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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<tr>
<th>Abbreviation</th>
<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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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, Stroulias, Nikolaidis, Miguel-Cruz, & Rios Ricon, 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, Thiem, 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.
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:

**Paper 1**  

**Paper 2**  

**Paper 3**  

**Paper 4**  

**Paper 5**  
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 \textit{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, Møgensen, & 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>
<thead>
<tr>
<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
et al., 2017); simultaneously, the risk of harming vulnerable users is higher (Ferguson et al., 2017).

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>
<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>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>• Joined the CHIPS project in the spring</td>
<td>• Personas and scenarios in CHIPS</td>
<td>• Paper 1 published</td>
<td>• Paper 1 published</td>
<td>• Future workshops in LwS</td>
<td>• Paper 2 published</td>
<td>• Paper 3 submitted for second round</td>
</tr>
<tr>
<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>• Paper 4 accepted for publication</td>
<td>• Paper 4 accepted for publication</td>
<td></td>
</tr>
<tr>
<td>• Design workshops in CHIPS</td>
<td>• LiwS project initiated</td>
<td>• Stakeholder interviews in LiwS</td>
<td>• Future workshops in LiwS</td>
<td>• Literature review on ethics in design</td>
<td>• Evaluations in LiwS</td>
<td>• Evaluations in LiwS</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>
</tr>
<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>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Project</td>
<td>CHIPS</td>
<td>CHIPS</td>
<td>LiwS</td>
<td>LiwS</td>
</tr>
<tr>
<td>Problem</td>
<td>Proactively adapting design activities to ethical considerations</td>
<td>Involving children in the evaluation of DPS</td>
<td>Understand the wickedness in the design of DPS for people diagnosed with schizophrenia</td>
<td>Involving people diagnosed with schizophrenia in the design of digital technology</td>
</tr>
<tr>
<td>Theoretical concepts</td>
<td>Participatory design with children Ethics in design with children</td>
<td>Involving children in evaluations Research with vulnerable children</td>
<td>Schizophrenia Wicked problems</td>
<td>Schizophrenia User participation in design</td>
</tr>
<tr>
<td>Data collection</td>
<td>Design workshops Usability test Diary study Focus group interview Survey</td>
<td>Interviews Focus group interviews</td>
<td>Interviews Design workshops</td>
<td>All data from CHIPS and LiwS</td>
</tr>
<tr>
<td>Analysis</td>
<td>Abductive thematic coding Deductive thematic analysis</td>
<td>Grounded theory analysis</td>
<td>Inductive thematic analysis</td>
<td>Variation of Critical Incident Technique</td>
</tr>
</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.
CHAPTER 4

The Design Study

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 & Sendor, 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, Boehmer, 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, Brusilovskyi, & 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/

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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**
- Project: CHIPS 2012-2013
  - Design workshops
  - Persona development
  - Scenario development
  - Iterative design and prototyping
  - Feedback workshop
- Contribution: Ethical perspective of design activity adaptation
- Communicated in: Paper 1

**Iteration 2**
- Project: CHIPS 2014
  - Evaluation: usability tests
  - Evaluation: diary study
  - Evaluation: focus group interview
  - Evaluation: survey
- Contribution: Challenges and strategies for user involvement
- Communicated in: Paper 2

**Iteration 3**
- Project: LiwS 2014-2015
  - Stakeholder interviews
  - Future workshop round 1: Focus group interview
- Contribution: Complexity of user involvement
  Grounded situational understanding
- Communicated in: Paper 3

**Iteration 4**
- Project: LiwS 2014-2016
  - Stakeholder interviews
  - Future workshops
  - Iterative design and prototyping
- Contribution: Challenges and strategies for user involvement
- Communicated in: Paper 4

*Figure 4. Summary of the research 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 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.
CHAPTER 5

Summary of the Research

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.


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 **acknowledgement** 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 **acknowledgement** 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>
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<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 \textit{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.
REFERENCES


