Involving Children in the Design of Online Peer Support for Children with Cancer

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Thesis submitted for completion of Master of Science (60 credits)
Main field of study: Computer Science
Specialization: Informatics

January 2013
This thesis is submitted to the School of Computing at Blekinge Institute of Technology in partial fulfillment of the requirements for the degree of Master of Science (60 credits) in Computer Science with specialization in Informatics. The thesis is equivalent to 10 weeks of full time studies.

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ACKNOWLEDGEMENTS

I would like to thank Maria Åkesson and Michel Thomsen for taking the time to read and give me feedback on this thesis. I also want to thank Pontus Wärneståhl, Jens Nygren, Petra Svedberg and Eva-Lena Einberg, my fellow CHIPS project group members, for making this past autumn so much fun. Finally, I would like to give a big thanks to my supervisor Bo Helgeson, who has guided me through the process of writing this thesis.
ABSTRACT

Information Technology (IT) in health services has become increasingly important for people's wellbeing. The nature of design of these technologies is complex – even more so when the context is of a sensitive nature, such as the user's health. Furthermore, when the users are children, several additional difficulties surface. Apart from the design context being sensitive, children have cognitive and communicational limitations that make any design method employed require adaptations.

This thesis is conducted within the research project Child Health Interactive Peer Support (CHIPS) at Halmstad University. The project aims at developing Online Peer Support (OPS) for advancing the wellbeing of children who have or have had cancer. The project thus presents a unique design situation, and the aim of this thesis is to answer the question: How can children participate in the design of Online Peer Support for children with cancer?

In order to answer this question, a literature review was performed to identify common properties of design methods with children, children were involved in the design of OPS for children with cancer, and the lessons learned from the empirical case were discussed. The properties of design methods with children were organised into three categories and later supplemented with properties of methods for performing research in a sensitive context.

The empirical material was made up of six design workshops with two groups of children who were, or had previously been treated for cancer. From the design workshops and the subsequent discussions several lessons were learned, in addition to the result from the literature review, about how children can be involved in the design of OPS for children with cancer. Based on this, seven suggestions were made for adapting methods to suit design with children in a sensitive context.

Keywords: design methods, children, sensitive subjects
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1 INTRODUCTION

The use of Information Technology (IT) in health services has become an increasingly important aspect of people's wellbeing. Within the Digital Agenda for Europe there is for example a focus on how digital technologies can promote health and improve quality of life (European Commission, 2012). Yet, in the design and development of these digital technologies, designers face a complex situation.

The design of digital technologies involves creating meaning in the connection between behaviour and technology; it has to deal with conflicts among users, interests and contexts (Cooper, Reimann & Cronin, 2007). When the users are children, and the context relates to their wellbeing, a number of specific difficulties emerge. Firstly, children have a different culture than adults, have a lesser ability than adults to communicate abstract thoughts, have cognitive limitations and express themselves in actions more than in words or writing (Druin, 2002). Secondly, when the situation being designed for relates to circumstances that can be sensitive to the participants, in the way that they awaken negative emotions, for example health related issues, extra care needs to be taken to ensure that they are not unduly upset or affected (Elmir, Schmied, Jackson & Wilkes, 2011).

When designing, it is common to use a method for helping control, handle or understand the complexity of the given situation. When designing for children, using a method that includes the children in the design process and not only relies on e.g. parents and teachers, is recommended (Druin, 1999). Participatory design is considered beneficial for designing with children (Nesset & Large, 2004; Druin, 2002; Read et al., 2002). However, any design method intended for use with adults needs adaptation when used for designing with children (Guha, Druin, & Fails, 2011; Farber, Druin, Chipman, Julian & Somashekhar, 2002).

Participatory Design (PD) values the active participation of future users throughout the design process (Bjerknes & Bratteteig, 1995). One of the first to adapt design methods meant for work with adults to the work with children was Druin (1999), who presented a method for actively including children as co-designers. Since then, a number of adaptations of typical PD techniques to suit design with children have been made. These include the creation and use of personas and scenarios (see e.g. Antle, 2008; Chung & Gerber, 2010; Moser, Fuchsberger, & Tschelig, 2011; Moraveji, Li, Ding, O'Kelley, & Woolf, 2007), and prototyping (Walsh et al., 2009; Hemmert, Hamann, Löwe, Zeipelt, & Joost, 2010).

This research for this thesis was conducted within the frames of a project where IT is used to promote children's wellbeing. The research project Child Health Interactive
Peer Support (CHIPS) at Halmstad University aims at developing and investigating how an Online Peer Support (OPS) solution can promote the mental health status of children between 8-12 years old, who have or have had acute lymphoblastic leukaemia. The project takes a participatory approach and is an example of a complex design situation. Since the reason for the children's participation is that they have had cancer, there is a risk of them becoming upset. Furthermore, because of the complexity of the situation, the method for involvement of the children needs to be specifically adapted for the project's prerequisites. The question is how this situation can be handled.

Most of the research conducted with children focuses on the engineering and evaluation of digital artefacts (Garzotto, 2008; Jensen & Skov, 2005). Obrist et al. (2011) call for further discussion on how children can participate in the design process, particularly how they can participate over an extensive period of time. Add to this the sensitivity of the health care related situation. A design process should be adapted to suit the requirements of the specific situation (Stolterman, 2008), and in this case it entails using a method which it suitable for work with children in a sensitive context.

1.1 Aim and Objectives

Because the context at hand is complex and sensitive, and because the users are children, there is a need to specifically adapt the method used during the design process. The aim of this thesis is therefore to answer the question: How can children participate in the design of Online Peer Support for children with cancer?

In order to answer this question, it has been broken down into three objectives:

- Through a literature review, identify properties of design methods that include children;
- In an empirical case involve children in the design of OPS for children with cancer;
- Formulate suggestions for how methods for designing with children can be adapted to suit research in sensitive contexts.
2 BACKGROUND

2.1 Design
Designing Information Systems is a complex activity. Often a designer has to deal with “an unknown or only partially known situation, with demanding and stressed clients and users, with insufficient information, with new technology and new materials, with limited time and recourses, with limited knowledge and skill, and with inappropriate tools” (Stolterman, 2008, p. 55). Not until there is a finished artefact can the designers know exactly what the problem was, and how to solve it (Carroll, 2000). Design is, in essence, about dealing with complexity and doing so with rigour and discipline (Stolterman, 2008).

However, complexity is not only a bad thing. A complex situation is rich and presents a challenge which can motivate and drive the development of a solution. In fact, Stolterman (2008) argues that complexity is a requirement for creativity and innovation. Therefore, any design method employed ought to support understanding and handle complexity, yet not attempt to simplify it (ibid.).

There is no specific interaction design process that can be applied to all projects, but each process has some generic, iterative steps in common: (1) establishing requirements; (2) designing alternatives; (3) prototyping; and (4) evaluating (Rogers, Sharp & Preece, 2011). The six steps of the design process presented by Cooper et al. (2007) can be said to cover step two and three of Roger et al.’s steps: (1) research; (2) modelling; (3) requirements; (4) framework; (5) refinement; and (6) development support.

![Figure 1. The Goal-Directed Design Process (Cooper et al., 2007)](image1)

In the initiation of the design process, research is usually performed to establish who the potential users are, and in what context the design can be used (Rogers et al., 2011; Cooper et al., 2007). Typical activities performed at the early design stages are observations, stakeholder interviews, and literature reviews. The creation of models such as personas and context scenarios is a way to focus the design throughout the entire process, and is considered an essential aspect of the Goal-Directed Design Process (Cooper et al., 2007).
As the process continues, the focus turns to the creation of one or more design suggestions – either in the form of design patterns and design concepts, or as physical design suggestions (Rogers et al., 2011; Cooper et al., 2007). These are then refined, for example by prototyping, and a final product is developed (by a software development team) and evaluated (ibid.).

2.2 Participatory Approaches

The idea behind participatory design (PD) is that of democracy; of allowing users to have a say in the development of a system they will later have to use (Bjerknes & Bratteteig, 1995). This is argued to improve system quality, and also have a positive effect on acceptance of the new system (ibid.). In traditional Scandinavian PD, not only is there a focus on the development of computer systems, but on developing individuals and understanding their interaction, culture and society (Gregory, 2003). This view stemmed largely from the union influence in Scandinavia, where workers early on were able to exert their influence when change that effected their work situation was imminent (ibid.). Lately there has also been a shift towards product development using PD, instead of work place systems (Svensson, Ihlström Eriksson, Ebbeson, & Åkesson, 2009). PD can also be extended other kinds of design than typical software development projects (Dittrich, Eriksén & Hansson, 2002).

User-Centred Design (UCD) is based on a slightly different foundation than PD. The UCD movement was critical to the human factor being ignored in development, and advocated a user focused process (Marti & Bannon, 2009). From being the centre of observations, interviews and questionnaires, users became increasingly viewed as equals in the design process, much as in PD (ibid.). Gulliksen et al. (2003) present twelve principles for UCD, which include active user involvement, prototyping, having a user-centred attitude and customising the design process. However, there remain discussions within the community on how, how much, and when users are to be involved in the design process (Marti & Bannon, 2009).

A design has to result in something that supports the actions it was intended to support and be used because of it; involving users in the design will make it more likely that the design achieves this (Dittrich et al., 2002). Participatory approaches are further considered to increase the effectiveness of the finished design, and have democratic advantages when performed within a workplace setting (Marti & Bannon, 2009). By placing a focus on the fact that the design has to function in a use context – like the workplace – and is an iterative process, aspects such as flexibility and sustainability become essential in PD (Dittirch et al., 2002). Furthermore, participatory approaches have functional and ethical benefits, since they require sensitivity to the environment and users (Marti & Bannon, 2009).
In participatory approaches “Establishing mutual trust and rapport between researchers and participants is one of the most challenging tasks. It usually requires a creative approach and an individual strategy” (Foth & Axup, 2006, p. 94). Relationships built during the design process have to be sustainable because the work is long term and iterative, and there are going to be constant changes that require user input (Gregory, 2003). Some other major challenges in PD include how to involve users without interrupting day to day business in the company (Elovaara, Igira, & Mörtberg, 2006), how to keep projects going over a long period of time (Balka, 2006), and how to translate many different opinions into a single solution (Sanders, Brandt, & Binder, 2010). Participatory approaches in general require great efforts from both researchers and participating users (Marti & Bannon, 2009). There is a trend towards where time mattering more than workplace quality, and speedier methods are preferred over PD (Kensing & Blomberg, 1998).

Participatory approaches frequently use more informal methods and techniques, and adapt these to suit the current user participation situation. There is also a preference for ethnography in PD (Foth & Axup, 2006). Due to the nature of these kinds of approaches, the methods and tools used support cooperation and user design, and include for example probing techniques, prototyping, diaries, and even acting (Sanders et al., 2010).

Different tools have different purposes: some are more suitable for creating and understanding, while others might be more suitable for performing the actual design (Sanders et al., 2010). For example making collages or keeping diaries are suitable for probing and priming users, while techniques like mock-ups, cards or acting are more suitable for understanding and designing (ibid.). Cooperation is essential, and there are plenty of design methods which reinforce this. Prototyping, scenario techniques, probing and workshops are examples of techniques which achieve this (ibid.). However, just using these techniques once in a development process is not the same as conducting PD; there need to be activities performed over a longer period of time, in an iterative fashion, to achieve full participation (Sanders et al., 2010).

2.2.1 Techniques
Among the techniques common in participatory approaches, and prescribed in the Goal-Directed Design Process, are personas and scenarios. Personas are prescribed by Cooper (1999) as being not real people, but they represent them throughout the design process. They are hypothetical archetypes of actual users. Although they are imaginary, they are defined with significant rigor and precision. Actually, we don’t so much “make up” our
In other words, personas are imaginary users based on an archetypal user; they are generally created by the designers themselves, but are based on research and experience. Personas can be created in order to help the designer understand and focus on the users (Chang, Lim & Stolterman, 2008). They are also used as an aid in communicating with stakeholders, and validation of design decisions (Chang et al., 2008).

Communication is intrinsic to persona use; the persona’s “greatest value is in providing a shared basis for communication” (Pruitt & Grudin, 2003, p. 3). The persona’s goals help determine what the design should encompass and look like, and can later work as sounding boards for design suggestions (Cooper et al., 2007). Personas are also beneficial for introducing participatory design (PD) elements in standard product development; the elements mentioned include long-term user engagement and what Grudin and Pruitt (2002) call “quality of life” issues. However, personas are not used to their full advantage alone, but “can be more powerful if used to complement, not replace, a full range of quantitative and qualitative methods” (Pruitt & Grudin, 2003, p. 3).

Personas are often used as the basis for scenarios; they are what scenarios later build on (Grudin & Pruitt, 2002). Scenarios are defined as “informal stories about user tasks and activities” (Rogers et al., 2011, p. 415), and are used in design primarily for communicating design suggestions. While scenarios are generally textual stories, when adapted to step-by-step illustrations they are called storyboards (Rogers et al., 2011). Scenarios are built around settings, actors, and the actors’ goals (Carroll, 2000). Personas and scenarios can be used in combination, where the persona is used as the actor (Cooper et al., 2007).

Cooper et al. (2007) describe three types of scenarios:

- **Context scenarios** are made before a design solution is in existence, and is used to try out the design ideas, by describing the ideal user experience;
- **Key path scenarios** are a further developed context scenario, which focus on the specific interaction a user has with the design. This scenario develops along with the product;
- **Validation scenarios** are used to test the finished design, or the design ideas, in different kinds of situations.

When trying to make a usage situation more concrete, scenarios can help by both being developing and describing (Cooper et al., 2007). As with personas, scenarios
help keep the focus on usage situations and the consequences for its use a design decision can have (Carroll, 2000).

While being concrete, scenarios allow for easy change and adaptation, thus being simultaneously flexible. Furthermore, scenarios are beneficial for design performed in areas where there has been little work done previously, as they can be a way to discover practices, see relationships between different use contexts and fields, and create design suggestions that can be adapted to other contexts (Carroll, 2000).

2.3 Participatory Approaches with Children

In the past, design for children as target group was done by asking parents and teachers what they thought children might want and like (Druin, 2002). However, since the beginning of the 21st century, there has been a movement towards involving the children themselves in the design process. Children generally want to be part in the design process, and despite historical claims, they do have different opinions and needs than adults (Ruland, Starren, & Vatne, 2008; Komlodi et al., 2007). As Nesset and Large (2004) argue, “having children as part of the design team will provide that all-important information about the intended user and usage” (p. 150).

Druin (2002) identifies four different roles children can have in the design process: user, tester, informant, and design partner. As users, children test the finished technology while being observed or tested by researchers, while they try to understand what impact the use of the technology might have on the children. In the role of tester, children test prototypes and again observation is used as a way to inform and develop the design further. As informants, children participate at certain points in the design process, for example to give their opinions on design suggestions and prototypes. Finally, as design partners the children are part of the entire process and have an equal status to the adult stakeholders.

Participatory design is considered well suited for work with children (Nesset & Large, 2004; Druin, 2002; Read et al., 2002). However, any methods or activities made for use with adults need to be adapted when used with children (Komlodi et al., 2007; Kelly, Mazzone, Horton, & Read, 2006). First, children have a different culture than adults, have a lesser ability to communicate abstract thoughts, and they express themselves in actions more than in words or writing (Druin, 2002). Second, in order to keep up the children's interest, their participation needs to be made fun (Thomas & O’Kane, 1998).
2.3.1 Methods
Since its introduction by Druin (1999), Cooperative Inquiry (CI) has become one of the most influential approaches for working with children as design partners. CI is based on ideas from PD, particularly in its view of the children as partners in design. The work with CI includes building long-standing relationships with children, over a long period of time. The children take part in data gathering activities, like for example observation and interviews, alongside the researchers (Druin, 1999). Field work is relied on to reduce the effects of children’s difficulties in verbalising and abstracting their needs. In the same spirit, low-tech prototyping is used as a way of communicating thoughts and ideas (Druin, 1999).

Within CI, a number of techniques adapted for working with children are included. One, called contextual inquiry, allows for the discovery and exploration of a multitude of different ideas. In this technique, children work together with adult researchers while observing other children performing tasks (Druin, 1999). The adults take detailed notes while the children take notes by combining drawing and writing, and the material is later analysed by comparing the adults’ compiled material with that of the children (Druin, 1999).

The second technique Druin (1999) calls participatory design, as the technique bears similarities to low-tech prototyping sessions commonly performed within PD. Here, the ideas from contextual inquiry are made more concrete by using low-tech materials for prototyping. Children again work in teams with adults, where all participants should contribute equally (Druin, 1999).

The third technique was dubbed technology immersion and aims to study how children use technology when given the opportunity to use it in a variety of ways and over a certain amount of time (Druin, 1999). The children are then observed, using contextual inquiry, while using the technology. In this way the techniques of CI are interconnected. Technology immersion sessions are intensive and can span several days. Critique against CI includes that it requires too many resources in the form of time, money and facilities (Dindler, Eriksson, Sejer Iversen, Lykke-Olesen, & Ludvigsen, 2005).

Several new techniques have since its introduction been created within the span of CI (see e.g. Guha et al., 2011; Walsh et al., 2009; Guha, Druin, & Fails, 2008; Komlodi et al., 2007; Farber et al., 2002), and the approach has inspired many other approaches (see e.g. Frauenberger, Good, Keay-Bright, & Pain, 2012a; Garzotto, 2008; Kelly et al., 2006). Some examples include Guha et al. (2011), who develop CI for use within an educational context, Farber et al. (2002) who adapt CI to suit work with younger children (aged 4-6) and Walsh et al. (2009) who describe their technique Layered Elaboration which is a further development of the CI techniques,
and can be used to create storyboards, low-fi prototypes or interface designs. There does thus not, however, appear to be a generic method for designing with children.

2.3.1.1 Properties of Design Methods with Children

While there are many different methods specifically adapted for designing with children, they have a number of properties in common. These properties can be separated into three categories depending on what part of the design method they relate to: the activities performed, the designers who prepare and lead them, and the participants.

2.3.1.1.1 Activities

A prevalent property of design methods with children is that the activities should be fun for the children (Frauenberger, Good, & Alcorn, 2012b; Giaccardi, Paredes, Diaz, & Alvarado, 2012; Hemmert et al, 2010; Mazzone et al., 2010; Komlodi et al., 2007; Dindler et al, 2005). If the activities are fun, they are more likely to engage the children, and motivate them to participate (Thomas & O’Kane, 1998). What activities are considered fun must invariably vary from child to child, as it is a subjective opinion. However, the activities presented in the literature are often described as being perceived as fun by the participating children (Horton, Read, Mazzone, Sim, & Fitton, 2012; Mazzone et al., 2010), thus allowing the conclusion that creative, low-tech activities are considered fun by many children.

The descriptions of physical settings where the activities take place vary throughout the literature. Some visit the participating children at their schools (Giaccardi et al., 2012; Grundy, Pemberton, & Morris, 2012), while others have design labs to which the children come (Horton et al., 2012; Xie et al., 2012, Stringer, Harris, & Fitzpatrick, 2006), or both (Kelly et al., 2006). A school setting can make children more inhibited, and worried about giving a “wrong” answer (Thomas & O’Kane, 1998), which is not mentioned in regards to a non-school setting. Others promote the school as an environment familiar to the children (Giaccardi et al., 2012), and also as a place where they are more easily reached (Horton et al., 2012).

Several methods start with a “get to know each other” activity (Frauenberger et al., 2012a; Xie et al., 2012; Moser et al., 2011; Read et al., 2002). This activity is motivated by the fact that the children need to find a sense of trust for, and build a relationship with the designers (Frauenberger et al., 2012a; Moser et al., 2011). Having a variety of activities is common (Mazzone et al., 2010; Guha et al, 2004; Guha et al., 2005). Including different kinds of activities allows children who are strong in one area, but perhaps weaker in another, to participate and contribute in at least one activity (Mazzone et al., 2010; Guha et al., 2004). It is also mentioned as a
way to avoid the children becoming bored or running out of ideas (Mazzone et al., 2010; Guha et al., 2005).

Some methods include more physical activities (i.e. where the children use their bodies) (Giaccardi et al, 2012; Guha et al., 2004), typically in the form of acting. This is described both as being fun, but also as a way to express themselves and tell stories, while not including writing or drawing (ibid.).

Many activities with the purpose to find and explore ideas include elements of creativity, and allow the children to express themselves creatively in different ways (see e.g. Frauenberger et al., 2012a; Grundy et al., 2012; Moser et al., 2011; Antle, 2008; Stringer et al., 2006). This takes expression, for example, as the telling of stories (Frauenberger et al., 2012a; Grundy et al., 2012; Moser et al., 2011; Antle, 2008; Komlodi et al., 2007; Moraveji et al., 2007), acting (Giaccardi et al., 2012), crafts (Giaccardi et al., 2012; Xie et al., 2012; Moser et al., 2011; Druin, 1999), or, most commonly, drawing (Horton et al., 2012; Xie et al., 2012; Hemmert et al., 2010; Mazzone et al., 2010; Walsh et al., 2009; Garzotto, 2008; Komlodi et al., 2007; Kelly et al., 2006; Stringer et al., 2006; Guha et al. 2005; Jones, McIver, Gibson, & Gregor, 2003). The children are allowed to express their imagination, and come up with new ideas. A downside to this is that children who are creative and expressive give richer materials than other children, and are thus preferred as participants (Moraveji et al., 2007). Most of the described activities use low-tech materials (pens, paper, glue, scissors etc.); only in a few of the reviewed articles did the children use an IT artefact (Grundy et al., 2012; Garzotto, 2008; Moraveji et al., 2007), and in those cases usually as a supplement to other, low-tech activities.

It is important for the participating children to have a sense of what they have contributed with (Mazzone & Read, 2005; Guha et al., 2004). A common tactic is to have summarising activities at the end of the day, or at the end of another activity – that is, each smaller group is allowed to present what they have done to the others, who can then comment on it (Walsh et al., 2009; Garzotto, 2008; Guha, 2005; Mazzone & Read, 2005). It is also recommended to have a session later on in the development process to show the children what exactly their contributions have led to – for example to show that one of their ideas actually has been developed into a working prototype (Thomas & O’Kane, 1998).

Not only is giving feedback to the children on their participation important, but having them give feedback on the interpretation of the material is also essential. When the material has been collected and studied, the final conclusions should be presented to the children so they are able to correct anything that may have been misunderstood (Horstman, Aldiss, Richardson, & Gibson, 2008).
The activities should be familiar to the children (Giacchardi et al., 2012; Xie et al., 2012; Moser et al., 2011), and this is one motivation for the use of low-tech materials – that the children are familiar with them and their use (Grundy et al., 2012; Xie et al., 2012; Kelly et al., 2006). Some authors have used comics in their activities as well, arguing that children are generally familiar with the concept (Guha et al., 2012; Moraveji et al., 2007).

Children need boundaries (Mazzone & Read, 2005; Jones et al., 2003). The contribution of the children has been experienced to be lower when they are given fewer boundaries, or less strict instructions (Moraveji et al., 2007; Jones et al., 2003). Brainstorming has for this reason been found less effective when performed with children than with adults (Moraveji et al., 2007; Guha et al., 2005). On the same note, it is mentioned that instructions should be very clear, and preferably with examples illustrating what the children are expected to be doing (Mazzone & Read, 2005).

It can be the case that activities included in the design process with children are lengthy (Dindler et al., 2005). CI (Druin, 1999) is particularly time consuming, where children can be members of the design team for years. Some authors have attempted to reduce the time required in different ways. For example Horton et al. (2012) attempt to increase the efficiency by setting up different “stations”, between which the children alternate, and Moraveji et al. (2007) use the familiar concept of comics in order to reduce the learning curve for the children when brainstorming.

2.3.1.1.2 Designers

As designers, there are a number of things that one needs to take into account when preparing activities and working with children. It appears common to have prepared several activities that can be flexible as to time (see e.g. Horton et al., 2012; Xie et al., 2012; Garzotto, 2008; Kelly et al., 2006). Preparing well is a key to a successful workshop (Mazzone et al., 2010), and also how the activities are structured matters (Garzotto, 2008); the order of the activities should follow logically and increase in involvement. If more than one session is conducted with the same children, a connection can be made between these by preparing activities based on the results from earlier sessions (Guha et al., 2005).

There are many people with whom communication needs to occur during a design process. During the activities, problems that occur with for example understanding instructions can be solved by maintaining an open dialogue with the participating children (Jones et al., 2003). Communicating the outcomes of the workshops can be done in many ways, but Frauenberger et al. (2012a) solved this by together with the children creating videos explaining the results.
Children are not experts on design, nor are they meant to be. However, this means that they do not know what is feasible, nor what is expected of them (Nesset & Large, 2004; Farber et al., 2002). Early on in the process, the designers need to handle their expectations, and make them understand what is possible, in order to make the design suggestions feasible (Farber et al., 2002; Read et al., 2002). Although, focusing too much on what is realistic might stifle the children's creativity (Nesset & Large, 2004). Further, the children should know what is expected of them, and the activities they perform, or they might become upset when for example their idea is not chosen for further development (Guha et al., 2004).

Because children are both lower in the power hierarchy, and are used to obeying adults, interacting with adults on a more equal level as design partners can prove difficult. Therefore, when working with children, it is recommended to be informal, and avoid showing authority (Read et al., 2002; Druin, 1999). If the children are sitting on the floor, so should the adults (Walsh et al., 2009), and informal clothing should be worn and an informal language used (Read et al., 2002; Druin et al., 1998). If note-taking is necessary, this should be done discreetly (ibid.).

2.3.1.1.3 Participants

The participating children are by some described to have limitations in various areas, for example: verbal expression (Mazzone et al., 2010; Komlodi et al., 2007; Guha et al., 2004; Druin, 1999); abstraction (Bratteteig, Wagner, Morison, Stuedahl, & Mörtberg, 2010; Kelly et al., 2006); writing (Guha et al., 2004; Farber et al., 2002); and social interaction (Hemmert et al., 2010; Mazzone et al., 2010; Komlodi et al., 2007). These limitations have to be taken into account when setting up activities. Activities that involve practically making something are more suitable for work with children, rather than talking or observation (Grundy et al., 2012). Talking, in the form of interviews or questionnaires, is difficult for young children who are verbally limited, and observation requires interpretation by the designers who, being adults, are likely to misinterpret the children (Frauenberger et al., 2012a; Mazzone et al., 2010; Komlodi et al., 2007). Finally, the limitation in social interaction can make it difficult for children (particularly younger children) to work in groups, wherefore it is advisable to have one or more adults present within the group (Hemmert et al., 2010; Komlodi et al., 2007).

Furthermore, there is a difference among the power relations between children and adults (A. Antle, personal communication, Nov 21, 2012; Frauenberger et al., 2012b; Stringer et al., 2006; Druin, 1999). Adults have rights in society, and children are generally not expected to take responsibility, and are thus not given any either. When working together, it is important to reduce this discrepancy, for example by acting in
an informal manner (Read et al., 2002; Druin, 1999). In a participatory process, children and adults are equal partners (Antle, 2008; Komlodi et al., 2007; Moraveji et al., 2007; Guha et al., 2004; Druin, 1999). The children have an equal say in decisions and idea generation, and should be given equal opportunity to do so. However, it might easily happen that the participating adults forget that they are equal too, and leave it all to the children (Guha et al., 2005), which of course is not advisable either. In the end, building trust between the participants is an essential factor in being able to work together successfully (Frauenberger et al., 2012a; Frauenberger et al., 2012b).

How the group is set up varies in the literature, but does come with certain consequences for the activities performed (Guha et al., 2004). Children in the ages of 10-11 are considered the best prototyping partners (Druin, 1999), and many seem to prefer including children in this age (Moraveji et al., 2007; Dindler et al., 2005; Garzotto, 2008). The size of the group also affects the activities performed. Some work with large groups, like entire school classes (Frauenberger et al., 2012a; Horton et al., 2012; Mazzone et al., 2010; Garzotto, 2008), while others set up small groups (Walsh et al., 2009; Jones et al., 2003), or work with one child at the time (Kelly et al., 2006; Guha et al., 2005). When working in large groups it is common to split the group into smaller constellations with a number of adults for each constellation (Horton et al., 2012; Mazzone et al., 2010; Garzotto, 2008).

The relation between the amount of adults and children varies; often there is a larger number of children to the number of adults (Frauenberger et al., 2012a; Horton et al., 2012; Mazzone et al., 2010; Garzotto, 2008). This can be an attempt to reduce the discrepancy in the power relations between adults and children; if the adults outnumber the children they can seem even more likely to “gang up” on the child. However, working one child with one adult allows the children to express their ideas, and simultaneously make it possible for the designers to document the ideas well (Kelly et al., 2006; Guha et al., 2005).

Sometimes so called gatekeepers (primarily teachers) participate in the design process along with the children (Frauenberger et al., 2012a; 2012b; Mazzone et al., 2010; Komlodi et al., 2007; Stringer et al., 2006; Farber et al., 2002). This is positive in several ways: there is an increased adult presence (Grundy et al., 2012; Komlodi et al., 2007); the children already trust the gatekeepers (Horton et al., 2012; Stringer et al., 2006); and the gatekeepers can contribute with their knowledge of the children (Frauenberger et al., 2012a; Farber et al., 2002).
2.3.1.1.4 Summary

Table 1 below presents a summary of the properties for design methods with children that have been described above. These properties are not necessarily present in all design methods, but permeate the literature on the subject, and make up some common denominators for these kinds of methods.

<table>
<thead>
<tr>
<th>Activities</th>
<th>Designers</th>
<th>Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low-tech</td>
<td>Preparation</td>
<td>Group setup</td>
</tr>
<tr>
<td>Fun</td>
<td>Communication</td>
<td>Limitations</td>
</tr>
<tr>
<td>Sense of contribution</td>
<td>Handle expectations</td>
<td>Power relations</td>
</tr>
<tr>
<td>Familiarity</td>
<td>Informal</td>
<td>Equality</td>
</tr>
<tr>
<td>Time</td>
<td></td>
<td>Gatekeeper participation</td>
</tr>
<tr>
<td>Physical</td>
<td></td>
<td>Trust</td>
</tr>
<tr>
<td>Variety</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Environment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Contextually unique</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Boundaries</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Creative</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

However, there was only found a limited amount of research on the design with children in a context which can be considered to be sensitive. Therefore, the properties presented in table 1 primarily relate to design methods used in contexts which are not of a sensitive nature. How these need to be adapted for a sensitive context remains to be studied.
3  **RESEARCH APPROACH**

The research reported in this thesis was carried out within the CHIPS project at Halmstad University. In order to study how children can participate in the design of OPS for children, a design research approach was chosen. Design research has a pragmatic nature, and attempts to contribute with relevant artefacts in a rigorous way (Hevner, 2007). These qualities were considered advantageous in relation to the aim of this thesis.

### 3.1 Design Research Approach

Design research is problem solving and focuses on building and evaluating the artefacts created (March & Smith, 1995). The artefacts can be constructs, models, methods or instantiations (ibid.). One common framing for this type of research is based on the Hevner, March, and Park (2004) framework for Information Systems research. The framework illustrates how the research performed (in iterations between building and evaluating) is applied in the environment and adds to the knowledge base. The environment in turn provides the problem areas to which the research can be applied, thus providing relevance. The knowledge base makes up the knowledge on which the research is based, and the methods and techniques with how the research is conducted, thus providing rigour (Hevner et al., 2004).

In this case, the knowledge base is made up of previous research with children, as well as participatory design with adults. The method used in the CHIPS project is based on the Goal-Directed Design Process by Cooper et al. (2007). Meanwhile, the environment consists of, amongst others: the children who are potential users of the future application, as well as participating in the process; the designers who are part of the design process, and also other designers who intend to perform similar research; and the health care to the finished design can be of use to improve the children's well-being. The research consists of iterations between design workshops and discussions relating to these workshops, which in turn inform and adapt forthcoming workshops. Figure 2 below is an illustration of my design research process.
3.2 Research Process

The CHIPS project follows the Goal-Directed Design Process described earlier (see Cooper et al., 2007), of which the first half if covered within the scope of this thesis.

The activities that make up the empirical data for this thesis were intended to inform this first part of this design process. A literature review was performed in order to find properties that methods for involving children in design have in common. Based on the outcome of the literature review a number of design workshops were conducted together with children, with the goal of beginning the development of the OPS solution for children with cancer. The first workshop was preceded by a pilot workshop with the CHIPS project group members as participants. After each workshop the participating researchers discussed the session and these discussions led to adaptations of the upcoming workshops.
3.2.1 Literature Review

The search for literature was performed primarily using Google Scholar, which in turn led to articles found in databases such as ACM, JSTOR, Academic Search Elite, Science Direct and IEEE. The first of these was primarily used. Search words used were different combinations of design, children, method, personas, scenarios, participatory design and development.

Searches were performed both backwards and forwards (see Webster & Watson, 2002). The first by scanning the found articles' reference lists for relevant titles and authors, and the latter by using the Google Scholar option “Cited by…”.

The search was limited to literature published since the year 2000, with the exception of the work by Druin (1999; Druin et al., 1998) as this was identified as key works within the area of design with children. This limitation was done for several reasons: within the field there is much development and what was current more than twelve years ago is unlikely to be relevant now; and further, research with children as design partners is a relatively new occurrence and was not performed to a greater extent before that time. Since the work by Druin has been a forerunner in the area, most relevant publications have been made since then.

Articles were chosen based on their relevance to the subject of design with children. The focus was on participatory design with children, but any literature found relating to design where children had an active part was included. The relevance of the articles was first judged by a scan of the abstracts. The chosen articles were read in their entirety and some more were discarded if it was found that they were not relevant. A summary record sheet was maintained during the reading, as per Hart’s (1998) recommendation. While reading I made annotations, which later were compiled into analytical codes (see Fink, 2010) that made up the properties of the methods under study. During a second read-through of the articles, the notes were then translated into codes, and if necessary, additional codes were added.

The identified codes were organised into three themes based on an emerging relationship between them – the codes familiar and fun for example were both properties within the theme of “Activities”, as they relate to the activities performed during the design process. Lastly, a summary was made of the articles in which the codes had been identified. When summarising the literature review, it was easy to return to the articles and find the relevant sections that mentioned the properties in question. See appendix A for a full list of the identified codes and articles.
3.2.2 Design Workshops

All in all, six design workshops were performed with five children. The children were divided into two groups, and each group participated in three workshops. Three to four researchers participated in each workshop.

Before the first workshop with the first group of children, the concept of using comics as a common thread throughout the workshops was tested with a pilot workshop. The researchers who later participated in the workshops were all participants in the pilot, making a total of five participants.

In the pilot the first activity for getting to know each other was tested, as well as the completion of comic scenarios for workshop two. The first activity included drawing a scene from a favourite movie. The activity was changed from having one person guess what movie it was, to leaving it open to all participants to guess. This took the pressure off of guessing, since the purpose of the activity was not to show knowledge about movies, but to make the participants comfortable with each other. Further, the comic scenarios which had been prepared for the pilot were discussed and changed slightly.

The three design workshops with the first group were then conducted in succession, before the workshops with the second group. The workshops consisted of a number of prepared assignments which each child performed together with one of the researchers. Each workshop built on the previous as the resulting materials from the children's assignments was adapted into the input to the next assignment. This served to maintain familiarity.

The concept of all three workshops was built around comics. Before each workshop, an online comic creation application was used to prepare the graphical material. The tool Bitstrips† was chosen for this because the comics could be kept private, and it provided ample opportunity to customise the characters, props and backgrounds. In the cases where this tool was unable to do what was necessary, the created comics were adapted using image editing software.

The workshops took place at a room at the local library in the city of Lund in Sweden. Each workshop was three hours long (with the exception of workshop 3 for group 2, which was two hours), during which a warm meal was included, as well as fruit for a snack. Each workshop started with a brief introduction of what was intended to be done during the following three hours. A printed agenda was hung on the wall, to which the facilitator referred for each activity. After approximately two hours the warm meal was served.

† http://www.bitstrips.com
The five children who participated in the design workshops were between the ages of 11 and 13, and were currently, or had previously been treated for leukaemia. The children had met during a previous activity within the CHIPS project, and were thus acquainted with each other. The first group consisted of three boys aged 11-12, and the second group consisted of two girls aged 11-13. The intention was that the second group should consist of three girls, and three girls were recruited, but one of the girls was unfortunately unable to attend any of the workshops at the last minute.

The children were recruited to the CHIPS project from a contact nurse at Lund's University Hospital. The basis for their participation in the project was that they were or had been treated for leukaemia, and were between the ages of 8-12. Among the recruited children, six were chosen for participation in the workshops. These children were chosen because they had been well functioning groups in the previous CHIPS activities and had shown a high level of creativity. It was believed that they would contribute with high quality materials.

Children who had the experience of having cancer were chosen as participants since they are the ones who have the most intimate knowledge about their own situation, and therefore can be assumed to be as close as possible to the end user. When designing an application for children with cancer to report their symptoms, Bratteteig et al. (2010) involved children who had never had cancer as participants, but found that those who had experience of for example a relative with cancer were able to maintain a more realistic discussion than the other children. And even though they used acting as a way to let the children experience the feeling of being in a hospital, the children were unable to fully represent children who have cancer (ibid.).

During their illness, sick children have additional limitations for participating in design, as there are periods when they are physically weak and have lowered mobility (Woodgate & Degner, 2003). Both the cancer itself and the treatment can cause side effects like nausea, fatigue, mood swings and, worst of all, pain (Pöder, Ljungman, & von Essen, 2010). There is not always effective treatment of these side effects either, and having strong social support becomes essential (Enskär & Berterö, 2010). Also, after finishing their treatment, they might have physical scars, and often experience a feeling of being different from their peers because of their experiences (ibid.).

The adult participants were made up of two researchers from the medical science profession and one to two design researchers. There were never more than four adult participants. When there were more adult participants than children, one of the design researchers acted as facilitator. The intention was to have a facilitator who was not part of the design activities for each of the workshops, but due to scheduling
problems this was not always possible. For two of the workshops the participating designer had to act as facilitator while taking part in the design work.

All the workshops were documented with video recordings, sound recordings as backup, and written reflections. The workshops, and the input and output of each workshop, are summarised in the table below.

<table>
<thead>
<tr>
<th>Design workshop</th>
<th>Input</th>
<th>Output</th>
</tr>
</thead>
<tbody>
<tr>
<td>Workshop 1: Personas</td>
<td>Group 1</td>
<td>Paper cut-out dolls</td>
</tr>
<tr>
<td></td>
<td>Group 2</td>
<td>Paper cut-out dolls</td>
</tr>
<tr>
<td>Workshop 2: Scenarios</td>
<td>Group 1</td>
<td>Beginning and ending of comics (scenario introductions)</td>
</tr>
<tr>
<td></td>
<td>Group 2</td>
<td>Beginning and ending of comics (scenario introductions) + Mobile phone templates</td>
</tr>
<tr>
<td>Workshop 3: Further development</td>
<td>Group 1</td>
<td>Context scenarios (comics) + Photos taken by the children</td>
</tr>
<tr>
<td></td>
<td>Group 2</td>
<td>Design premises + mobile phone and tablet templates for sketching + Photos taken by the children</td>
</tr>
</tbody>
</table>

The aim of the first activity in the first workshop for both groups was to become familiar with each other in the design team, introduce the workshops and the work we were going to do together, as well as start creating personas. It was a “get to know each other”-activity, which doubled as a “get going”-activity, and started the process of building trust, since we shared personal opinions and feelings with each other.

Most of the work during the workshops was conducted in pairs with one child and one adult, starting with the second activity of workshop 1. The activity entailed creating the characters, or personas, to be used in the following two workshops. Printed paper cut-out dolls for cutting out and colouring were provided. The dolls were based in the graphics from the Bitstrips comic creation tool and the children were given materials to they could cut out and colour the characters as they wished. The children used the paper cut-out dolls, gave them names and personalities, as well as chose their appearance. The third activity served as a “warm up”-exercise for the second workshop. The children were given A3-sized papers with six squares printed on them, and were asked to draw a comic with the characters they had just created. The stories in the comics should relate to something the characters liked to do.
At the end of the session the children were given an assignment to perform before the next workshop. They were supposed to take three photos of and send to the designers by e-mail prior to the second workshop. The photos were supposed to depict something they liked to do with a friend, their favourite activity outside, and their favourite software or mobile application.

The aim of the second workshop was to create possible context scenarios and potential design ideas. While the intention also was that the children present their photos from the assignment, this was postponed in both groups due to different complications.

As a summary of the characters created in the first workshop, a short comic for each character had been prepared. These were read through together as repetition. The children were also asked whether or not they wanted to change or add anything to their characters.

The first activity was the same for both groups. I had prepared comics using the Bitstrips tool with beginnings and endings of stories, as inspired by comicboarding (see Moraveji et al., 2007). The children were asked to fill in the middle of the comics while working in pairs with an adult. This was intended as a way to create context scenarios, while keeping an emotional distance to the scenario itself. Between four and five comics had been prepared for each group, and the comics utilised the characters which the children had created during the first workshop. The comics for the second group were based on the specified properties of peer support. The pairs chose which comics they wanted to work with and finished as many as they could during the time allotted for the activity.

The second group was given a second activity which served as preparation for workshop three. The children were given mobile phone templates printed on A4 paper, and asked to sketch either one of their favourite applications or an application of their own imagining. The goal was for them to gain a better understanding for the technique of sketching applications. Their finished sketches were photographed and using the POP² application quick interactive prototypes were created to show the children how their sketches might work as applications.

The third workshop had differing aims for the two different groups. For group 1 the aim was to gain opinions on and reactions to presented design suggestions. Because there were difficulties in achieving the amount and quality of feedback wished for during the third workshop with group 1, the concept was amended for group 2. Instead, the aim for group 2 was to identify ideas for and begin the design of one or

² http://popapp.in/
more mobile applications. However, the first activity for both groups was for the children to tell us about the photos they had taken as part of the assignment given after workshop 1. For each photo they explained what it was they had photographed and why they had chosen that particular subject.

The work in group 1 continued with a presentation of design suggestions. The comics created during workshop 2 had been transferred to Bitstrips and each had been continued with a context scenario where the character used the suggested designs. The second activity for group 1 served a similar purpose as the first, that is to gain opinions on the presented ideas, but was performed in pairs instead of the whole group. Each pair wrote down opinions, suggestions and questions on post-it notes which they attached to the comics.

Group 2 had one main activity during the third workshop. Again, I had transferred the comics they had drawn during workshop 2 into Bitstrips. For each comic they were given a design premise to which they were asked to, in pairs with an adult, sketch an application. For example, if a comic contained a scenario which did not include a mobile or tablet, they were asked how they might change this to achieve the same result using an application instead. In this way, we hoped to create ideas for applications that allowed children who could not be present due to for example an illness to still participate socially. The sketches that the girls created were then transferred into the POP application to create a quick prototype.

3.2.3 Follow-Up Discussions
After each workshop, the participating researchers gathered to discuss and reflect on the workshops, and how to continue with the remaining workshops. During these meetings the material for the workshops was also planned, for example some of the stories for the comics that were to be the basis for the workshop activities during workshop 2. Notes and reflections were taken down as recordings of these discussions.

These discussions functioned as evaluations of the design workshops. Based on these discussions, changes were made to the structure of the activities, and in the case of the third workshop, the entire aim of the session. It was these discussions that drove the progression of the workshops, and served to refine the final result.

3.3 Discussion
When performing research which includes both children and a sensitive context, it is particularly important to take ethical considerations into account. One aspect includes designing the activities so that they do not burden the participating children,
with particular care for those who are still under treatment for cancer and can become tired and unable to continue (Lindberg, Thomsen & Åkesson, 2012). This consideration was met by none of the activities for the workshops being physical, and the work was conducted in pairs where the adult was well positioned to notice if the child was becoming tired. Also, as the subject of the children's participation (them having or having had cancer) can cause them to be upset, it is important to be sensitive to their moods and wellbeing (Lindberg et al., 2012). Again, working in pairs enables the partnering adult to pay close attention to the child they are working with and they can take action if they notice that the child becomes upset. All participating adults were aware that the context was of a sensitive nature, and that the children might become upset.

Further, as the context is especially sensitive, it is essential to maintain the integrity of the participants (Lindberg et al., 2012). Therefore, all the recorded material was stored in a secure location with controlled access, and none of the children are mentioned by name in either notes or texts.

Rigour and relevance are essential to good quality design research, and are what separate design research from regular design (Hevner, 2007). Rigour means using the knowledge base in a relevant way to inform and guide the research (Hevner et al., 2004), and describing the design process unequivocally in order to show clearly from where the results stem (Iivari, 2007). I have attempted to maintain a high level of rigour, not only by performing an in-depth literature review on design methods with children, but by maintaining a clear structure throughout the upcoming chapters. The following chapter is structured chronologically by workshop, with a sub-structure which is repeated for each workshop. The discussion in then organised by themes that emerged through the study, with the purpose of making the arguments easy to follow.

Relevance relates to the environment, and implies that the research is pertinent to the problem area it intends to contribute (Hevner, 2007). Relevance is what drives research, since research should always begin by identifying a gap where it can be useful, and is what decides if the research meets the criteria of a contribution (ibid.). I will argue that the contribution of this thesis lies in answering how children can participate in the design of OPS for children with cancer. This is a unique design context, and thus is set for high relevance. However, I will also argue that working closely with users contributes to the relevance of this thesis, as the result maintains a focus which lies close to reality.

With the choice of performing qualitative design research, the ability to generalise and maintain a level of objectivity is limited. These are not aspects that reflect the
nature of qualitative research, nor what this study aims at achieving. However, it is important to note that this study is limited in these aspects.

3.3.1 Design Research Guidelines
Along with the criteria of rigour and relevance, Hevner et al. (2004) present seven guidelines for design science. These guidelines are considered to make up the requirements of design research. I will round off this section by discussing the thesis on the basis of these guidelines.

Hevner et al. (2004) follow the definition of artefact by March and Smith (1995), who define it as being either constructs, models, methods or instantiations. The first guideline states that an artefact should be created as part of the design research; in this case the artefact is the method by which children can participate in the design of OPS for children with cancer. By creating an artefact, one shows that both the process and the artefact itself are feasible (Hevner et al., 2004). In other words, the process of creation shows that creation is possible. By designing OPS for children with cancer together with children, this thesis has thus shown that such an act is possible.

The second guideline specifies that the artefact should be relevant to a problem (Hevner et al., 2004). It has been argued in this thesis that designing OPS for children with cancer together with children constitutes a specifically complex design situation. I have identified common properties for existing methods for design with children, but there is a lack of research on how to involve children when the subject is of a sensitive nature (Obrist et al., 2011). For this problem, the result of this thesis is relevant.

The way in which the children have participated in the design of OPS for children with cancer, as described in this thesis, was subject to continuous reflection and discussion during the process. The workshops functioned as a way of using the suggested method, that is, as a way of experimenting with the underlying assumptions of how children could participate. These two aspects make up the evaluation of the artefact, as prescribed in the third guideline by Hevner et al. (2004).

Further, guideline four relates to the clarity of the research contribution (ibid.). In this case the contribution is the artefact and suggestions how similar artefacts can be created. It makes a contribution to both the knowledge base and the environment: to the former the contribution is made up of both the identified properties from the literature review, which were later applied during the design workshops, as well as the experiences from conducting the workshops. The contribution to the latter consists of the method used, which is relevant for anyone pursuing a similar design
context. Furthermore, the contribution to health care with the finished OPS solution will be affected by the research in this thesis, as it affects the outcome of the finalised design.

The rigour with which the research has been performed makes up guideline five (Hevner et al., 2004). The research should be conducted with appropriate methods and techniques, and these should be selected from the existing knowledge in the knowledge base (ibid.). Also, the participants should be suitable to the aim of the research (ibid.). The Goal-Directed Design Process (see Cooper et al., 2007) used in the CHIPS project is an established way of working, and the techniques included within the process (for example the use of personas) are common. The activities in the design workshops are meant to support this process, and the creation of these is based on the literature review performed for this thesis. They are thus established in the current knowledge from the knowledge base. The participating children have or have been treated for cancer, and thus had the experience necessary to contribute with realism. While the participation of children with the experience of having cancer caused complications, these were considered necessary to the rigour of the research.

Design is iterative, and as its goal is to discover something, it is inherently a search process (Hevner et al., 2004). Guideline six supports this by claiming that in order to achieve a successful artefact, the research should iterate between generating design and testing against requirements and constraints (ibid.). In this study, there were iterations between design workshops and discussions relating to the workshops. These discussions were a way to evaluate the past workshops and plan the following. In this way, each workshop was evaluated and any necessary changes could be identified and made for the future workshops.

According to the seventh guideline, it is essential to make the design process understood to the reader in order to enable a contribution to be made (Hevner et al., 2004). I have attempted to describe the basic concepts relevant to this study in the background section, and further lay out the research approach used. This discussion on the seven guidelines is also part of this attempt. The empirical research with the design workshops is presented in a chronological order by each workshop, which is also an attempt to make the material easy to follow. In the final section I will up the contributions made of this paper, in order to clarify the contribution to the environment and the knowledge base.
4 DESIGNING ONLINE PEER SUPPORT WITH CHILDREN

The empirical material presented in this section is organised chronologically by the performed workshops. These are in turn organised after the activities performed, the outcome of the activities, and how these activities were intended to inform the design process. First, however, I will present the context of the design process in more detail.

4.1 Design Context

The empirical research for this thesis was conducted within the early stages of the project CHIPS at Halmstad University. The CHIPS project was initiated in the autumn of 2011 as a collaborative project between medical science and Information Systems researchers. The objective of the project is to develop and investigate how an OPS solution can promote the mental health status of children with severe illnesses.

The CHIPS project has a participatory approach and follows the Goal-Directed Design Process (see Cooper et al., 2007). Of the four roles children can have in the design process, all are applied in the project. For the part of the project which is covered in this thesis, the children primarily have the role of design partners (see Druin, 2002). The children participating in the project are between 8-12 years, and are or have been diagnosed with acute lymphoblastic leukaemia.

Peer support builds on the underlying idea that people who have shared experiences can better help each other deal with some issues caused by their problem than physicians can (Klemm & Hardie, 2002). Peer support can provide invaluable social support when dealing with, and recovering from severe diseases like cancer (Klemm & Hardie, 2002). A commonly mentioned problem with face-to-face peer support is the difficulty of attendance; people have difficulties finding time to participate, have a great distance to travel, or are too weak or ill to attend (Giesbers, Vendonck-de Leeuw, van Zuuren, Kleverlaan, & van der Linden, 2010; Potts, 2005; Klemm & Hardie, 2002). By adapting peer support to an online environment, these issues can be addressed. OPS can also be more specific and specialised than face-to-face peer support groups, and bring together people who would otherwise never have had the opportunity to meet (Klemm & Hardie, 2002).

For people with different forms of cancer, taking part in OPS can improve their knowledge about their disease, and be a way to connect with others who are going through similar issues; there are indications that OPS can reduce depression, stress...
and loneliness among cancer patients (Eysenbach, 2003). When the person affected by cancer is young, not only their childhood but the rest of their lives is changed (Enskär & Berterö, 2010). Children with cancer do not have the same ability as adults to understand and deal with their disease (Ruland, Slaughter, Starren, & Vatne, 2006). Peer support would allow them to initiate contact with other children with similar experiences, who can help them comprehend what they are going through. These children can be too sick to partake in physical peer support groups, or not have any groups near home, and thus an online solution is a feasible option.

4.2 Workshop 1: Personas

4.2.1 Activities
The first activity was a “get to know each other”-activity. Each participant individually drew a scene from, or something relating to, one of their favourite movies. We then showed the others our finished drawing and were asked to guess which movie it was. In the case when someone drew something the others hadn’t heard of, they were asked to explain the plot as well, so the others could know what kind of movie it was. One of the girls was given the opportunity to work together with one of the adults as she said that she did not know how to draw the movie she had in mind.

The second part of the activity entailed drawing something we liked to do together with other people. Again each participant drew individually, including the girl who had worked together with a researcher in the first part. When finished, each participant held up their drawing and explained what they had drawn, and why they liked doing it.

For the second activity the participants paired up with an adult and were asked to use the paper cut-out dolls to create characters, or personas. The printed paper cut-out dolls were based in the graphics from the Bitstrips comic creation tool and the children could cut out and colour the characters as they wished. The boys were asked to create personas in the age of 11-12, which was their own age. However, in the upcoming workshops the boys all spoke about their characters in first person, showing that they identified with their characters to some extent.

*Am I in your comic?* [Boy in group 1, workshop 2]

Since the intent was to place the characters in potentially sensitive scenarios in future workshops, this was unwished for. Thus, as a precaution the girls in the second group were instead asked to create characters aged of 8-9 years, assuming that this would make the characters less like themselves.
Table 3. Questions the children answered about their characters

<table>
<thead>
<tr>
<th>Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>What’s the character’s name?</td>
</tr>
<tr>
<td>How old is the character?</td>
</tr>
<tr>
<td>Where does the character live?</td>
</tr>
<tr>
<td>What does the character like to do...</td>
</tr>
<tr>
<td>... with their friends?</td>
</tr>
<tr>
<td>... on their own?</td>
</tr>
<tr>
<td>What do they think is important?</td>
</tr>
<tr>
<td>What do they think is hard?</td>
</tr>
<tr>
<td>What do they think is boring?</td>
</tr>
<tr>
<td>What are their favourite things?</td>
</tr>
<tr>
<td>Do they have any pets?</td>
</tr>
</tbody>
</table>

This activity took a large part of the three hours for the workshop for both groups. When the warm meal was served towards the end of the workshop the work on the characters felt finalised. During the meal we took the opportunity to, in a more informal way, ask about what the children liked to do, what mobile applications they enjoyed and how they used their mobile phones on a daily basis. All the children had smartphones, and were well acquainted with their use.

When the meal was finished only approximately thirty minutes remained for both groups. They were asked to draw a comic containing the character they had created. The stories in the comics should relate to something the characters liked to do. The children were provided with A3 papers with six squares on them as a template.

Finally, the children were given an assignment to perform before the second workshop. They were asked to take photos of something they liked to do outside, something they liked to do together with others, and a favourite mobile or computer application. These photos were intended to give us insight into what the children liked doing, and in what kind of environments the finished OPS might be used.

Table 4. Summary of activities for workshop 1

<table>
<thead>
<tr>
<th>Activity no.</th>
<th>Group</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>#1</td>
<td>Group 1 &amp; 2</td>
<td>Get to know each other</td>
</tr>
<tr>
<td>#2</td>
<td>Group 1 &amp; 2</td>
<td>Create characters</td>
</tr>
<tr>
<td>#2</td>
<td>Group 1 &amp; 2</td>
<td>Draw comic with character</td>
</tr>
</tbody>
</table>

4.2.2 Outcomes

The first activity proved to be suitable as a warm up activity. Since there were no requirements on how to draw, and the mood was high, it set the tone for the rest of the workshop. For the second activity, the boys spent a great deal of energy on the
details of the character's clothes and personalities. A fruitful way of working turned out to be to let the boys draw while the adults asked questions about the characters, and wrote down their answers. That way they were free to commit as much time as they wanted on the details of the drawings, while the work with the characters still moved forward.

When the characters were considered to be finished, the boys presented their characters to the others. Some of the boys wanted to present the characters themselves, while others asked their partnering adult to do it. However, all the boys expressed that they were happy with their characters, and showed excitement over using them in cartoons.

The work with the characters was in many ways similar in the second group. The girls expressed more doubt as to the favourite activities and interests of the characters, saying that they did not know what girls that age like.

_I don't remember what I did when I was 8. It was ages ago._
[Girl in group 2, workshop 1]

One of the girls had a younger sister the same age as the character and she used her as inspiration, but also found it difficult when she did not know what her sister's opinion on a question was.

Furthermore, the girls were noticeably more concerned with doing things “right” than the boys were. One girl expressed worry about whether her drawing would be good enough or not. When the adult participants hinted that they had difficulties as well, she appeared to relax somewhat. The boys did not exhibit the same worries. Also, while the boys simply drew immediately onto the character, the girls practiced on another sheet of paper first. For example, one of the girls experimented with different ways of drawing noses before she decided on which she wanted, something none of the boys did.

_I usually draw noses like this._ [Boy in group 1, workshop 1]

However, while some of the boys showed more reluctance to write, the girls showed no hesitation about that. Nevertheless, all of the children at one time or another asked
one of the adults to draw or write something for them. In other words, the adults had to be prepared to be flexible and contribute where they were needed.

Most of the children expressed eagerness in using their characters in a comic in the third activity, and the stories varied from realistic to fantastic. However, the one of the children who was still under treatment was too tired to go on by this time, and chose to only draw a very short comic, and spent the rest of the time speaking to one of the adults.

The concept of the first workshop was deemed highly successful after both sessions. It was agreed among the participating researchers that no other way of working seemed as good. It was found to be an efficient way of working while it also allowed all the children to make their voices heard. It was also successful for keeping the children focused on the tasks at hand. The pairing did not inhibit the children’s interaction with each other; they commented on each other’s characters and statements even though they were working on their own characters. Sitting around the same large table was most likely a contributing factor to this.

However, in the discussion after workshop 1 it was agreed that as per our experience of working with the girls, they (in particular the girl of 13) would have been able to keep a distance to the characters without the age difference. In hindsight, we should have had an age difference for the boy group and not for the girl group.

The outcome of the first workshop consisted of the characters, or personas, that would not only be the base for the comics in the second workshop, but also the base for the personas used throughout the design process. For the latter the information about the personas would be supplemented with the other information we were given by the children, for example from the photos they would send in.

*Image 1. Christoffer, a character created during workshop 1*
4.2.3 Intentions
The first design workshop aimed at becoming familiar with each other in the group, and creating the personas that were to be characters in the comics for the upcoming workshops.

The initiating activity in the workshop served as both a “get going”-activity, and as a way to start the process of building trust as it entailed sharing personal opinions and feelings with each other. Furthermore, the activity taught us about pastime activities for children their age: while the boys drew themselves playing sports or computer games, the girls were more specific, drawing themselves sharing digital photos with their friends or jumping in a pile of leaves.

The second activity was aimed at creating characters, which were to be used as personas during the rest of the design process. The characters created by the children were supplemented with material from the other assignments the children were given, and the conversations had with the children during the workshops.

The third activity served as a “warm up”-exercise for the second workshop, where the children would continue working with comics.

4.3 Workshop 2: Scenarios
4.3.1 Activities
The second workshop was initiated with a repetition of the first workshop. I had summarised the characters that they had created in short, six square-long comics in order to make the information more attainable during the activities of this workshop. These comics were handed out and we read them together in order to freshen up our memories of the characters. The children were also asked if they wanted to add or change anything about their characters, but all of them declined.

For the first activity, building on the concept of comicboarding (see Moraveji et al., 2007), I had prepared comics (using Bitstrips) with a beginning and an ending, leaving it up to the children to fill in the middle to make it add up with the story presented. The ending square was loose so that the children could decide for themselves how long the story would be. The concept of the comics was presented to the participants, and each scenario was read through. We then divided into pairs again, though different pairs than in the first workshop, and the children were asked to choose which comic they wanted to begin with. Between 4 and 5 comics had been
prepared for each group, and the comics included the characters the children had created during the first workshop.

In the boys’ group, the warm meal was served at the end of the workshop, due to which two of the boys had finished before it was time to eat. Therefore, they were asked to draw a comic of their own together. After eating, the second activity, which was only performed with the girls, was presented. The girls were asked to draw a sketch of one of their favourite mobile applications, in an attempt to introduce the activities for the third workshop, and teach them how to create sketches for applications. To their aid they had templates for mobile phones printed on A4 paper. Their finished sketches were then photographed, and with the POP application quick interactive prototypes were created.

<table>
<thead>
<tr>
<th>Activity no.</th>
<th>Group</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>#1</td>
<td>Group 1 &amp; 2</td>
<td>Repetition of characters</td>
</tr>
<tr>
<td>#2</td>
<td>Group 1 &amp; 2</td>
<td>Completing comics</td>
</tr>
<tr>
<td>#3</td>
<td>Group 2</td>
<td>Sketch mobile phone applications</td>
</tr>
</tbody>
</table>

4.3.2 Outcomes

During the first activity I experienced a difference between the two groups: the boys had no trouble choosing comics, and all chose the one with the character they had created, while particularly one of the girls expressed great difficulties with choosing one.

This was the only one I thought that maybe I could come up with something for. [Girl in group 2, workshop 2]

Further, the children approached the activity differently. One of the boys did not like drawing so much and asked his partner to draw while he came up with the story instead. He also expressed disinterest for one of the comics which the other two boys showed a specific affinity to. Another of the boys showed great focus on details, and would not continue with the story until the previous square had been completely filled with colour. The other two boys mostly settled for drawing stick-men. Additionally, he came up with an idea he greatly liked, and asked to change the ending square of the comic to suit his story. Once finished with that comic he asked to draw a comic completely of his own, but with the same ending.

The third boy adhered to the assignment the closest, and connected his story with the characters’ personalities. He and his partnering adult also spent some time going back
to the comics when they had finished all of them and added details that they had come up with during the work with the others.

While two of the boys finished all four of the comics, the girls barely finished two each. One of the girls found it difficult to come up with a story, and her partnering adult had to suggest and create a large part of the stories in her comics. She also did not want to draw, but preferred only colouring the outlines that the adults had drawn. Finally, the second girl finished one of the comics and then with the help of one of the designers adapted the scenario to incorporate an application of her own design, instead of the one which she had used in the comic.

The free drawing which two of the boys finished the workshop with, was an unplanned activity, but turned out to be appreciated. Both boys expressed satisfaction with their comic, even though they barely had time to finish it.

Overall, the children used technologies and applications that they were familiar with (such as the application Skype, the online game League of Legends, tablets, digital cameras etc.). Only one of the comics featured an application which was entirely and spontaneously made up by the child.

Further, the feature of illness in the scenarios was treated without special regard. The comics did not specify what was wrong with the characters that were unwell, and all the children interpreted it as a cold or a regular stomach ache.

The meal was served slightly earlier for the girls, as it was apparent during the boys' workshop that they were hungry and tired about two hours into the workshop. The girls therefore had slightly less time to work with the comics, but as this turned out to be a less enticing activity for them than for the boys, more time wouldn't have been fruitful.

While eating, one of the girls told us about an activity which her favourite teacher had performed with her school class in order for them to learn about geography. The activity bore similarities with geocaching and had a competitive element. This was later turned into a sketch for an application suggestion.
For the second activity, one of the girls began by drawing a copy of an application she liked to use, and the other girl drew an application of her own creation. The participants all drew sketches. The sketches were then photographed with one of the researcher's smartphones and using the mobile application POP a quick prototype was created for the children to test themselves.

Both girls expressed a great interest and pride in having created their own applications and asked questions about the third workshop and whether they would be allowed to draw more applications then. However, one of the girls asked when they would be able to download one of the finished applications to their mobile phones, and we had to explain that it was still a long process until there would be a finished application.

In contrast to the first workshop, the work with the second workshop varied greatly from child to child. I, for example, experienced some difficulty in keeping one of the boys focused on the activity. Furthermore, we noted that the girls expressed more eagerness to continue sketching applications than to draw more comics, and reasoned that this might be because it was the kind of activities they were expecting from design workshops. At least one of the girls expressed little interest in drawing the comics, but was instead eager to create an application of her own.

Image 2. Comic about the character Lindsey, drawn in workshop 2

4.3.3 Intentions

The aim of the second workshop with both groups was to create possible context scenarios, continue working on the personas, and come up with application ideas which would be further developed for workshop 3.
The initial presentation of the characters was both meant as a reminder, and intended to affirm that the characters were as the children wanted them to be. It was further intended that the children should present the photos they had taken for the assignment after workshop 1, but there were complications before both workshops which prohibited this. They were instead discussed during workshop 3.

The comics themselves were meant to present a scenario in a way that distanced the children from the subject discussed, thus allowing for a sensitive subject to be brought up. The scenarios presented were different for the two groups, since they were based on the characters created in workshop 1. While the comics for group 1 were the result of brainstorming during a discussion, the comics for group 2 were based on the properties of peer support. This was intended to bring the resulting scenarios closer to the concept of peer support as some concern had been expressed during the discussion after the workshop with group 1 as to how relevant the comics were to the concept of OPS.

Furthermore, the third activity was added to the girls' workshop in order to create a transition to their third workshop and also to transform the scenarios into more concrete design ideas. It also allowed them to gain a better understanding for the technique of sketching applications.

4.4 Workshop 3: Concretisation

4.4.1 Activities

The activities for workshop 3 were different for the two groups, with the exception of the initial activity. The workshops with both groups were initiated with the children telling us about the photos they had taken for the assignment after the first workshop. As they talked about what their photos depicted, we asked questions, and sometimes the other children commented on something – if they liked the same thing or didn't like it at all.

*I used to have a lot of Legos, but not anymore. My little brother has them now.* [Boy in group 1, workshop 3, commenting on another boy's photo]

The work in group 1 continued with a presentation of design suggestions, presented with comics. Five comics had been prepared based on the comics created during workshop 2. These had been transferred to Bitstrips and each had been continued with a context scenario where the character used the suggested designs. For example,
a comic where the character Tiggo woke up from a dream was continued by him using an application to share the dream with his friends. For each comic the children were asked what they thought of the idea, how they would change it, if they would use it if they were the characters in the stories and what they wanted the contents to be like.

After the meal, the final activity was presented to the boys. We were to work in pairs and write keywords on post-it notes and attach to the comics which had been discussed. The keywords could relate to things we wanted to change, what our opinion of the design idea presented was, what we wished for the idea to have, and such. The facilitator showed an example of what they could do, and the pairs initiated the work. This activity was inspired by the alternative to brainstorming included in CI (Druin, 1999). One of the boys hurried through the comics and when finished, asked if he could draw freely. When another of the boys saw this he asked if he could do the same thing, and they used the last few minutes of the workshop to draw their favourite computer games.

Because the discussions on the comics were difficult to maintain, and the last activity did not give the hoped for result, the concept of the third workshop was changed entirely for the second group. Their second activity was a continuance from their last activity in workshop 2; they were also presented with the comics they had drawn during the second workshop, but instead of having prepared design suggestions, the girls were asked to create these themselves. They were given four design premises related to the comics from which to proceed. Each comic had an element which we asked them to change together with an adult; for example, in one comic the character Lindsey was unable to go to school due to being ill, and she ended up playing the piano at home instead of having music class, which was her favourite. The children were now asked to draw an application for a tablet of mobile phone which would allow Lindsey to participate in the class instead of having to play the piano alone. From this and three other premises the children were given a choice of which to design. As help they had templates for mobile phones and tablets printed on A4 paper. The sketches that the girls created were then transferred into the POP application to create quick prototypes.

Table 6. Summary of activities for workshop 3

<table>
<thead>
<tr>
<th>Activity no.</th>
<th>Group</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>#1</td>
<td>Group 1 &amp; 2</td>
<td>Present photos</td>
</tr>
<tr>
<td>#2</td>
<td>Group 1</td>
<td>Discuss design suggestions</td>
</tr>
<tr>
<td></td>
<td>Group 2</td>
<td>Sketch design suggestions</td>
</tr>
<tr>
<td>#2</td>
<td>Group 1</td>
<td>Brainstorm with post-its</td>
</tr>
</tbody>
</table>
4.4.2 Outcomes

While the boys appeared to be more bashful about their photos in the first activity, the girls did not. Due to bad weather the girls’ third workshop had to be postponed, and one of the girls expressed that if she had taken the photos at the time when the workshop took place she would have taken different photos.

During the second activity, the boys seemed hesitant to give any negative opinions on the suggestions, but by the nature of their answers it was possible to tell that they were not always positively inclined to the ideas.

*It's ok.* [Boy in group 1, workshop 3]

*I don't know. I guess so.* [Boy in group 1, workshop 3]

However, after discussing the ideas further, a few stood out as more popular among the boys. One idea which included missions to be performed led to a discussion on what these missions might be and where the line between a good mission and one that was too embarrassing was to be drawn. Furthermore, a discussion on whether or not these missions should be posted on a social networking site led to questions on how the boys viewed privacy on these kinds of websites.

During the third activity, using only keywords proved difficult, and most post-it notes contained questions and descriptive sentences. It also proved difficult for some of the boys to focus on the design idea, when they instead focused on the part of the comic which had been drawn during the previous workshop.

*You can't eat pancakes for breakfast! Who does that?* [Boy in group 1, workshop 2]

For this assignment the pairs were the same as for workshop 2, but as an afterthought we reflected that perhaps they should have changed so that those who did not work together to create the comics were those who put the keywords to them. Further, one of the boys had problems sitting still and drowned out the others several times when they tried to speak. It might have been advisable for his partner to take him aside and let him do something else to use up some energy.

During the girls' second activity, the choice of design premise turned out to be difficult. One of the girls was of the opinion that there were already applications available that solved these problems, even though they were not specifically adapted for the situations (e.g. the application Skype for participating in class). After a short discussion the suggestion was made that the application could be used after the class was finished, and not during class, to which she could not think of an existing
application. Together with her adult partner she then started designing an application for meeting those requirements. The facilitator also provided some help as to how she could draw certain elements (like scrolling and a keyboard) and how she could think about the flow of the design.

The other girl, who was younger, had a more difficult time understanding the assignment. She chose to begin with the design of an application she had started during workshop 2, and develop it further. During her work she related back to a game she had on her mobile phone, and used elements from the game in her sketches. However, these elements were not always relevant to the application being designed, which led me to the conclusion that she had not fully understood the activity. She also showed a lower attention to detail than the older girl, and it did not matter as much to her if for example the buttons were not consistent on the different pages.

When the girls felt finished with their designs we took photos of them and transferred them into the POP application. We provided tablets with the application for each girl for this purpose. Using the POP application they could then step through their design and have a feeling for how it might work if it was a fully functioning application.

When asked at the end of workshop 3, the boys were in agreement that the first workshop had been the most fun. They still expressed pride in their characters. The girls had been less positive towards the concept of comics, particularly the older girl. She did however show great inclination towards the design of the mobile application, and her sketches bore a high level of detail.

On reflection, the second group could have benefited from a third child participant, as there was less interaction among the girls than among the boys. This might also have been due to the age difference among the girls.

For all children there was one out of the three workshops which was less beneficial than the rest. For the boys and the younger girl it was the third workshop, while it was the second workshop for the older girl. For the boys there was too much focus on talking in the last workshop, and I assume that they would have benefited from a
more active activity. The younger girl had difficulties with understanding how she should draw the sketches for the application, which might have been due to her being too young. The older girl was not attracted to the concept of comics, and showed little interest in either drawing or coming up with any during the second workshop. However, even though not all workshops were successful for all children, the diversity of the activities turned out to result in a large variety of material that was beneficial to the design process.

Image 3. Sketches of Filmio, an application created by a girl in group 2, workshop 3

4.4.3 Intentions
The aim of the third workshop for group 1 was to gain opinions on and reactions to design suggestions. Because this workshop did not yield as much result as hoped for, the aim was adapted for the third workshop with group 2 into being to identify suggestions for mobile applications.

The second activity for the first group was to discuss design suggestions presented to them. In order to illustrate the suggestions comics was used. Some of the comics they had drawn during workshop 2 had been transferred into digital form using the Bitstrips tool. For each of these comics a continuation of the story had been created, containing one of the design suggestions. The suggestions themselves were the result of an analysis session where the material from the first two workshops with the first group was given keywords based on their contents (e.g. outside, fun, stories etc.), and the keywords were then grouped into word clouds. Design suggestions were then brainstormed in order to cover as many of the keywords as possible. The comics thus
represented context scenarios. The aim of the third activity was also to gain opinions on the design ideas, but also to further develop the ideas with specific suggestions.

The girls’ second activity served as a way to come up with design ideas, as well as increase the level of concreteness of the ideas gained from the workshops. The session was also an opportunity to further develop some of the ideas that had matured throughout the previous five workshops.
5 DISCUSSION

Designing IT health services is a complex task. When designing for children in a sensitive context it becomes even more complex. This thesis reports how this complexity was dealt with in the CHIPS project as well as presents lessons learned from performing a number of design workshops, and follow-up discussions on these workshops. The intent is to answer the question: How can children participate in the design of Online Peer Support for children with cancer? The themes into which this discussion is organised emerged as increasingly important during the conduction of this study.

5.1 Research in Sensitive Contexts

The context of this study was particularly sensitive since the children's participation was based upon them having, or having had, a painful and life threatening decease. A topic dealt with, if causing emotional or psychological distress to the participants or the researchers, is considered a sensitive one (Elmir et al., 2011). Involving those who have gone through traumatic experiences in research is necessary as they have unique knowledge on that specific topic (Elmir et al., 2011). Yet, talking about these topics can cause participants to feel angry, sad, embarrassed, anxious, or any number of negative emotions (Elmir et al., 2011). Therefore, when dealing with a sensitive topic, one must take special care to avoid, or at least lessen, this distress. Still, there is currently limited research on performing research with children who have chronic or terminal illnesses, in relation to how to deal with the sensitivity of the topic (Horstman, 2008).

Children are especially vulnerable to any distress that might be caused due to dealing with a sensitive topic, as they don't always have the experience to deal with and understand what has happened (Ruland et al., 2008). Since they have verbal limitations they can also find it difficult to communicate their distress (ibid.). Methods used to perform research on sensitive topics with children should be different from the traditional, “adult-centred” methods, which have to be adapted to suit the needs of the participating children (Drew, Duncan, & Sawyer, 2010). This naturally causes an even higher degree of complexity of the design situation, and must be supported by the chosen method. Because the work in the workshops was conducted in pairs, there was always an adult present who could be sensitive to any changes to the worst in the child's mood. While it did not happen during the workshops, the adult could have stopped the work and taken the child aside, had it been necessary.
When asking personal questions and relating to experiences which might be difficult, the researcher has to be prepared to reciprocate with their own personal information and opinions (Horstman et al., 2008). This relates to the power relationship; if the researcher is not willing to divulge the same amount of personal information, then the children, who are expected to do so, are not equals. While working with the children, it was apparent that they considered the adults as equals in the pairing; they asked questions, prompted for their contribution to the characters and stories, and expected the adults to also answer the questions given to the design group by the facilitator.

5.1.1 Using Proxies
When dealing with a sensitive subject, it can be advisable to distance the children from the topic by using for example a proxy of some kind (Grundy et al., 2012). If a proxy is used as the base of the conversation, instead of speaking about themselves, the children can speak about the proxy, thus creating a “barrier” to reduce the emotional involvement. The proxies can be in the form of stories or characters; they can be non-human as in Grundy et al. (2012), or as human characters as in Moraveji et al. (2007), and can be used stand-alone (Grundy et al., 2012) or as part of scenarios (Moraveji et al., 2007).

For this thesis, inspiration was taken from Moraveji et al. (2007), and the workshop activities were based on the concept of comics. The characters in the comics were thus used as proxies, with which the children could create scenarios and use their experience of having cancer in a way which did not relate to themselves. While this was a possibility, the experience from the workshops was that the children did not include their illness to any great extent. When a character in the girls’ workshop 2 was at home from school, she was assumed to be so because she had a cold. Also, since the boys identified to some extent with their characters, their use as proxy was diminished. Nevertheless, the children were familiar with the concept of comics, and most showed an interest in storytelling. Therefore, with some tweaking, the comic concept could function as a way to distance the subject from the participants themselves.

5.1.2 Setting up the Activities
When designing with children, low-tech activities like drawing and acting are common. Similar activities appear common in other kinds of research as well when dealing with a sensitive subject (see e.g. Grundy et al., 2012; Horstman et al., 2008; Moraveji et al., 2007; Ruland et al., 2007; Driessnack, 2006; Thomas & O’Kane, 1998). The argument for these is the same as with design methods for children; that is, that the children understand what is expected of them, and are comfortable with the forum (Grundy et al., 2012). Also, drawing makes it easier for children to talk
Being, and showing, patience and care is important for the researcher to do (Elmir et al., 2011; Horstman et al., 2008). The child should be given time to come up with a response they themselves consider complete (Elmir et al., 2001), and they should be allowed to work in silence in order to collect their thoughts (Horstman et al., 2008).

Children should be allowed to choose what activities they want to perform when participating in research of this nature, and they should be told that they do not have to do an activity they do not wish to do, or feel like doing (Thomas and O'Kane, 1998). Therefore there is a high amount of flexibility needed from the designer, and the schedule. While there should always be enough activities planned so as not to experience a lull, if there are too many activities to be performed the participants can feel stressed and not be able to do their best. Having different kinds of activities also helps making the children more engaged (Crivello, Camfield, & Woodhead, 2009). The amount of activities for the design workshops was overall experienced as just right, with the exception of the third workshop with the second group which was an hour shorter than the others. The participating researchers agreed that they felt rushed during that workshop.

5.1.3 Power Relations

Because children are less able to protect themselves, and are the weaker party in the power relation between children and adults, there are special regulations for their protection in research (Thomas & O'Kane, 1998). Also, asking the children many questions serves a dual purpose: the information about, and interpretation of the material created by the children improves as the researcher's knowledge increases; and the children are given the role of “expert”, where the adults are those who the children have to “teach” (Horstman et al., 2008), placing them higher in the power balance. From the design workshops, I experienced that the children in general appreciated being asked to explain something.

Children are not required to give informed consent to participate in a study, only their parents. However, it is recommended, and considered ethically correct, that the children also give consent (Thomas & O'Kane, 1998; Horstman et al., 2008). In order to make sure that the children have properly understood what they are consenting to, Thomas and O'Kane (1998) for example handed out tape recordings where they orally explained the study, in order to make sure children who couldn't read well also understood, and they could take the tape home and listen to it as many times as they chose.
5.2 Applying the Knowledge

Of the six design workshops performed for the study, the boys' third workshop was deemed the least successful. In the literature review it is mentioned that children have a lesser ability than adults to express abstract thoughts (Druin, 2002), have a tendency to worry about giving “correct” answers (Thomas & O'Kane, 1998), and activities such as brainstorming have been found less successful (Moraveji et al., 2007; Guha et al., 2005). It can be assumed that the two final activities during that workshop were too difficult in those respects. Nevertheless, there was a need in the design process to solicit opinions and reactions to design ideas in order to continue with the designing. As this proved difficult to do by discussing, for the third workshop the girls were asked to draw their views of the presented ideas instead. While this yielded a different kind of result, it proved more accessible to the participating children. Additionally, the difficulties of the third workshop for the boys can relate to the level of concreteness in the assignments. While not specifically mentioned in the literature review, this relates to the need of children to have boundaries (Mazzone & Read, 2005; Jones et al., 2003).

Further, it was noted in the literature review that the researchers should be clear about what the children could expect about the results, and during the design workshops it was for example necessary to explain to one of the girls that the development of mobile applications was a long process and she should not expect to have a finished application available for download for a long time. However, handling the researchers' own expectations also proved difficult. Before each workshop, the participating researchers usually expressed some sort of expectations, and the aims of the activities in the workshops reflected these. Nevertheless, surprise was frequently expressed during the discussions after the workshops, and as in the case of the boys' third workshop, the expectations turned out to be mistaken. Nevertheless, this does not mean that the material gained from the workshops was unusable, but it does show the necessity of experimenting with the methods used and gaining experience from field work.

5.3 Differences between the Groups

A number of differences between the two groups of children emerged during the workshops. Firstly, opposed to the indications from the literature review, it turned out that when working on the characters during the first workshop the boys showed more attention to detail than the girls did. Both girls took less time than the boys to finish their characters, and they did not express the same amount of care for the characters' appearance. In comparison, the boys were very particular with the appearance of their characters: all the boys added details which were not part of the prepared cut-out dolls, for example a hood, a striped shirt and a print on the shirt.
The boy who drew the striped shirt used his own shirt as a guide for how he was supposed to draw the lines so as to make them look just right.

However, the groups differed in the opposite way in a related aspect: when drawing, the boys simply drew right on the paper, with little concern for how the result looked. The girls, on the other hand, both preferred to try out their drawings on a different paper before drawing onto the final character or comic. One of the girls experimented with different ways of drawing noses before she decided on which she wanted, something none of the boys did.

Thus, on the one hand the girls showed less attention to detail, while they showed more care about quality than the boys. This incongruity suggests that flexibility is essential for the participating adults to have. Furthermore, the work setup needs to support the child's will to work on the details and quality to the extent they want. It cannot be anticipated what the children will focus on, so both the activities and the researchers need to be prepared to support the children's work in any way necessary.

5.4 Existing Technologies

During the design workshops the children all related to existing technology and applications in one way or another. However, it appeared more difficult for them to come up with and consider new technology and applications. The older girl in the second group was for example unwilling to design an application which adapted Skype to a more specific context, arguing that it wasn't necessary. She could not imagine herself using another application than the ones she was already using, even if it would be more specifically tailored for the purpose.

Furthermore, the boys were given an example of a design solution in their third workshop that included a carpet with a map on it, on which they could see where their friends lived, and interact with them by walking to their geographical location on the map while holding their mobile phones. This idea did not receive positive feedback, and while the boys were careful with expressing themselves negatively it was apparent that they were not keen on the idea. They thought it was weird to have the carpet as part of the interaction with the application. Also, when given a scenario with endless possibilities during the second workshop, most of the children chose to create realistic scenarios which included applications they used themselves. Only when specifically asked during the second workshop what might be used instead, did one of the girls come up with an application which did not already exist.

The one time when more creative stories emerged was when the scenarios in the comics related to dreaming – for the boys' second workshop there was a comic which took the character Tiggo to the moon during a dream. It would seem as though more
than the constraints of the assignment must support creativity. If that kind of material is wished for, it needs to be built into the scenarios as well, and not expected from the children to make the leap themselves.

5.5 Summary
Table 1 presented earlier contained a summary of the properties of design methods adapted for work with children. From the discussion above, several other properties explicit for research on a sensitive subject have emerged. These properties relate to the same aspects as the previous, and can thus be organised into the same three groups. A summary of these properties is presented in table 3 below. The properties that are inherent in methods for researching sensitive contexts with children that were not identified previously are presented in bold, while those that coincide with existing properties are in italics.

<table>
<thead>
<tr>
<th>Activities</th>
<th>Designers</th>
<th>Participants</th>
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<td>Low-tech</td>
<td>Preparation</td>
<td>Group setup</td>
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<tr>
<td>Fun</td>
<td>Communication</td>
<td>Limitations</td>
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<tr>
<td>Sense of contribution</td>
<td>Handle expectations</td>
<td>Power relations</td>
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<tr>
<td>Familiarity</td>
<td>Informal</td>
<td>Equality</td>
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<tr>
<td>Time</td>
<td>Personal</td>
<td>Gatekeeper participation</td>
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<tr>
<td>Physical</td>
<td>Flexible</td>
<td>Trust</td>
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<tr>
<td>Variety</td>
<td>Asking questions</td>
<td>Informed consent</td>
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<tr>
<td>Environment</td>
<td>Patience</td>
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<td>Contextually unique</td>
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<td>Proxy</td>
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Notably, out of ten identified properties, five relate to the designer. Since there were only four properties identified that related to the designer for methods that are not specifically adapted for a sensitive context, it is evident that this is an aspect which carries particular weight when the subject is sensitive. In other words, a majority of the changes that need to be made to methods in order to adapt them for a sensitive context need to be made in how the designer approaches the work. How the designer acts is thus an area of particular importance in this case.
6 CONCLUSIONS

The aim of this paper was to answer the question: How can children participate in the design of Online Peer Support for children with cancer? In order to answer this question, I performed a literature review to identify properties of design methods that include children, involved children in the design of OPS for children with cancer, and discussed the lessons learned from the empirical case.

Through the literature review I identified a number of properties of design methods involving children, and organised these into three different categories. They were later supplemented with properties of design methods for performing research related to a sensitive subject. Table 8 below summarises the properties design methods involving children in a sensitive context have. It forms the answer to the first objective of this thesis.

<table>
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<tr>
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<th>Designers</th>
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These properties can function as guides for anyone intending to design with children, and tailoring a method for their design context, particularly when the subject is of a sensitive nature. The properties also make up a contribution to the knowledge base as to what properties design methods with children in a sensitive context have.

The design method employed in the empirical case in this thesis was informed by the identified properties of design methods with children. The empirical material was made up of six design workshops with five children who were at the time, or had previously been treated for cancer, as well as follow-up discussions with the participating researchers after each workshop. Specific aspects of the design method which were applied due to the sensitive nature of the subject include using characters as proxies, working closely in pairs with the children, and planning activities with a high level of flexibility as to how many and for how long they were to be performed. The design workshops were part of the CHIPS project at Halmstad University and
aimed at designing OPS for children with cancer. This fulfilled the second objective of this thesis.

From the design workshops and the subsequent discussions several lessons were learned, in addition to the result from the literature review, about how children can be involved in the design of OPS for children with cancer. Based on these experiences, I suggest the following for adapting methods to suit design with children in a sensitive context:

- If imaginative ideas are wished for, the assignments can support this by not adhering too closely to realistic scenarios;
- If proxies are used, make sure they are different enough from the children themselves to provide the distancing effect wished for;
- If conducting design workshops, working in pairs can be beneficial to productivity, as well as a way watching the participating children's wellbeing;
- If adults and children are working together, they are expected to contribute equally and share the same level of personal information;
- If asked for feedback, children can have difficulties expressing negative opinions;
- If the subject is sensitive, the designer's role is particularly important, and they can expect to have to show flexibility in their role and actions;
- If the children are taking part in activities, it is suggested to vary the nature of these activities, and not be too set in the expectations on the outcome of these.

These suggestions make up the answer to the final objective for this thesis, and together with the result from the literature review it fills the knowledge gap, and answers my question on how children can participate in the design of OPS for children with cancer. The conclusions from this thesis can be of use to designers who wish to involve children in design, particularly when the subject is of a sensitive nature. It also contributes to the knowledge base on how to approach a similar design situation.

### 6.1 Future Research

There is more to learn about children's participation in design. Interesting areas for future research include adapting the method used in this thesis for other contexts, further developing the concept of comics in the design process, as well as the ways in which personas can be used with children. Also, more research still needs to be done on how to perform design research with children when the subject is sensitive, as it is a precarious circumstance.
7 REFERENCES


# Appendix A: Identified Codes from Articles

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<th>Activities</th>
<th>Properties</th>
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<td></td>
<td>Fun</td>
<td>Frauenberger et al., 2012b; Giaccardi et al., 2012; Grundy et al., 2012; Horton et al., 2012; Hemmert et al., 2010; Mazzone et al., 2010; Komlodi et al., 2007; Moraveji et al., 2007; Dindler et al., 2005</td>
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<td></td>
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<td></td>
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<td></td>
<td>Time</td>
<td>Bratteteig et al., 2010; Walsh et al., 2009; Moraveji et al., 2007; Kelly et al., 2006; Guha et al., 2005; Guha et al., 2004; Druin, 1999</td>
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<td>Physical</td>
<td>Giaccardi et al., 2012; Bratteteig et al., 2010; Guha et al., 2005</td>
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<td>Horton et al., 2012; Mazzone et al., 2010; Guha et al., 2005; Guha et al., 2004</td>
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