IADIS International Journal on Computer Science and Information Systems
Vol. 10, No. 2, pp. 79-94
ISSN: 1646-3692

TRANSITION CARDS: DESIGNING A METHOD WITH AND FOR YOUNG PATIENTS

Margaret Machniak Sommervold and Maja van der Velden. *Department of Informatics, University of Oslo, Gaustadalléen 23 B, 0373 Oslo, Norway*

ABSTRACT

Participatory Design (PD) is a methodology concerned with bringing the voices of future users into the design process, as well as with the design of tools and methods that enable the participants to engage in design activities. While user participation in design of new technologies is a well-researched field, this paper presents user participation in the design, implementation, and appropriation of a card-based method. The purpose of the method was to support young patients in organizing and explaining their experiences and expectations surrounding their transition from pediatrics to adult healthcare. Application of PD and the concept of *cool* in the process of designing the method resulted in a method that the participating young patients could redesign and appropriate to better fit their particular situation. Hence, the paper argues in favor of not only including users in the design of new technologies, but also in the design of methods. Our results indicate that user participation in the design of methods, for use in Participatory Design processes, enable the appropriation of the methods, rather than mastery of the methods. This appropriation may increase the space for mutual learning and may result in better methods and participant-empowerment.

KEYWORDS

Participatory Design; young patients; transition; card sorting; appropriation; cool.

1. INTRODUCTION

The field of Participatory Design (PD) has traditionally been concerned with bringing the voices of future users into the design process of the technology and the design of appropriate methods and tools that facilitate *mutual learning* and sharing of power with the users across the design process (Simonsen and Robertson 2012). In the design of information technology we design both the product, or the design result, and the design process itself. Brandt et al. (2012) have argued that it is important that research and practice with the tools and techniques used in PD processes are published and shared for all of us to use in the future. Van der Velden (2014, p.12) has argued that we need to expand the design process, finding "ways to bring the voices of the future generations into today's design practices". We argue that we need to bring users' experience and knowledge also into design of the methods and tools. This paper presents how we designed and implemented a card-based method in a study exploring young IBD (Inflammatory Bowel Disease) patient's experiences and expectations surrounding their transition from pediatrics to adult medicine.

1.1 Transition

During the course of our lives, we all undergo transitions. Transitions are processes or periods "in which something or someone undergoes a change and passes from one stage, state, form, or activity to another" (Fernandes and Landzberg 2004). Transition is a life altering part of our lives (ibid). Young people with chronic health challenges have their transition from puberty to early adulthood compounded by the challenge of moving from pediatric to adult medicine (Resnick and Bowes 2007). Transition in healthcare is being defined as "the purposeful, planned movement of adolescents and young patients with chronic physical and medical conditions from child-centered to adult-centered healthcare systems" (Blum 2002). A successful transition process is critical for ensuring patient compliance with future medical treatment (Alpay 2009). A significant amount of literature stresses the importance of good transitions (Baldassano et al. 2002; Alpay 2009; Fernandes & Landzberg 2004; Sawyer & Ambresin 2014; Campbell et al. 1996; Callahan et al. 2001) and presents the various problems that can occur during transition (Patterson and Lanier 1999; Kleinert 2007; Applebaum et al. 2013; Reiss and Gibson 2002).

Despite the growing body of research, adolescents with chronic health challenges seldom make a smooth transition to adult healthcare (Patterson & Lanier 1999) and often have substantial, unmet needs (Bowen et al. 2010). While introducing technology is not always the answer, research indicates that ICTs hold the potential to support patients in various challenges related to their condition.

There is a lack of understanding of the teenage agenda and the challenges they face in transition – both as patients and adolescents (Patterson and Lanier 1999; Jacobson et al. 2001). There is also a lack of research involving teenagers (Fitton et al. 2012). While there is little research with teens, there is even less with teenage patients who are for good reasons 'protected' by ethical guidelines and restrictions. But while ethical guidelines and restrictions have been implemented to protect vulnerable populations, they may hinder the inclusion of adolescent patients in research, which in itself is unethical (Lang et al. 2012). This is especially challenging in the context of Participatory Design. Because of ethical and practical restrictions, vulnerable stakeholders' views and experiences are often excluded from the design solution (Robertson and Wagner 2012, p.73).

1.2 Structure of this Paper

This paper describes the design, implementation, and appropriation of a card sorting method, which is a widely used method in Human Computer Interaction (HCI), and discusses how it helped to address the challenges of doing Participatory Design (PD) in a hospital setting with young patients. The paper focuses on i) the process of designing the cards, including a discussion of the underlying methodological and conceptual frameworks, ii) implementation of the card sorting exercise in a study mapping the transition experiences of young patients, and iii) what considerations must be taken when moving methods from PD into a hospital setting.

This paper is structured as follows: first we will present the design process behind our card sorting method and the methodology and concepts that formed the framework for this study. In section 3 we will present the implementation of the method, Transition Cards, at two hospitals in Norway, where we interviewed young patients before and after transition. We will discuss our insights in section 4 before presenting concluding remarks and areas for future research.

2. DESIGN OF THE TRANSITION CARDS

Although there is a scarce amount of research done with teenage patients, there exists a large amount of websites and mobile applications developed to support self-management and social connection between patients. Few of these initiatives have been designed together with patients, or aimed specifically at young patients. As Kanstrup et al. (2014) put it, "[p]atients tend to be human factors rather than human actors in the design of digital technology for healthcare" (ibid., p. 12). The authors interpret the absence of patient participation as an underestimation of patients' ability to contribute in design and innovation, and provide a list of studies demonstrating that given a chance, patients of different ages and capabilities can contribute to design and innovation of healthcare technologies. Mazzone et al. (2008) argue that teenagers are not only capable of productively contributing to design, but that they may benefit from the design process itself. Based on these arguments and our previous experience (van der Velden and Machniak 2014), we decided to take a PD perspective on transition and possible ICT solutions, because this perspective "takes into consideration the needs, interests and abilities of the youngsters, but also includes a more profound interest in their hopes, fears, dreams, and opportunities to express themselves as someone of importance" (Iversen and Smith 2012, p.113).

Carroll and Rosson (2007) propose that PD integrates two radical propositions: one moral and one pragmatic. The moral proposition embraces that the people whose lives will be affected by the design must have a say in what it will be, and the pragmatic proposition is that inclusion of future users will lead to a more successful design outcome. In the context of design for healthcare, PD has been successfully applied and led to improvements of healthcare services (Bate and Robert 2007).

The study we report from has been a part of a larger design and research project, KULU (www.kulu.no), which stands for the Norwegian acronym for 'Cool technologies for youth with long-term health challenges'. The project aims to understand digital media and design new ICTs with and for young people with long-term health challenges. The overarching principles behind KULU are those of user inclusion and age-appropriate methods. We believe that by giving young people, who are avid users of digital media, a voice in the design process and facilitation of mutual learning may lead to design of *cool* technologies on young people's terms. The motivation for using the notion of *cool* is that when designing with and for teenagers, we need to understand them and their worlds (Horton et al. 2012). The concept of *cool* has been used extensively in marketing and has recently gained attention in the field of design. As a phenomena, *cool* is a social construct belonging to and being recognized solely by the teenage population (Fitton et al. 2012) and, as such, an indicator of what is age-appropriate for this population.

The debates surrounding *cool* resolve around the beholders of *cool*, which has implications for design. On one side, *cool* is argued to be a personality trait, which entails that we can only approach the concept through the perception of *cool* people. The other side of the debate, dominant within the field of design is that *cool* can be an attribute of a product and can therefore be designed for. Machniak (2014) argues that while the main debate surrounding the concept of *cool* has resolved around whether *cool* was an attribute of a product or a personality trait, *cool* can also become a value that guides the design a *cool* product. This entails allowing *cool* to become a part of the design process through *cool* methods focusing on pursuing *cool* in perceptions of participating teens. In this view, the "front-loading" (van den Hoven 2007) of the value of *cool*, guides the whole design process, may result in a *cool* result (see also van der Velden and Mörtberg 2014).

Moore (2004) argues that the subjective qualities of *cool* imply certain *knowingness.* Knowingness obtained through the perceptions of the relevant social group. This concept is highly relevant in the context of PD, as it assumes teens in an expert position. There are benefits in achieving a better understanding of how young people act in and perceive the world, and the context we design for (Hagen et al. 2012). As a research methodology, PD puts users in an expert position, as they are the only ones with insights into their own practices and perceptions of the world, and aims to explore how these practices might be changed or supported productively (Spinuzzi 2005). This knowledge is generated through methods, which are designed to support *mutual learning* and create a ‘shared language’ between the designers and users (Hagen et al. 2012). One of the main strengths of PD is its focus on developing innovative methods, tools, and techniques to fit with the specific context of every design project (Kensing and Bloomberg 1998). There are, however some user groups which require more attention to the methods and techniques, such as patients and vulnerable users.

When implementing Participatory Design activities with teenage patients, two issues need to be taken into consideration. Firstly, teenage patients may identify first of all as teens, not as patients (van der Velden and El Emam 2013). Their needs and interests as teenagers may thus be different from their needs and interests as patients. Secondly, these teens may have cognitive, social, and/or physical challenges related to their diagnosis or treatment, which may limit their participation in design activities. Hence, the card sorting method we present in this chapter had to be designed with these considerations in mind.

2.1 Card-based Method

Card-based tools, such as the Card Sorting method (Hudson 2005), are popular design methods and serve different purposes and stages in the design process. Wölfel and Merritt (2013) provide an analysis of existing card-based design methods based on five dimensions: intended purpose of use, duration of use, methodology, customization, and formal/material qualities. Within the PD methodology, they found patterns cards being customized for a specific point during the design process. This was also the case in our study. The method we present was used early in the PD process as means of investigating real life practices and uncovering problem areas (Bratteteig et al. 2012). In order to envision alternative practices, we needed to examine the practices and needs of teenage patients, for which we decided to conduct card sorting with young patients. For the purpose of our work, we needed to design a new set of context-specific cards, which we called Transition Cards. Our work with the Transition Cards builds on previous work of (Culén and van der Velden, 2015), in which the authors designed and used Travel Experience Cards (TEC) to capture user experiences in public transportation. Inspired by Service Design Cards (Clatworthy 2011), the TEC card set was designed as a visual tool to both visualize a so-called customer journey with its service moments, such as checking departure times or buying a ticket, and to capture the travel experiences between those service moments.

The underlying motivation for the design of the Transition Cards was not visual methodology and service design, as in the case of the TEC cards, but rather an effort towards designing an age-appropriate tool for Participatory Design with young patients. In addition, when looking at transition as a process affected by and influencing the whole life of a patient, rather than a process taking place within a healthcare institution, operating with concepts such as touch points or services does not provide a holistic picture of patients' experiences and expectations surrounding transition. The goal of the Transition Cards method was not to generate quantitative data for detailed analysis, but rather to aid participants in talking about transition.

2.2 Preparing the Content of the Cards

We started the design of the cards with a study of the main points and aspects surrounding transition. We reviewed published literature on transition, national guidelines for transition, and various tools for transition offered by healthcare institutions, such as checklists and other paper-based tools. We conducted a thematic analysis of the literature, and 4 themes emerged: people, things, skills, and feelings. Within each theme we tried to identify as many keywords and concepts as possible to give the participants a rich selection to choose from. Based on our previous research with teenage patients, we wanted the cards to represent both things related to being a patient as well as regular teenager, in order to encapsulate the holistic view of transition as something affecting all aspects of life as well as allowing the participants to present their stories not only as patients, but also "regular" teenagers (van der Velden and El Emam 2013). Our work resulted in 70 different keywords presented in Table 1.

Table 1. List of the different keywords within the four themes represented by a Transition Card during the interviews.

People	Things	Skills	Feelings
Parents	School	Treatment	Alone
Family	Work	My condition	Lonely
General Practitioner	Home	Sleep	Choice
Doctor	Hobby	Emergency (get help)	Afraid
Nurse	Medications	Informed consent	Worried
Friends	Map (Where to go)	Prescriptions	Excited
Boy-/girlfriend	Examinations	Book appointments	Loss
Supporter	Surgery	Patient rights	Unknown
Stranger	Training plan	Own contribution fee	Insecure
People online	Diet	Exemption card	Waiting
Other patients	Aids	Confidentiality	Proud
Patient organization	Diagnosis	Needs	Independent
Psychologist	Sports	Obligations	Cool
Someone you can trust	Tests	Checklists	Uncool
Pets	NAV (social services)	Accessibility	Responsibility
		Pharmaceutical label	Trust
		Nutritional diet	Grown up
			Legal
			Well-being
			Dread
			Despair
			Confused
			Stress

Our main interest was not only to find out what or who was important during transition, but also to place these elements on a timeline. Therefore we decided that the cards should be sorted into time periods during the interviews. Brucker (2010) distinguishes between “open” and “closed” sort, where in open sort, the users sort the cards into meaningful categories, which they name themselves, while in “closed” sort the users are asked to fit each card into a predetermined category. Each of these approaches comes with its drawbacks and advantages. For the purpose of our study, we decided on a “closed” sort where the participants would sort the cards into time-periods, which were used to mark different stages in transition according to the Norwegian guidelines for transition. The categories we used were: *Child and Youth Clinic* representing the time between the age of 13 and 17, the number *18,* which was the recommended age for transition, and *Adult Medicine* which enveloped the period after transition. At that time, we believed these categories to be meaningful – both for the participants and for our analysis.

2.2.1 Anatomy of the Transition Cards

Based on our experiences with the TEC cards, we decided to use visual materials, such as pictures, in our cards. The use of images as representations augments cognition (Culén and van der Velden 2015). Images hold the potential of freeing the working memory and allow for “offloading of cognitive processes onto perceptual process” (ibid.). However, while images would provide sufficient information in the mapping of experiences in public transportation, visual representations of things related to transition could confuse the participants. Therefore we used images not as the primary source of information on the cards, but rather as illustrations for the key words and concepts written on the cards.

The images used on the cards were partly taken by us and partly taken from Internet sites. Our previous research showed that when rating different social networking sites according to their level of *coolness* as perceived by the participants, Instagram, with its filters and editing functions, was one of the most popular image sharing apps among teenagers (Machniak 2013). Because of our commitment to designing *cool* methods, we decided to apply instagram filters to the images, which we then placed into Polaroid frames together with the keywords (Figure 1). The cards contained three pieces of information: a keyword, image, and a colored dot representing one of the four themes (*people, things, skills, feelings*), allowing for easier analysis after the interviews. The cards were printed out and laminated to allow for easy disinfection (van der Velden and Culén 2013).

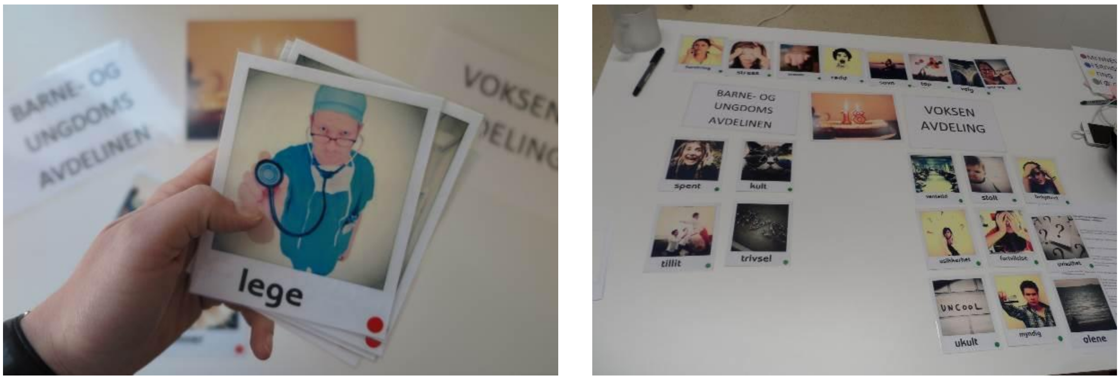

Figure 1. Transition Card with the keyword "Doctor" (left) and a participant's organization of the cards in categories.

3. IMPLEMENTATION AND APPROPRIATION OF THE CARDS

The first design iteration of the Transition Cards was performed by the KULU researchers and was based on existing literature and our commitment to creating *cool* tools. We envisioned the cards to be used during group interviews, in which young patients would pick relevant cards, place them within the three preselected categories, and discuss transition to give us a nuanced view of transition representing multiple voices. Following this exercise, the participants would share their thoughts on where and when ICTs could support them in transition and what ICTs they envisioned. In this section we present how the method and the tool changed through testing and appropriation during our studies in the field.

3.1 Recruitment and Participants

In total 23 young patients participated in this study, 14 girls and 9 boys, their ages between 13 and 25. We first applied and tested the method in a workshop with the Youth Council of the Akershus University Hospital (AHUS) in Norway. The Youth Council serves as a representative organ for young patients at AHUS and advices the hospital on how to improve their services and make AHUS more youth-friendly. Five girls and three boys participated in the workshop. We conducted a pilot interview with a young patient, 22 years old girl, who was recruited through a patient organization. We then implemented the method during individual interviews with 8 patients recruited by the head of Research and Development of the Pediatric Clinic at AHUS, while they were receiving treatment at the clinic. Their ages were 13-18. The final implementation of the method was at adult clinic at the Central Hospital in Vestfold (SiV) where we interviewed 6 patients, ages 21 to 25, who were recruited by the head of research and the nurse responsible for their treatment.

The Head of Research and Development of AHUS, and the nurses at SiV made sure that the participants were well enough to participate and ongoing consent (Culén and van der

Velden, 2013) was maintained throughout the interview session. The participants received a leaflet with information and a consent form, which was signed by the participants, researcher, and the guardians of participants under the age of 16. The participants were informed that their diagnosis would not be discussed, that they remained anonymous, and that they could retract their participation at any point in time. The Norwegian Data Authority, the Privacy Regulator of AHUS, and the Privacy Regulator of SiV approved the study.

3.2 Workshop with the Youth Council and pilot interview

In the period 2013-2015, the KULU team conducted 4 workshops with the AHUS Youth Council. During one of the workshop at AHUS, we tested the cards and the method with the Youth Council by splitting them into two groups of 4 participants. Each participant in a group received a set of cards with one theme (*people, things, skills or feelings*). They were then asked to choose three cards and place them under each category (*Child and Youth Clinic, 18, and Adult Medicine,* see Figure 2). Once the participants were done with a theme, they handed the deck of cards to the next person and received a new deck representing a different theme and were asked to repeat the exercise. This proved to be difficult for several reasons. First, as we thought the Transition Card sorting to be a collective effort, we operated with only one set of cards, which presented the next participant with a smaller selection of cards. Second, some of the participants had trouble choosing which cards they thought were most important for them. According to our observations, it seemed as the participants had problems with viewing the card exercise as a group process, which would result in showing their collective perception of transition. They seem to want to tell their individual stories. In their feedback, they advised us to implement the Transition Card sorting on individual basis or with maximum one more participant. The argument was that stories around transition and life with a diagnosis were so private and personal, that they didn't feel comfortable with sharing them with a larger group of people.

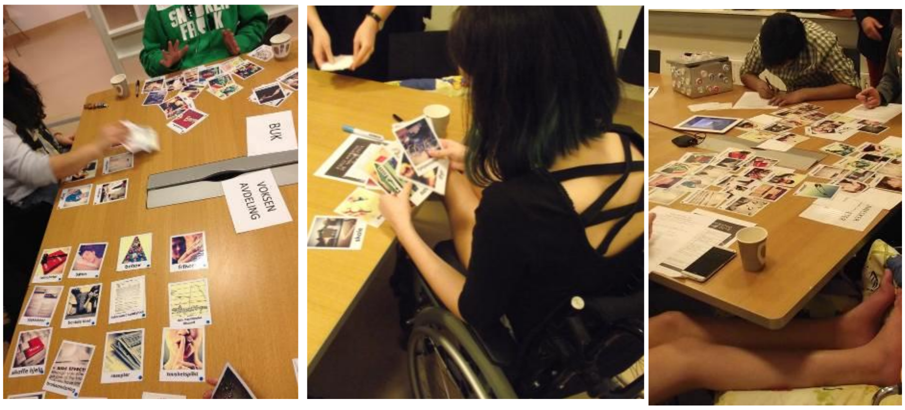

Figure 2. Workshop with the Youth Council

Another comment was that choosing a limited amount of cards made it difficult to tell the whole story as they thought that it was important to convey that patients are also regular teens. In the evaluation of the workshop, the teenagers responded that they liked the cards and thought that this was a cool way to talk about transitions. The cards covered most of the things they wanted to talk about, but they wished to have separate categories for being a patient and a regular teenager. Since they could only choose a limited number of cards, they did not think that the result represented them as a patient *and* as a teenager.

3.2.1 Pilot Interview

After we received the feedback from the Youth Council, we re-evaluated our method and moved it from a group-based approach to individual approach, as proposed by the participants. A pilot card sorting exercise was conducted with a young patient (girl 22), who had already transitioned to adult healthcare. Because of the lessons learned from the Youth Council, we asked the participant to use as many cards as she felt were relevant for her. This approach proved itself to be successful and the participant commented that she enjoyed using the cards. However, the categories we provided did not fit the participant's story. The participant decided to use the space above the category-cards as a space that covered both pediatrics as well as adult medicine (see Figure 1). She explained that many of the things represented by the cards could be important in all of the stages during transition. This alteration resulted in better and broader descriptions of the cards by the participant. In addition, the participant did not use the "18" category other than commenting that it marked being legally an adult. When asked about possibilities for ICTs and design, the participant expressed that the cards helped her to see spaces for technologies.

3.2.2 Final Adjustments and Implementation at Pediatric Clinic at AHUS

After the feedback from the pilot exercise, we re-evaluated the categories and decided to continue with the categories suggested by the last participant, namely *Child and youth clinic, Adult Medicine,* and a new category *Both* which contained the first two categories. Because the Transition Cards method was to be implemented at the pediatric clinic while the participants received treatment, we had to re-think the physical qualities of the cards. The treatment rooms were not equipped with the large tables we had used during the previous sessions and the patients could not use both arms due to the IV. In our earlier research, we used the "Cool Wall", which was a magnetic white board that we used for research on cool social networking sites and designing a health-oriented social networking site for teenagers (Machniak 2014; Culén and van der Velden 2013). Our experiences showed that magnets representing different social media sites and functions allowed us to work with bed-ridden patients and the whiteboard offered a great deal of flexibility during the interviews. In addition, several of the participants in the previous study expressed that they thought that the magnetic board was *cool* and were even interested in buying one. Drawing on this experience, we produced a set of smaller-sized Transition Cards and applied magnetic tape to their backs. We drew the categories on the whiteboard and the participants could choose as many cards as they wished.

We interviewed the youth while they received treatment at the Pediatric clinic at AHUS. The majority of participants had no trouble with understanding the task and even made their own categories such as 'in-between', showing that they understood the purpose of the cards and the categories on the board (see Figure 3). Two of the participants, however, showed some signs of confusion around the task, which proved that the Transition Cards sorting wasn't intuitive and self-explanatory, but rather dependent on careful explanation, especially with regard to the purpose and objective of the study. Once the purpose of the study was clear, the participants showed no signs of confusion and completed the exercise.

Following each theme, we asked the participants whether we had covered all aspects that they thought were important for young patients awaiting transition. We received most suggestions on the *people* theme, where the participants would like to include specific nurses, friends, or family members. Two participants elaborated that while friends were important to them as means of socializing, only their best friends knew about their condition, and emphasized that the card “Friends” represented one-two best friends who supported them in their role as patients.

After sorting the four sets of cards, we asked the participants how and where they thought that ICT and other interventions could support them in transition. Because the participants had just categorized and talked about the various challenges and expectations related to transition, they could more easily target specific challenges and suggest how they could be supported in tackling these.

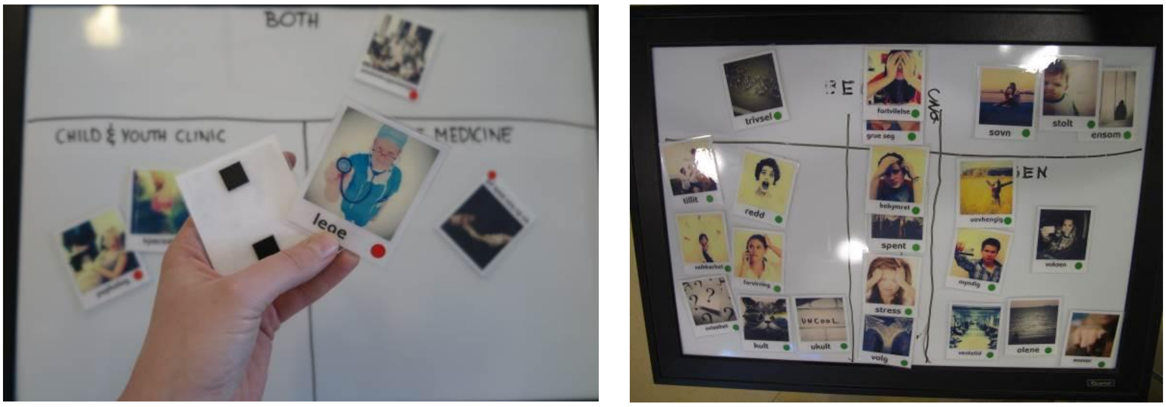

Figure 3. The final set of transition cards and the magnetic whiteboard (left) and an example of a participant altering the categories on the whiteboard (right).

3.2.3 Interviews with young adults at SiV

Based on the positive experiences with the Transition Cards at AHUS, we decided to use the same set of cards and approach with the young adults at the medical gastroenterology clinic at SiV. The patients we interviewed were all above the age of 22, and some had already transitioned at the age of 16, due to different transition policies. Hence, the role of the TCs had changed; instead of helping the participants with expressing their expectations toward transition, the cards were now supposed to help them remember what had happened and the differences between pediatrics and adult medicine.

As with the pre-transition patients at AHUS, the majority of the participants had little trouble understanding the task and the different categories on the board. They expressed that the cards made it easier to remember what they went through and to recognize the differences between the two wards. As one of the participants expressed *“You get to tell more through cards. Because if I had to say what the difference was, I would say there was no difference between the two [wards]”* (boy, 21).

However, while the Youth Council and the pre-transition patients emphasized the importance of expressing themselves as regular teenagers and not *just* as patients, several of the transitioned participants expressed some confusion around cards representing aspects of life outside of the hospital. One of the participants discarded of the card with the word "pets" saying *"I have a dog, but it has never played a role in this [transition]"* (boy, 21).

We were pleased to hear that the participants did not think that the cards were childish even though they were informed that we had used them in interviews with younger patients. However, two of the participants expressed that they felt unprepared and that if we were to do it again, they would have liked to have a chance to prepare for the interview. One of the participants suggested that we should send a list of the different keyword before the interview to give the participants a chance to prepare for the interview, a form of a probe kit as introduced by (Gaver et al. 1999). Unfortunately, he was the last participant we interviewed.

We noticed the creative use of the whiteboard also in the interviews with post-transition patients. The participants would draw their own spaces on the board to place cards relevant in both pediatrics and adult medicine, and they would explain what they meant with the different cards. When asked about whether they missed any keywords on the board, in line with their younger peers, they would clarify the difference between friends and best friends. Because they understood the Transition Cards to be tools for talking, they did not feel the need to add cards, but included this distinction in their explanations.

4. DISCUSSION

Participatory Design is a methodology concerned with the design of technological artifacts as well as with design processes that enable participants to engage in design activities (Simonsen and Robertson 2012). Methods, tools, and techniques need to be appropriated, altered, and made relevant for whatever participatory action we get involved in (Brandt et al. 2012). In a way, "[d]esign methods are like toothbrushes. Everyone uses them, but no one likes to use somebody else's" (Harrison and Tatar 2011, p.11). PD does not call for the creation of new, or the adaptation of existing, methods for the sake of more methods, but rather all methods need to fit the situation at hand (Bratteteig et al. 2012). While card-based methods are widely used and adapted in PD, descriptions of their design process and development are scarce.

In this project, due to its specific age group, life situation, and design setting; the card sorting method needed to be tailored and re-appropriated. What needed to be taken into account was: i) the challenges of designing with teenagers, ii) physical constrains (such as patient connected to an intravenous system or IV using only one arm, interruptions from the medical staff, need for disinfection), and iii) creating a method that was engaging and easy to understand and allowed the participants to express themselves in a meaningful way – both to the researcher and to themselves.

Designing the Transition Card method and fulfilling the aforementioned criteria showed itself to be a larger project than we had anticipated. Even with our experiences in working with teenagers, we acknowledge how fortunate we were to have an expert panel consisting of the members of the Youth Council who tested and gave us feedback on our method. Much of the literature on designing with future users and on card sorting as a method, suggest group activities as they result in more accurate and average representation of user needs. What we learned from the Youth Council was that talking about transitions or personal stories about managing one's condition in everyday life requires a high degree of sensitivity and confidentiality, and should be done on an individual basis.

When working with vulnerable users (Culén and van der Velden 2013; Vines et al. 2014), we first and foremost need to strive toward protecting and respecting their integrity and privacy. When using card-sorting methods, Brucker (2010) suggests to advice the participants against overthinking the exercise. However, while rapid associations or 'quick and dirty' approaches might work when conducting the Card Sorting method, we cannot ask young patients to map their lives, including their needs, hopes, fears, and apprehensions, etc., by "just putting the card somewhere". Because the Transition Cards are meant to help them with envisioning their futures side by side with technologies, we need to allow them the time they need to carefully and meaningfully sort the cards into right place. In the case of young adults, we needed to allow them some time to remember things that they did not necessarily think about everyday, as for some the transition process happened over a course of two-three years and they struggled with connecting the events to times and places.

PD has traditionally been interested in finding tools for envisioning future ways of living through artifacts. Brandt et al. (2012) present how *enactment* helps people to envision themselves with new designs. Many methods such as scenarios, mockups, prototyping, etc. are being designed to enable future users to envision futures with new, unknown technologies. What is less researched is how future users envision not only new solutions, but also *their own* futures. In the case of transition, our research shows that young patients don't know much about what transition entails or what will happen. Some of the teens we interviewed had simply not thought about it because they had some years left at the pediatric clinic, while other consciously avoided thinking about transition and the responsibilities their adult life would bring. Therefore several participants expressed that they found the Transition Cards helpful in structuring and organizing their thoughts and expectations. As one of our participants expressed *"Actually, I think it was great to have a lot [of cards] to choose from. Then you start to think about what the differences are, what you're going to miss, and what's going to be new. I feel that maybe it's good to have some cards to look at and talk about instead of just getting questions. Yeah, I don't know. It's just the way it is, but when you have a card to talk about – it gets better. So I think it's been great"* (girl, 17). The cards also proved to be helpful in remembering the pasts of the post-transition patients. Being able to physically separate the different aspects of their lives across two time periods helped them to see the differences and to express their thoughts and feelings toward the two very different sections of the hospital.

Because the participants could visualize their expectations and concerns through cards, they easily suggested areas where they felt that ICTs could support them in their transition. This showed that the Transition Cards could be helpful in envisioning both their own futures and technological solutions. We did, however, find the younger participants more motivated and creative in their suggestions for possible technologies and tools to support them in their future transition. The older participants who had managed their transition and adapted to the new situation did not have as many suggestions, which reassured us that PD and involvement of future users and 'transitioners' was important and pragmatically correct.

Our previous research indicates that young patients, teenagers in particular, tend to separate their identity as patients from their identity as young persons (van der Velden and El Emam 2013; van der Velden and Machniak 2014). Therefore it was important to meet the participants in a setting where they felt safe to talk from a patient perspective. Meeting patients in hospitals does however have its drawbacks. As the patients were receiving treatment, nurses, who needed to check on the patients or adjust the medical equipment, often interrupted us. The cards then served as a great way to pick up the interview just where we left it. The participants seamlessly continued on with the next card.

The Transition Cards fulfilled the criteria we mentioned in the beginning of this chapter. Because they were laminated, they could be easily disinfected. The magnetic board allowed the participants to sit or rest comfortably while using it and they were able to see the results in front of them. Although we had set the categories on the whiteboard, the participants could easily change these as they saw fit. The method allowed them to use only one arm. The visual appearance of the cards made the Transition Cards more attractive to use and several participants commented on them and thought they were nice and reminded them of Instagram pictures, which they considered *cool*. One of the post-transition participants expressed that *"I think it was a nice way of doing it. I had like an image, and something to attach it to, so that was nice"* (girl, 25).

The card sorting was split into sessions through the use of themes. The success of splitting the exercise into shorter sessions showed that many short activities with immediate output were appropriate for this age group as argued by Mazzone et al. (2008). The authors also recommend the tasks to be simple and with defined objectives. In our study we found that the participants found the tasks easy, as long as they understood the purpose of the tasks. In addition, we found that the participants were more motivated and understood the task better when we provided a thorough description of the study as a whole, which indicated that they wanted to be well informed, not treated as merely informants, and contribute to the study in a meaningful way. When understanding that their contribution could help others in the same situation as their own, the participants also tended to think of other patients when sorting the transition cards, thus strengthening our claim that PD is a very appropriate methodology for young participants as it allows them to assume the expert position and establish themselves as someone of importance (Iversen and Smith 2012). This makes the whole experience more engaging and fun and strengthens mutual learning (Simonsen and Robertson 2012).

We attribute a lot of the success of the Transition Cards to our design workshop with the Youth Council. The method started out as something that belonged to us, the researchers, and during the project, the Youth Council and our participants made it their own, by adapting it to their own use and story telling. We understand this process as appropriation. Appropriation is defined as "the process by which individuals transform their understanding of and responsibility for activities through their own participation" (Rogoff 1995 in Overdijk and van Diggelen 2006). What has been appropriated in our case was the method. Overdijk and van Diggelen (2006) argue that appropriation differs from mastery, because while mastery refers to taking something that belongs to others and internalizing it, appropriation refers to taking ownership over something and adapting it to one's own use. If the Youth Council or the participants would use the Transition Cards in the shape and approach we intended and designed for, the participants would achieve mastery. However, as we have described in this paper, the participants appropriated the method: the Youth Council by re-designing it and the participants through rearranging and changing the categories and meanings of the cards.

The process of appropriation, where users take technologies, and as in our case – methods, and shape these to their own ends can lead to empowerment (Bannon and Ehn 2012), which is one of the pillars of and motivations for applying PD. It is important to stress that the method is not created anew each time it is used, removing all possibilities for consistency in the results. Overdijk and van Diggelen (2006) explain that "tools are created and transformed during the development of an activity and carry with them a particular culture – the historical remnants from this development". Our proposition is that by allowing a method to be flexible and open for adaptation in use, we enable the ongoing improvement of the method as well as empowerment through the process of appropriation. The participatory process and values should be transferred to the process of methods design for the same pragmatic and moral reasons as application of PD in design of technologies.

5. CONCLUSION

Through the process of designing the Transition Cards, we learned that future users should not only be involved in the design of technological solutions, they should also be involved in the methods for designing such solutions. If we are to call our participants co-designers, we need to open up the process of designing the methods for their input. Especially in the context of vulnerable users or vulnerable life situations, it is important to consult the participants about which methods are adequate to elicit their contribution in terms of knowledge, experience, needs, etc.

We would like to note that using methods designed together with the users in a Participatory Design process does not ensure that the whole design process is PD. As Iversen et al. (2010) argue, "[i]t's about how, when and why these methods are used that renders the approach as being Participatory Design". As described in section 2, the concept of *cool* framed our efforts and motivations behind the Transition Cards. This did not necessarily result in the method being *cooler* than any other method, but led to a specific way of designing it. By following the notion that *cool* requires *knowingness* obtained only through the perceptions of teens, we were compelled to seek out their opinions and enable ongoing appropriation of both the tool and the method. There is nothing new about the fact that designers must adjust their methods during a design sessions with the users. The novelty of this approach is about creating opportunities for appropriation by the users through adjustments initiated by the users. When working with hard-to-reach populations, such as young patients in hospitals, there is little space and time for failure or adjustments. By keeping the method and tools flexible enough for appropriation by the users during the interviews, we can create participatory processes and allow the users to truly establish themselves as co-designers even in the phase of exploring existing practices.

This article presented a discussion and analysis of including users in the design of a participatory method. While this approach is still in its early stages, we hope that it will inspire designers to include users in the design of their methods and further work in this field. We also hope that the Transition Cards method described here will help both designers and healthcare practitioners in learning more about the experiences and needs of young patients.

ACKNOWLEDGEMENT

The authors gratefully acknowledge the support and cooperation of the Children and Youth Clinic of Akershus University Hospital and the Medical Gastroenterology Clinic of the Central Hospital in Vestfold during the planning and implementation of the study and their staff for facilitating the interviews. We thank all the participants for sharing their knowledge and experiences. We especially would like to thank the Youth Council for their willingness to spend time with us and share their expertise.

REFERENCES

Alpay, H., 2009. Transition of the Adolescent Patient to the Adult Clinic. *Peritoneal Dialysis International*, 29(Supplement 2), pp.S180–S182.

Applebaum, M.A. et al., 2013. Perception of transition readiness and preferences for use of technology in transition programs: teens' ideas for the future. *International Journal of Adolescent Medicine and Health*, 25(2), pp.119–125.

Baldassano, R. et al., 2002. Transition of the Patient With Inflammatory Bowel Disease From Pediatric to Adult Care: Recommendations of the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition. *Journal of Pediatric Gastroenterology & Nutrition*, 34(3), pp.245–248.

Bannon, L.J., Ehn, P., 2012. Design matters in participatory design. In *Routledge Handbook of Participatory Design.* New York: Routledge, pp. 37-63.

Blum, R.W., 2002. Introduction. *Pediatrics*, 110(Supplement 3), pp.1301–1303.

Bowen, M.E. et al., 2010. Health Care Transition in Adolescents and Young Adults With Diabetes. *Clinical Diabetes*, 28(3), pp.99–106.

Brandt, E. et al., 2012. Tools and techniques: Ways to engage telling, making and enacting. In *Routledge Handbook of Participatory Design*. New York: Routledge, pp. 145–181.

Bratteteig, T. et al., 2012. Methods: Organising principles and general guidelines for Participatory Design projects. In *Routledge Handbook of Participatory Design*. New York: Routledge, pp. 117–144.

Brucker, J., 2010. Playing with a Bad Deck: The Caveats of Card Sorting as a Web Site Redesign Tool. *Journal of Hospital Librarianship*, 10(1), pp.41–53.

Callahan, S.T. et al., 2001. Transition from pediatric to adult-oriented health care: a challenge for patients with chronic disease. *Current opinion in pediatrics*, 13(4), p.310.

Campbell, F. et al., 1996. Interventions to improve transition of care for adolescents from paediatric services to adult services. In *Cochrane Database of Systematic Reviews*. John Wiley & Sons, Ltd.

Clatworthy, S., 2011. Service innovation through touch-points : development of an innovation toolkit for the first stages of new service development. *15-28.*

Culén, A.L. & Velden, M. van der, 2013. The Digital Life of Vulnerable Users: Designing with Children, Patients, and Elderly. In M. Aanestad & T. Bratteteig, eds. *Nordic Contributions in IS Research*. Lecture Notes in Business Information Processing. Springer Berlin Heidelberg, pp. 53–71.

Culén, A.L. & Velden, M van der, 2015. Making Context Specific Card Sets – A Visual Methodology: Capturing User Experiences with Urban Public Transportation. *International Journal On Advances in Intelligent Systems*, in press.

Fernandes, S.M. & Landzberg, M.J., 2004. Transitioning the young adult with congenital heart disease for life-long medical care. *Pediatric Clinics of North America*, 51(6), pp.1739–1748.

Fitton, D. et al., 2012. Constructing the Cool Wall: A Tool to Explore Teen Meanings of Cool. *PsychNology Journal*, 10(2), pp.141–162.

Harrison, S. & Tatar, D., 2011. On Methods. *interactions*, 18(2), pp.10–11.

Hagen, P., Collin, P., Metcalf, A., Nicholas, M., Rahilly, K., Swainston, N., 2012. Participatory Design of evidence-based online youth mental health promotion, intervention and treatment. *Melb. Young Well Coop. Res. Cent.*

Horton, M., Read, J.C., Fitton, D., Little, L., Toth, N., 2012. Too Cool at School - Understanding Cool Teenagers. *PsychNology J.* 10, 73–91.

Hudson, W., 2005. Playing Your Cards Right: Getting the Most from Card Sorting for Navigation Design. *interactions*, 12(5), pp.56–58.

Iversen, O.S., Halskov, K., Leong, T.W., 2010. Rekindling values in participatory design. In: *Proceedings of the 11th Biennial Participatory Design Conference*. pp. 91–100.

Iversen, O.S. & Smith, R.C., 2012. Scandinavian Participatory Design: Dialogic Curation with Teenagers. In *Proceedings of the 11th International Conference on Interaction Design and Children*. IDC '12. New York, NY, USA: ACM, pp. 106–115.

Jacobson, L. et al., 2001. How do teenagers and primary healthcare providers view each other? An overview of key themes. *British Journal of General Practice*, 51(471), pp.811–816.

Kanstrup, A.M. et al., 2014. Patient innovation: an analysis of patients' designs of digital technology support for everyday living with diabetes. *Health Information Management Journal*, pp.1–9.

Kensing, F., Blomberg, J., 1998. Participatory Design: Issues and Concerns. Comput. Support. *Coop. Work CSCW 7*, 167–185.

Kleinert, S., 2007. Adolescent health: an opportunity not to be missed. *The Lancet*, 369(9567), pp.1057–1058.

Lang, A.R. et al., 2012. Not a minor problem: involving adolescents in medical device design research. *Theoretical Issues in Ergonomics Science*, pp.1–12.

Machniak, M. 2013. Sprinklr: Designing a "cool" health-oriented social networking site with and for teenagers.. *University of Oslo.*

Machniak, M., 2014. In pursuit of cool and its implications for the design process. In *Celebration, Transformation, New Directions.* CATAC'14. Oslo, Norway, pp. 66-82.

Mazzone, E. et al., 2008. Design with and for disaffected teenagers. In *Proceedings of the 5th Nordic conference on Human-computer interaction: building bridges*. NordiCHI '08. New York, NY, USA: ACM, pp. 290–297.

Moore, R.L., 2004. We're Cool, Mom and Dad Are Swell: Basic Slang and Generational Shifts in Values. *Am. Speech 79*, 59–86.

Overdijk, M., van Diggelen, W., 2006. Technology appropriation in face-to-face collaborative learning, in: *First European Conference on Technology Enhanced Learning.* pp. 1–8.

Patterson, D.L. & Lanier, C., 1999. Adolescent health transitions: focus group study of teens and young adults with special health care needs. *Family & Community Health*, 22(2), pp.43–58.

Reiss, J. & Gibson, R., 2002. Health care transition: destinations unknown. *Pediatrics*, 110(Supplement 3), pp.1307–1314.

Resnick, M.D. & Bowes, G., 2007. Us and them: worldwide health issues for adolescents. *The Lancet*, 369(9567), pp.1058–1060.

Robertson, T. & Wagner, I., 2012. Ethics: Engagement, representation and politics-in-action. In *Routledge International Handbook of Participatory Design*. New York: Routledge, pp. 64–85.

Sawyer, S.M. & Ambresin, A.-E., 2014. Successful Transitions: Beyond Disease Control to Better Life Chances. *Journal of Adolescent Health*, 54(4), pp.365–366.

Simonsen, J. & Robertson, T., 2012. *Routledge international handbook of participatory design*, New York: Routledge.

Spinuzzi, C., 2005. The Methodology of Participatory Design. *Tech. Commun.* 52, 163–174.

van der Velden, M., 2014. Re-Politicising Participatory Design in the Fairphone Project - P2P Foundation. In: Proceedings of CaTaC 2014, the 9th International Conference on Culture, Technology, Communication, pp. 139–157.

van der Velden, M. & Culén, A., 2013. Designing privacy with teenage patients: Methodological challenges. In *Methods of Working with Teenagers in Interaction Design*. Workshop at CHI 2013.

van der Velden, M. & El Emam, K., 2013. "Not all my friends need to know": a qualitative study of teenage patients, privacy, and social media. *Journal of the American Medical Informatics Association: JAMIA*, 20(1), pp.16–24.

van der Velden, M. & Machniak, M., 2014. Colourful Privacy: Designing Visible Privacy Settings with Teenage Hospital Patients. In *ACHI 2014, The Seventh International Conference on Advances in Computer-Human Interactions*. pp. 60–65.

Vines, J. et al., 2014. Special topic: Designing for and with vulnerable people. *Interactions*, 21(1), pp.44–46.

Wölfel, C. & Merritt, T., 2013. Method Card Design Dimensions: A Survey of Card-Based Design Tools. In P. Kotzé et al., eds. *Human-Computer Interaction – INTERACT 2013*. Lecture Notes in Computer Science. Springer Berlin Heidelberg, pp. 479–486.