Properties of Participatory Approaches for Designing with Children

Susanne Lindberg

Halmstad University
susanne.lindberg@hh.se

Abstract. Information technology in health services has an increasingly important role in people's lives. However, the design of this constitutes a complex situation in a sensitive context. The complexity further increases when the users are children. Participatory approaches are beneficial for design with children, but there is limited research on how to design with children and how existing methods can be made to suit a health related context. This paper aims identifying common properties of participatory design methods when performed in a health related context. The identified properties of design methods were found to relate to three different categories: activities, designers and participants. To these were added properties of research methods with children in health contexts, where a majority related to the category of designers. This indicates the designers' responsibilities are particularly important when designing with children in a sensitive, health related context.

Keywords: Participatory design, health, children, methods, properties

1 Introduction

The use of information technology (IT) in health services is an increasingly important part of people's lives. There is for example a focus on how IT can promote health and improve qualities of life within the Digital Agenda for Europe [1]. However, the design of these technologies presents a complex situation for designers, who have to not only deal with conflicts among users and interests, but also deal with a context which relates to the users' health and wellbeing – a potentially sensitive context.

Furthermore, when the users are children, additional complexities emerge. For one, children have a different culture than adults, have a lesser ability to communicate abstract thoughts than adults do, and express themselves more in actions than in writing [2]. Also, when the circumstances that are the basis for the children's participation, for example health related issues, can awaken negative emotions, extra care needs to be taken that the children are not unduly upset or affected [3].

During design it is common to use a method for helping control, handle or understand the complexity of the situation. When designing with children, it is common to use participatory approaches, which are considered beneficial for

designing with children [2], [4], [5]. However, any method that is initially intended for work with adults needs to be adapted to suit designing with children [6], [7].

One of the first to adapt participatory approaches to the work with children was [8], who presents a method for actively including children as co-designers. Since then, a number of adaptations of this method have been made, along with other methods to, for example, create personas and scenarios [9], [10], and prototyping [11], [12]. However, there is still research needed on how children can participate in the design process [13].

The research for this paper was conducted within a project that aims at developing Online Peer Support (OPS) for children diagnosed with acute lymphoblastic leukemia. The project takes a participatory approach, but since the context is health related and of a sensitive nature, it was necessary to find out about the nature of design methods in similar contexts. Therefore, the aim of this paper is to identify common properties of participatory design methods when performed in a health related, sensitive context.

2 Participatory Approaches with Children

The foundation of Participatory Design (PD) is that of democracy; the approach values active and extensive user involvement throughout the entire design process [5]. User-Centered Design (UCD), also a participatory approach, is based on slightly different ideals. The UCD movement was critical to the human factor being ignored in design and development, and therefore advocated a process with focus on users in different ways [14]. Participatory approaches are generally considered to increase the effectiveness of the finished design [14].

In participatory approaches, it is common to use less formal methods and techniques such as prototyping, mock-ups, diaries, probing etc. [15]. Establishing trust among the participants is essential in participatory approaches [16], and the relationships have to be sustainable because the work is often long term and iterative [17]. These kinds of approaches can require great effort from both the researchers and participating users [18].

Participatory approaches are well suited for design with children [2], [4], [5]. Cooperative Inquiry (CI) was introduced by [8] as an approach specifically suited for design with children. CI has its roots in participatory approaches, and children are involved over a long period of time as users, testers, informants and design partners. A number of methods have, since its introduction, added to (e.g. [6], [11], [19]), and been inspired by CI (e.g. [20], [21]). Some examples include [6] who adapt CI for use in an educational context, and [7] who adapt CI to suit design with children aged 4-6 years.

There are many design methods specifically adapted for designing with children, and no generic method appears to exist. Yet, these methods have a number of properties in common. I found that these properties could be separated into three categories depending on what part of the design method they relate to: the *activities* performed, the *designer* who prepares and leads them, and the *participants* of these activities.

2.1 Activities

Something which is often mentioned in the literature relating to design methods with children is that the activities should be fun (e.g. [12], [22], [23]). Activities that are fun are more likely to engage and motivate the children [24]. What each child considers fun is naturally a subjective opinion, but many activities that are usually described as fun are creative, low-tech activities.

Mostly the activities revolve around the use of low-tech tools such as pens, papers, glue, scissors etc. Only a few of the reviewed articles mention the children having used an IT artifact as a part of the activity [25], [31], and then the material was usually supplemented by other, low-tech activities.

The activities should be familiar to the children [23], [28], which is one motivation for the use of low-tech tools. The children are often familiar with them and their use [25]. Some for example use comics in their activities, with the argument that children generally are familiar with the concept [6], [31].

The physical setting where the activities take place varies throughout the literature. Some designers visit the children at their schools (e.g. [23], [25]), while others have dedicated design labs (e.g. [26-27]). A school setting can make children more inhibited and worried about giving a "wrong" answer [24]. On the other hand, schools are familiar to the children, and can make them more comfortable than an unfamiliar setting, and it is also a place where they are easily accessed [26].

There is frequently a "get to know each other" activity at the beginning of the process which is intended to build trust and a relationship with the designers (e.g. [20], [28]). It is also common to have several different kinds of activities (e.g. [29-30]). Varying the activities allows children who are strong in one area, but weaker in another, to participate and contribute in at least one activity [29-30]. It also prevents the children becoming bored or running out of ideas [29-30].

Having physical activities (where the children use their bodies) is not uncommon. A typical activity is acting [23]. This is described as both fun and a way to tell stories without including drawing [23], [30].

There is often a creative element in the activities [20], [25], [28]. This can be, for example, telling stories [20], acting [23], crafts [27], or, most commonly, drawing [26]. The children are allowed to express themselves, and their imagination. However, the downside it that those children who already are creative and expressive give a richer material than other children, and are thus preferred as participants [31].

Giving the children a sense of contribution, and how their contribution has been used, is important [32]. A common tactic is to have summarizing activities at the end of the session [11], [33]. It is also recommended to have a session further on in the development process for showing the children what their work has led to [24].

Not only is it important to give feedback to the children on their contribution, but it is also essential to have them give feedback on the interpretation of the material. When the material has been collected and analyzed, the conclusions should be presented to the children so they can correct anything that may have been misunderstood [34].

Children need boundaries [32], [35]. It has been experienced that children contribute less when they have fewer boundaries [31]; brainstorming has for example been found less successful with children for this reason [33]. Similarly, any

instructions should be very clear, and preferably presented with examples of what is expected of the children [32].

Finally, it is often the case that the activities are lengthy in regard to time [36]. CI is for example particularly time consuming, and children can be members of a design team for years. There have been attempts at reducing the time needed; [26] for example attempt to increase efficiency of workshops by setting up different "stations" that children can alternate between.

2.2 Designers

It is common to prepare several activities that can be flexible as to time [26], [27]. Being well prepared is obviously important, but also providing a structure among the activities, having them follow each other logically and incrementally [21]. If more than one session is conducted with the same children, these sessions ought to be somehow connected [33].

Communication is at the heart of the design process, and any problems that can occur for example with the understanding of instructions can be solved by maintaining an open dialogue [35]. Further, communicating the outcomes of the results can be done in several ways, for example as [20] solved it, by creating videos with the children themselves explaining the results.

Children are no design experts, nor are they meant to be. This means that they may not know what is feasible or what is expected of them [4], [7]. From the start, the designers need to handle the children's expectations and make them understand what is possible in order to make the design suggestions feasible [7], [5]. However, focusing too much on what is realistic might stifle the children's creativity [4]. Also, the children should know what is expected of them and the activities they are asked to perform, or they can become upset if, for example, their idea is not chosen for further development [30].

Lastly, children are lower in the power hierarchy and are used to obeying adults. This can make interacting with adults on an equal level as design partners difficult. Therefore, it is recommended to be informal and avoid showing authority when working with children [5], [8]. Further, informal clothing should be worn and an informal language used [5], [37], and if the children are sitting on the floor, so should the adults [11].

2.3 Participants

Children are sometimes described as having limitations in various areas, for example: verbal expression [19], [29]; abstraction [38], [39]; writing [7], [30]; and social interaction [12], [32]. These limitations have to be taken into account when planning the activities. Practical activities are for example more suitable for work with children, rather than talking or observing [25]. 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, may misinterpret the children [20]. Limitations in social interaction can make it difficult

particularly for younger children to work in groups, making it advisable to always have an adult present [12], [19].

The difference in the power relations between children and adults can also affect the process [22], [8]. Adults have more rights in society and children are not always expected to take responsibility, and are therefore not given any. Acting in an informal manner can help reduce this discrepancy [5]. In a participatory process, children and adults are meant to be equal partners, and the children have an equal say in decisions and idea generation [8], [10], [31], and should be given the opportunity to exercise that right. However, it can also happen that the participating adults forget that they are equal in this process, and leave it all to the children [33], which is not advisable either. All in all, building trust between the participants is an essential factor in being able to work together successfully [20].

The group setup varies throughout the literature. Children in the ages of 10-11 are considered the best prototyping partners [8], and many seem to prefer including children that age (see e.g. [31], [36]). Some work with large groups, like entire school classes [20], [26], while others set up smaller groups [11], [35], or work with one child at the time [39], [33]. When working with large groups these are often split into smaller constellations, possibly with an adult presence in each [26], [32].

The relation between the amount of children and adults varies; there is often a larger number of children than adults [20], [26]. This may be an attempt to reduce the discrepancy in power relation between adults and children. 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 [39], [33].

Sometimes so called “gatekeepers” (primarily teachers) participate in the design process along with the children [20], [40]. This can have a positive effect because there will be an increased adult presence [25], the children already trust the gatekeepers [26], and the gatekeepers can contribute with their knowledge of the children [7].

2.4 Summary of Properties of Design Methods with Children

Table 1 presents a summary of the identified properties of design methods with children that have been described above. The properties are not necessarily present in all methods, but make up common denominators for design methods with children.

Table 1. Summary of properties of design methods with children

Activities	Designers	Participants
Low-tech	Preparation	Group setup
Fun	Communication	Limitations
Sense of contribution	Handle expectations	Power relations
Familiarity	Informal	Equality
Time		Gatekeeper participation
Physical		Trust
Variety		
Environment		
Contextually unique		
Boundaries		
Creative		

Since only a limited amount of research on design with children in a health related context was found, these properties thus relate to design methods in general. The next section will detail properties identified relating to other research methods with children in health related contexts of a sensitive nature.

3 Research with Children in a Health Related Context

A sensitive context is defined as one where the topic dealt with can cause emotional or psychological distress [3]. A health related context can fall under this definition, particularly when relating to life threatening diseases. Children are particularly vulnerable to the distress that can be caused by dealing with a sensitive topic since they do not always have the experience to deal with what they have been through [41]. Still, there is limited research on performing research with children when the context is health related [34]. Methods which are used to perform research with children in sensitive contexts have to be adapted from the more "adult centered" methods [42].

The use of proxies can be advisable when the context is of a sensitive nature [25]. A proxy creates a "barrier" between the child and the topic, thus reducing the emotional involvement. Proxies can be in the form of stories or characters; they can be non-human [25], or human characters [31], and can be used stand-alone [25] or as part of scenarios [31].

When designing with children, low-tech activities like drawing and acting are often performed. Similar activities appear common also in non-design research when the context is sensitive (see e.g. [24], [25], [43]). The argument for this is the same as with design methods: that the children understand what is expected of them and are comfortable with the tools [25]. Furthermore, drawing makes it easier for children to talk [43].

Moreover, being and showing patience and care is important when doing research with children [3], [34]. The child should be given time to come up with a response they consider complete [3], and should be allowed to work in silence in order to collect their thoughts [34]. They should also be allowed to choose which activities they want to perform, and it should be made clear that they do not have to do something they do not want to [24]. Therefore, a high amount of flexibility is necessary from the designer, as well as the schedule. There should be enough activities planned so that there is always something to do, but not too many so that the children feel stressed and are unable to do their best. Having different kinds of activities also help making the children more engaged [44].

The power relation between children and adults is, as mentioned above, unequal in our society. There are recommendations for how this inequality should be reduced when designing with children, but also in literature relating to research in a sensitive context. It is for example recommended to ask the children questions [24]. This serves a dual purpose: the children are given the role of "expert" where the adults are the ones the children have to "teach", thus inverting the power relations; it also improves the interpretation of the material since the researcher's knowledge of the children increases [34].

Children are not required to give informed consent to participate in a study, but it is recommended from a research ethical standpoint [24], [34]. The preconditions for the study should be explained in such a way that the children can understand them. [24] for example used tape recordings where they orally explained their study in order to make sure the children who did not read well could also understand what they consented to.

Furthermore, the researcher should, when working with children in a context which requires asking personal questions, be prepared to reciprocate with their own personal information and opinions [34]. If the researcher is not prepared to divulge the same amount of personal information as the children are expected to, they are not equals in the power relations either.

3.1 Summary of Properties of Research with Children in a Health Related Context

In Table 1 earlier, the identified properties of design methods with children were presented, organized into three categories. The properties detailed in this section, relating to research with children in a health related context, relate to the same aspects as the properties of design methods, and can thus be organized into the same categories.

Table 2. Properties of research methods with children in a health related context

Activities	Designers	Participants
Low-tech	*Communication*	*Power relations*
Familiarity	Personal	Informed consent
Proxy	Flexible	
	Ask questions	
	Patience	

In the summary presented in Table 2 above, the properties of research methods with children in a health related context which overlap with identified properties of design methods with children are presented with italics.

Notably, out of ten identified properties, five relate to the designer. Also, out of these five, four had not been identified as properties of design methods with children. It is thus clear that this is a category which carries particular weight when the context is health related; in other words, the responsibility of the designer increases in such a situation. When a design method is adapted to suit a health related context, a majority of the changes thus need to be made in how the designer approaches the work.

4 Design Workshops with Children with Cancer

The research for this article was conducted within a project aimed at developing an OPS solution in order to promote the mental health status of children between 8-12 years old who have or have had acute lymphoblastic leukemia. The project takes a participatory approach, and an early stage of the project involved five children in the ages of 11-13 in design workshops. Since the children's participation was based on them having had a serious illness such as cancer, it could cause them to become distressed or upset. Yet, involving those who have gone through traumatic and difficult experiences in research is necessary since they have unique knowledge on that specific topic [3].

It was thus essential to take special care to avoid making the participating children upset. Children are particularly vulnerable to the distress caused in this kind of situation since they do not always have the emotional experience to handle what they have been through [41]. Still, there is limited research on performing research with children when the context is health related [34]. As argued above, one cannot simply apply a method used with adults to the work with children.

In this case, six workshops were performed with five children split into two groups. The first group was made up of three boys aged 11-12, and the second group consisted of two girls aged 11 and 13. The children had been, or were still under treatment for leukemia. Three to four researchers participated in each session. The workshops were based on the concept of comics in order to create a common denominator that permeated all workshops: during the first workshop the children created characters, during the second workshop they drew comics that had these characters as protagonists, and for the third workshops these comics were used as a

basis for discussion and further development of design ideas. Figure 1 below shows an overview of the main workshop activities that the children were asked to perform during the workshops.

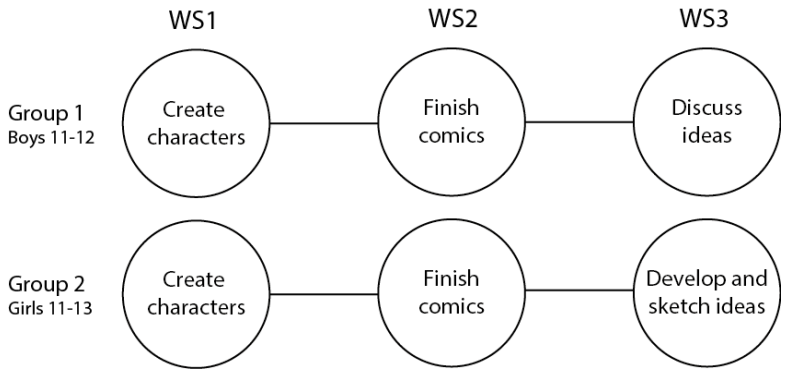

Figure 1. Overview of main activities of workshops

The characters and comics were digitized using an online comic creation application, allowing the children to see their creations as finished comics. Comics are considered to be familiar to most children [31]. Since the deliverables in this case (characters and comic stories) mapped reasonably well with the concepts of personas and scenarios, using comics suited the work well. It was also assumed that by using characters as proxies, instead of the children themselves as a basis when creating these comics, the children would distance themselves from the scenarios, hopefully reducing any distress caused by the context of their participation.

The purpose of the first workshop was to create familiarity within the group and develop the characters that were to be the protagonists of the comics in the upcoming workshops. These characters were also meant to be the basis for the personas which would be used throughout the rest of the design process. The children each worked in pairs with one adult, and with the use of cut-out dolls they came up with for example the characters' names, what they liked and disliked, and what they were interested in. The boys in the first group were asked to create characters their own age, but during the second workshop we noticed that they spoke about their characters as though they were themselves. Since the intention with the use of the characters was to maintain a distance between the child and the events in the comics, this was not wished for. The second group was therefore asked to create characters a few years younger than themselves in order to increase the disparity between them and the characters. This group proved less inclined to identify with their characters, but this may not only have been due to the age difference of the characters, but also due to at least one of the girls being older and more mature than the boys.

The second workshop aimed at creating possible context scenarios and identifying potential design ideas. A summary of each character from the first workshop was provided, along with the beginning and ending of comics which the children were

asked to complete. This activity was inspired by comicboarding (see [31]). The stories contained aspects that related either to the properties of peer support, or to for example feeling unwell. For each group, four to five comics had been prepared, and the children again worked in pairs with one adult.

The concept for the third workshop differed completely between the two groups. For the first group, the comics which the boys had drawn during the previous workshop had been transferred to a digital format, and had been extended with a scenario where the protagonist(s) interacted with a design suggestion. The design suggestions were based on the results from the analysis of the first two workshops. The aim was to gain opinions and reactions to these suggestions. The scenarios were thus presented to the boys, who were asked of their opinion, if they would use it and if they wanted to change anything. However, it was clear that the boys were not comfortable giving negative feedback. They expressed that they thought the ideas were "OK", but it was clear that they were not always positively inclined towards them. It was assumed that the format for the workshop, which was based mostly on talking, was the reason why the boys found it difficult. Therefore, the third workshop was changed for the second group.

The aim of the third workshop for the second group was to identify and further develop ideas for one or more mobile applications which could be applied to the OPS concept. Again, the children's comics from the second workshop had been transferred to digital format. Their comics either did not include a digital artifact at all, or included an already existing application. The children were thus asked how they would change the story to achieve the same result using an application of their own design. They were given templates of smartphones and tablets and were asked to sketch what such an application could look like. The activity suited the older girl very well, but proved difficult for the younger girl. It was, however, an opportunity to further develop and concretize the ideas gained from the workshops.

Finally, after both groups had performed all three workshops, a summative session was conducted where the children and their families were invited to see and listen to the current results from the workshops. The occasion intended both to inform the parents of what their children had been doing during the workshops, but primarily to show the children what they had contributed to and what their contribution had been used for. Since the way of working with comics can seem somewhat abstract in relation to what might be expected from a design process, it was considered necessary to more concretely show the children what their work had resulted in. Besides some analytical material, two low-fi prototypes of mobile applications had been prepared (one based on the workshops with the first group, and one on the second) and were presented to the children and their families. The session also yielded useful feedback from both the children and their parents.

5 Discussion

A health related context of a sensitive nature can cause design participants to be upset or otherwise affected from their participation. Children are specifically sensitive to this. The context in this study was sensitive since the basis of the children's

participation was that they had been, or were still under treatment for cancer. Their participation could thus awaken emotions caused by having a life threatening disease. We therefore had to make sure that the children were not affected in a negative way.

For the workshops conducted within the scope of this research, the group setup for a majority of the work was made up of pairs with one adult and one child. This was found to be a successful format for several reasons. Firstly, working in pairs allowed the adult to keep a close eye on the child and their mood. It was not necessary during these workshops, but the adult could have stopped the work and taken the child aside if anything had occurred to upset them. Secondly, working in pairs allowed all children to express their opinions to an equal degree; no single child dominated the discourse, but all had the opportunity to make their voices heard. Thirdly, it proved to be an efficient way of working since the adult could keep the child focused on the activity. Also, when working with the characters and comics, the pair could for example discuss the character's personality while the child was drawing, thus both allowing the child to spend as much time as they wanted on the details of the character's appearance while still keeping up the work.

The use of proxies can be advisable when the context is of a sensitive nature [25]. During our workshops with the children we used characters of the children's own creation as proxies. The assumption was that with the use of comics instead of the children themselves as the protagonists of the comics, they would be distanced from the events of the stories. However, the first group clearly identified with their characters, and several times referred to their characters as "I". To counteract this, the children in the second group were asked to create characters that were younger than themselves. This resulted in it becoming more difficult for them to create the characters and stories, since they expressed that they did not know what children younger than them liked. We felt that the children in the second group had been better able to keep a distance with their characters even if they had been their own age. The use of proxies is thus a matter of balancing the children's abilities with the distance wished for to the proxies. In a sensitive health context it is not advisable that the children identify too closely with the proxies, but if they are too distant from the children, they will not be a useful tool for design.

Using low-tech activities such as drawing is very common when designing with children. It is considered more appropriate than using interviews, which is more difficult for children than for adults, particularly when the children are very young [20]. The third workshops for the first group mostly consisted of the children giving verbal feedback on ideas presented in comic form. The group had participated with much enthusiasm in the previous workshops, but found it difficult to express their opinions in this way. They were particularly careful with expressing negative opinions. We reflected after the workshop that a more active and creative format had been better, and adapted the workshop for the second group accordingly. That workshop was considered more successful.

As recommended in the literature, the activities during the workshops were planned flexibly as to time and how they were performed. One of the boys for example did not like the ending of one of the comics he was asked to finish in the second workshop, and was thus allowed to create his own ending.

The participating adults also had to be flexible in their role. Some of the adults for example wrote and talked with the child they were working with, while the child was

drawing, to make the work progress faster. As another example, one adult was instead asked to draw by one of the children who did not have the energy to draw anymore, but still wanted to keep going. At other times, some children needed a high degree of guidance, while others preferred to work independently.

In a health related context, the participating adults should be prepared to reciprocate with the same level of personal information as is asked of from the child [34]. During the design workshops, the children simply seemed to assume that the adults would give the same kind of information as they did. They for example cooperated with the adult in the creation of their characters, asking what kind of hobbies we had, and incorporating these into their characters if they found them appropriate to the character in question. There was no noticeable hesitation on the children's part to ask for this reciprocity, and the adults were prepared to share their information, just as they asked the children to do.

6 Conclusions and Future Work

The aim of this paper was to identify common properties of participatory design methods when performed in a health related context. Properties of design methods with children were identified from a literature review. These were separated into three areas: the performed activities, the designers and the participants. Further, properties of research methods with children in health related contexts were identified and separated into the same categories. It became clear that many of these properties relate to the designers, wherefore it is this category which must be the primary focus when a design method for design with children is adapted for a sensitive context.

Table 3. Properties of design methods with children in a sensitive context

Activities	Designers	Participants
Low-tech	Preparation	Group setup
Fun	Communication	Limitations
Sense of contribution	Handle expectations	Power relations
Familiarity	Informal	Equality
Time	Personal	Gatekeeper participation
Physical	Flexible	Trust
Variety	Ask questions	Informed consent
Environment	Patience	
Contextually unique		
Boundaries		
Creative		
Proxy		

Table 3 presents a summary of the properties of design methods with children in a health related context. This is also a summary of the contribution of this paper. These properties can function as guides for anyone intending to design with children, particularly when the context is of a sensitive nature. However, more work still needs to be done relating to how children can participate in health related research, as the need for IT in health care increases. More extensive studies can be made, as well as studying whether there are properties that are more essential than others, and how to combine these properties in order to achieve the best conditions possible for the children.

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