ethical challenges into consideration. In this paper we report from an on-going design research project aimed at designing digital peer support (DPS) for children cured from cancer. Peer support can meet the children’s imperative need for social support. However, the design context is sensitive and gives rise to ethical challenges and considerations. We illustrate how participatory design (PD) activities can be designed to handle ethical challenges when designing for and with children. We present lessons learned, including using familiar activities, using personas and including healthy children when possible. Further, we reflect on the need to proactively design an ethical perspective into the entire design process, introducing the concept Ethics in Design.

1 Introduction
The rapid development of ICT enables innovative digital services, targeting new user groups. This expands design into new contexts, confronting designers with social and ethical challenges. One application area where new innovative services are being developed is health promotion. Two examples of this are independent living for elderly (Frantzidis & Bamidis, 2009) and medical support in homes for people with diabetes (Kanstrup, Bertelsen, Glasemann, &
Boye, 2008). In this paper we report from an on-going design research project aimed at designing digital peer support (DPS) for children cured from cancer.

Children who have had cancer at a young age are vulnerable and need social support. Such support can be health promoting long after the treatment for cancer has ended (Enskär & Berterö, 2010). Peer support – people with similar experiences supporting each other on a mutual basis (see e.g. Solomon, 2004) – can meet this need and promote post cancer psychological wellbeing. Children cured from cancer are, however, a relatively small group. In countries like Sweden, there are about 300 children diagnosed with cancer every year ([National board of health and welfare] Socialstyrelsen, 2009). The children are also distributed over a wide geographical area, making it difficult to organize face-to-face peer support. Hence, the overall project goal is to enable peer support by designing DPS for these children.

PD has proved useful in design with children (Druin, 2002; Farber, Druin, Chipman, Julian, & Somasheker, 2002; Nesset & Large, 2004; Read et al., 2002). However, children are a vulnerable user group (Graham, Powell, Taylor, Anderson, & Fitzgerald, 2013), and when their medical history is the basis for their participation, the context is particularly sensitive. In past attempts in similar design contexts, children without the medical history have participated as a substitute for children from the target user group. However, it was found difficult for these children to understand and empathise with the full extent of the experience (Bratteteig, Wagner, Morrison, Stuedahl, & Mörtberg, 2010; Ruland, Starren, & Vatne, 2008).

In order to design for children who have gone through cancer treatment, it is important to involve children sharing this medical history. However, involving children cured from cancer can be challenging in more than one way. It is for example particularly important to get informed consent from both parent and child to ensure that the child understands the conditions of participation (Powell & Smith, 2009). Involving children under these circumstances clearly causes ethical considerations. If ethical considerations are identified early in the design process and continuously dealt with, the risk for possible harm to the children can be reduced. Consequently, integrating ethical considerations in the design process is important (Tee & Lathlean, 2004).

In this paper we address the following question: how can PD activities be adapted to proactively meet ethical considerations when designing for and with children in a sensitive context?
The overall aim is to explore how ethical considerations can inform participatory design for involving children in health promoting PD.

2 Participatory Design with Children

PD is considered beneficial when designing with children (Druin, 2002; Nesset & Large, 2004; Read et al., 2002). Design activities performed with children are commonly informal and playful, like drawing or acting (Lindberg, 2013). It has been suggested that PD can build trust between designers and children (Komlodi et al., 2007) and help resolve ethical issues that might occur (Thomas & O'Kane, 1998). However, there are several challenges when designing with children. For example, children have a lesser ability to articulate abstract thoughts (Druin, 2002) and they are motivated to participate by other incentives than adults (Powell & Smith, 2009). Working with children also places different requirements on the designers, for example in their ability to communicate with and engage the participating children (Powell & Smith, 2009).

One influential approach to meet the challenges of PD with children is Cooperative Inquiry (CI), introduced by Allison Druin (Druin, 1999). CI stems from Scandinavian participatory practices and involves children in the design team as equal partners in activities such as prototyping, observation and testing. The activities focus on creativity because children often express themselves better in actions than words (Druin, 2002).

CI has in the past been adapted to suit specific contexts, for example an educational context (Guha, Druin, & Fails, 2011), and adapted for design with young children aged 4-6 years (Farber et al., 2002). There are examples of PD involving sick children. In research aimed at designing a symptom reporting system for children with cancer, children under treatment for cancer participated together with healthy children (Bratteteig et al., 2010; Ruland et al., 2008). The healthy children had difficulties empathising with sick children as users of the system and could thereby not fully represent the target group. These findings suggest that involving children from within the intended target group is important. As Ruland et al. (2008) put it, "personal experience may be an important factor for valuable design contributions" (p. 634).

3 Ethics in Design with Children

Ethics and morals are closely linked. The latter indicates a certain belief or norm-system, while ethics is the science of moral systems (Mingers &
Walsham, 2010). What makes an action ethically justified stems from a complex philosophical debate (Mingers & Walsham, 2010). Ethics in research builds on principles of autonomy, non-maleficence, beneficence and justice (Flicker, Travers, Guta, McDonald, & Meagher, 2007; Graham et al., 2013; Mingers & Walsham, 2010). In essence, research should do good and bring no harm to those involved (Graham et al., 2013). However, it is generally more complicated than that (Byrne & Alexander, 2006), for what is good for a group or community can bring harm to individuals.

In healthcare research projects, it is difficult to identify and involve representative user groups due to the heterogeneity of potential users (Mønsted & Onarheim, 2010). Furthermore, participation in research can for example evoke negative emotions, being selected for research can reveal to others that participants have certain diagnoses, researchers can accidentally upset participants by unwittingly asking sensitive questions, or have other unforeseen consequences. Complexities such as these oblige researchers to make ethical considerations in their research.

Ethical considerations vary from situation to situation. One important aspect is to ensure that there is significant reason for including participants from a vulnerable user group (CIOMS, 2002; Graham et al., 2013). If such is not the case, involving vulnerable user groups should be avoided. However, this mindset has lead to many vulnerable groups never being allowed to express their views (Tee & Lathlean, 2004). According to Tee and Lathlean (2004), researchers should show sensitivity to the participants and implement a safe and supportive process that does not require exclusion of vulnerable participants. It is a balancing act; while researchers should think twice about including vulnerable groups, these groups also have a right to participate and be heard (Graham et al., 2013).

Research needs to be ethically vetted in order to ensure that it maintains a high ethical standard. According to the Swedish Central Ethical Review Board (EPN) (2013), any research that could for example cause physical or psychological harm to the participants needs to be ethically vetted. Ethical reviews require specification of for example how informed consent is going to be retrieved, what the goal of the research is, how data will be collected and how participants are selected (EPN, 2013). However, these normative, reactive ethical guidelines, while necessary, are not always specific enough to help researchers handle their specific ethical situation. It is therefore crucial to design an ethical perspective into the entire research process (Tee & Lathlean, 2004).
From the reviewed literature emerged several themes related to ethics. We summarised each theme and grouped these into categories. Each category was then summarised into an ethical consideration. In total, we identified six considerations with bearing on ethics in design with children and in particular with children in a sensitive context: power balance, informed consent and gatekeeper complexity, equal say and unequal abilities, place for activities, emotional load and target group size. Each ethical consideration creates a specific set of challenges that research in this context will need to meet.

**Power balance**
There is an inherent difference in power balance between children and adults (Morrow & Richards, 1996). Adults have more power in society and children are raised to do what adults such as their parents and teachers tell them (Thomas & O'Kane, 1998). This is a major ethical challenge in research (Graham et al., 2013) and can cause difficulties with cooperation in settings where participants are meant to be equal. Power is a major factor in decisions taken in the PD process (Bratteteig & Wagner, 2012). However, PD and cooperative approaches can also be useful in dealing with differences in power balance (Morrow & Richards, 1996; Tee & Lathlean, 2004).

Moreover, who participates is also an influencing factor; children can be able to speak more openly on certain subjects when their parents are not present (Thomas & O'Kane, 1998) and too many adults in relation to the number of children can cause an imbalance in power. However, including teachers who are familiar with the children can help since the children already trust them (Stringer, Harris, & Fitzpatrick, 2006).

**Informed consent and gatekeeper complexity**
It is the parent, not the child, who is required to give informed consent to participate in research. It is recommended that children also give consent (Graham et al., 2013; Morrow & Richards, 1996) and it is important to ensure that the children understand what they are consenting to (Powell & Smith, 2009). CIOMS (2002) specifies that children over 12 are more readily able to understand the implications of participation and should if possible be chosen over young children and infants.

There are also other parties that may need to give consent; in fact, Powell and Smith (2009) average a number of 3.5 consent givers for each participating child. So-called "gatekeepers" such as teachers are also relevant to approach
(Graham et al., 2013). The amount of gatekeepers in research with children adds a high level of complexity to the process.

*Equal say and unequal abilities*

The activities performed must ensure that all children have a say and not only the children who are the most creative, best able to read, or express themselves most clearly verbally (Graham et al., 2013). Having different kinds of activities lets children who are strong in one area, but weaker in another, participate and contribute in at least one activity (Mazzone, Iivari, Tikkanen, Read, & Beale, 2010). Other challenges include making sure that the activities can be understood by the children (Graham et al., 2013) and are motivating and engaging (Thomas & O'Kane, 1998).

*Place for activities*

Another consideration is where the activities should take place. Schools are common settings for research as homes can be more difficult to gain access to (Thomas & O'Kane, 1998). However, children can be more inclined to worry about giving "correct" answers (Thomas & O'Kane, 1998) and believe that assignments are obligatory in a school environment (Morrow & Richards, 1996).

*Emotional load*

In a sensitive context there is a possibility that mere participation can distress the children as they are participating based on previous experience of perhaps unpleasant events (Powell & Smith, 2009). The context places a possible emotional load on the participants. Also, if children who are still under treatment are included they may be unable to continue due to health reasons, or have special needs due to side effects (Ruland et al., 2008).

*Target group size*

The target group can be small and distributed. In Sweden, 300 children are diagnosed with cancer every year (Socialstyrelsen, 2009). They are spread over a large geographical area and engaging them can thus be challenging. Secondly, it is important that research does not burden a specific user group (Graham et al., 2013). Since PD requires activities to be performed over a longer period of time, including children in too many activities will take up much of their time and effort. If the target group is small, there is a risk to overuse these participants, making them disinclined to continue or even jeopardise their health.
The ethical considerations and challenges derived from the literature are summarized in Table 1.

Table 1. Ethical considerations and challenges

<table>
<thead>
<tr>
<th>Ethical Consideration</th>
<th>Challenge(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Power balance</td>
<td>• Deal with power balance between adults and children</td>
</tr>
<tr>
<td></td>
<td>• Which adults participate</td>
</tr>
<tr>
<td>Informed consent and</td>
<td>• That children understand implications of participation</td>
</tr>
<tr>
<td>gatekeeper complexity</td>
<td>• Consent from non-family stakeholders</td>
</tr>
<tr>
<td>Equal say and unequal abilities</td>
<td>• Children have different abilities to perform and understand activities</td>
</tr>
<tr>
<td></td>
<td>• Motivation to participate</td>
</tr>
<tr>
<td>Place for activities</td>
<td>• Location influences participation</td>
</tr>
<tr>
<td>Emotional load</td>
<td>• Emotional stress related to the medical history</td>
</tr>
<tr>
<td></td>
<td>• Physical health</td>
</tr>
<tr>
<td>Target group size</td>
<td>• Risk of overusing participants</td>
</tr>
<tr>
<td></td>
<td>• Time-consuming</td>
</tr>
</tbody>
</table>

PD clearly has positive ethical tendencies in research with children in a sensitive context. PD aims to do more than simply design an effective IT artefact; the aim is for the artefact to embody for users ethically important values (Mingers & Walsham, 2010). By involving users, there is a greater likelihood that the finished design is relevant to the user group (Byrne & Alexander, 2006; Flicker et al., 2007). But participation also creates a higher likelihood that participants (especially from vulnerable user groups) have their voices heard and that the finished design meets their requirements (Flicker et al., 2007).

4 Research Setting

In this paper we report from an on-going design research project. The main project goal is to design DPS for children who have survived cancer. The project is multidisciplinary, involving researchers from information systems and health sciences, and is currently in its third and final year. The project is organized with a PD approach, engaging children, stakeholders and researchers. The target group for the DPS system is children between 8-12 years that have been treated for cancer. Cancer treatment can be traumatic and participation in the design process therefore requires explicit attention to ethical considerations. Accordingly, ethical considerations have been integrated in the PD approach.
This study was approved by the regional ethical board (dnr 2011/307). The application for ethical review foresaw difficulties in recruiting children to a study with a pathogenic focus. Health related contexts can be split into two perspectives: the pathogenic and salutogenic (Antonovsky, 1979). The pathogenic perspective relates to disease and treatment, while the salutogenic relates to health promotion and wellbeing. In order to pass the ethical review we had to specify that we would not broach the pathogenic perspective with the participating children, as it could upset them. We are thus unable to speak of the subject of our research with our participants, and have had to find another way to appropriate this perspective. Our application instead specified that stakeholders would be interviewed to attain a pathogenic perspective, while a salutogenic focus would be prevalent in the activities where children participated. This combination of salutogenic and pathogenic perspectives was approved by the regional ethical board and has guided the design process.

<table>
<thead>
<tr>
<th>Design Activity</th>
<th>Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Stakeholder interviews</strong></td>
<td>approx. 1 hour each 8 health care professionals (1 medical doctor, 1 clinic leader, 1 oncology nurse, 2 consultancy nurses, 2 occupational therapists, 1 sibling supporter nurse) 1 representative from a childhood cancer patient organisation 4 parents of children with history of cancer</td>
</tr>
<tr>
<td><strong>Design workshops 1-3</strong></td>
<td>3 hours incl. meal break video + sound recorded Location: room at library Group 1: 3 boys 11-12 with history of cancer Group 2: 2 girls 11 &amp; 13 with history of cancer 3-4 researchers</td>
</tr>
<tr>
<td><strong>Reconnecting</strong></td>
<td>2 hours incl. snack Location: room at Lund University Same children from workshop 1-3 and their parents and siblings 5 researchers</td>
</tr>
<tr>
<td><strong>Persona development</strong></td>
<td>4 researchers</td>
</tr>
<tr>
<td><strong>Iterative design</strong></td>
<td>4 researchers</td>
</tr>
<tr>
<td><strong>Feedback workshop</strong></td>
<td>2 hours incl. break video + sound recorded Location: premises at researcher's home 7 children total, no history of cancer 3 boys, 4 girls 10-12 4 researchers + 2 master students</td>
</tr>
</tbody>
</table>
This paper aims at exploring how ethical considerations can inform PD activities. In the following section we report on how the identified considerations unfolded in forming and carrying out design activities in the project. Table 2 summarizes design activities and participants in the design process.

5 Designing Digital Peer Support with Children Cured from Cancer

Here we present our case of designing DPS for children who have been cured from cancer. The project is on-going and this is a summary of the activities performed so far.

5.1 Stakeholder Interviews

Since the context of the research is of a sensitive nature and the children could become upset by their participation, we were unable to broach the pathogenic perspective of peer support with them. In order to get insight into the children's medical history, understand the pathogenic perspectives of the requirements for DPS in this context and the positioning of DPS in existing health care processes, we interviewed 9 health care professionals, 1 representative from a childhood cancer patient organisation and 4 parents of children who had been treated for cancer. In semi-structured interviews, the stakeholders gave insight into, firstly, that DPS should be salutogenic and social (Wärnestål & Nygren, 2013). Secondly, that DPS should be introduced in post-intensive care instead of during intensive care (Wärnestål & Nygren, 2013). Lastly, from the interviews a number of "wicked" problems for design in the same context were identified (see Wärnestål & Nygren, 2013).

5.2 Design Workshops

Three design workshops were conducted with children with a medical history of cancer. The design workshops were approached from a salutogenic perspective as the pathogenic perspective was ethically out of bounds, instead focusing on promoting health and wellbeing. Each workshop was conducted twice – once with three boys aged 11-12 and once with two girls aged 11 and 13. The children had met previously and worked well together, though they were unfamiliar with some of the researchers. For each workshop, 3-4 adult researchers participated, allowing for formation of pairs with one adult and one child, while having one facilitator.
The children who participated in the design workshops had been diagnosed with cancer and were currently in remission or under maintenance treatment. The children and their parents were informed orally and in writing about the circumstances of the study. They were further informed that participation was voluntary and they were free to withdraw at any time. The two groups were chosen for participation because they had previously showed a high level of creativity and a good group dynamic.

The design workshops were progressions of each other and the second and third workshops were initiated with a summary of the previous workshop, allowing the children to comment on the activities and add or change anything should they wish. This served to validate the data from the previous workshop. Comics were prevalent in various forms in all workshops in order to create a recurring theme. Familiar concepts such as comics are suitable for design activities with children (Lindberg, 2013). The workshops were a total of three hours including meal breaks and took place at premises provided by a local library, which was deemed to be neutral ground.

Workshop 1: Creating Characters
The first workshop was aimed at creating familiarity within the group of children and adults and creating the characters that were later to be the basis for the comics in the two upcoming workshops. The workshop began with a drawing activity where the participants were all asked to draw something they liked and the other participants then guessed what they had drawn. The activity opened up for discussion and several children found that they had common interests. This was a first step to building trust and making the participants comfortable with each other.

The remaining activities were performed in pairs of one adult and one child. This setup was chosen because we wanted to keep an eye on the children's wellbeing. We also noted that this setup allowed all children the opportunity to express their opinions to an equal extent and the researchers were able to keep the children on track with the assignment (Lindberg, 2013). This was a strategy to handle the ethical considerations of emotional load and equal say.

The remainder of the workshop was devoted to the single activity of creating characters that were meant to function as proxies in the upcoming workshops. When dealing with a sensitive subject, it can be advisable to distance the children from the topic of the research with a proxy of some kind (Grundy, Pemberton, & Morris, 2012). The boys were asked to create characters, or proxy personas, their own age. They were given cut-out dolls which they
coloured while their partnering researcher initially asked more tangible questions such as "What is his name?" and "What family members live in his house?", and then moved on to questions such as "What does he think is important?" and "What makes him happy?". The latter part of the question battery related primarily to the concepts of friendship and peer support with the aim to map behaviour patterns that would be relevant for the latter creation of personas.

Nevertheless, while the purpose of using characters as proxies was to distance the children from the topics of the workshops and handle the ethical challenge of emotional load, we noted that the boys identified with their characters to a high extent. For example, during the second workshop, one of the boys asked "Am I in your comic?", referring not to himself but to his character. Because of this, we decided to distance the proxies further for the girls, asking them to create characters a few years younger than themselves. We found that the girls were more able to clearly separate themselves from their characters (Lindberg, 2013).

The work was conducted differently in the pairs, as some children preferred to draw while others wanted to write. However, in all pairs both the child and the adult contributed to the creation of the characters. While the researchers prompted the children with questions and primarily asked their opinions, all children reciprocated and expected the adults to contribute to the collaboration. The power balance in the pairs was thus quite equal.

Image 1. The character Jacob, created by one of the children in the first workshop

The work was conducted differently in the pairs, as some children preferred to draw while others wanted to write. However, in all pairs both the child and the adult contributed to the creation of the characters. While the researchers prompted the children with questions and primarily asked their opinions, all children reciprocated and expected the adults to contribute to the collaboration. The power balance in the pairs was thus quite equal.
Finally, each pair presented their characters to the others and recounted everything they had come up with. The others were thus able to ask questions and comment on the characters. This also served as a way to sum up the work for the day.

*Workshop 2: Comicboarding*

The second workshop began with a recap of the first workshop and the characters the children had created were presented adapted to digital format in the form of comics. The children were asked to adjust the characters if they wanted.

The main focus of this workshop was to create stories using the characters. The concept was loosely based on Moraveji, Li, Ding, O'Kelley, and Woolf (2007). Comics had been prepared with the beginning and ending squares and the children were asked to fill in the middle. The stories related to the concept of peer support (Einberg, Svedberg, Enskär, & Nygren, 2013; Solomon, 2004) and illustrated for example one of the characters being home sick, or feeling that her friends did not understand her. The ending showed the situation resolving itself, i.e. a redemption scenario, and the children thus came up with the story in between.

Pairs were formed again and the children chose which comics they wanted to complete. They completed as many comics as they wanted and had time for. Also, one boy was particularly inclined to one specific idea and chose to create his own ending to one of the comics. Flexibility thus became key.

Again, the purpose of using comics and characters in this way was to distance the children from the topics that were broached. In this way, we were able to explore subject areas that would have been impossible to speak of directly with the children from an ethical standpoint. The scenarios that these workshops resulted in laid the base for the third workshop.

*Workshop 3: Design Sessions*

The third workshop differed from the first two in that focus was on furthering ideas on specific concepts. Before the workshop, the children's comics had been transferred to digital format. At the beginning of the workshop, these were read through by all participants in order to promote recall. For the boys' workshop, the comics had been complemented with a continuation of the story where a design idea was being used. These scenarios were the basis for discussion and critique, and more promising ideas were further developed.
For the girls' workshop, the comics were the basis for further ideation and the girls were asked to sketch design solutions that related to the redemption scenarios in their comics. The work in both groups was conducted with pen and paper, but the girls also used the mobile prototyping software POP to create interactive prototypes. In this activity, the researchers assisted the girls in a greater extent due to the added complexity.

While the approach for this workshop built on the development of specific design concepts identified from the first two workshops, the children were still encouraged to explore and express new concepts and ideas. Some of the ideas were feasible as design concepts while others would be impossible to implement. However, our goal was not to identify specific design concepts but to explore areas of interest and potential use settings. The design concepts were further refined in a generative fashion after the workshops were finished.

*Reconnecting with Participants and Families*
A few months after finalising the design workshops, all participants and their families were invited to a presentation of the results from the workshops. It was an opportunity to inform the children of what they had contributed with, finalising their participation, and get feedback from both the participating children and their families. The design process was outlined and the results presented. We had also prepared two prototypes of early design ideas that were results from the design workshops. The participants reflected on the material presented and the feedback allowed refinement and further development of the design ideas. It was also a way to verify that the work so far was representative and accurate.

5.3 Persona Development
The data collected from the stakeholder interviews and design workshops was analysed qualitatively. From the input from the design workshops, the researchers identified terms that occurred in the proxy personas and comics. This was complemented with the findings from the stakeholder interviews. These terms related to everything from technology use (e.g. mobile) to behaviour (e.g. "support each other") and motivation (e.g. "make family happy").

The identified terms were grouped together based on commonality in themes and comprehensive clusters were identified. These clusters formed categories in two affinity diagrams, one for the girls and one for the boys. The diagrams contained similarities, but also major differences, which lead to the conclusion that we needed two different personas to reflect these two diversities.
The two personas that we developed were Anton, a 10-year-old boy, and Julia, an 11-year-old girl. Anton was treated for leukaemia at a young age and was discharged at the age of 5. He has no memory of his illness, but has some concentration difficulties due to treatment. He likes playing video games and building things with for example Lego®. Touch points include his school, his family, consultancy nurse and the gaming community Steam®.

Julia was treated for leukaemia at the age of 6 and discharged at the age of 9. She has memories of pain and social isolation from the treatment and she has scars that remind her of her disease. She likes taking photographs and uploading them to Instagram®, shopping with her friends and always has her mobile phone with her. Julia's touch points include her school, Instagram® and popular Swedish youth magazines such as Glitter®.

Using personas is not always supportive of PD but in some cases they can be intermediaries in the design process (Bødker, Christiansen, Nyvang, & Zander, 2012). However, in our case they provided two additional functions. Firstly, having included both the data from the stakeholder interviews and the design workshops, the personas thus became syntheses from both a pathogenic and a salutogenic perspective. Including both of these perspectives was found necessary in this case (Wärnestål, Svedberg, & Nygren, 2014). Secondly, due to the limited size of our target user group we could not include children in all activities. The personas were therefore used in order to maintain a user focus throughout the activities where users were not included.

5.4 Iterative Design Practice
When the personas had been developed, the designers continued developing and refining the design concepts that had been identified. In several iterations, low-fi sketches and prototypes were created in order to critically assess these concepts. From a large number of ideas, a few stood out, and these were chosen for context scenario development. The personas were used as actors in the context scenarios. As the scenarios were developed, the sketches were revised and further increased in detail, until three concepts remained.

5.5 Feedback Workshop
We performed a workshop with seven children aged 10 to 12, without a history of cancer, to get feedback on our design concepts (cf. Lindberg, Wärnestål, Nygren, & Svedberg, 2014). The children had not been part of the previous design workshops. The choice to include healthy children instead of children from our target group at this stage was made because we did not want to
overuse our limited target group. Including children without the medical history was possible as the feedback we were after was not unique to our target user group. The work was performed in groups of 2-3 children with 1-2 adults. The concepts were presented as low-fi prototypes and the children gave verbal feedback and drew modifications. Each group gave each concept approximately 30 minutes and we concluded with a snack and discussion.

All the design activities that were performed are summarised in Table 3, along with a summary of how they were adapted to handle the relevant ethical considerations. There is no norm from which these activities have been changed; therefore we chose the term adaptation instead of for example alteration.

Table 3. Ethical considerations and activity adaptations

<table>
<thead>
<tr>
<th>Ethical Consideration</th>
<th>Adaptation(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Design Activity</strong>: Stakeholder interviews</td>
<td></td>
</tr>
<tr>
<td><strong>Purpose</strong>: Pathogenic perspective of peer support.</td>
<td></td>
</tr>
<tr>
<td>Emotional load</td>
<td>• Interviews with stakeholders, as the pathogenic perspective was too sensitive to broach with the children.</td>
</tr>
</tbody>
</table>

| **Design Activity**: Design workshops (overall)  |
| **Purpose**: Salutogenic perspective of peer support, idea generation.  |
| Place for activities, emotional load, informed consent and gatekeeper complexity, target group size, power balance | • Focused on the salutogenic perspective.  
• Used activities familiar to the children.  
• Worked in child-adult pairs, combined with an informal and inclusive way of working, to level out the power balance.  
• Neutral location (library).  
• Both parents and children consented.  
• Workshops limited to 3 hours including meal.  |

| **Design Activity**: Design Workshop 1: Creating characters  |
| **Purpose**: Create familiarity, build trust and proxy personas.  |
| Equal say and unequal abilities | • Worked in pairs and used familiar activities such as drawing.  |

| **Design Activity**: Design Workshop 2: Comicboarding  |
| **Purpose**: Verify characters, explore use scenarios.  |
| Emotional load, equal say and unequal abilities | • Comics were used as proxies to distance the sensitive subject.  
• Worked in pairs and used familiar activities such as storytelling to promote equal say.  
• Worked in pairs to keep an eye on the children's wellbeing.  |

| **Design Activity**: Design Workshop 3: Design sessions  |
| **Purpose**: Furthering design concepts.  |
| Emotional load, equal say and unequal abilities | • Used comics and characters as proxies from the sensitive subject.  
• Comics were a basis for discussion and idea generation.  
• Worked in pairs, used familiar activities and directed questions to promote equal say.  |
<table>
<thead>
<tr>
<th>Ethical Consideration</th>
<th>Adaptation(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Design Activity:</strong> Design Workshops: Reconnecting with participants and families</td>
<td>Purpose: Providing closure for participants, gain feedback. N/A</td>
</tr>
<tr>
<td><strong>Design Activity:</strong> Persona development</td>
<td>Purpose: Synthesise pathogenic and salutogenic perspectives. Emotional load, target group size</td>
</tr>
<tr>
<td><strong>Design Activity:</strong> Iterative design practice</td>
<td>Purpose: Further develop design concepts. Target group size</td>
</tr>
<tr>
<td><strong>Design Activity:</strong> Feedback workshop</td>
<td>Purpose: Feedback and evaluate design concepts. Target group size, power balance, equal say and unequal abilities, place for activities</td>
</tr>
</tbody>
</table>

6 Experiences and Lessons Learned

Based on ethically informed design activities in our project to design DPS for children cured from cancer, we have distilled nine lessons learned. We learned to:

• use familiar activities and themes
• be flexible in activity execution
• work in pairs with children and adults
• use proxies to distance the sensitive subject
• reciprocate in informal interaction
• include stakeholders for context overview
• include healthy children when possible
• use personas to sharpen user focus
• summarise children's contributions with their families

*Use familiar activities and themes*

When designing with children it is recommended to use familiar techniques and activities to not make the design process unnecessarily difficult for the children (Lindberg, 2013). Any children who would have less ability than the other
participants to contribute are also promoted by the use of familiar activities, thus promoting equal say (Mazzone et al., 2010). Our choice to use the familiar concept of comics in the design workshops allowed us to use different techniques (e.g. drawing and storytelling) to meet the children's different abilities. The characters and comics were sources of data and were also used to communicate design concepts. The children expressed enthusiasm and interest in the activities.

Be flexible in activity execution
Several times during the design workshops and the feedback workshop we had to divert from our initial plan. In one case, one of the children preferred to create his own ending to a comic, instead of using the prepared one. While diverting from the activity's purpose, the resulting comic reflected the boy's view more than a comic with an ending he did not like would have. In another case, one of the children still undergoing treatment did not feel up to drawing at the end of the session. Still wanting to continue, he asked his partner to draw for him. Finally, during the feedback workshop one of the groups had a particular interest in one of the concepts we had not included in the workshop. We chose to present it, which led to a rewarding discussion with useful ideas. Being flexible as researchers thus emerges as important from an inclusion, equal say perspective, as well as a way to ensure that the children are not exposed to unduly emotional stress.

Work in pairs with children and adults
In order to be able to maintain a high sensitivity to the children's wellbeing during the design workshops we worked in pairs of one child and one adult. In a sensitive context such as ours, it is specifically important to be sensitive to how the participants are feeling. While researchers should always be concerned with the well-being of their participants, this context requires more than typical sensitivity. Should a child become distressed or upset, have difficulties understanding, or have trouble focusing on the tasks, the researcher needs to be able to intervene immediately.

Working in pairs also allowed each child to participate to an equal degree as no one dominated the discourse. It also let the children do what they felt most inclined to do. In this way we promoted equal say among the participants, as advocated by Mazzone et al. (2010). The adult could for example write if one of the children felt uncomfortable with writing. As a comparison, in the feedback workshop with children without the medical history we worked in groups of 2-3 children to 1-2 adults. Here we noticed that some of the children were more forward and spoke more than others. We were to some extent able to pose
questions and prompt the children who spoke less. However, we did not need to do this while working in pairs.

**Use proxies to distance the sensitive subject**

We chose to use fictional characters and comics as proxies in the design workshops in order to distance the potentially upsetting subject from the participants. Using proxies in this way is suitable in sensitive research (Grundy et al., 2012). Instead of referring to themselves, the children spoke of the characters and it was the characters that experienced the events in the comics. Nevertheless, we learned that simply distancing the children with characters was not enough. The boys identified too much with their characters. The girls then created characters younger than themselves to increase the distance to the proxies. Clearly, it is a balancing act to create proxies that are distant enough that the children do not identify with them, but are not so distant that the children cannot work with them.

**Reciprocate in informal interaction**

Difference in power balance is a major challenge in research with children (Graham et al., 2013), and interacting with and dressing informally is one aspect that can help alleviate this difference (Druin, 1999). For this reason, the collaboration with the children in the design workshops was informal. The children were given the primary say in decisions on the characters and comics. However, all children prompted their adult partners for information, expecting reciprocation and collaboration.

**Include stakeholders for context overview**

Since we were unable to speak of the pathogenic perspective with the children, we included a number of different stakeholders to complete our understanding of the children's background. These stakeholder interviews allowed us to approach a sensitive context without broaching a potentially upsetting subject with the children. However, the medical history of the children affects their need for peer support. As a result, it was crucial to include stakeholders to provide the pathogenic perspective.

**Include healthy children when possible**

At one stage in the process when we needed feedback on concepts that was not specific to our target user group, we included children without the medical history in order to not overuse our limited user group. Again, research participation should not be taxing to the participants (Graham et al., 2013). The children were from the same age range and they contributed with feedback on
interaction, on how appealing the concepts were and on ideas for further development.

**Use personas to sharpen user focus**
In our case the target user group is limited in size and it would be impossible to include them in all activities. Overusing a user group in research must be avoided from an ethical standpoint (Graham et al., 2013). In order to promote a continuing user focus throughout the design process we therefore chose to create personas. In referring to the personas during the generative design work, we could make sure that the needs of the users were represented. Using personas also allowed us to combine the pathogenic and salutogenic perspectives (Wärnestål et al., 2014), thus establishing a synthesis of these that we otherwise would not have had.

**Summarise children's contributions with their families**
We reunited with the participating children and their families in a finalising discussion where we presented our findings so far. Not only could we show the children what they had contributed with, as recommended by Thomas and O'Kane (1998), but they could also show their work to their families. The parents also gave valuable input on the material. The children seemed proud to show their families what they had accomplished and seemed eager to test the two prototypes we had prepared. In this way, there was a finalisation to this stage of the children's participation and the children were given an impression of what their work had achieved so far.

7 Discussion and Conclusions
The aim of this paper is to address how PD activities can be adapted to proactively meet ethical considerations when designing with children. We have illustrated that design with children in a sensitive context comprises an utmost complex design situation. We have also explored how ethical considerations can inform participatory design when involving children in health promoting PD.

Designing with children in a sensitive context constitutes a complex ethical situation with many ethical considerations. We identified relevant considerations, including for example the difference of power balance, the size and spread of the target group and the suitability of the performed activities to the children's abilities. Doing PD with vulnerable user groups requires that these complexities are responsibly dealt with. From the lessons learned we suggest
that the major ethical principle in health promoting PD with children is to include an ethical perspective early and throughout the entire design process.

We also learned that design activities adapted to the context support health promoting design. Each activity should be evaluated from a perspective of what ethical challenges are present and how these can be handled. In some design situations it is advisable to not perform the activities at all and in other situations activities can be adapted. It is important though, to be aware that the situation is sensitive and ethical considerations need to be continuously handled throughout the design process. If ethics is designed into process activities, our experience is that we can include users in design in sensitive contexts.

Finally, based on the literature review and project experiences, we propose the concept of Ethics in Design. Ethics in Design shall be seen as an attempt to shift the focus from reactive ethics to proactively designing ethics into the design process (cf. Cavoukian, 2011 and Privacy by Design). While ethical guidelines are regulatory, promoting a reactive mind-set of trying to "not do wrong", there should to be a shift to considering ethical considerations throughout the entire process – to trying to "do good". We therefore name this concept Ethics in Design.

Ethics in Design can be a guide to keep ethical considerations prevalent throughout the design process. Ethical considerations can then be strategically handled in design activities. With this concept we aim to contribute with insights to specific PD activities as well as to the overall organisation of the design process.

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Evaluating Digital Peer Support for Children Cured from Cancer

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Abstract
This article describes a case study of the challenges that emerged from a formative evaluation process with the purpose to evaluate a Digital Peer Support (DPS) service for children between 8-12 cured from cancer. The evaluation of DPS for children is particularly challenging. While the literature on evaluation with children is extensive, challenges such as risk assessment that become prevalent in the evaluation of DPS are not highlighted. This case study analyses how the DPS service was evaluated over the course of two usability tests, a two-week diary study, a focus group interview and a survey. Challenges relating to ethics, trust, risk assessment and recruitment emerged during the evaluation process. We identify key strategies to handle these challenges: progression, proxies and reflection. Performing a multi-stage evaluation process with progressing sensitivity allowed control of some of the complexities of the context in order to balance the degree of the children's involvement with the degree of sensitivity.

1 Introduction
Social support is an essential part of dealing with consequences of serious illnesses and recovering quality of life (Luszczynska, Pawlowska, Cieslak, Knoll, & Scholz, 2013). Peer support has been promoted as an important kind of social support where people with similar experiences help each other to better wellbeing (Meyer, Coroiu, & Korner, 2015). In some situations, peers can better provide support than healthcare professionals can (Klemm & Hardie, 2002). Recent developments include Digital Peer Support (DPS) to cope with the fact that face-to-face peer support is limited to geography, time and
attendance. In some contexts it can for example be difficult to achieve critical mass, as self-experienced peers can be rare and live far apart (Ali, Farrer, Gulliver, & Griffiths, 2015; Klemm & Hardie, 2002). Adapting peer support to a digital platform can overcome these difficulties, using accessible and asynchronous technologies.

300 children are diagnosed with cancer each year in Sweden (Gustafsson, Kogner, & Heyman, 2014). Fortunately, today most children survive. However, during treatment, children are challenged physically, mentally and socially. This can lead to psychological late-effects that may not manifest themselves until years later (Eiser, 2007). Further, many childhood cancer survivors report feeling like outsiders among their peers, yet have a stronger relationship with immediate family (Enskär & Berterö, 2010). At the same time, those who perceive that they receive more social support report less depression and anxiety (Enskär & Berterö, 2010). There are indicators that DPS could be beneficial for children in general, and children with experience of cancer in particular; yet most existing DPS services are designed to suit the abilities of adults and not children.

We have designed a DPS service for children between 8-12 who have been cured from cancer. During a design process it is essential to continuously involve users in the evaluation of prototypes (Gulliksen et al., 2003; Iivari, Isomäki, & Pekkola, 2010; Kujala, 2003). This is even more important when the design is health related, and when the users' wellbeing may depend on how well the service works. However, involving users in the design and evaluation of DPS is particularly challenging due to the built-in complexity of the context as DPS relates to the experience of difficult ordeals that have occurred in the participants' lives. Participation in evaluation of DPS is important but can awaken unpleasant memories.

There have been attempts to involve children in design in other complex and sensitive contexts. Examples include design with children undergoing dialysis (Bers, Gonzalez-Heydrich, & DeMaso, 2001), deaf children (Potter, Korte, & Nielsen, 2014) and several cases where children with autism and other developmental diversities have been involved in design (Börjesson, Barendregt, Eriksson, & Torgersson, 2015). However, in the evaluation of DPS with children we encounter a unique set of challenges and need to adapt the utilized methods and techniques to be able to successfully include the children in the evaluation process. Children are generally considered vulnerable when participating in research, as they do not have the same power in society as adults (Liampputtong, 2006). Furthermore, children's abilities to perform typical
usability test activities, such as think-aloud, vary greatly over age (Hanna, Risden, & Alexander, 1997). Moreover, children's verbal skills can affect their participation in interviews (Irwin & Johnson, 2005). An evaluation of DPS with children thus needs to be adapted to suit both the participating children's abilities as well as the complexities of the context. Yet, existing literature on involving children in evaluations does not align with the kind of challenges that occur in contexts such as this. The focus is primarily on practical issues, and not on issues of ethics and wellbeing.

Therefore, this paper intends to answer: How can children be involved in the evaluation of DPS?

In order to answer this question we draw on literature and data gathered during the formative evaluation of a prototype of a DPS service for children cured from cancer.

In the next section we provide a brief overview of related literature on DPS and evaluations with children. The method section then presents the method used. This is followed by a section that describes the case studied in this paper, the evaluation process, and briefly the outcomes from the evaluations. The discussion then describes the experienced challenges with involving children in the evaluation of DPS, and identifies strategies for handling these challenges. The contribution is then summarized in the conclusion.

2 Background
2.1 Digital Peer Support
Peer support is a type of social support, which is based on self-experienced people providing each other with support in order to improve their wellbeing (Barak, Boniel-Nissim, & Suler, 2008; Klemm & Hardie, 2002). A commonly known example of peer support is such support groups as Alcoholics Anonymous. Peer support can extend social networks, increase social interaction, emotional well-being and positively affect quality of life (Ali et al., 2015; Solomon, 2004). Peer support has also been found to reduce symptoms of depression and improve the emotional state and self-confidence (Barak et al., 2008; Schwartz & Sendor, 1999). Providing support also causes benefits (Meyer et al., 2015; Solomon, 2004). Since participation in peer support increases wellbeing, it can also lead to fewer hospitalizations and thus generate societal benefits (Solomon, 2004).
Face-to-face peer support is limited, as it requires physical attendance. Participants may have to travel long distances, may not be able to find time or be physically unable to attend (Giesbers, Verdonck-de Leeuw, Van Zuuren, Kleverlaan, & Van der Linden, 2010; Potts, 2005). When peer support is moved to a digital platform, these difficulties can be overcome by the possibilities granted by digital technology. Digital Peer Support (DPS) can bring together peers who are geographically dispersed and would otherwise not have been able to meet (Klemm & Hardie, 2002), can offer anonymity and play down social factors such as age and gender (Ali et al., 2015), making sensitive subjects easier to discuss (Bell, 2007; Potts, 2005). DPS can also be more specific and specialized than face-to-face peer support, and create camaraderie between people with similar backgrounds (Barak et al., 2008). Users of DPS have been found to feel more empowered, less isolated and better able to deal with their circumstances (Melling & Houguet-Pincham, 2011).

However, the design and evaluation of DPS comes with a built-in complexity that makes it particularly challenging and sensitive. For one, DPS often relates to experiencing difficult ordeals. Examples of such DPS implementations include a discussion forum for people undergoing cancer treatment (Klemm & Hardie, 2002) and a web service aimed at supporting pediatric transplant patients (Bers et al., 2010). Secondly, participants may have cognitive or physical impairments. An example of a study with such a context is Coulson, Buchanan, and Aubeeluck (2007) who study the provision of social support in DPS for people with Huntington's disease, an incurable disorder that affects coordination. Thirdly, users may have reduced status in society. Examples of implementations of these kinds of DPS services include a discussion forum for adolescents with mental health difficulties (Webb, Burns, & Collin, 2008) and DPS for people with depression (Melling & Houguet-Pincham, 2011). Lastly, users may be difficult to gain access to, for example for reasons of confidentiality or gatekeeper complexity. Implemented DPS services where this complexity would emerge if the users participated in the design process is for example DPS for adolescents living in close proximity of someone with mental illness (Elf, 2013; Elf, Rystedt, Lundin, & Krevers, 2012), and DPS for children coping with parental cancer (Giesbers et al., 2010).

Considering the sensitivity and variety of subjects that can be dealt with using DPS services, user participation in the design and evaluation of these becomes highly complex. In the case presented in this paper, a prototype of a DPS service for children between 8-12 years who have survived cancer treatment is evaluated. This is another example of a complex and challenging context for
evaluations. Involving children in evaluations is challenging even when the context is not as complex as this.

2.2 Involving Children in Evaluations
In this paper, we contribute with research on evaluation of DPS, for which there are unique challenges, as described in section 2.1. This section first gives an overview of common methods for evaluating usability and UX with children. We then discuss how these methods need to be adapted to suit the evaluation of DPS.

It is considered essential to involve users in regular evaluations of design concepts and prototypes throughout the design process in order to achieve a positive user experience and high usability (Rogers, Sharp, & Preece, 2011). In this paper we understand usability in line with McGee, Rich, and Dumas (2004); as a design quality based on the user perception point of view: "Usability is your perception of how consistent, efficient, productive, organized, easy to use, intuitive, and straightforward it is to accomplish tasks within a system." (p. 909). Usability is considered one component of User Experience (UX) (Diefenbach, Kolb, & Hassenzahl, 2014). In contrast to usability, which focuses on avoidance of negative emotions, UX focuses on the creation of positive emotions (McNamara & Kirakowski, 2005). In this paper we use the definition provided by Hassenzahl (2010), who defines UX as being subjective, holistic, situated, dynamic, and positive.

Usability is typically evaluated with a focus on behavioral goals (Bevan, Kirakowski, & Maissel, 1991), using usability tests, observations, interviews, and expert evaluations such as heurist evaluations. Evaluations of UX focus on both pragmatic aspects as well as hedonic and subjective aspects (Hassenzahl & Tractinsky, 2006), and is often done using interviews, diary studies, and observations in the field. Usability tests primarily identify usability issues with first time use, while other methods such as diary studies gather data on long-term use and users' experience (Cooper, Reimann, & Cronin, 2007). When children are involved in these kinds of evaluations, the methods should be familiar, and have to be adapted to suit the abilities of the children (Lindberg, 2013).

Usability tests evaluate how usable the designed artifact is, usually by measuring users' performance while performing specified tasks (Rogers et al., 2011). Usability tests are traditionally, though not always, performed in a lab environment (Rogers et al., 2011). Hanna et al. (1997) present guidelines for lab based usability testing with children between 2-14, adapted to the child's age
span. These include making the lab child-friendly and placing expectations on a suitable level by emphasizing that the prototype is not finished, so that the children are not disappointed.

A problem when performing usability tests with children is that of task management; tasks should be small and possible to remember, be performed independently, and both be read to the children and handed to them on paper (Markopoulos, Read, MacFarlane, & Hoysniemi, 2008). Bigger tasks need to be broken down into sub-tasks (van Kesteren, Bekker, Vermeeren, & Lloyd, 2003), which helps with focus and aid the children in understanding what they are asked to do (Hanna et al., 1997). Furthermore, children may need "warming up" with a conversation prior to the usability test or interview (Hanna et al., 1997; Hoppe, Wells, Morrison, Gillmore, & Wilsdon, 1995), and the children's abilities to adjust to unfamiliar environments, along with their motivation for participation, are among those characteristics that can affect the outcome of a usability test (Markopoulos & Bekker, 2003). Using generic positive feedback on the children's performance can keep them motivated and focused (Hanna et al., 1997). It has been found that so called active intervention, asking questions during the usability test, gives good results (van Kesteren et al., 2003), and children are also more used to answering questions (Markopoulos et al., 2008).

One commonly used method for evaluating both usability and UX is the think aloud method, where the participants verbalize their thoughts, typically during a usability test (Rogers et al., 2011). A problem with think aloud when the participants are children, who particularly under the age of 8 may have limitations in verbal expression (Druin, 1999) and expression of abstract thoughts (Bratteteig, Wagner, Morrison, Stuedahl, & Mörtberg, 2010), is that think aloud comments can become too general to be of use (Markopoulos et al., 2008). The number of usability problems found also depends on the participating children's personalities. Some have found that shyer children find think aloud more difficult (van Kesteren et al., 2003), while others are not able to verify that extroversion has any effect on the number of usability problems found (Markopoulos & Bekker, 2003). There are indications that gender and testing method are more determinant of the number of usability issues found than verbalization ability or extroversion (Als, Jensen, & Skov, 2005; Donker & Markopoulos, 2002; Markopoulos & Bekker, 2003). To aid children in using think aloud, they can be given communication aids to support them in thinking aloud (Markopoulos et al., 2008).

One generally considered advantage of think aloud, which instead becomes a drawback when involving children instead of adults, is that verbalization...
happens concurrently with use of the evaluated artifact (Baauw & Markopoulous, 2004; van Kesteren et al., 2003). While this negates the issue of the user forgetting encountered usability issues, it adds extra cognitive load for the children (van Kesteren et al., 2003). While some claim that task length is important, and that children cannot maintain focus for longer periods of time, others are more critical and claim that children can maintain focus as long as they find the activities enjoyable (Donker & Markopoulos, 2002; Markopoulos & Bekker, 2003). Further, participating in an evaluation using think aloud can be a socially awkward situation that can make the participants feel uncomfortable (Baauw & Markopoulous, 2004).

Another method for evaluating UX is performing interviews, either individually or in focus groups. Interviews can be performed in connection with prototype use, or revolve more generally on use of similar products. Focus group interviews are an effective way to collect information in all stages of design (Kuhn, 2000). Similarly as with usability tests, the interview should not be too extensive as children become tired and lose focus; it is better to have several shorter interviews than one long interview (Irwin & Johnson, 2005). It can be necessary to break questions down into more concrete, less abstract questions and use concrete examples (Hoppe et al., 1995).

One problem with performing interviews in order to evaluate usability and UX is that the interview happens after the use situation. Children can forget usability issues by the time they are asked questions (Donker & Markopoulos, 2002). This problem is thus not relevant to methods like think aloud. However, like think aloud, interviews can be challenging due to children's lower ability to verbalize (Irwin & Johnson, 2005). Children can have difficulties answering unstructured, open questions, and there is a risk of leading the children on when helping them verbalize (Irwin & Johnson, 2005). During focus group interviews participants have to feel comfortable enough to discuss the topics in front of others (Hoppe et al., 1995). For gathering data on usability issues, interviews have also been found to be a time consuming alternative (Adams & Cox, 2008).

A more time efficient method for gathering data on usability and UX is the use of questionnaires. However, questionnaires for adults cannot be used for children (Borgers, De Leeuw, & Hox, 2000). Grading along scales and following instructions on a questionnaire have been found difficult for children (Hanna et al., 1997; Read & MacFarlane, 2006; Read, MacFarlane, & Casey, 2002). Particularly children under the age of 8 tend to stay to the extreme values on either end of the scale (Read & MacFarlane, 2006), and until the age of 11-12, children interpret questions literally, which can affect the validity of...
the answers (Borgers et al., 2000). Other issues with satisficing, suggestibility and understanding are also relevant when performing questionnaires with children (Read & MacFarlane, 2006).

In order to facilitate children filling out questionnaires, a survey method toolkit for children has been created: the Fun Toolkit (cf. Read & MacFarlane, 2006; Read et al., 2002). The revised Fun Toolkit consists of three different survey methods with different purposes: the Smileyometer, the Again-Again table and the Fun Sorter (Read & MacFarlane, 2006). Methods such as these have been compared favorably with questionnaires designed for adults, while comparisons with similar methods designed for children highlight both advantages as well as disadvantages (Sim & Horton, 2012).

Diaries are a type of survey that the participant writes in frequently – for example every day (time-based sampling) or with each use of the artifact (event-based sampling) (Markopoulou et al., 2008). The major challenge with diaries is how to motivate participants to write in them, and children may need parents to remind them (Markopoulou et al., 2008). Some of the same issues that exist with questionnaires are also relevant for diaries, for example the use of scales (Markopoulou et al., 2008). Diaries with event-based sampling do not suffer from such issues as interviews, where children have to recall any experienced issues (Colombo & Landoni, 2014).

Each method described here has been adapted to suit evaluation of usability or UX with children. We have described each method's challenges, and how the literature proposes to handle these. This is summarized in table 1 below. No method suits all children, and each method aims at evaluating different aspects of usability or UX; therefore it is recommended to use a combination of different methods (Darbyshire, MacDougall, & Schiller, 2005; Lindberg, 2013).

2.3 Evaluating Digital Peer Support with Children
The above described methods for evaluation usability and UX with children are adapted to handle challenges such as the varying abilities of children, and are organized to motivate children to participate. Each method has some built-in challenges, which literature has attempted to handle in the past. However, none of these methods are adapted to suit a complex and sensitive context such as ours. The design and evaluation of DPS has inherent challenges due to the nature of DPS itself; for example, use of DPS happens as a consequence of having had difficult or traumatic experiences, and users may be vulnerable and experience a reduced status in society.
One challenge in the evaluation of DPS with children is that the designer needs to take particular care to build trust with the participants (Liamputtong, 2006). Building trust is especially important, but also time-consuming, when working with children (Irwin & Johnson, 2005). It may be necessary to have more than one meeting with the children to establish trust, and it can be advisable to transfer some level of control to the children (Irwin & Johnson, 2005).

Another challenge in the evaluation of DPS with children is to gain access to participants (Liamputtong, 2006; Moore & Miller, 1999). Many times there are gatekeepers that grant or deny access to participants, and these can be highly protective (Liamputtong, 2006). In some cases, teachers and other caretakers need to be consulted (Graham, Powell, Taylor, Anderson, & Fitzgerald, 2013) – in fact, for each child there is an average of 3.5 consent givers (Powell & Smith, 2009). It may be necessary to include a less than ideal sample because it is better than not involving anyone at all (Melrose, 2002).

Further, risk assessment is both important and challenging in the evaluation of DPS (Moore & Miller, 1999). It can be difficult to understand the risks to the participants beforehand, and the risks can be physical, psychological, social, economical and legal, depending on the type of study (Moore & Miller, 1999). This makes it particularly important to constantly evaluate the study from an ethical perspective (Lindberg, Thomsen, & Åkesson, 2014), and to always place the participants' wellbeing first (Kavanaugh, Moro, Savage, & Mehendale, 2006). While some of this seems obvious, it is sometimes difficult to set aside time to continuously evaluate a research approach; however, it is necessary (Kavanaugh et al., 2006).

Any research involving children is considered sensitive as there is a societal power imbalance between children and adults (Morrow & Richards, 1996). Children also do not always have the emotional experience to handle traumatic events (Ruland, Starren, & Vatne, 2008). There is a risk that vulnerable groups are excluded completely, or that the evaluation is not successful if researchers do not critically reflect on their chosen methods and how the users are able to participate (Aldridge, 2012; Punch, 2002). The challenges that have been highlighted in this section are vital to handle in this kind of research, yet are rarely mentioned in literature on evaluation with children. It is challenges such as these that this paper intends to further study and attempt to handle.
3 Method
This paper describes a case study of the evaluation of a DPS service. The study intends to answer how children can be involved in the evaluation of DPS. Case studies are studies of contemporary, social phenomena, that can be limited to a specific time, place, event or process (Ragin, 1992; Yin, 2014). Case studies are considered particularly suitable in such circumstances when boundaries to the studied phenomena are not distinct, and when the phenomena are particularly complex (Yin, 2014). The method was chosen as it provides a distinct opportunity to analyze the challenges and complexities of evaluating DPS with children. Few studies have been done in this context, making this case unusual and revelatory, which fits the single-case study approach (Yin, 2014).

Case studies have traditionally been performed by non-involved researchers, often retrospectively when the outcome is known (Byrne, 2009), and when the researcher has little control over events (Yin, 2014). However, this study follows a design oriented approach, where knowledge is gained through a design process, and the researcher is more actively engaged (Hevner, March, Park, & Ram, 2004). This case study thus follows the traditions more common in the field of Human-Computer Interaction, where researchers are typically engaged in the case that is being described. Examples include Andrews, Nonnecke, and Preece (2003); Ellis and Kurniawan (2000); Kuhn (2000); Lindgaard (2015).

3.1 Evaluating DPS with Children
The case study presented in this paper analyses the evaluation of the prototype Give Me a Break (GMaB), a DPS service we are designing for children cured from cancer, over the course of two usability tests, a two-week diary study, a focus group interview and a survey. This section describes the evaluation process in detail, with a brief summary of the outcomes. Section 5 will then in more detail discuss the challenges that we experienced, and strategies for handling these challenges.

3.2 Context: Give Me a Break
Give Me a Break (GMaB) is a prototype resulting from a design project with the aim of designing and developing DPS for children cured from cancer. The project was motivated by previous research on how peer support can for example help extend users' social networks, and positively affect their quality of life (Solomon, 2004). The intent was therefore to design such a service for children cured from cancer, specifically aimed at a digital platform in order to
suit the use circumstances. Children cured from cancer in Sweden are often spread out geographically which calls for DPS to overcome such barriers.

GMaB is a prototype of a mobile application that consists of four sections: the playground, campfire, photo park, and photo gallery. The design of GMaB is described in more detail in Einberg, Svedberg, Enskär, and Nygren (2014); Lindberg (2013); Lindberg, Thomsen, et al. (2014); Lindberg, Wärnestål, Nygren, and Svedberg (2014); Wärnestål and Nygren (2013); Wärnestål, Svedberg, and Nygren (2014). At each section, children are able to communicate publicly with other children. Children can customize their own profile and avatar. Activities are organized at predefined times where the children interact. The goal is for the users to form friendships and build long-term relationships.

There is a specific user called the pedagogue, who is an adult with the purpose of facilitating activities. This user has a specific avatar with a different, identifying appearance. During the evaluation process, the pedagogue was played by one of the researchers, but the role is meant to be held by a teacher or medical professional.

The context for the evaluations in this case was particularly complex for several reasons. Firstly, children are considered a vulnerable user group (Liamputtong, 2006). Children do not have the same influence in society as adults and there is a power imbalance between children and adults. Secondly, the context is health related, as the target user group has experience from going through cancer treatment at a young age. Participation can thus awaken unpleasant memories.

Thirdly, because of the two aforementioned complexities, gatekeepers such as parents, teacher, doctors, and nurses want to protect the children from anything that might upset them, and may therefore not allow them to participate. Additionally, the gatekeepers that can help identify children from the target user group (such as medical professionals) are often in professions of high stress, reducing their ability to facilitate recruitment.

Fourthly, children with a history of cancer in Sweden are widespread geographically and are therefore difficult to recruit. As the target user group is limited, there is a risk of overusing participants, yet it is important that research never burden the target group (Graham et al., 2013). The users may also have very different medical history; while some children have recent experience with cancer, others were treated as toddlers and may have no memory of the treatment.
3.3 The Evaluation Process

The process to evaluate GMaB was designed to consist of four stages with different aims: (1) two formative usability tests to evaluate usability; (2) a two week long diary study to evaluate usability and user experience; (3) a follow up focus group interview with children from (1) and (2) to evaluate user experience and goal fulfillment; and (4) a survey study to evaluate goal fulfillment and contextualize to the target user group. The children in (4) had a history of cancer, while the children in (1) – (3) did not. Table 2 summarizes the evaluation process.

3.3.1 Participants

Prior to designing the evaluation process, the intent was to include children with a history of cancer in all stages of the evaluation. We attempted recruitment in several ways. We first approached already established contacts in child oncology care, but while they expressed interest, they could not aid in recruitment. An attempt to recruit using contacts in the regional child cancer association also yielded nothing. As a result, we had to design the evaluation process around this difficulty. In order to do this, activities 1-3 were aimed at evaluating more general usability and user experience issues, while activity 4 contextualized these results to the intended target user group.

Children without a history of cancer participated in evaluation parts 1-3. They were between 10 and 12 years old, five boys and five girls. Due to recruiting difficulties, we had to exclude children from the lower age range of our target group (8-12). The teachers of the younger classes at the school with which we established contact were too busy to facilitate recruitment. This was a similar problem as the one we encountered with recruitment through hospitals. A consequence of this is that children under the age of 10 were not able to evaluate the prototype at this stage.

In part 4 of the evaluations, we reconnected with the children who had participated in the early stages of the design phase of the project. The 14 children that were contacted had gone through treatment for cancer. They had been between 8-12 when they first participated and were now between 11-16. The survey was important as a way to get first-hand information from children with an actual experience of cancer treatment. 7 children chose to fill out the survey, giving a response rate of 50%. The children had all been diagnosed with leukemia or lymphoma, but had been cured or were in remission during their
first participation. The survey purposed to more specifically evaluate the prototype from the context of cancer surviving children.

3.3.2 Usability Tests

The setup of the usability tests was primarily inspired by Hanna et al. (1997) and Markopoulos et al. (2008). The usability tests had formative goals, that is to identify usability problems in order to enable the correction of these in upcoming design iterations (Lewis, 2014). The setup of the usability tests followed the recommendations from literature. For example, the children's tasks were broken down into small subtasks, each researcher was guided to use active intervention, and we provided picture cards inspired by Barendregt and Bekker (2005) to aid the children in giving feedback.

Two usability test sessions were performed, each with three children. The usability test was introduced to the children as a group, and the goal and expectations of the usability test were explained to make the children's expectations realistic. Then the children were individually given five tasks to perform by a facilitator, who sat with them throughout the tasks to keep them on point and answer any questions they might have. All usability tests were video recorded. For each task, the children answered a questionnaire where smileys had been used to illustrate the likert scales. The children chose whether they or the researcher wrote down the answers to the open questions in the questionnaires.

The questions for each questionnaire were: "Would you like to do this activity again?", "How much fun was it?", "Did you know what to do the entire time?", "Write/draw something that was fun, something that was boring, something that was easy and something that was hard", "What would you change?", and space for additional comments. The video recordings and the questionnaires were thematically coded using a top-down thematic analysis (cf. Braun & Clarke, 2006) driven by the usability attributes: effectiveness, efficiency, safety, utility, learnability and memorability (Rogers et al., 2011). For example, one child only noted that there was a robot providing helpful suggestions after being explicitly asked about the robot. This was coded under learnability. Another child expressed a wish to use their avatar to wave at the other children, and suggested several physical actions for the avatar to perform. This was coded under efficient.

This method of analysis was chosen primarily due to its flexibility, suitability to participatory contexts, and ability to highlight both similarities and differences between multiple data sets (Braun & Clarke, 2006). While this kind of analysis
does not tend to yield as rich descriptions, it does analyze the chosen aspects (in this case the chosen usability attributes) of the data in more detail than if a bottom-up thematic analysis would be performed (Braun & Clarke, 2006).

3.3.3 Diary study
The second part of the evaluations consisted of a two-week diary study. The six children who participated in the usability tests, along with an additional four children who had not been part of the usability tests, were given diaries with questions for each day. Each weekday at a specified time, the children were asked to log in and perform an activity together. The pedagogue, played by one of the research team, facilitated all activities. Before and after the activity, the children filled in the diary. Thus, event-based sampling (Markopoulos et al., 2008) was used for the diaries.

The activities the children were asked to perform meant to deepen their friendship, starting out more superficial, increasing in level of trust and engagement. For example, for the first activity, the children were asked to visit and comment on each other's profiles. For the last activity, the children themselves had to agree on and perform a game together.

After each activity, the participating researcher took notes and videotaped the on-screen conversation in order to log the data from the activities. The diaries and video recordings were compiled and thematically coded in a similar way as the usability tests. In addition to the usability attributes, codes relating to UX were used in order to focus more on utility and desirability. Since UX is more difficult to define and measure than usability (Bevan, 2008), and since UX is subjective (Hassenzahl et al., 2013), the codes used for this part of the analysis were more open: positive emotional response, negative emotional response. The data that was coded within these two codes was in turn analyzed using a bottom-up approach (cf. Braun & Clarke, 2006). This resulted in sub-codes within the two primary codes that were based on the empirical data.

For example, one of the children wrote in their diary that it was fun to do whatever you wanted, and another child wrote that it was fun to suggest games. Both of these were coded under positive emotional response, and then grouped under the sub-code freedom of activities.

3.3.4 Focus Group Interview
After the diary study was complete, seven of the children from the diary study participated in a focus group interview. This aimed at creating a deeper understanding of how the children had experienced the use of GMaB. The 7
children who participated in the focus group interview had all been part of the diary study, and 5 also participated in the usability test. The interview guide that was used to focus the discussions on the participants' experiences started with open questions and continued with more specific follow-up questions, in order to aid the children, as recommended by Irwin and Johnson (2005).

A challenge with performing focus group interviews with children is to make the children feel comfortable (Hoppe et al., 1995). As we had met the children during the previous activities in the evaluation process, we had already established rapport and the children alluded to our previous interaction with them, showing relative comfort in the interview situation.

The focus group interview was video taped and transcribed. The transcription was analyzed using a similar top-down thematic analysis as the diary study. The codes used were based on UX as well as goal fulfillment (i.e. provision of peer support). The latter codes were based on our earlier studies how friendship was described among children from the target group (Einberg et al., 2014): common interests and experiences, mutual emphatic action, and mutual trust and understanding. From the analysis another code also emerged: the role of the adult. For example, one of the children told us how they had been late once, and one of the other children helped them to get started with the day's activity. This was coded under mutual emphatic actions. Another one of the children said that they felt more comfortable knowing there was an adult playing the pedagogue, someone who could show compassion. This was coded under the role of the adult.

3.3.5 Survey
The 15 children who had been a part of the project at an earlier stage of the design process were approached to fill in a survey relating to goal fulfillment. As the children had not been part of the evaluation process and had not seen the prototype, the survey both described and included a video showing the prototype in use. The video described the concept, and exemplified the functionality of the prototype, illustrated by video taken from the prototype during play. This would serve to inform the children about the prototype and its functionality. The children were then asked: "Do you think GMaB would have helped you…", "…to meet others who have been treated for cancer?", "…to do fun things with others?", "…to get to know others with similar interests as you?", "…to find friends you can get help from?", "…to find friends you can trust?". The survey was designed like the usability test questionnaire, using smileys to represent likert scales. 7 children with a history of cancer filled out the survey.
The survey was analyzed using a similar thematic analysis as the focus group interview, with a similar focus on goal fulfillment using the same codes. For example, one child wrote that they thought it would be easy to find friends because you would know that the other users had gone through the same experiences as yourself. This was coded under mutual trust and understanding.

3.4 Evaluation Outcomes
Table 3 and 4 briefly summarize the outcomes from the evaluation process with focus on the contributions from each step of the evaluation. The summary does not classify outcomes in terms of severity.

In summary, the children experienced the use of GMaB to be creative, fun and enabled them to interact with friends. The usability issues that were identified related primarily to communication possibilities, and critical mass of users. The children who filled out the survey highlighted potential with GMaB, particularly for creating friendships with other children with the same background. A strength that was emphasized was knowing that all other users had the same background and that they shared the same experiences, while at the same time it would be possible to do fun activities together.

3.5 Method Discussion
A particular challenge during the evaluation process was the decision by the regional ethical review board (dnr 2011/307), which concluded that we should not focus explicitly on the children's experience of cancer treatment. From an ethical standpoint, we were to focus on salutogenic (that is, health promoting) aspects. During the earlier design process, we implemented strategies to include the target group without explicitly discussing cancer (Lindberg, Thomsen, et al., 2014; Wärnestål et al., 2014). The same considerations were made during the evaluation process.

There are limitations to the participant selection for the usability tests. Due to the relatively limited resources of the project, it proved impossible to include more than ten children in the study. This led to only a total of six children participating in the usability tests, which is a relatively small sample. Rubin and Chisnell (2008) propose a minimum of four participants, but recommend a larger number of participants for summative usability tests. In this case, as formative usability tests were performed, it can be enough to involve as little as five participants if the usability problems are likely to occur in 50% or more cases, and will lead to the identification of enough usability problems for further design and development (Lewis, 2014).
Being aware of the small number of participants, the evaluations were set up to produce qualitative data in addition to frequency measures, through the use of the questionnaires. It is not uncommon to use more than one evaluation technique during formative usability tests (Lewis, 2014). Except one technical error, no metrics indicated any usability issues. However, the qualitative analysis yielded a number of usability issues. The metrics have therefore been excluded from this paper, while the qualitative results are summarized in table 3. The focus is on the users' perceptions of usability and UX, in line with our understanding of these concepts.

Further, the case presented in this paper highlights how evaluation of usability and user experience of a DPS service can be achieved by including some of the children in more than one stage of the evaluation process. Within-subject design is often used in cases when it is not possible to involve a large number of participants, and can also lessen the impact of individual differences (Rogers et al., 2011). In this case, the within-subject design was purposely done in order to evaluate use over time; it was important to ensure that the prototype was fun and engaging to use over an extended period of time and not only during first time use. Furthermore, the within-subject design also allowed some of the children to function as mentors for the children who did not receive an introduction to the use of the prototype.

Furthermore, five of the children went to the same school, and thus knew about each other prior to participating. However, only three considered themselves friends and the remaining children had never met. Since one of the goals was to evaluate whether the children could become friends using the prototype, this could have been a hindrance to the evaluation. It did not prove to be so in this case. We found no indications that the children included their existing friends more than any of the other children, and while we could not evaluate if these three particular children formed friendships with each other, we could evaluate how they befriended the other participants.

4 Discussion
This paper intends to answer how children can be involved in the evaluation of DPS. While the reviewed literature is expansive on handling challenges when involving children in evaluations (summarized in table 1), the challenges encountered in the evaluation of DPS were of a different nature. We encountered challenges in this context that went beyond the scope of previous literature; the described case contained complexities regarding ethics, trust and
risk assessment, due to the vulnerability of the user group, the sensitivity of the subject and the risk of upsetting participants, and recruitment complexity, due to gatekeepers' stressful professions, users' geographical spread and the user group's abilities to participate in evaluations.

To build trust was particularly important, but also challenging in this evaluation process. The subjects that were discussed during the focus group interview, for example, required that the children trusted both the researchers as well as the other children enough to speak about how they experienced the use and interaction with the other children, and whether or not they felt like they had made new friends. The challenge of building trust is not unique to the evaluation of DPS; building trust is important in all research, and particularly when performing research with vulnerable users such as children (Irwin & Johnson, 2005; Liamputtong, 2006). Nevertheless, the reviewed literature on evaluation methods with children did not highlight how to build trust, nor whether it was possible to do so using the described methods.

One challenge during the evaluation process was to assess the risks to the participants’ wellbeing beforehand, as there was a risk of upsetting participants due to the context of the study. In order to meet the specific challenges of vulnerability of the children as participants in research (Liamputtong, 2006), we adapted the evaluation process based on recommendations from literature. For example, an informal setting and informal manner was adopted to set the children at ease. Because research should cause no harm to participants (Graham et al., 2013), the evaluation process maintained a salutogenic (health related) focus throughout. Activities and questions related to the use of the prototype, and not to the illness.

However, adapting the evaluation process based on recommendations from literature was not sufficient. There were possibilities for other harm to the participants that was not highlighted in the reviewed literature. For example, there was a risk to awaken painful memories for the children who participated in the survey. To handle this, the children were for example asked if they thought that the prototype would help them meet friends that they could trust. Instead of focusing directly on the experience of cancer, the children were given the control of whether they wanted to breach the subject or not.

Recruitment also proved a challenge in this case, due to the gatekeeper complexity. Because this project extended over several years, the children who had participated in the early stages of the project had aged out of the target age group. It was necessary to recruit more participants. The gatekeepers such as
medical professionals and teachers showed interest but were unable to aid recruitment due to high stress in their professions. Additionally, the target age group is small and widespread geographically. Only a few children with a history of cancer were able to attend physically, which was required for the usability tests and focus group interview. There was a risk of overusing the children with whom we had already established contact and who had participated previously in the design process; this is a common risk in similar situations (Graham et al., 2013).

We were faced with the possibility of not being able to include our target user group when we could not recruit children with a history of cancer. Instead of excluding the user group completely, we designed the evaluation process to allow them to participate to the largest possible extent. When research is sensitive or users are vulnerable and difficult to access, there is a risk that the user groups in question are excluded completely from research (Aldridge, 2012). We do not consider the fact that children cured from cancer participated in only one evaluation activity as a limitation to the study; in fact, it is an opportunity to show that it is possible to perform an inclusive evaluation process even under complex circumstances.

This kind of multi-stage evaluation, where each stage has a different focus, allowed us to control the complexities and challenges of the context. The first three stages, the usability test, diary study and focus group interview, focused on more general usability and user experience aspects that did not specifically relate to the context. This enabled us to include children without a history of cancer. Yet, the final stage, the survey, allowed us to evaluate goal fulfillment for the target user group, which was not possible to evaluate with children without the desired background. It is not uncommon to experience difficulties with recruitment in research with vulnerable users (Liampittong, 2006) and this process design allowed us to evaluate all aspects of the prototype when it was not possible to include users from the target group throughout the entire evaluation process.

The challenges described above are not all uncommon, yet there is little support in literature on how to handle them when evaluating digital services. When evaluating DPS, a particularly complex context, these challenges become particularly prevalent, yet they are relevant in all research involving children. We will now summarize the strategies we identified for handling these challenges in an attempt to contribute to the much needed discussion on how researchers who intend to involve children in design in complex contexts can approach similar challenges.
4.1 Strategies for Meeting the Identified Challenges
Within the frame of a multi-stage evaluation process, we identified from the case study three key strategies for meeting the many challenges of involving children in the evaluation of DPS: progression, proxies and reflection.

4.1.1 Progression
As this context was particularly complex, we considered trust to be essential and we experienced that the possibility to build a relationship over time was even more beneficial. Both Irwin and Johnson (2005) and Liamputtong (2006) recommend spending time familiarizing with and building trust between researchers and participants at the beginning of an activity. The evaluation process was performed in multiple stages with progressively increasing sensitivity. This multi-stage design gave a certain level of control over the complexities of the context, aided in risk assessment, and also granted the possibility to build trust with the participants. The progressing activities also allowed the participants to bond.

Additionally, the progression allowed us to build on the children's understanding of cancer treatment through storytelling. They could then allude to this knowledge during the activities, and some did so explicitly. While the children could never achieve a full understanding of the experiences of going through cancer treatment, they used the information we gave them, showing empathy.

4.1.2 Proxies
The challenges of this case required that we design an evaluation process that could involve both children who had and who had not been treated for cancer. In this case, there were several challenges to achieve this goal. The children without a history of cancer in essence functioned as proxies. They participated in activities that related to more general aspects of the evaluation: usability and user experience. These children were still peers, though not due to a shared background. While it was not possible to include children without a history of cancer to evaluate goal fulfillment in relation to the context that was designed for, we involved children that had mostly aged out of the age span of our target group, but who had the same background as the target user group, to evaluate this.

Difficulties with access to participants is common when involving vulnerable participants (Liamputtong, 2006; Melrose, 2002), for example due to gatekeeper complexities (Graham et al., 2013; Powell & Smith, 2009), and this
way of designing the evaluation process can help circumvent some of these difficulties, yet still allow the target user group influence on the evaluation. We managed to maintain the influence of the target group even when they could not be involved in all steps of the evaluation process, and argue that it is better to include them in some steps rather than none at all.

4.1.3 Reflection

When summarizing the experiences from the case study, we note that there is a high level of critical reflection required on the part of the researcher. Risk assessment and taking measures such as adapting activities to the abilities of the participants, buffering the subject, and simply being particularly cautious in one's own actions and communications are essential. These are deceivingly simple things, but they are essential no matter what kind of research we do. Researchers should always consult common sense, and most important is to build on literature and critically reflect on the nature of the evaluation process and adjustments to suit the target user group. These kinds of reflections and adjustments will also facilitate for any upcoming step in the research process; if researchers can show awareness to the situation and the participants' needs, issues such as research financing and the establishment of partnerships will inevitably be made simpler.

5 Conclusion

This paper intended to answer the question: How can children be involved in the evaluation of DPS? While the literature highlights how evaluation methods can be adapted to suit the abilities and motivations of children, evaluating DPS proved to be particularly complex due to challenges relating to ethics, trust, risk assessment and recruitment complexity. We identify three key strategies for handling these challenges and involving children in the evaluation of DPS: progression, proxies and reflection. Progressing the activities in a multi-stage evaluation process allowed control of some of the complexities of the context, and let us build trust. By designing the evaluation process in such a way that children without a history of cancer could participate in more general usability and UX evaluations while serving as proxies, children with a history of cancer could evaluate goal fulfillment. Finally, there is a high degree of common sense involved in this kind of research. Prior and continuous critical reflection was essential in the execution of the evaluation process.
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Wickedness in Design for People Diagnosed with Schizophrenia

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Abstract
With the digitisation of society, e-health technology increasingly supports new design situations that extend those traditional to Information Systems, and therefore need to be better understood. In design for complex, new and sensitive design situations, it is not possible to apply known methods and solutions without deeper situational understanding. These design situations are fraught with wicked problems that are contradictory and complex. This paper intends to answer how the wickedness of the design situation when designing e-health technology for people diagnosed with schizophrenia can be understood and what consequences the design situation has for the design process. The paper presents a grounded theory analysis of stakeholder interviews and focus group interviews with people diagnosed with schizophrenia. Four wicked problems are identified: struggle of dependence, contradiction of social interaction, contradiction of trust and counteracting improvement behaviour. The problems are interrelated and have consequences for user involvement in design, and the design, acceptance and use of e-health technology for people diagnosed with schizophrenia. The paper also shows the viability of using grounded theory for studying and describing situational wickedness.

1 Introduction
During the last decades, technical advances have created a digitalised society. This has in turn expanded the use of digital technology to new situations and user groups; groups that are heterogeneous, and that use digital technology in a multitude of contexts (Iivari, Isomäki, & Pekkola, 2010). E-health technology is no exception. With the digitalisation of society, e-health technology has to be
designed to support previously unsupported user groups. Examples include Tokar and Batoroev (2016) who explore mobile health care for people with depression, Aardoom, Dingemans, and Van Furth (2016) who study e-health technology for people with eating disorders and Kowatsch et al. (2014) who study the design of a health information system for reducing childhood obesity. Advances such as these have paved the way for innovative ways to support patients at different stages of their lives.

In order to design digital technology, it is necessary to understand the circumstances in which it is to be designed and used (Hevner, March, Park, & Ram, 2004). In this paper, the design situation concept includes both the situation in which the information system is designed, as well as its subsequent context of use. It is not possible for one person to have all the necessary knowledge of the complexities of a design situation; it therefore becomes imperative to involve stakeholders and support their communication and collaboration (Arias, Eden, Fischer, Gorman, & Scharff, 2000). When the context of use has been frequently designed for in the past, or is easily relatable, designers can rely on routine in their design actions (Gregor & Hevner, 2013). However, in design for new, complex and sensitive design situations such as design of e-health technology with vulnerable users, it becomes more difficult to both study and understand the design situation.

This paper focuses specifically on understanding the situation for design of e-health technology for people diagnosed with schizophrenia. Approximately 1% of the world's population is diagnosed with schizophrenia (Mueser & McGurk, 2004) and have symptoms such as hallucinations, psychoses, apathy, and cognitive impairment (Frangou, 2008). Symptoms and treatment for schizophrenia can affect the ability for creative thinking (Andreasen, 2000), clear expression of ideas (Schulberg, 2001), and social interaction (Couture, Penn, & Roberts, 2006). The treatment for schizophrenia is typically antipsychotic medication, but this has only a limited effect (Frangou, 2008).

Designing e-health technology for people diagnosed with schizophrenia is an example of a complex and sensitive design situation; it involves encountering contradictory and sensitive problems that affect the design situation, such as paranoia and delusions (Mueser & McGurk, 2004), and social stigmatisation (Campellone, Caponigro, & Kring, 2014; Davidson et al., 2004). Further, many in the target user group tend to have limited experience with digital technology (Firth et al., 2015), and cognitive limitations can restrict ability for verbally expressing (Bowie & Harvey, 2006) technology needs. Any process for
designing e-health technology for people diagnosed with schizophrenia will have to cope with such problems.

These types of problems that are contradictory, incomplete or have constantly changing requirements, are often referred to as "wicked problems" (cf. Rittel & Webber, 1973). Design, which is aimed at iteratively solving problems, is particularly suitable for handling wicked problems (Hevner et al., 2004; Zimmerman, Forlizzi, & Evenson, 2007). Understanding a wicked problem is also part of understanding its possible solution, since they are only possible to be understood once they have been solved (Rittel & Webber, 1973). This makes understanding the wickedness of a design situation critical to the entire design process; it is the essence of the design process.

Understanding the wickedness of designing e-health technology is therefore essential but at the same time challenging. However, not attempting to do so when it is possible can have negative consequences for the quality of the designed technology. With the current increase of interest in and need for e-health technology for mental health (see e.g. Firth et al., 2015; Firth & Torous, 2015; Gay, Torous, Joseph, Pandya, & Duckworth, 2016; O'Leary, Bhattacharya, Munson, Wobbrock, & Pratt, 2017; Tokar & Batoroev, 2016), it becomes particularly important to understand the complexities of the design situation when designing for people diagnosed with schizophrenia.

Therefore, this paper intends to answer the question: How can the wickedness of the design situation when designing e-health technology for people diagnosed with schizophrenia be understood, and what consequences does the design situation have for the design process?

Due to the explorative and open nature of the aim, this paper proposes a grounded theory analysis to understand the wickedness of the design situation. The purpose is to both describe the nature of the wickedness and its consequences for design, as well as to discuss the applicability of the grounded theory approach to understand wickedness in design situations.

2 Schizophrenia
Symptoms of schizophrenia can be positive (in the sense that they constitute an addition of abnormal symptoms and behaviours), negative (constituting a lack of normal symptoms and behaviours), or cognitive (Frangou, 2008; Mueser & McGurk, 2004). These symptoms are manifested to a different degree among individuals (Frangou, 2008). Positive symptoms include delusions and
hallucinations (Frangou, 2008); in essence a loss of contact with reality (Mueser & McGurk, 2004). Negative symptoms include flat affect, social withdrawal and reduced speech (Frangou, 2008; Mueser & McGurk, 2004). Many also have cognitive impairments, such as problems with attention, learning and memory, illogical thinking, confusion, delusion and strange linking of thoughts (Mueser & McGurk, 2004; Schuldberg, 2001; Wilder-Willis, Shear, Steffen, & Borkin, 2002). There is no objective, diagnostic test for schizophrenia; the diagnosis is made based on a criterion-based system where other illnesses are excluded (Frangou, 2008). Due to the different nature of the illness there are subsets of schizophrenia, for example paranoid schizophrenia and disorganised schizophrenia (Frangou, 2008).

There is no cure for schizophrenia, only ways to cope with the illness. Most recover after the first onset, but about 10% never do (Frangou, 2008). The outcome seems more promising in developing countries than in developed countries (Frangou, 2008); there are indications that this may be connected to the mode of treatment. The primary treatment in developed countries is antipsychotic medication that primarily treats positive symptoms (Frangou, 2008). Antipsychotic medication does not appear to improve cognitive function, and even though other symptoms improve, these cognitive symptoms tend to remain (Wilder-Willis et al., 2002). Psychosocial treatment such as supported employment and social skills training has been found to improve the outcome of schizophrenia (Mueser & McGurk, 2004).

The social and emotional limitations that people diagnosed with psychotic disorders, such as schizophrenia, experience can often lead to isolation (Castelein, Bruggeman, Davidson, & van der Gaag, 2015). Social support has been found to benefit people diagnosed with schizophrenia (Castelein et al., 2008; Chinman et al., 2014; Davidson et al., 1999; Lloyd-Evans et al., 2014). However, due to both social stigma and symptoms such as reduced vocal ability, lack of motivation, and difficulties with memory and concentration, it is difficult for people diagnosed with schizophrenia to organise social support themselves (Castelein et al., 2015). Increasingly, people diagnosed with schizophrenia are turning to social media not specifically designed for their needs, risking low quality support and being identified as an individual with such an illness and its associated stigmatisation (Naslund, Grande, Aschbrenner, & Elwyn, 2014). People diagnosed with mental health conditions in younger generations are also more likely to use social media to build friendships (Gowen, Deschaine, Gruttadara, & Markey, 2012).
E-health technology for mental health has in recent years been gaining more attention (Firth et al., 2015; Firth & Torous, 2015; Gay et al., 2016; O'Leary et al., 2017; Tokar & Batoroev, 2016). For example, Melling and Houguet-Pincham (2011) study e-health technology for people who are experiencing depression, O'Leary et al. (2017) involve individuals with mental illnesses to design technology for peer support, and Lederman, Wadley, Gleeson, and Alvarez-Jimenez (2013) design online social therapy meant to detect warning signs among young people with psychoses. Each of these cases illustrates a complex and sensitive design situation, and the necessity to understand the design situation as part of the design process in order to adapt both the design process and the e-health technology.

Studies have shown high feasibility for using e-health technology, and specifically mobile health technology for supporting people diagnosed with schizophrenia (Firth & Torous, 2015). E-health technology for mental health has shown promise for reducing the health care barrier, dealing with stigmatisation, and individualising treatment (Tokar & Batoroev, 2016). However, while several studies look at use of e-health technology (e.g. Firth et al., 2015; Firth & Torous, 2015) and social media for health support purposes (e.g. Gowen et al., 2012; Naslund et al., 2014), studies on the design of such technology are scarcer.

People diagnosed with schizophrenia are seldom involved in design activities; symptoms such as cognitive limitations (Bowie & Harvey, 2006) for example in verbal expression (Andreasen, 2000) combined with social stigmatisation (Imhoff, 2016) limit the possibilities of their involvement. Symptoms of schizophrenia can for example impair the ability for creative thinking and imagination (Andreasen, 2000). There are indications that people diagnosed with schizophrenia are more likely to jump to conclusions (Dudley, Taylor, Wickham, & Hutton, 2016; Moritz, Woodward, & Hausmann, 2006). Socially, people diagnosed with schizophrenia can have difficulties maintaining employment and regular societal functioning (Couture et al., 2006) and tend to use passive coping strategies, meaning that they tend to withdraw (Wilder-Willis et al., 2002). Symptoms such as these can make design of digital technology for and with people diagnosed with schizophrenia more complex than for people who do not experience such symptoms.

However, other vulnerable user groups have been involved in design under different circumstances, for example children with a history of cancer (Lindberg, Svedberg, Bergquist, & Nygren, 2017), people with dementia (Branco, Quental, & Ribeiro, 2017), women with breast cancer (Skeels, Unruh,
Powell, & Pratt, 2010), homeless (Le Dantec et al., 2011), and people with aphasia (Wilson et al., 2015). These studies encountered challenges with for example ethics, user access, and adaptation of techniques for user involvement. Approaches to user involvement, such as co-design and participatory design, thus encounter many challenges but also many opportunities for involving users who are considered vulnerable (Vines et al., 2017).

3 Wicked Problems
When designing e-health technology for people diagnosed with schizophrenia, the design situation contains unique complexities and sensitivity, for example related to the symptoms of the illness and social stigmatisation. The concept of wicked problems was initially described by Rittel (1972) and Rittel and Webber (1973). The difference between typical, simple problems with established procedures and wicked problems, is that wicked problems do not have clear solutions, it is not always possible to know when or if they have been solved, and they are not possible to delineate and clearly define (Rittel & Webber, 1973). Social problems (Rittel & Webber, 1973) and problems approached using non-linear design processes are usually of a wicked nature (Farrell & Hooker, 2013). In fact, all problems in design, except those taken on by routine design, are wicked problems (Hevner et al., 2004). There is no single right or wrong solution (Nelson & Stolterman, 2003); the solution to a wicked problem lies in the world view of the solver (Rittel & Webber, 1973), in this case the designers and users (Buchanan, 1992).

In the attempt to solve wicked problems, all actions taken will affect the surrounding context and there is thus no way to undo mistakes (Rittel & Webber, 1973). Therefore, it is important to reduce the possibility for mistakes. Yet, wicked problems cannot be sorted into predefined categories, nor are there any predefined ways of solving them; all wicked problems are unique (Rittel & Webber, 1973) and must be handled in a manner appropriate to their complexity, ambiguity and uniqueness, with a focus on achieving a desirable outcome instead of a clear problem solution (Nelson & Stolterman, 2003).

The collaboration between different people in design is suitable for tackling wicked problems (Hawryszkiewycz, 2014) and the iterative, practice based approach to design is considered appropriate for handling wicked problems (Buchanan, 1992; Farrell & Hooker, 2013; Hevner et al., 2004). Designers who approach a wicked problem invariably, due to the nature of the problem, have to face design situations with little prior work that call for new and diverse skills (Howard & Melles, 2011).
McCall and Burge (2016) critically examine the theory of wicked problems and emphasise four amended features. Firstly, they highlight that there is a cause and effect relationship between wicked problems, and that identifying cause and effect relationships is the main focus in handling them (McCall & Burge, 2016). Secondly, they revise the notion put forward by Rittel (1972) that trial-and-error cannot be used when solving wicked problems. This relates to their third conclusion, that previous projects can inform future projects, which was also refuted in Rittel and Webber (1973). Fourthly, they conclude that wicked problems always have unforeseen consequences, and this capricious nature of wicked problems is what causes the primary difficulty of solving them (McCall & Burge, 2016).

The literature suggests that wicked problems can be conceptualised along a scale, with problems varying in degree (Farrell & Hooker, 2013) or along a spectrum of wickedness (Burge & McCall, 2015). One example of such a gradation is the concept of the so-called super wicked problem, which has additional features that increase its wickedness in relation to regular wicked problems (Levin, Cashore, Bernstein, & Auld, 2007). Viewing the concept as a spectrum indicates that there are certain problems that are more wicked than others, and that certain design situations can have a higher level of wickedness.

Research within Information Systems (IS) and related design fields has previously tried to approach wicked problems, for example by using game design to increase awareness of climate change (Coulton et al., 2014), by using participatory design to design sustainable communities (McGinley & Nakata, 2012), and by using user-centred design tools such as personas to reduce ICT4D project failures (Peter, 2015). Dealing with complex problems requires that the designer considers the whole as well as the parts; that is, to not only focus on the specifics of the identified problem but also on the nature of the circumstances within which the problem resides (Nelson & Stolterman, 2003). Instead of oversimplifying, it is important to consider the problem on different levels, systemically (Nelson & Stolterman, 2003). Familiarizing oneself with the design situation is also an important step in better utilizing the empirical material (Alvesson & Kärreman, 2007). Wicked design problems have for example been identified as part of the design of health-promoting resources for children cured from cancer (Wärnestål, Svedberg, & Nygren, 2014). This paper is a step towards creating an understanding of the wickedness of the design of e-health technology for people diagnosed with schizophrenia.
4 Method
This paper employs a grounded theory analysis to answer how the wicked problems in the design situation of e-health technology for people diagnosed with schizophrenia can be understood and what consequences this has for the design process. The approach was considered appropriate because it is a way to make sense of stories told by interviewees, a way to stay close to the empirical material, and to learn about the situation under study (Charmaz, 2006). Grounded theory was first introduced by Glaser and Strauss (1967) and has since developed in different directions. This paper relies on the work of Charmaz (2006) as a foundation for the employed methodology. Charmaz (2006) emphasises that theories are not found, but constructed by the researcher in an interpretive process of analysis. Grounded theory can be successfully combined with design research, and one use of performing a grounded theory analysis is in the early stages of a design process, in order to gain a systematic and deep understanding of the design situation and problem area (Gregory, 2010), as in this case.

Grounded theory has been increasing in use within IS, as it is considered useful for describing processes and phenomena (Hughes & Jones, 2003). However, the existence of myths about the nature of grounded theory has been considered the cause of its misuse or lack of use (Urquhart & Fernandez, 2006). These myths include the misconception that literature cannot be studied before performing a grounded theory analysis (Urquhart, 2001; Urquhart & Fernandez, 2006). Instead, literature should be studied beforehand, but not in order to integrate into the yet unidentified theory (Urquhart & Fernandez, 2006); it should be used strategically (Charmaz, 2006). In this paper, the intent was not at the onset of the analysis to identify wicked problems. However, the results that emerged from the application of grounded theory showed many sensitive and contradictory circumstances within the studied design situation, and these were then identified to be wicked problems. The literature on wicked problems was thus incorporated after the analysis was performed.

4.1 Study Design and Analysis
The empirical material included in this study consisted of: (1) semi-structured stakeholder interviews, four with relatives of people diagnosed with schizophrenia and three with medical professionals; and (2) two focus group interviews, each with two people diagnosed with schizophrenia. The focus group interviews were part of the first of three design workshops in a larger research project. The empirical material consisted of a total of 540 recorded minutes.
The individual and focus group interviews were all transcribed and coded line-by-line using open coding. The codes were formulated closely to the original wording per recommendation by Charmaz (2006); this close attention to early coding resonates with the concept of grounded theory, which highlights a closeness to the empirical data. The open codes were then grouped into categories using focused coding. The core to grounded theory is considered to be constant comparison between data, codes and categories (Charmaz, 2006). The open and focused coding was therefore done iteratively, and each new code was compared with the existing codes and categories. Category identification was done by using the most significant codes as a starting point. Examples of categories include depending on others, having illness awareness, and using strategies.

The relationships between the identified categories were then axially coded. Axial coding serves to make sense of the relations between categories and subcategories, and return a holistic perspective on the data (Charmaz, 2006). This was done using analysis software visual mapping functionality. For example, the category depending on others related to the category fearing since fear affects the ability to depend on other people. It was at the axial coding stage that the wicked problems were identified in the conflicting nature of the categories. A total of 58 memos were written throughout the analysis process. Memos are an important part of a grounded theory analysis as they function as a tool for analysis, theory creation and idea generation (Charmaz, 2006). In this paper, the memos were important for recording insights and interpretations throughout the analysis, for example to record reflections on the contradictions that emerged.

The result presented in this paper is only part of the results from the grounded theory analysis. As the result was rich and diverse, it became more suitable to present it over the course of more than one paper for the sake of clarity. This paper relates to the entirety of the result related to wicked problems, while other aspects of interest emerged at the later theoretical coding stage, in accordance with a grounded theory analysis (Charmaz, 2006). The result from the grounded theory analysis was thus more extensive than the wicked problems described in this paper.

4.2 Participants
The participating stakeholders were four parents of people diagnosed with schizophrenia, one activity coordinator, one psychiatric nurse, and one assistant nurse working with housing support. The participating users all had a diagnosis
of schizophrenia, were between 45-51 years old, and had been treated for more than 10 years. They all relied on support from medical treatment and were on a disability pension. In total, four people diagnosed with schizophrenia participated in pairs in the focus group interviews. All participants' and their relations' names have been changed. There was no relationship between the participants. Table 1 shows an overview of the participants and their roles.

Table 1. Overview of participants.

<table>
<thead>
<tr>
<th>Participant role</th>
<th>Participants</th>
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<tbody>
<tr>
<td>Parent</td>
<td>The mother of Jack</td>
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<tr>
<td></td>
<td>The father of Brock</td>
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<tr>
<td></td>
<td>The mother of Carl</td>
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<tr>
<td></td>
<td>The mother of Dani</td>
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<tr>
<td>Medical professional</td>
<td>Alfred, activity coordinator</td>
</tr>
<tr>
<td></td>
<td>Benjamin, psychiatric nurse</td>
</tr>
<tr>
<td></td>
<td>Chris, assistant nurse</td>
</tr>
<tr>
<td>Target user</td>
<td>Frank</td>
</tr>
<tr>
<td></td>
<td>Scott</td>
</tr>
<tr>
<td></td>
<td>David</td>
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<tr>
<td></td>
<td>Angela</td>
</tr>
</tbody>
</table>

4.3 Research Setting

The research in this paper was performed as part of a research project aimed to design Digital Peer Support (DPS) for people diagnosed with schizophrenia. Peer support is a type of social support that connects people with shared experiences in mutual support based on a shared understanding and empathy (Mead, Hilton, & Curtis, 2001; Solomon, 2004). A well-known example of peer support is Alcoholics Anonymous. DPS has shown similar benefits as face-to-face peer support, for example in the treatment of mental health (O’Leary et al., 2017). Technical developments have extended the possibilities for enhancing accessibility (O’Leary et al., 2017) and use of social interaction afforded by social media (Obar & Wildman, 2015).

The data collected for this paper was part of an early part of the project focused on understanding the design situation and prerequisites for design. Later stages of the project included participative design workshops together with people diagnosed with schizophrenia with the aim to involve them in design, prototype development and evaluation. As an outcome of this design process, a prototype of a DPS service for people diagnosed with schizophrenia was created. Results from the participative design process have been published in Lindberg et al. (forthcoming).
4.4 Ethics

The project that this research is part of was approved by the regional ethical review board (Dnr 2011/267). When the design situation is sensitive, as in this paper, there is a risk of harming the participants. The participants' wellbeing may be affected, and if the information on their participation would be made public, they can suffer social consequences due to the stigmatization of mental health illnesses (Campellone et al., 2014). During the interviews, two relatives of people diagnosed with schizophrenia expressed concern that if their participation became known, it could negatively affect their children. To ensure anonymity, all participants' names have been altered, and any information that might lead to their identification has been excluded.

Furthermore, one of the researchers who participated in the focus group interviews had a background in nursing and many years experience of supporting people diagnosed with schizophrenia. As the focus group interviews were only the first in a set of three workshops, she maintained contact with the participants between and after the time of the workshops, in order to ensure their wellbeing.

5 Outcome

This section presents the results from the grounded analysis. Table 2 summarizes the identified wicked problems that are described in detail in the remainder of this section.

5.1 Struggle of Dependence

The analysis indicates a struggle between being dependent and wanting to lead an independent life. The illness usually manifests itself in your twenties, when quite abruptly something starts to feel wrong, and normality is lost. Medical professional Alfred describes it like:

The withdrawal [from society] starts because something happens in your body or your head that you can't really... that doesn't feel right.

And Frank says that when he fell ill:

It didn't add up for me at all, my damn voices.

However, the memory of a normal life still exists and is something that the users in this study expressly want. Angela describes how she attempts behaviours and activities that the group home personnel do, because it seems healthy:
The staff at the group home work out a lot and that and... /.../ they feel well so I thought that I will do the same.

Similarly, Brock's father describes how it gives his son, who has recovered enough to maintain a regular job, pleasure in life to be able to buy things like everyone else. Nevertheless, Alfred explains that the treatment system does not have as a goal to create a normal life for people diagnosed with schizophrenia. Instead, the system treats the care recipients collectively, removing independence. David describes how he is no longer allowed to work by the Social Insurance Agency, despite previously being able to maintain a part-time job. Jack's mother describes her son's group home as "storage", and psychiatric nurse Benjamin describes his patients as being "preserved":

_The illness becomes a kind of formalin. You get stuck where you become ill sometimes, and there is little new added._

Frank says that in some ways he felt better when he lived on the streets, because he was able to make his own decisions.

People diagnosed with schizophrenia are described by the participants as having no or few hobbies, and even fewer that they can afford. As a result, they are dependent on others to be activated. Dani's and Jack's mothers, psychiatric nurse Benjamin, and David all describe a need for other people to help with activation. However, the care system does not currently provide adequate support for this.

Furthermore, the stakeholders express that people diagnosed with schizophrenia use little digital technology. This is due to a combination of factors. For one, the user group is to a large extent on disability pension and therefore cannot afford digital technology. Frank and Scott both own smartphones, but explain that most in their situation do not, and that they have only been able to buy them since mobile subscriptions became more affordable. Medical professional Alfred tries to help:

_We try to offer different kinds of study groups, and it's often computers that is being requested. So it's not about not being interested, but about not having the opportunity to._

Additionally, psychiatric nurse Benjamin describes issues with cognitive ability to learn how to use digital technology:

_Patients that are chronically ill with a psychotic illness and have recurring periods of symptoms get a kind of cognitive impairment as well. /.../ They may have a more difficult time to take it in._

The stakeholders express a need to increase digital technology use among this user group. Jack's mother describes it as this group being left out, and therefore
also ending up outside of society. As a result, they become even more dependent. Nevertheless, this is a generational issue. Several stakeholders agree that with the coming generations, some of the described issues relating to the use of digital technology will no longer be valid. However, it will still be many years when these issues stay relevant.

5.2 Contradiction of Social Interaction

The analysis further shows a contradiction in the social interaction of people diagnosed with schizophrenia. People diagnosed with schizophrenia are described as exceedingly lonely. For example, assistant nurse Chris says that social life becomes minimal after becoming ill, Carl's mother says that her son has lost all former friends and made no new ones, and Jack's mother says that her son's friendships have been forced on him, as they are all people who live in the same group home. Medical professional Alfred summarises:

*When the person in question falls ill most contacts disappear. You have your parents left, and maybe some childhood friend who gets in touch once in a while, mostly because they feel guilty.*

Nevertheless, despite the lack of close relationships, people diagnosed with schizophrenia meet a great number of people in their everyday lives. The majority of people they meet are medical professionals. Many have weekly visits from nurses, housing support help with everyday tasks, and most have to meet an assistant nurse daily to take their medication, as they are not allowed to handle it themselves. Yet, this is only superficial social interaction. Frank describes the isolation as the worst part of the illness:

*The hardest part of the illness was the isolation, the loneliness in the beginning, at first when you were lying at home.*

Scott says that there cannot be too much social interaction. Yet both Frank and Scott agree that it is easier to interact with others who have a similar understanding of the illness. Scott wants more information from self-experienced online, and Frank chooses friends that have similar experiences.

Another issue that is raised is stigmatisation of the illness. Psychiatric nurse Benjamin explains that the diagnosis itself can act as a deterrent, something that Frank experienced when he tried telling people around him about his experiences. Both Brock's father and Carl's mother express concern about revealing their names, as they fear that their sons will be negatively affected if the interviews can be traced back to them.

Further, people diagnosed with schizophrenia can sometimes engage in alienating behaviours that may strengthen that stigmatisation. For example,
assistant nurse Chris describes how some of his patients have lost any chance to befriend their neighbours because they have tried to borrow money from them in the past. Further, Frank explains how he has had to learn that the kind of behaviour his nurse and care staff want is not acceptable elsewhere:

*It's mostly medical personnel and those who have experience... that get to hear some things. /.../ The friends... they just think that you're insane and that it can't be right, you know.*

Since the people he mostly meets, medical professionals, enforce a behaviour that alienates his other relationships, he has had to adapt his behaviour in order to maintain the friendships that he values.

5.3 Contradiction of Trust

From the analysis emerged a contradiction in how people diagnosed with schizophrenia trust others. Due to their dependence on others, people diagnosed with schizophrenia have to place a great deal of trust in the people they are dependent on. However, people diagnosed with schizophrenia often have misplaced suspicions, and can sometimes be paranoid. Jack's mother describes how he does not trust the staff at his group home:

*He experienced chest pains he told me one morning last week or a fortnight ago... And he hadn't said anything to the staff. He doesn't have that much confidence in them.*

At the same time, she describes her son as being too trusting of strangers:

*He thinks good of people and... he gets robbed. That's why he doesn't have an ATM card anymore. /.../ They emptied it for him. So he is a bit unsuspecting- has become after the illness.*

The other stakeholders describe similar behaviours in their children or patients. Dani's mother says that her daughter always wants to be able to keep an eye on any visitors, even when it is her mother. Brock's father describes his son as being kind to the verge of wanting to buy friends with gifts. Angela tells us of how she has repeatedly been robbed of large sums of money.

People diagnosed with schizophrenia are a group of people vulnerable to fraud and theft, yet one symptom of schizophrenia is paranoia, as Jack's mother describes:

*He called my house... and accused me of having started the Second World War /.../ and he couldn't eat because the food was poisoned...*

Trust and distrust appears to be misplaced and irrational. Yet people diagnosed with schizophrenia have to rely on and trust other people to help them manage their everyday lives. Dani's mother describes it as:
They should actually have a real personal assistant all the time, really.

Irrational fear also affects digital technology acceptance and use. Jack's mother describes how she has to take care of his finances because he refuses to own as much as an ATM card. He flushed his mobile phone down the toilet due to his fear of technology. Similarly, Scott says that he has never dared use Facebook because he is afraid that everyone in the world will see his information.

Furthermore, there are also risks with technology use. Carl's mother describes how her son used online information to convince himself of not taking his medication:

At one point in the period of his illness he found some contacts online, or information, and he used that to show me, "Look here, this is the way it is, this is what they are putting me through." And it got worse from that.

Some stakeholders describe negative consequences like posting rants online during a psychosis for everyone to see, and assistant nurse Chris describes how one of his outpatients had their credit card emptied while playing an online game. This kind of naïve use, combined with being vulnerable to fraud and theft, can thus cause an increase of fear of digital technology, and reduce its use.

5.4 Counteracting Improvement Behaviour

The results further indicate that people diagnosed with schizophrenia can behave in ways that counteract their improvement. The participants for instance describe avoiding strategies to cope with the illness. Jack's mother says about Jack:

He had this in himself that he runs- or he used to run away.

Frank also describes an avoiding behaviour. He found it easier to live on the streets than to be medically treated because there he could flee from his problems. He eventually realised that he could not run away from the voices.

Another behaviour that the participants describe is an isolating behaviour. Medical professional Alfred says that people with psychoses often tend to isolate themselves, and Dani's mother describes her daughter as exhibiting both avoiding and isolating behaviours:

And it's not easy to help her, because she doesn't want to either. "I have to cancel," she says. "I can't." /.../ She just isolates herself in the apartment.

The stakeholders describe employment as particularly important for improvement. Carl's mother believes her son's job to be one of the main reasons
why he is better, and psychiatric nurse Benjamin expresses that access to meaningful employment would be key in treatment:

... there are sometimes more medical solutions that there need to be. If you would have a meaningful occupation and something that distracts you from the symptoms of your illness, I think there would be a lessened need for medication compared to what is being prescribed today.

There is a constant struggle to maintain a balance in life. Having schizophrenia means losing normality, and the illness is often described as going through periods. David describes himself as currently going through a rough period:

I am in a period when I don't think it's fun to do things and... /.../ I'm in a difficult period that is maybe quite hard to get out of too.

He describes his days as being spent mostly in bed. In contrast, he describes a period when he felt better:

I got out of bed at a normal time like... around eight then... and then I had chores and stuff. I was on my father's computer a lot... and downloaded music...

In contrast, Angela has the opposite problem of tending to do too much:

And then I worked out and went swimming on the same day, on Mondays, and Tuesdays, and Wednesdays, and Fridays and Saturdays. /.../ But my body spoke up, because I did too much, so I became ill instead.

Alfred, one of the medical professionals, describes this lack of balance as being common among people diagnosed with schizophrenia:

Those basal functions are somehow affected in this. Either you fall behind or you sort of... overdo it in some way. That you stodge and... things like that. The normal sort of goes away.

Illness awareness also affects ability to cope and ability to maintain a meaningful everyday life. Several of the stakeholders describe how their children or patients do not want treatment simply because they do not think of themselves as ill. Brock's father describes his son's lack of illness awareness and its effects:

We tried to get our kids – our grown kids – to be interested in something, so we had some activities and things, but he... he didn't consider himself ill so he didn't go to things like that.

In order to improve, it is important to maintain a balance. The avoiding coping strategies and isolating behaviours that are exhibited by people diagnosed with schizophrenia thus directly counteract the activities that would help them improve their lives.
6 Discussion
This paper studies the wickedness of the design situation when designing e-health technology for people diagnosed with schizophrenia. The analysis identified four wicked problems. Thereby, this paper demonstrates the viability of a grounded approach to study wickedness of a design situation with the intent to gain situational awareness in complex and sensitive design situations. In this section, the wickedness and its consequences for design will be discussed, along with the approach to studying it.

The identified wicked problems are interrelated, and not mutually exclusive. As any wicked problem, they are indefinable, untestable, and unique to the situation (Rittel & Webber, 1973). For example, the wicked problems struggle of dependence and contradiction of trust are related in that dependence causes a need to trust. If people diagnosed with schizophrenia had not been dependent on others, they would not be contradictorily trusting. However, it is equally possible that if there had been no contradiction of trust, there would not be a struggle of dependence. As such, the wickedness of this design situation is not a single problem, but a chain of interrelated wicked problems that together make up the wickedness of the design situation.

The wickedness that this paper has explored consists of struggles between dichotomies, or opposite forces, such as dependence versus independence. This is an important part in the discovery of how to design e-health technology for people diagnosed with schizophrenia. As Buchanan (1992) explains, wicked problems stem from the nature of the design subject; wicked problems are wicked because design implies discovery. In this case, each identified wicked problem presents consequences for the design of e-health technology for people diagnosed with schizophrenia.

Firstly, the wicked problems present consequences for involving users in the process of designing e-health technology. The wicked problems struggle of dependence and contradiction of trust show that the use of digital technology is low among the target user group for reasons of economy, cognitive ability and paranoia; while this is in part a generational issue and use of for example mobile technology is increasing among people diagnosed with schizophrenia (Firth et al., 2015), many still remain in economical hardship and cannot acquire expensive digital technology. Cognitive limitations and paranoia aimed at digital technology also restrict the possibilities for learning how to use this technology. Furthermore, the symptoms of schizophrenia can be diverse (Frangou, 2008), making it difficult to predict or understand the challenges of
user involvement in advance. Literature on participatory design and co-design with other vulnerable user groups for example highlight challenges related to ethics, user access and flexibility in design techniques for involvement (Culén & van der Velden, 2013; Lindberg et al., 2017; Wilson et al., 2015).

As a consequence, a design process that aims to involve people diagnosed with schizophrenia has to support the participants in expressing their technology needs. Culén and van der Velden (2013) outline similar conclusions from involving elderly in design, and surmise that users who cannot express their needs also cannot be representative of the user group. In this case, the users' abilities for expression are further complicated by their limitations in social skills and cognitive ability. People diagnosed with schizophrenia may have affected verbal fluency (Tsakanikos & Claridge, 2005) and cognitive limitations (Bowie & Harvey, 2006), and the contradiction of social interaction shows that the social behaviour that is enforced by medical contacts serves to alienate others in social interaction. The struggle of dependence also shows that users are treated collectively, and therefore, individual expression can be a challenge. Any design process that aims to involve people diagnosed with schizophrenia in design thus has to be flexible and support the participants in their social interaction and expression of individual needs.

Furthermore, as the wicked problem counteracting improvement behaviour shows, people diagnosed with schizophrenia tend to use behaviours that counteract possibilities for improvement, and they tend to use avoiding coping strategies (Wilder-Willis et al., 2002). This presents a risk for user involvement as users may choose not to participate despite the potential benefits that participation presents.

Secondly, the wicked problems present consequences for the design of e-health technology. For example, the wicked problems contradiction of trust and contradiction of social interaction indicate that e-health technology for this user group would need to enforce healthy social interaction, build trust and protect users from harm; at the same time, these goals are particularly difficult to achieve due to the identified contradictions.

There is potential in e-health technology for reducing stigma of mental illness (Tokar & Batoroev, 2016), and this study further shows that there is need to reduce the loneliness felt by people diagnosed with schizophrenia. Nevertheless, the wicked problem contradiction of trust emphasises that people diagnosed with schizophrenia can be suspicious of digital technology, and refrain from using it despite possible benefits. This means that any e-health
technology aimed at people diagnosed with schizophrenia would have to be transparent enough to create trust.

Additionally, some users experience negative consequences from previous use. Similarly, Naslund et al. (2014) focus on one aspect of this, that is, the social consequences that can occur from exposure and stigmatisation on social media. A consequence for design would be the necessity to allow anonymity. At the same time, the contradiction of trust shows that fraud and misinformation can be harmful. A consequence for design, which contradicts that of anonymity, is to moderate information and interaction. These contradictory consequences for design would need to be handled in the design of e-health technology for people diagnosed with schizophrenia.

Thirdly, the wicked problems present consequences for acceptance and use of the e-health technology. The lack of technology use shown in struggle of dependence and the paranoia aimed at technology shown in contradiction of trust naturally present obstacles for use of e-health technology among people diagnosed with schizophrenia; if the users do not own or trust the technology, they will not use it. The users are also described as living outside of society, partly due to this lack of technology use, and therefore may be difficult to reach.

Furthermore, the avoiding coping strategies and lack of illness awareness described in counteracting improvement behaviour may not only affect participation in the design process, but also the use of e-health technology. If the users do not consider themselves ill or do not realise that they are ill, then they will not use the technology.

In summary, the wickedness of the design situation in this study emphasises consequences for user involvement in design, and the design, acceptance and use of e-health technology for people diagnosed with schizophrenia. The literature suggested that there can be different levels of wickedness (Burge & McCall, 2015; Farrell & Hooker, 2013); the range of complexity and sensitivity of the design situation described here suggests that design of e-health technology for people diagnosed with schizophrenia has a high level of wickedness. Not only is the design situation complex and largely unexplored, but the vulnerability of the users also increases risks and raises ethical considerations for user participation and subsequent use.

This paper shows that grounded theory is a viable approach for understanding wickedness in a design situation. In this case, neither the interrelatedness of the
nature of the wicked problems, nor their contradictory nature emerged from the literature. In IS, grounded theory is used to analyse phenomena from a process or situational perspective (Myers, 1997; Urquhart, 2001). The rigidity of the method allowed for a structured analysis that led to the identification the contradiction and complexities that cause the wickedness in this design situation.

Furthermore, it was not only considered necessary to ground the study in empirical data from a perspective of understanding, but also from an ethical perspective. Often people who are considered vulnerable, such as people with mental illness, are excluded from research due to the difficulties of involving them (Liamputong, 2006), yet they may still want to participate despite the challenges (Usher & Holmes, 1997) and excluding users can affect the design quality (Bravo, 1993). Similarly, both the stakeholders and the people who were diagnosed with schizophrenia who participated in this study expressed that their participation was important to them. The stakeholders further highlighted that there is a great need for anything that can help their children or patients. As a result, when a subject like this is not only rarely studied, but users are often excluded from the research, the ethical value of being grounded in the empirical data is high.

As a final reflection, the grounded approach used in this study was both helpful and led to important insights that have expanded the understanding of the wickedness of designing e-health technology for people diagnosed with schizophrenia. The approach can be useful beyond this study; as the approach is grounded in the perspectives of the participants, and the methods for data collection primarily consists of dialogue, combined with a structured process for analysis focused on identifying relationships, it is transferable to other complex and unexplored design situations. It would seem particularly suitable in health-related situations where sensitivity is high and situational understanding is paramount.

7 Conclusion
This paper intended to answer the question: How can the wickedness of the design situation when designing e-health technology for people diagnosed with schizophrenia be understood, and what consequences does the design situation have for the design process? From a grounded theory analysis of stakeholder interviews and focus group interviews with people diagnosed with schizophrenia the wickedness is described as consisting of four wicked problems: struggle of dependence, contradiction of social interaction,
contradiction of trust and counteracting improvement behaviour. These problems are not mutually exclusive, but together make up the wickedness of the design situation.

The four identified wicked problems have consequences for the involvement of users in design of, and the design, acceptance and use of e-health technology for people diagnosed with schizophrenia. These consequences include the necessity to support expression of technology needs and social interaction, supporting anonymity while at the same time monitoring content quality, and overcoming limited technology use and experience.

In addition to the description of the wickedness of the design situation, this paper also contributes with a viable approach for studying complex and sensitive design situations of this kind. The grounded theory analysis that was used was valuable for capturing, understanding and describing the wickedness of the design situation.

Since the design situation is particularly complex, there is a continuous need for research. In order to continue the design of e-health technology for people diagnosed with schizophrenia, it will be important to include users throughout the design process. But more research is also needed on how to involve people diagnosed with schizophrenia in design, and how to begin to tackle the wickedness described here.

8 Acknowledgments
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9 References


Unlocking Design Potential: Design with People Diagnosed with Schizophrenia

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Abstract
With the expansion of e-health systems to more diverse and heterogeneous contexts and user groups it is increasingly important to include users in design. Designers recognise the benefits of user participation, but including users with lowered cognitive and social abilities can be difficult. This paper intends to answer how these users can participate in the design of e-health systems. We conducted a case study with stakeholder interviews and design workshops with users diagnosed with schizophrenia to identify and overcome challenges for participation. From the stakeholder interviews we identified challenges relating to social interaction, technical experience, cognitive ability and loss of individuality. We designed workshops that addressed these challenges and identify five strategies for unlocking the design potential of the participants: (1) work together with concrete materials and examples; (2) maintain a positive focus; (3) accept all ideas; (4) maintain and require realism; and (5) use previous interaction. We conclude that, when supported appropriately, it is possible to involve people diagnosed with schizophrenia. We also highlight the difficulty for someone not self-experienced to understand contexts as challenging and sensitive as this, and thus the value of user participation.

1 Introduction
Society is becoming increasingly digitised, and healthcare is no exception. As e-health systems become available to progressively heterogeneous user groups, research on design of health and e-health systems has increased its focus on involving users (Björkquist, Ramsdal, & Ramsdal, 2015; De Rouck, Jacobs, &
Leys, 2008; Kushniruk & Turner, 2012). Not only does user participation in design influence user satisfaction positively (Bano & Zowghi, 2015; McKeen, Guimaraes, & Wetherbe, 1994), it also links to accuracy of requirement specification, acceptance, understanding and cost avoidance (Kujala, 2003). In addition to this direct influence of user participation on software quality and user experience, participation is valued as a means to achieve democratic (Bjerknes & Bratteteig, 1995), empowering (Sanoff, 2008) and ethical (Robertson & Wagner, 2012) software development.

Nevertheless, user participation can be difficult to achieve in practice (Iivari & Iivari, 2006). With the spread of digital technology in society, it has become increasingly important to involve users who have not traditionally participated in design, due to vulnerability such as limitations in social and cognitive ability. Most design situations assume a user with full cognitive function (Wu, Richards, & Baecker, 2004). In cases when users are vulnerable, someone who is not self-experienced cannot have the complete understanding necessary to design artefacts that fill the users' needs (Lindsay et al., 2012; Wu, Baecker, & Richards, 2005), and in such cases the methods and techniques for participation must be adapted to accommodate these users (Wu et al., 2004).

Schizophrenia is an illness that affects about 1% of the world's population (Mueser & McGurk, 2004). Symptoms of schizophrenia are mainly cognitive; these can include deficits in memory, attention, lack of verbal ability, illogical thinking, confusion, delusion and strange linking of thoughts (Schuldberg, 2001; Wilder-Willis, Shear, Steffen, & Borkin, 2002). Cognitive impairments can further manifest as difficulties with attention, verbal learning and working memory (Bowie & Harvey, 2006). Such symptoms of schizophrenia can impair the ability for creative and imaginative thinking (Andreasen, 2000). Indications have been found that people diagnosed with schizophrenia are more likely to jump to conclusions based on little evidence (Dudley, Taylor, Wickham, & Hutton, 2016; Moritz, Woodward, & Hausmann, 2006).

Treatment mostly consists of antipsychotic medication with limited effectiveness (Fleischhacker & Uchida, 2014; Frangou, 2008), with few, if any, other choices of treatment (Calton & Spandler, 2009), and side effects such as tremors, diabetes, and embolisms can be severe. Antipsychotic medication has a varying effect on cognitive function, and even though other symptoms improve, these cognitive symptoms tend to widely remain (Désaméricq et al., 2014; Wilder-Willis et al., 2002). Decline of and limitation to cognitive function can be considered the main components of schizophrenia, and relates to the outcome of the illness (Désaméricq et al., 2014; Kahn & Keefe, 2013).
Symptoms such as these can make it difficult for people diagnosed with schizophrenia to participate in design.

Additionally, people diagnosed with schizophrenia experience social stigmatisation (Imhoff, 2016); expressing ideas clearly can be difficult, resulting in problems communicating with others (Andreasen, 2000; Schuldberg, 2001) and a reduced ability to understand social cues leads to inaccuracy in empathy (Green, Horan, & Lee, 2015) and impacts social outcomes (Kalin et al., 2015). This can lead to passive coping strategies, in that people diagnosed with schizophrenia tend to withdraw from social situations (Wilder-Willis et al., 2002), causing difficulties maintaining employment and regular societal functioning (Couture, Penn, & Roberts, 2006).

Design is not only cognitively demanding, but also a social activity and presents a challenge for people diagnosed with schizophrenia. Due to the difficulty of being involved in design, users with reduced social abilities often participate to a limited degree, while the designers do a majority of the work (Wu et al., 2004), and has sometimes led to vulnerable user groups being completely excluded (Tee & Lathlean, 2004). Excluding these user groups from design can have possible consequences for user satisfaction, acceptance and understanding, but more importantly it would be ethically reprehensible to not include users when it is possible.

There have been attempts to involve user groups with related challenges, such as people with aphasia (Wilson et al., 2015), people with amnesia (Wu et al., 2004), and people with dementia (Lindsay et al., 2012; Pakrasi, Burmeister, Coppola, McCallum, & Loeb, 2015). Nevertheless, people diagnosed with schizophrenia have a unique set of challenges that no other user group has, and which can only be fully understood by studying their participation in design. Therefore, this paper intends to answer the question: How can people diagnosed with schizophrenia participate in design?

To answer this question, this paper presents a case study of a design project with the overall aim to design Digital Peer Support (DPS) to improve the wellbeing of people diagnosed with schizophrenia. Social support of different kinds, such as peer support, has been found to have a positive outcome on some symptoms and consequences of schizophrenia (Alexander, Haugland, Ashenden, Knight, & Brown, 2009). The aim of this paper is to gain a better understanding of the challenges of involving people diagnosed with schizophrenia in design, and to identify strategies for overcoming these challenges and unlocking their design potential.
2 Method
2.1 Study Design
This paper presents a qualitative case study, consisting of several data sets to contextualize and get detailed insight into the research problem. As (Ragin, 1992) argues, any study that examines "social phenomena specific to time and place" (p. 2) can be considered a case study. Case studies are suitable for studying complex phenomena (Yin, 2014) such as this case, which presented a unique opportunity to explore the challenges of involving people diagnosed with schizophrenia in a design process; the case identifies complexity of both social and ethical challenges for user participation in design. As this is a context in which few studies have been previously done, it was suitable to conduct a single-case study (Yin, 2014). The knowledge in this case was gained through a design study informed by action research in the sense that the users were involved in design activities in collaboration with the researchers, who took a more active part of the activities (Hevner, March, Park, & Ram, 2004) than what is traditional in typical case studies, when the researcher is not actively engaged in the case under study (Byrne, 2009).

2.2 Data Collection
The data was collected between 2014 and 2016. The data collection followed a strategy consisting of two phases: (1) stakeholder interviews with relatives of, and health-care personnel caring for people diagnosed with schizophrenia; and (2) two rounds of design workshops with people diagnosed with schizophrenia, each round consisting of three workshops. Figure 1 presents an overview of the data collection phases.

The stakeholder interviews in phase 1 purposed to gain an understanding of the design context and the challenges people diagnosed with schizophrenia are faced with when participating in design. The findings from phase 1 determined the choices made for the workshops in phase 2. For example, the stakeholder interviews showed that many people diagnosed with schizophrenia have less than average experience with digital technology. Therefore, during the workshops in phase 2, we worked with analogue materials to make the step to designing digital technology smaller, and to not discompose the participants if they were unused to digital technology.

In phase 2, four people diagnosed with schizophrenia participated in three design workshops. Two rounds of workshops were conducted, each with two participants. The design workshops purposed to together with people diagnosed with schizophrenia design Digital Peer Support (DPS). The participants had
been under treatment for schizophrenia for more than 10 years and had unique insight into their requirements for a DPS service. The workshop activities were made to suit the abilities of the participants and aimed at unlocking their design potential. Four of the design concepts that were identified during the workshops were at a later stage developed into mixed fidelity prototypes.

**Future Workshop**

The workshops conducted during phase 2 were inspired by the concept of Future Workshops (FW) (Denvall & Salonen, 2000; Müllert & Jungk, 1987; Vidal, 2005). The FW concept was first introduced by Jungk and Müllert (1987), and values learning, democracy and empowerment (Vidal, 2005). FWs have long been used within the scope of for example participatory design (Muller & Kuhn, 1993) to facilitate work in groups (Vidal, 2006). The choice was made to base the workshops in phase 2 on FWs as findings from phase 1 indicated that people diagnosed with schizophrenia can find creativity, abstract thinking, and social interaction difficult, and they tend to have little technical experience (see section 3.1). As FWs are specifically aimed at supporting people without design experience to work creatively (Denvall & Salonen, 2000), this was suitable.

A typical FW consists of three main stages: (1) Critique where problems are identified; (2) Fantasy where the focus is on creativity; and (3) Implementation where the results from stage 1 and 2 are combined into a problem solution (Denvall & Salonen, 2000; Vidal, 2006). While each workshop corresponded to these stages, the activities were adapted to suit the abilities of the participants.

The first workshop corresponded to the critique phase of the FW concept (Vidal, 2005). Typically, this workshop aims at identifying current problems, specifically critical points that are the most important to address (Denvall & Salonen, 2000). In this case, this was expressed through a focus group interview setting with the goal to gain an understanding of the everyday lives and challenges of the participants. After the interview, we brainstormed with the users for keywords that highlighted the most important aspects of our conversation. These were then grouped into themes, depending on how the participants interpreted them. The results were summarised in affinity diagrams. The second workshop corresponded to the fantasy workshop of the FW concept (Vidal, 2005). The fantasy workshop is aimed at the future; the goal is to stimulate creativity and free ideation of possible utopias without technical or societal limitations (Denvall & Salonen, 2000). This was beforehand suspected to be the most difficult for the participants, as it requires considerable imagination and creativity, something that can be challenging due to symptoms
and medication side-effects (see section 3.1). In the first part of the workshop we discussed the affinity diagram from workshop 1. In the second part, the participants brainstormed on what they would do to feel better if they had access to magic. The metaphor of magic was used as it was judged to be accessible and easy to understand, and represented a scenario with no technical or social limitations.

The third workshop corresponded to the implementation workshop of the FW concept (Vidal, 2005). In this step, the results from the two first workshops are combined into a more realistic whole with concrete suggestions for change (Denvall & Salonen, 2000). We prepared six design concepts for each round of workshops (totalling 12 design concepts) based on the first two workshops. The participants first gave feedback on the design concepts. During the second part of the workshop, we provided the participants with cut-out prototyping equipment, including buttons, image placeholders, drop-down lists and textboxes. The participants, together with the researchers, prototyped either one of the presented design concepts or one of their own. For example, before workshop three, we prepared a design concept of a mobile application where users could contact a random peer. During the workshop, the participants gave the feedback that they were uncomfortable with speaking to random strangers, and they combined this concept with another to create a prototype of a mobile application where users were given a choice by selecting if they wanted to speak to a self experienced peer, medical personnel, or a family member. This concept was at a later stage of the project developed into a mixed fidelity prototype.

Table 1 summarises phase 2.

<table>
<thead>
<tr>
<th>Workshop 1: Critique</th>
<th>Workshop 2: Fantasy</th>
<th>Workshop 3: Implementation</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Aim</strong></td>
<td>Identifying current problems</td>
<td>Stimulate creativity</td>
</tr>
<tr>
<td><strong>Input</strong></td>
<td>None</td>
<td>Affinity diagram from workshop 1</td>
</tr>
<tr>
<td><strong>Output</strong></td>
<td>Affinity diagram describing current situation</td>
<td>Updated affinity diagram</td>
</tr>
</tbody>
</table>
2.3 Setting and Participants
The design process reported on in this paper was conducted in the context of a project about activating and including people diagnosed with schizophrenia, where one part aimed at designing Digital Peer Support (DPS) for people diagnosed with schizophrenia. There are indications that lifestyle interventions (Cabassa, Ezell, & Lewis-Fernández, 2010), supported employment and social support have a positive outcome in schizophrenia treatment (Alexander et al., 2009). DPS is a kind of social support where people who have gone through similar experiences support each other to achieve better wellbeing (Barak & Grohol, 2011; Meyer, Coroiu, & Korner, 2015). A commonly known example of peer support is Alcoholics Anonymous, but there are many forms of peer support. DPS can overcome issues with face-to-face peer support, such as access, critical mass (Potts, 2005), and lack of anonymity (Ali, Farrer, Gulliver, & Griffiths, 2015).

All names of the participants presented in this paper have been changed to grant anonymity. The stakeholders that were interviewed in phase 1 were four parents of people diagnosed with schizophrenia, one activity coordinator, one psychiatric nurse, and one housing support (n = 7). The empirical material from the stakeholder interviews consisted of a total of 340 recorded minutes. Participants were initially selected using purposeful sampling (Marton, 2013) based on their relationship to people diagnosed with schizophrenia; we aimed at including both relatives and medical professionals. Based on early analyses of the first interviews, more stakeholders were selected in order to achieve saturation in the empirical material.

In phase 2, two participants participated in each round of three workshops. Two rounds were conducted, totalling n = 4 participants. One participant chose to end his participation after the first workshop. The empirical material from the workshops consisted of a total of 596 recorded minutes. The participants all had a diagnosis of schizophrenia and had been treated for more than 10 years. They all relied on varying degrees of support from medical treatment and were on a disability pension. There was no relation between the participants of phase 1 and phase 2.

Table 2 summarises participants in both phases of the study.
Table 2. Summary of participants in the study.

<table>
<thead>
<tr>
<th>Phase</th>
<th>Parent</th>
<th>Activity coordinator</th>
<th>Psychiatric nurse</th>
<th>Assistant nurse in housing support</th>
</tr>
</thead>
<tbody>
<tr>
<td>Phase 1</td>
<td>Mother of Jack</td>
<td>Alfred</td>
<td>Benjamin</td>
<td>Chris</td>
</tr>
<tr>
<td></td>
<td>Father of Brock</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Mother of Carl</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Mother of Dani</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Phase 2</td>
<td>Workshop round 1</td>
<td>Frank</td>
<td>Scott</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Workshop round 2</td>
<td>David (quit after workshop 1)</td>
<td>Angela</td>
<td></td>
</tr>
</tbody>
</table>

2.4 Data Analysis
The case was analysed using a thematic analysis. This method of analysis was considered specifically suited to this context primarily due to its flexibility, suitability to participatory contexts, and ability to highlight both similarities and differences between several data sets (Braun & Clarke, 2006). Braun and Clarke (2006) delineate the different steps of thematic analysis in detail, and highlight the method's sometimes perceived vagueness as one of its strengths of flexibility. The aim of the method is to identify patterns – or themes – in the data, and analyse the meaning of these (Braun & Clarke, 2006). A theme summarises something that is interpreted as being important in the data in relation to the research question (Braun & Clarke, 2006).

This study implements a bottom-up, semantic thematic analysis (cf. (Braun & Clarke, 2006)). The data sets from phase 1 were first analysed separately through a thematic analysis. The process followed the six steps of a thematic analysis as described in Braun and Clarke (2006). The first author conducted the analysis, with frequent discussions with the second and third author. After familiarising ourselves with the data by transcribing the interviews and reading the transcriptions, the data sets from phase 1 were initially coded. Due to the nature of the research question in this paper, the focus of this coding was on potential challenges or possibilities for user participation in the design process. After initial coding was completed, the codes were grouped into potential themes. The data was then reviewed again to ensure that the identified themes were representative of the data. We then established that each set of codes was representative of the theme that it had been grouped into, and that the themes
did not overlap. Some of the identified themes were "cognitive ability", "economic situation", and "fear". Finally, the themes were further grouped into four main challenges for participation in design. For example, the themes "economic situation", "technology use", and "attitude to technology" were grouped into a challenge relating to *technical competence*. The challenges are presented in their entirety in section 3.1.

The themes that were identified from phase 1 were then used as a lens for the analysis of the data sets from phase 2. This part of the analysis process followed the same steps as the analysis of the stakeholder interviews, with the difference of the initial coding being based on the challenges that had been previously identified. This was done for the purpose of comparison; we wanted to analyse whether these challenges were present also in the data from the work with the users, and in that case how these challenges were dealt with, and what was successful.

### 2.5 Ethical Issues

The context for this study is particularly sensitive as it relates to an illness with much social stigma (Campellone, Caponigro, & Kring, 2014). The project that this study is part of has been approved by the regional ethics committee (Dnr 2011/267). Not only is anonymity important, but several of the interviewed parents of people diagnosed with schizophrenia expressed particular concern that their participation should not be made public as it could affect the lives of their children.

During the design workshops there was a risk of upsetting the participants. One of the researchers who participated in all workshops has a background in nursing and much experience with caring for people diagnosed with schizophrenia. She maintained contact with the participants between and after the workshops to ensure their wellbeing.

The choice was made to conduct phase 1 before involving people diagnosed with schizophrenia in an attempt to gain an in-depth knowledge about the design context and to minimise the risks for the participants. It was reasoned that the better our understanding was of the challenges of people diagnosed with schizophrenia, the better we could support their participation.
3 Results
3.1 Phase 1
The first step to answering how people diagnosed with schizophrenia can participate in design was to identify challenges for their participation. From the analysis of the stakeholder interviews from phase 1, we identified four areas that can challenge people diagnosed with schizophrenia when participating in design: social interaction, technical experience, cognitive ability and loss of individuality.

3.1.1 Challenges Relating to Social Interaction
The onset of schizophrenia is described as dramatic and momentous. All stakeholders describe how social contacts from before onset are lost; the only people who remain are family. Instead, all social connections have a professional capacity, that is, medical professionals. One of the stakeholders describes the shift in social relations:

But somewhere these social relations transition to paid relations. It's not like you don't have this contact anymore, but everyone that come to your home do so because they are paid to. And you only meet people because they do it in their professional capacity, not because they want to.

Jack's mother describes how he was diagnosed with schizophrenia in his mid-twenties and lost his fiancée and his job, while Carl's mother describes how he had friends who were bad for him, but that he does not have these contacts anymore.

Further, the stakeholders also describe a lack of ability to take social initiative. Brock's father describes his son as being unable to both initiate and maintain relationships:

I don't think that he has the ability. Unfortunately. Maybe he might want to, but he can't do it.

As a consequence, this user group is described by the stakeholders as lonely and outside of society. This is a consequence both from the symptoms of the illness, but also from a wish to avoid social interaction. The stakeholders describe how their relatives or patients tend to isolate themselves. Due to this lack of will for socialisation, one stakeholder explains that some people in this user group are averse to, or find it difficult to work in groups. The stakeholders mention a need for social support for this group of users, in addition to the typical medical support.

Additionally, because schizophrenia is stigmatised, it can be difficult to accept the diagnosis, and not everyone has complete disease awareness. Carl's mother
for example describes how her son refuses to participate in social activities organised for people diagnosed with schizophrenia because he does not consider himself ill.

It can also be difficult when the provided activities require active engagement. Several stakeholders describe an avoiding behaviour pattern, for example Dani's mother who says about her daughter:

*And it's not easy to help her, because she doesn't want to either. "I have to cancel," she says. "I can't take it." /*...*/ She just isolates herself in her apartment.*

Those who have an avoiding behaviour pattern, combined with lower disease awareness, will most likely not participate in activities provided for them. In summary, people diagnosed with schizophrenia tend to have low social competence due to a lack of ability to engage in spontaneous social relationships, a need to isolate oneself, avoiding behaviour patterns and lack of disease awareness. Since participating in design is often a social activity, it can be difficult for people diagnosed with schizophrenia to participate in design together with other people.

### 3.1.2 Challenges Relating to Technical Experience

From the stakeholder interviews emerge a view of a user group with generally little technical experience. This is due to several reasons. For one, people diagnosed with schizophrenia are described as living in economic hardship. Many receive a disability pension or similar financial aids, and thus have a limited income. Additionally, addictions such as smoking and gambling are not uncommon. One of the medical professional stakeholders summarises the users' financial situation:

*Many live on a subsistence level, almost. Especially considering that they smoke too. It's very expensive to finance a three-pack-a day habit. Then there is only enough money for that and rent.*

This means that people in this user group cannot afford to buy modern technology such as computers and smartphones. As a result, they do not have the opportunity to be exposed to and learn how to use such technology.

Secondly, symptoms such as paranoia and fear can also limit technological experience. Jack's mother describes her son as being scared of technology, and exemplifies one incident when he flushed his mobile phone down the toilet. Carl's mother also describes the paranoid tendencies of her son as being aimed at technology:
He has explained very strange technical features that can be used to disturb people, by aiming and designing sounds.

Thirdly, people diagnosed with schizophrenia can have lowered cognitive ability. Activity coordinator Alfred questions whether the most ill of his patients would be able to learn how to use computers:

...patients that are chronically ill with psychotic disorders, and have recurring periods with symptoms, get some sort of cognitive impairment too. So I don't know about the prerequisites for those who have been ill for a long time... They may have more difficulty grasping it.

In summary, due to their financial situation, symptoms such as fear and paranoia, and lowered cognitive ability, people diagnosed with schizophrenia are not generally a group with much technical experience. This would theoretically limit their ability to participate in design, as it would make it more difficult to understand possibilities with technology and communicate requirements.

3.1.3 Challenges Relating to Cognitive Ability

As the literature, the stakeholders highlight that the primary treatment for schizophrenia is medical. The medical treatment for schizophrenia has many side effects, and can affect one's cognitive abilities. The primary side effects that were highlighted by the stakeholders were issues with lethargy and excessive sleeping. One of the medical professional stakeholders explains that taking initiatives and thinking outside of the box is difficult for this user group. The stakeholders' views were that users express few ideas at all. Some people diagnosed with schizophrenia tend to interpret things too literally, which has led to misunderstandings. Other stakeholders describe how their children or patients find understanding their rights and standing up for themselves difficult. Dani's mother describes her daughter:

But [my daughter] has no strength for it. To speak up, you see.

Jack's mother describes how her son finds it difficult to understand the consequences of his actions.

This with understanding consequences. That... If I leave my front door open then people can come in and take my things.

Other aspects that are described as being difficult are routine things that require frequent attention, such as personal hygiene, cleaning, doing laundry, getting out of bed, and eating regularly and healthy. All stakeholders mention similar difficulties among their children and patients. One of the medical professionals describes what people with psychoses find difficult:
Well, it's about everything, isn't it. Nothing is particularly easy if you have a psychotic illness. Everything from getting up in the morning to going to bed.

In summary, the interviewed stakeholders describe people diagnosed with schizophrenia as having a low cognitive ability due to both illness and as a side effect of their medication. Basal activities that healthy people find natural to do every day may be impossible to accomplish. If daily activities are difficult, then it is likely that participation in design would be difficult for this user group. Furthermore, the creative approach associated with design thinking can be difficult, which can make participation in design a challenge.

3.1.4 Challenges Relating to Loss of Individuality

People with schizophrenia require support with many things in their daily lives. However, most stakeholders, medical professionals included, agree that there is currently not enough support or that the existing support is lacking due to insufficient funds or education of supporting staff. Dani's mother says that:

They should actually need to have a real personal assistant the entire time, really. /.../ How much better they would be, having someone- for they need social support the entire time. Because I notice how much better she functions when there is someone around her.

Not only do the stakeholders illustrate a group of people with need for support, but several stakeholders also express that they need to push their children or patients to activate them. All stakeholders present a picture of a group of people that are vulnerable and exposed in society. Many are reliant on family for social interaction, activation and stability.

While the stakeholders impress that there is no typical progression of schizophrenia, and many have different and individual symptoms, they also say that their children and patients are handled collectively. As this is a chronic illness with an onset in the early twenties, participants can have been in the care system for several decades. This would theoretically make them unused to expressing their individual needs and wants, which is something that is essential in a design process. One challenge would therefore be to enable the participants to identify and express themselves as individuals.

In summary, the stakeholders describe people diagnosed with schizophrenia as highly vulnerable and dependent on other people. Many require support every day, and therefore have had to become accustomed to collective, instead of individual, treatment. This affects their ability to participate in everyday activities that involve social interaction, and to claim their individuality in social situations. This would also affect design participation as they would not be used to expressing individual needs and wants.
3.2 Phase 2
The first step in answering how people diagnosed with schizophrenia can participate in design was to identify strategies for meeting the identified challenges for participation. Based on the stakeholder interviews, the challenges outweigh the possibilities. The findings from phase 1 indicated four areas that were particularly challenging; design activities should support the participants' social skills, technical experience, cognitive ability and creativity, and individuality. The design workshops in phase 2 were therefore inspired by the concept of Future Workshops (FW) (cf. (Denvall & Salonen, 2000; Müllert & Jungk, 1987; Vidal, 2005)) and were adapted to meet the identified challenges. See section 2.2 for an overview of the workshops. In this case, the workshops were aimed at designing DPS. The following section will describe how the identified challenges were met and which design practices were successful in unlocking the design potential of the participants.

3.2.1 Workshop 1: Problem Identification
From the analysis in phase 1, we concluded that people diagnosed with schizophrenia might have limited social competence, which poses challenges for a social activity such as participating in design workshops. All workshop participants describe similar social issues as the stakeholders. Frank describes how having only social contacts with medical professionals has affected his ability to interact socially with others, and how he experiences a discrepancy in what is expected of him:

> It's mostly medical personnel and people who are self experienced that get to hear certain things. /.../ My friends... they just think that you are completely mad and that... well, it can't be right and things like that.

As a result, both Frank and Angela express a preference for interacting with people who also live outside of society. For a time, Angela wanted to join a convent, because she identified with the nuns:

> They live a little outside of society and I live a little outside of society now that I live the way I live.

Social interaction can also be experienced as too intense. In these cases, Frank describes a wish to escape:

> Then you want to go away a little bit.... Getting away and be alone for a while. But not too much.

All participants say that they prefer personal meetings to written or solely oral communication.
During the workshops we attempted to meet the challenge of social interaction by being flexible in the group setup, creating familiarity among participants and by being accepting and open to everything the participants said. Frank and Scott who participated in the first round of workshops were previously familiar with each other, and showed little restraint in expressing themselves. In the second round of workshops, David and Angela had not met before, and both were somewhat withdrawn during the first workshop. After David ended his participation, we experienced Angela as being more open. If this was due to her being the only participant or her increased familiarity with us is unclear.

Furthermore, the stakeholder interviews in phase 1 indicated a loss of individuality among people diagnosed with schizophrenia, due to symptoms and the nature of their treatment. While the participants showed different levels of dependence on support, they all relied on others in different ways for their wellbeing. Angela showed signs of this when she more than once described how she was inspired by others to take up new habits that were not necessarily good for her. However, this did not manifest itself strongly during the first workshop and did not appear to be a major challenge for their participation. The primary design practice that was used to meet this challenge was to use patience and ensure that all participants were given time to answer all questions.

Challenges relating to technical experience were not experienced during the first workshop.

3.2.2 Workshop 2: Fantasy and Creativity
During the second workshop we first connected back to the previous workshop by looking at the affinity diagram created during workshop 1. The participants were asked if they wanted to change or add anything. We then discussed and highlighted only the positive keywords. We discussed how and why these aspects were positive for the participants, and identified aspects where there was an interest and a will to focus. The second part of the workshop consisted of brainstorming, using the metaphor of magic to represent unbounded prerequisites.

It was evident that the second workshop was the greatest challenge for all participants. We tried to open up for a free flow of unrestrained ideas without criticism and limitation. However, this proved too difficult. There were long silences and hesitant answers for as long as the discussion remained on the question of boundless idea generation. As soon as the discussion became more focused on realistic and bounded themes, the participants became more confident and expressive. For example, despite limitations in creative thinking,
Angela managed to synthesise the discussion from two workshops into one theme that described our goal and incorporated all highlighted subjects. According to her, the goal with the work we were doing was to create a meaningful everyday life.

In order to meet the challenges related to loss of individuality, we had to find a way to help the participants achieve increased empowerment and individual expression. We attempted to do this by creating a supportive and encouraging atmosphere, by supporting all kinds of ideas and by focusing on positive aspects.

Throughout workshop 2 and 3 one goal was to maintain positive thinking. Frank and Scott both expressed a preference of focus on positive subjects. However, Angela found this more difficult. We had to repeatedly remind her to focus on the positive, and not the negative aspects of her illness such as her obsessions and previous depressions:

*Researcher:* It was the positive things we were meant to focus on.

*Angela:* Well, it was hard to turn it into something positive.

One design practice devised during workshop 2 of aiding Angela was to hide the negative subjects on the affinity diagram under post-its. Then she was not reminded of the negative keywords, and we hoped that she would not focus on them. Some subjects that we removed were her obsessions, medication, digital technology and food portion size. This design practice was partly successful, as we had to remind her once during workshop 2 that these subjects were not in focus.

Challenges relating to cognitive ability were met by reconnecting to the results from the previous workshop, to aid the participants' recollection. Between the workshops we analysed the material and prepared a summary of the conversations in order to remind the participants of what had been said and done. This was done in order to improve their recollection of the workshop, but also to validate the outcomes with the participants. All participants added additional information to the summaries and it opened up for discussions that led to further idea generation. For example, Angela added several new subjects to the affinity diagram that were then part of the prototype creation during workshop 3.

**3.2.3 Workshop 3: Implementation**

Before the third workshop we prepared six design concepts based on the first two workshops. For example, from workshop 1 round 1 emerged that the
participants found it important to create routines. When they managed to do so, they said that they felt proud. To support this, we created a design concept where users would specify their chores and how often they wanted to do them. They would be given a to-do list each day, and a possibility to share achievements with others. In the first part of the workshop, the users gave feedback on the design concepts, and during the second part they used cut-out prototyping equipment to prototype either a presented design concept of one of their own.

The stakeholder interviews showed that people diagnosed with schizophrenia often lack technical experience. All four participants expressed this, yet both Frank and Scott owned and used smartphones. However, Frank had experienced that his subscription had been frozen due to inability to pay the bills, having a major disrupting effect on his life:

Well, it's happened that they've turned it off sometimes when you can't afford to pay bills and things, then it's happened that they've turned it off sometimes. /.../ Then chaos ensues for me.

David, in contrast, did not use his smartphone because his medication caused tremors that made it difficult. Angela further said that she thought digital technology was too difficult to use. If it would be possible, she would want to live in a world without technology:

Angela: You can't remove it – mobile and computer – you have to have it today. Otherwise you are completely lost.

Researcher: But if you would be able to choose yourself?

Angela: Then I would have scrapped it right away.

The difference in the participants' technical experience became evident during the workshops. Both Scott and Angela were unfamiliar with best practices and how functionality is usually designed. Angela often referred to analogue solutions rather than digital during the prototyping session. For example, she spoke of meeting with a writing group and helping each other work on texts they had written. Scott was concerned about social media privacy, and this affected his design choices.

We attempted to meet the challenge relating to technical experience by using prepared cut-outs for prototyping, by giving suggestions, by relating to our conversations and by discussing and explaining technology use. It was clear that, of the three participants who participated in all workshops, Angela had the least technical experience and had most difficulty relating to a digital context. However, despite this, she understood most of the cut-out elements and could
find the ones she needed to create the prototypes. None of the participants expressed hesitation or uncertainty as to the goal of the activity. All three participants chose cut-out elements themselves, showing that they understood how to use them.

All participants, unrelated to technical experience, had difficulties containing the scope of the prototypes to one specific idea. We tried to set the scope of the design concepts during our discussion prior to prototyping.

When the participants were stuck, we would think of suggestions and give them alternatives to choose from. In this way the participants maintained control of the content of the prototypes, and the work did not halt.

Researcher: Do you want to come to a page where you can call this person, or to a page where you can book transportation services, or to a page where you just see who it is – maybe you don't know who it is?

Angela: Call the person and ask if there is anything happening, so that you know that you don't go needlessly.

The participants sometimes found it difficult to maintain focus on the subject. We frequently had to return the focus to our conversation. Angela, for example, who was obsessed with the idea that she had murdered a prominent Swedish public figure, brought this up often. One example was when we were reasoning about the functionality of a prototype, and what should happen when she selected an option on the previous screen:

Researcher: Is there anything that you would want to happen when you click [the button]? For example that you call automatically, or just get information, or that you come to transportation services or something else?

Angela: That all of Sweden quakes.

Researcher: That may be a little difficult...

Angela: I don't know, but that was what happened when [public figure] was murdered, then all of Sweden quaked.

The stakeholder interviews showed that many people diagnosed with schizophrenia tend to take things too literal. We did not experience this with Frank and Scott, but Angela did show tendencies to this effect on a few occasions. When discussing a prepared design concept, she expressed dislike for it, which turned out to be because it contained horse racing.

Further, we saw indications that the participants were not used to expressing their individual needs and goals. All participants relied on others in different ways for their wellbeing. This did not appear to be a major challenge for their
participation. Angela showed some uncertainty when asked questions about what she wanted and worried about making mistakes, which we interpreted as being an indication of not having considered herself as an individual but more as a part of a collective in the system. Frank discussed this:

*Well, it's a matter of practice when you have been feeling bad, to be able to be yourself again. Or you should try to... what do you say, be the way you are.*

Nevertheless, the workshop proved to be too complex for the participants to work individually. The activities we asked them to conduct were not activities they were used to doing, and it was evident that their understanding of the activities was enhanced after we showed the prepared examples. During this workshop we had planned to work in pairs with one researcher and one participant. However, since both Scott and Frank expressed uncertainty about the activity, we ended up working together as a group where Scott and Frank took turns to design one prototype each. While Angela and David appeared to experience more cognitive difficulties than Frank and Scott, all participants were challenged cognitively by their participation.

During all workshops, some participants said things that may be provocative in more neutral settings. Angela, for example, brought up the subject of her obsessive fantasies about having killed a prominent Swedish public figure into discussions about the prototype:

*Researcher: The question is what would it look like then? /.../ You need to know who is there, you need to know what is happening, you need to know where it happens. Or?*

*Angela: At the murder scene.*

*Researcher: No [laughs] but where you are going if you are knitting for example.*

It was sometimes necessary to try to make her see that what she was suggesting was not reasonable. This was done by logically arguing for why it was impossible:

*Angela: They have no technical evidence for [public figure's] murderer. But I have. Do you know what I have? /.../ Cough drops and punch rolls.*

*Researcher: What kind of evidence is that? /.../ But you could say that you have an alibi that you didn't do it.*

*Angela: Yes it was I.*

*Researcher: I'm thinking that if you are eating cough drops and punch rolls then... then you don't have time.*

*Angela: [short laugh] I don't know...*
By doing so, we could maintain an open and non-judgemental atmosphere, while maintaining some control over the realism of the subjects that were discussed.

4 Discussion
This paper describes a case study to answer how people diagnosed with schizophrenia can participate in design. In phase 1 of the study we identified four categories of challenges for involving people diagnosed with schizophrenia in design: social interaction, technical experience, cognitive ability and loss of individuality. During phase 2 we conducted design workshops aimed at meeting these challenges. We will now discuss the key design practices that were used to drive the process, and summarise these as strategies for involving people diagnosed with schizophrenia in design.

**Strategy I: Work Together with Concrete Materials and Examples**
During the design process, the participants' abilities to participate in design were supported by the use of analogue materials to create prototypes and use of concrete examples to show the nature of the expected outcomes. Similar design practices have been applied in design together with other vulnerable user groups, such as children (Druin, 1999) and people with amnesia (Wu et al., 2004). During the workshops, open and creative activities were more challenging for the participants than activities with clear boundaries. This is not surprising, as both literature (see e.g. (Andreasen, 2000)) and the results from phase 1 highlight that people diagnosed with schizophrenia may find creativity difficult. Other design practices employed to support the participants was using alternatives, and adapting the work constellations based on the situation. These design practices we summarise as the strategy work together with concrete materials and examples.

**Strategy II: Maintain a Positive Focus**
Because the stakeholder interviews highlighted challenges related to loss of individuality and a focus on illness in the users' social contact with medical professionals, we developed the design practice of focusing only on positive aspects. When the purpose was to promote creativity and focus on solutions, we urged the users to focus only on positive subjects and leave out anything that might be experienced as negative. The participants themselves chose what they considered negative, and this was left behind. These design practices we summarise as the strategy maintain a positive focus in creative activities.
Strategy III: Accept All Ideas
Both literature (see e.g. (Andreasen, 2000)) and the stakeholder interviews indicated that people diagnosed with schizophrenia may cognitively be limited in creative ability. Additionally, the participants had spent years under treatment and become used to disregard their individual needs for the collective. The participants were clearly not used to being treated as active subjects. The participants also had little technical experience. To handle these challenges we employed design practices such as creating a supportive atmosphere, and to encourage all kinds of ideas regardless of the possibility of realising them. Despite the goal to design DPS, we opened up for analogue design concepts to make the participants feel that their ideas were accepted, which led them to show confidence enough to express their ideas. The ideas could later be adapted to be realistic. These design practices we summarise as the strategy accept all ideas.

Strategy IV: Maintain and Require Realism
While we did accept all ideas during the workshops, the role of designer increased both in the interpretation of these ideas but also to be able to maintain a level of realism and subject focus. We experienced that the participants were not always reliable. This stemmed from a varying level of disease awareness, inability to focus on one subject, and symptoms of the disease. While some of our participants demonstrated a high level of disease awareness at one time, the same people could show low disease awareness related to another aspect of their lives.

To meet these challenges, we employed design practices such as trying to keep the subject realistic and bounded, and to return the focus of the work to the subject at hand. Some participants had difficulties maintaining focus and tended to bring up unrelated subjects. Some people diagnosed with schizophrenia can experience attention difficulties (Bowie & Harvey, 2006) and the participants low technical experience at times led them to make unrealistic suggestions, and this was handled by discussions and explanations of the nature of the digital technology. These design practices we summarise as the strategy maintain and require realism.

Strategy V: Use Previous Interaction
Lastly, people diagnosed with schizophrenia may experience difficulties with verbal learning and working memory (Bowie & Harvey, 2006). We employed design practices such as summarising discussions before moving on to a new subject, and reconnecting to the previous workshops. Furthermore, as the participants' technical experience was limited, some found it difficult to connect
the design concepts to how they would work in real life. In these cases we related the ideas to the conversations we had had with them. These design practices we summarise as the strategy *use previous interaction*.

**Closing Reflections**  
During the workshops, more than one participant reacted strongly when their illness was being discussed. The participants' reactions indicate that there is a particular sensitivity to questions relating to the symptoms of their illness, to a degree that even questions that do not specifically relate to their illnesses may be interpreted as doing so. This makes it difficult to conduct workshops of this kind from an ethical perspective. Research is meant to do no harm, but it can be possible to inadvertently cause harm to a participants in this kind of research the researcher's intentions are misinterpreted. The question is whether or not users should be involved in a complex and sensitive context such as this. Based on this case study, we can support the need for involving users even when there are many challenges to doing so.

We identified a challenge-oriented mind-set from the stakeholders. The stakeholders expressed a great need for support for their relations and patients, but highlighted challenges with their involvement in design. In contrast, the workshop participants had a solution-oriented mind-set, and this case study shows that people diagnosed with schizophrenia are a resource to design. This difference between the view of the stakeholders and of the users themselves illustrates the importance of involving users in the design process, despite the challenges. If strategies such as those presented here are employed, it is possible to unlock the design potential of people diagnosed with schizophrenia, and for them to participate in design.

5 Conclusion  
The aim of this paper was to answer how people diagnosed with schizophrenia can participate in design. Phase 1 identified challenges for participation that relate to social interaction, technical experience, cognitive ability, and loss of individuality. In phase 2 we conducted design workshops with people diagnosed with schizophrenia. The design practices we used to meet the identified challenges during these workshops were then summarised as strategies for unlocking the design potential of people diagnosed with schizophrenia.

The paper shows that involving users in design gives an understanding that is otherwise lost, even when there are many challenges with that user
involvement. Further, we show that it is possible to involve vulnerable user groups in design when the methods for participation are adapted to their abilities and to the context. Lastly, the identified strategies can help researchers who intend to do similar research to unlock the design potential of their participants.

We encourage future work to involve users despite the challenges of doing so, and particularly in other stages of design and development, such as evaluation, implementation and use. The concept applied in this case – Future Workshops – is only one of several that may be suitable for design with people diagnosed with schizophrenia, and questions of how other methods can be adapted to meet the challenges identified here still require investigation.

6 Acknowledgements
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Ethics in Design: Guidelines for Ethical User Involvement

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Abstract
User participation in sensitive design situations is ethically challenging. In sensitive design situations, users are asked to share personal and private experiences, and fears and anxieties related to for example illness or impairment. Designing in such sensitive design situations inevitably creates ethical dilemmas for designers. Our literature review shows that literature on ethics is scarce, fragmented across several disciplines, and often too abstract to give adequate guidance to designers. In response, this paper presents a study of two health innovation initiatives involving vulnerable users in sensitive design situations. The study identifies ethical dilemmas and the resolving actions taken. Drawing on literature and the case studies, we propose three guidelines for ethical user involvement in sensitive design situations: anticipation, attentiveness and critical self-awareness.

1 Introduction
Ethics in design is becoming increasingly important as digitalisation pervasively shapes society (Walsham, 2012). One example is health, and the design of innovative services to support people’s wellbeing (see e.g. Luxton, McCann, Bush, Mishkind, & Reger, 2011; Singh, Wilkinson, & Braganza, 2014). Such services can address persistent problems related to, for example, mental health care (O'Leary, Bhattacharya, Munson, Wobbrock, & Pratt, 2017) and care of chronic conditions (Kanstrup, Bertelsen, & Nøhr, 2015). New design domains bring opportunities for social innovation through Participatory Design (PD) (Sanders & Stappers, 2008), but also create ethical challenges (Bannon & Ehn, 2012).
Ethical user participation is imperative in PD. The argument is rooted in the discourse on equal contribution, emancipation and workplace democratisation (see e.g. Bravo, 1993). One ethical stance in PD is that participation is motivated by people's right to shape their world (Robertson & Wagner, 2012). This includes respecting people's right to represent their own interests in design processes, instead of being interpreted by others. Another stance is that different voices need to be heard and understood (Bannon & Ehn, 2012; Robertson & Wagner, 2012). In recent years, the scope of PD has expanded to social innovation initiatives, and in some cases sensitive design situations (see e.g. Branco, Quental, & Ribeiro, 2017; Lindberg, Thomsen, & Åkesson, 2014), with designers as one amongst many professional actors promoting social change (Hillgren, Seravalli, & Emilson, 2011). By sensitive, we mean situations where design activities can distress or otherwise negatively impact participants' health or wellbeing (see e.g. Waycott et al., 2015). Health innovation initiatives (e.g. Noergaard et al., 2017; Robinson et al., 2017) for example trigger situations that cause harm. Sensitive design situations gravitate around vulnerability, that is, individuals with for example diminished capacity to make life decisions (due to mental or physical health issues) and individuals who have been subjected to traumatic experiences (Liamputtong, 2006).

It is not possible to guarantee that no harm will come to participants in sensitive design situations, as there are unforeseen risks related to involvement (Liamputtong, 2006; Waycott, Davis, Warr, Edmonds, & Taylor, 2017). Participants may experience emotional and psychological distress, and therefore need support (Waycott et al., 2015). Designers engaging in such initiatives inevitably face ethical dilemmas (Lindberg et al., 2014). While participants and future users can gain from PD, participation can also harm (Ferguson, Crist, & Moffatt, 2017). However, excluding users would, in turn, be unethical (Bravo, 1993; Satterfield, 2017), and involving representatives is insufficient (Brereton, Sitbon, Abdullah, Vanderberg, & Koplick, 2015). Clearly, guidance for how to approach ethics in sensitive design situations is essential to PD. Such guidance could encourage research with potential to contribute to wellbeing and social benefit, and encourage research that due to ethical challenges would otherwise not be performed.

Our literature review shows that knowledge on ethics is fragmented across disciplines and that practical support for designers is scarce (see e.g. Brooks & Atkinson, 2008; Chatterjee, Sarker, & Fuller, 2009; Walsham, 1996). National ethical review boards (e.g. the Swedish Research Council) and associations, for example the American Psychology Association, provide general ethical guidance for user involvement. These guidelines focus on the artefact (Stahl,
Eke, & Fidler, 2015), rather than on co-design of digital technology. Questions of ethics, engagement and empathy are raised by the unique methodological challenges for participation that sensitive design situations present (Branco et al., 2017). Approaches such as Value Sensitive Design (VSD) (Friedman, 1996; Friedman, Kahn, & Borning, 2002) and frameworks for negotiating ethics in sensitive design situations (Ferguson et al., 2017) help designers solve ethical conflicts. Yet, VSD has been criticised for lack of methodological guidance (Ferguson et al., 2017) and recent literature still calls for research on ethics in sensitive design situations (see e.g. Vines et al., 2017; Waycott et al., 2015).

In this paper we inquire into how ethics can be approached in sensitive design situations. We survey the current state of knowledge on ethics in design through a systematic literature review and analyse two empirical health innovation initiatives, and contribute with three guidelines for ethics in sensitive design situations: anticipation, attentiveness and critical self-awareness.

2 Research Approach
The research presented in this paper is part of a design study on user involvement in design of Digital Peer Support (DPS). DPS facilitates reciprocal, social support between peers who share similar, often difficult, experiences. These experiences can stem from for example mental ill health (see e.g. O'Leary et al., 2017). First, we review the literature on support for ethics in design, and second, we analyse how we approached ethical dilemmas for user involvement in the design of DPS for children cured from cancer and for adults diagnosed with schizophrenia.

2.1 Literature Review on Ethics in Design
The literature review explored existing practical support for ethics in design. Following Webster and Watson (2002), we carried out the review in five steps.

First, we used Scopus to search the major outlets for PD, IS, Human-Computer Interaction (HCI), design, and selected journals targeting ethics and IT, to identify papers with the string "ethic*" in abstract, title or keywords. Outlets not available in Scopus were searched manually. A backwards search was performed by scanning the references of the identified papers for the string "ethic*", filtered using the string "design". We also included seven papers from a 2017 special issue of Interacting with Computers on ethical matters in design research. In total 296 papers, published between 1996 and 2017, were reviewed.
Second, we performed an open Scopus search using the string "ethics W/3 design" within the subject area Computer science. This resulted in 109 papers.

Third, we screened titles and abstracts of all 405 papers to identify and include papers with bearing on ethics in the design process, user involvement, or in sensitive design situations. Papers dealing with a range of subjects, such as privacy, the socio-technical approach ETHICS, or corporate ethics were excluded, and 33 papers remained.

Fourth, we did a forward search of all papers citing the included papers. The citations of these papers were searched for the string "ethic*". No further papers were included.

Fifth, we examined the introductions, discussions and conclusions of each of the 33 papers. We excluded 14 papers that did not relate to ethics in the design process, user participation, or in sensitive design situations. One additional paper was excluded because the authors of this paper wrote it. The final number of papers for the review was 18 (see table 1). The remaining 18 papers were read in full to explore the support for ethics in design.

2.2 Study of User Participation
We studied two ethically challenging cases of user involvement in sensitive design situations. In both projects, the first author was actively involved in designing participative activities.

Case I: Involving Children Cured from Cancer
The first case aimed at designing DPS for children between 8-12 who have been cured from cancer. Cognitive and societal power differences between children and adults lead to children being considered vulnerable in research (Liamputtong, 2006). Additionally, going through cancer treatment is physically, mentally and socially challenging, and can lead to psychological late effects that can appear years later (Eiser, 2007). Possible side effects from the treatment include cognitive limitations, such as a pronounced inability to focus on a task (Ellenberg et al., 2009). Some children find it difficult to start new friendships, and experience a feeling of being different (Enskär & Berterö, 2010).

The project ran between 2011 and 2015 and was approved by the regional ethical review board (dnr 2011/307). The project group consisted of interdisciplinary researchers from nursing, health innovation and design. Children from the target group were involved in focus group interviews, design
workshops and a survey. Children without a history of cancer were involved in evaluations and a diary study. In order to gain an understanding of the sensitivity of the design situation, stakeholders such as health care professionals and parents of children cured from cancer were interviewed (see table 2).

The design outcome was a prototype of a mobile application offering gaming spaces where children can participate in activities facilitated by an adult. The game promotes friendship between peers, in order to lay the groundwork for future support.

**Case II: Involving People Diagnosed with Schizophrenia**

The second case aimed at designing DPS for people diagnosed with schizophrenia, who experience symptoms such as psychoses, apathy, and cognitive impairment (Frangou, 2008). Treatment primarily consists of anti-psychotic medication that can have severe side effects. Combined with social stigmatisation (Imhoff, 2016), this affects the users' abilities for participating in design.

The project ran between 2014 and 2017 and was approved by the regional ethical review board (dnr 2011/267). The project group consisted of interdisciplinary researchers from nursing and design. The project involved users from the target group in a focus group interview and design activities. Stakeholders were interviewed as part of understanding the sensitivity of the design situation (see table 3).

The design outcome was the prototype of a mobile application focusing on transparency and privacy control. The application encourages sharing of feelings and experiences by providing tools for self-expression, and aims to connect peers and promote reciprocal support.

### 2.3 Analysis

The two cases were analysed using a variation of the Critical Incident Technique (CIT) (see e.g. Flanagan, 1954). CIT focuses on incidents of significance and the relationships between incidents and human action (Butterfield, Borgen, Amundson, & Maglio, 2005; Flanagan, 1954). The method supports the classification and understanding of significant incidents. Each design process was analysed for critical incidents in terms of ethical triggers. An ethical trigger is a circumstance provoking an ethical dilemma. We define an ethical dilemma as a choice between two morally challenging courses of actions. A resolving action is an action taken to deal with a dilemma.
The analysis followed three steps: (1) ethical triggers were identified (eight in total); (2) associated ethical dilemmas and resolving actions were identified; and (3) the outcome was related to literature and conceptualized to guidelines.

3 Ethics in Design: Examining the Literature

The literature review explored existing support for ethics in design. Table 4 provides an overview of the 18 papers that were included in the review.

We have placed each paper in the discipline of the respective publication outlet where it was published. The column Empirical study marks if papers include an empirical study (Y) or not (N).

**Information Systems**

Mingers and Walsham (2010) discuss two aspects of ethical importance for design: embedding values in the designed artefact and the process of design. VSD, social informatics, computer-supported cooperative work and PD are highlighted as approaches that emphasise ethical values. Chatterjee et al. (2009) discuss the importance of addressing ethical considerations throughout the design process. They suggest shifting focus from the development methods to the teams; they are ultimately morally responsible.

Brooks and Atkinson (2008) provide a concrete approach to ethics by adapting an ethical decision-making tool for medical professionals. The framework is meant for ethical analysis of design processes, focusing on external, deontological and consequence considerations.

Walsham (1996) identifies four ethical implications for IS research: system efficiency conflicts, what entails "good" IS practice, moral development and participant rights. Walsham suggests that involving users is one way of dealing with ethics.

**Human-Computer Interaction**

Ferguson et al. (2017) analyse codes of ethics and create a framework for ethical reflection: (1) how to prevent harm to participants; (2) justice, and societal benefit; (3) property and participant benefit; (4) effect of power, conflicts of interest and culture; (5) obligations and acting in the best interest of the participants; (6) informed consent as an on-going dialogue; and (7) competence development.
Shilton and Anderson (2017) discuss the designer's ethical role. They highlight methods for including ethical questions in the design process: PD, values advocates, embedding values discussions, and moral exemplars. Which method combination that should be used is situational. Similarly, Vines et al. (2017) highlight the situational nature of ethics in design, and the necessity of attempting to anticipate ethical challenges in design processes.

Design
d’Anjou (2011) claims that there is no objective model for ethics, only for the designer's own awareness. He proposes an ethical decision-making model: (1) acceptance of freedom and responsibility; (2) reflection on prior design choices; (3) reflection on demands of external actors; (4) reflection on practical limitations; and (5) enacting the design choice.

Keinonen (2010) focuses on participant benefits, reflecting on whether or not ethical justification can come from simply satisfying the users' fundamental needs. He identifies a shift in focus from avoiding harm to the creation of pleasure and experience. Keinonen describes two fundamental dimensions of design practice: to avoid harm and to respect the participants' agency and autonomy.

Lloyd (2009) discusses design thinking in relation to ethical thinking, and concludes that imagination is vital for ethics in design. Designers make ethical decisions by imagining potential scenarios and focusing on the users' values; imagination allows the designer to consider the consequences of each situation.

IT and Ethics
Stahl et al. (2015) argue that all design should undergo ethical scrutiny. However, researchers find this process complex and impeding, and lack knowledge of ethics specific to design. It is unclear whether ethical reviews are the most suitable for ensuring ethically responsible design, or whether there are more situationally appropriate tools. Gerdes (2014) extends this by claiming that user participation is insufficient, but that stakeholders, designers and ethical experts need to maintain a dialogue to incorporate ethics.

Stahl (2014) emphasises that engaging participants can surface ethical values, and reasons on how to include judgement in the design process. Yet, Stahl cautions that user participation can also miss ethical aspects and may limit the designer's possibility to question established circumstances. Christiansen (2014) proposes activities such as prototyping and use of narratives for incorporating ethics, as it creates shared knowledge and understanding.
Drawing on VSD, Knight (2008) proposes three principles for ethically grounded design: (1) participation to include the users' values; (2) reflexivity to be sensitive to both the participants' and stakeholders' needs, and the designer's values; and (3) situated research as a critical approach to be situationally sensitive.

**Other**
Satterfield (2017) presents best practices for inclusion of persons with cognitive disabilities. Using multiple methods of data collection when participants have different abilities gives richer data, and the design team needs training to observe the state of, and create minimal impact on participants.

Steen (2015) examines the design practices of selected approaches, including PD, from three ethical perspectives. Values such as empowerment, cooperation, and joint imagination are implicitly built into these approaches, but researchers are rarely explicit about ethical practices. Therefore, explicit reflection on ethics is needed.

Albrechtslund (2007) focuses on VSD. He highlights issues such as the lack of separation between design intention and use; in highlighting this, he argues that ethics in design is unpredictable, but it is possible to anticipate ethical dilemmas.

### 3.1 Reflection on the Literature Review
Out of the 18 papers in this literature review, only four [5; 7; 11; 16] are based on empirical studies. The main conclusion in the literature is that the designer has to be reflecting in practice. Ethics in design is portrayed as situated [6; 7; 13; 15] and unpredictable [5; 7; 10; 18]. The character of most (10 of 18) papers is general discussions, implications, challenges and critique. Seven papers provide explicit guidance in terms of frameworks, models, principles or best practice contributions. Three papers [3; 5; 9] provide practical guidance for designers, though none of those are based on empirical studies. Only three papers are explicitly focused on ethics of user involvement in design [7; 9; 16].

Five papers [4; 12; 14; 15; 17] emphasise user involvement itself as a way to incorporate ethics into the design process. Despite this, practical guidance for how to handle ethical dilemmas arising from user involvement is limited. The support for ethics for user involvement in situ is abstract, and does not provide practical guidance to designers in sensitive design situations. In summary, we
conclude that support for ethical design practice is scarce, fragmented, vague, and spread over several disciplines.

4 Involving Users in the Design of Digital Peer Support

This section presents the two cases of designing DPS and the ethical dilemmas that emerged. Ethical triggers and dilemmas are numbered according to table 5.

4.1 Case I: Involving Children Cured from Cancer

Children with a history of cancer were initially recruited. The participation took up much of the children's time; they were already involved in medical treatment, hobbies and activities important for their wellbeing. This limited access to users (in both numbers and allocation of time) triggered [I.1] the ethical dilemma of choosing between involving the children with the risk of wearing and stressing them, or proceeding without active involvement in parts of the design process. The compromise of involving children in the same age group but without a history of cancer along with the use of personas (created together with the target group children) were resolving actions taken to be able to keep pace with the research plan.

One prerequisite from the ethical review was that the focus of the project should not be on the experiences related to cancer treatment, but on salutogenic (health promoting) aspects. This vulnerability of the children triggered [I.2] the ethical dilemma of choosing between the risk of emotionally distressing the children by speaking of their cancer experience, and the need to understand these experiences as important design input. As a resolving action, design techniques such as comic characters and comic creation were used as proxies to buffer the sensitive subject.

In the activities, we followed guiding literature of PD with children. We experienced how the side effects of their treatment, for example difficulties to concentrate and maintain focus, affected their ability to participate in accordance with the literature. This triggered [I.3] the dilemma of choosing between involving the children autonomously, and the need to support the children and be attentive to their individual wellbeing during the activities. The resolving action was to work with design techniques that were flexible and less demanding. We also worked in child-adult pairs to help the children maintain focus, and also keep an eye on the wellbeing of each individual child.

During the design process, we encountered situations when there was a risk of adults misinterpreting the children's input. This triggered [I.4] the ethical
dilemma of choosing between involving the children in activities to confirm and re-evaluate interpretations, and dealing with the risk of requiring too frequent participation given their health status. The resolving action in this case was to limit the reconnecting activities to two times, once in person and once through a survey, with the purpose of confirming interpretations.

4.2 Case II: Involving People Diagnosed with Schizophrenia

The project was initiated with stakeholder interviews before involving users, with the purpose of gaining as much understanding as possible of experiences that people diagnosed with schizophrenia go through. The situation and symptoms of schizophrenia vary, and some require daily assistance to handle everyday activities. Therefore, there was a need to carefully plan and adapt design activities to the individual user’s situation, and to re-design activities in situ as they sometimes triggered [II.1] negative experiences. We faced the ethical dilemma of choosing between the value of engaging the users in activities to speak for themselves and the risk of negative impact on the participants. Resolving actions taken were to interview stakeholders before designing the activities and in the activities, we only focused on positive experiences, encouraging the participants to put aside the negative. The psychiatric nurse in the project team maintained contact with the participants between workshops to secure their wellbeing.

During the design activities, symptoms such as hallucinations and obsessions influenced the reliability of the input from participants. All participants experienced these symptoms as negative, and were reluctant to discuss them [II.2]. We faced the ethical dilemma of choosing between the fundamental value of involving users to understand the sensitive design situation, and the risk of negative implications for the users as well as risking unreliable design input. This dilemma was met with two resolving actions. First, we encouraged participants to disregard negative subjects in order to avoid triggering symptoms. Second, when necessary, the psychiatric nurse used logical arguments to challenge clearly illness-related ideas.

Due to the illness, the user group has cognitive and social limitations. These limitations affected the design activities [II.3]. We experienced the ethical dilemma of choosing between involving users in the design process, which is cognitively and socially demanding, and the risk of distressing them. The resolving actions were to work in small group settings of two participants and three researchers, to make the participants feel comfortable. We initially planned to work in user-designer pairs to support the participants. The participants expressed discomfort at this, so a group setup was used instead.
Users had problems making clear and realistic decisions due to the illness [II.4]. In some situations where design decisions were needed it was challenging to rely on direct user input. We faced the ethical dilemma of choosing between the designers taking a greater role in decisions and the risk of misinterpreting or marginalizing user input. The resolving action was to reconnect to previous activities during the workshops. At the beginning of each workshop we presented our interpretation of the participants' input from the previous workshop, and encouraged to add or revise.

5 Discussion
This paper explores how ethics of user involvement in design in sensitive design situations can be approached, through a systematic literature review and analysis of two cases of designing DPS. The literature review portrays ethics in design as situated and unpredictable. This was also reflected in the two empirical cases. Drawing on the literature review and the empirical exhibits we propose three guidelines. These guidelines presuppose following the ethical conduct of research and design practice in general. They foreground how ethics can be approached when design situations are sensitive and users vulnerable. In sensitive design situations, users are asked to share personal and private experiences, and fears and anxieties related to for example illness or impairment. Underlying principles of the guidelines are to cause no harm, to do good, and to cater for user autonomy and conditions for equal participation. The guidelines focus on preparation and performance of PD activities.

Guideline I: Anticipation
The first guideline is to, as far as possible, anticipate ethical dilemmas that may emerge in the sensitive design situation. That is, to anticipate in advance any risks to the participants, in order to reduce these risks to the greatest possible extent. The guideline of anticipation addresses the situatedness of ethical dilemmas; the nature of ethical dilemmas is grounded in the situation. Attempting to anticipate the risks to participants in each design project and for each activity enables the designer to adapt to the uniqueness of the design situation.

In the DPS cases, this was reflected when interviewing and engaging with users and stakeholders in order to ground an in-depth understanding of the sensitive design situation and the specific conditions for each individual's participation. Activities were organised with individual support and adapted to the users' abilities both before the activities and in situ. From this experience, we
concluded that grounded anticipation could help anticipate and prepare for ethical dilemmas.

It is not possible to predict all ethical dilemmas that can occur in design (Albrechtslund, 2007; Vines et al., 2017), but by attempting to anticipate them, it is possible to better prepare, and to train designers to identify possible risks in situ, as recommended by Satterfield (2017). As highlighted by Lloyd (2009), imagination is an important part of both design thinking and ethical thinking. Ferguson et al. (2017) also underline that designers should reflect on and prevent the ways in which participants may be harmed in the process beforehand. This is similar to Vines et al. (2017), who conclude that reflection and anticipation of ethical challenges in advance are crucial to involving vulnerable participants.

Guideline II: Attentiveness
The second guideline is to be attentive to the vulnerabilities, integrity and wellbeing of the individual users in order to avoid and minimise any negative effect. The unpredictable nature of these sensitive design situations requires an ability to adapt to unexpected and unfamiliar conditions. This guideline directly relates to readiness to act and meet ethical dilemmas in the de facto design activities. We highlight the ethical stance that the needs and wellbeing of the participants always come first, and that measures are taken to provide conditions for equal participation.

Both cases in the study required special attention to how the symptoms of the illnesses influenced the individual user’s ability to participate. Throughout the design projects, attention was required to adapt to the participants’ prerequisites in situ. This was for example shown when the design team restrained the involvement of children with illness symptoms, and instead involved representatives in the same age group. During those activities, design aspects related to the age group than the specific target group were prioritized. Another example was when activities were changed in situ when the participants diagnosed with schizophrenia felt uncomfortable with the social setup. From these experiences, we conclude that it is essential to be constantly attentive as unexpected actions can have unanticipated consequences.

Protection of participants (Keinonen, 2010) and sensitivity to the needs of the participants (Knight, 2008; Satterfield, 2017) are key aspects to ethics in design. As Ferguson et al. (2017) point out, there is a greater risk of harming participants in sensitive design situations. Vines et al. (2017) argue that a designer needs to be prepared to negotiate and put the participants’ needs before
their design needs. Furthermore, attentiveness also involves an understanding of the fact that conditions for prescriptive ethical routines, such as informed consent, can change over time (Ferguson et al., 2017).

**Guideline III: Critical Self-Awareness**

The guideline of critical self-awareness refers to awareness *in situ*, as well as to critical self-awareness of one’s own interpretations and actions. Ultimately, it is the designer’s responsibility to follow general research and design ethics, but also to reflect on the specific design situation. The unpredictability of the sensitive design situations may require to re-think and re-evaluate activities as well as to challenge one’s own actions and assumptions about the sensitive situation. This ability might in turn require special competencies (such as medical professionals) to make balanced judgements and interpretations. Further, critical self-awareness is a means for designers to develop empathy for the target group.

In both cases, this was reflected when the designers were observant of their own interpretations and the risk of misinterpretation, and also when medical professionals supported the users in being critical of their own statements. Given our project experiences, we conclude that continuous critical self-awareness could contribute to minimising negative effects that inevitably occur.

All things considered, designers are morally responsible for ethical conduct throughout the design process (Chatterjee et al., 2009; d’Anjou, 2011). Knight (2008) emphasises sensitivity to both stakeholder needs and awareness of one’s own values, as necessary for ethically grounded design. The inclusion of ethical and subject matter experts may be necessary (Gerdes, 2014). The designer also needs to be aware of the creation of a culture of ethics in the design process, and how power relations and conflicts affect participation (Ferguson et al., 2017).

5.1 The Relationship between Guidelines

The three guidelines are interrelated and complementary. They are intended to be guiding in concrete design situations, and when analysing and reflecting on ethical dilemmas in sensitive design situations.

Implicit in all three guidelines is reflection; the guidelines posit that the designer reflects as a starting point to applying these guidelines. Reflection is a key element to ethics in design (Chatterjee et al., 2009; d’Anjou, 2011; Ferguson et al., 2017; Knight, 2008; Steen, 2015; Vines et al., 2017), but in
proposing these guidelines, we claim that there needs to be more than reflection; there also needs to be guidance to action.

We emphasize that the guidelines are neither mandatory nor prescriptive, nor static rules of moral. Each sensitive design situation is unique, with unique ethical challenges (Branco et al., 2017). Designers must use their judgement as to how they decide whether, how, and if the guidelines are applicable. The guidelines are intended to ensure that user involvement is ethically defensible, yet does not lead to the exclusion of users from the design process. User involvement cannot either be replaced by involvement of representatives (Brereton et al., 2015). The goal with proposing the three guidelines is instead to encourage user participation, with an awareness of the challenges that involving users in design in sensitive design situations presents. There are many opportunities for social innovation through PD in a vast number of domains (Sanders & Stappers, 2008), and even though it is challenging, there are good reasons for involving users in sensitive design situations.

6 Concluding Remarks
In this paper, we examine how ethics can be approached when involving users in sensitive design situations. We contribute with a literature review on ethics related to user participation in sensitive design situations that shows that the literature is scarce, fragmented and often too abstract to be of guidance to the individual designer. Moreover, we contribute with three guidelines for ethical user involvement in design in sensitive design situations: anticipation, attentiveness and critical self-awareness. The three guidelines build on the prerequisite of reflection, and are suitable to the nature of ethics in design in sensitive design situations, which is situated and unpredictable.

7 References


