
Designing Privacy with Teenage Patients: Methodological Challenges

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Abstract

We report from a study with 16 teenage hospital patients, who participated in the design of the visibility of privacy settings in a social network. We describe some of the challenges of design work in a hospital setting, the methods we used in this study, and the development of a new method based on the 'cool wall'.

Author Keywords

Cool; Design methods; Patients; Privacy; Teenagers

ACM Classification Keywords

H.5.2. User interfaces (evaluation methodology, interaction styles, prototyping, theory and methods).

General Terms

Design; Human Factors.

Introduction

Interactive technologies, in particular social media, are perceived as particularly appropriate for teenage patient – health care provider communication. There is a growing body of online and mobile health care technologies for young patients. In several of these initiatives teenagers, mostly chronically ill teens, were actively involved in the design process [1,8,9,10,12,16].

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Chronically ill teens (12-18 years old) are born with a medical condition or they develop a condition during their childhood (rare diseases, cancer, chronic organ diseases, etc.). They require continuous treatment and follow-up, often for the rest of their lives. From developmental and disease management perspectives, these teens are considered a distinct group of patients. The teenage period is viewed as preparation for the transition to the adult healthcare system, where young patients take increasingly more responsibility for their health and treatment [3,5].

Chronically ill teenagers have, in addition to their information and communication needs and interests as teenagers, additional needs and interests as patients. In our research with teenagers, we focus on how interactive technologies are, and can be, used to support their information and communication needs as patients. We are especially interested in their online privacy needs and privacy related activities. One of the aims of our study is to contribute to the development of methods for including teenage patients in the design of technologies that matter to them. In this paper, we report on the methodological challenges of working with teenage hospital patients as participants in design.

Including young patients in the design of interactive technologies is an important requirement for patient-centered design and participatory design [4,14,16]. Designing with young patients is perceived as difficult because of the extra challenge involving ethical issues and consent [10]. Secondly, they may have self-esteem issues or not associate their personal identity with their diagnosis, and may, therefore, not want to participate on the basis of being a patient [6,11,15].

Designing Privacy with Hospitalized Teens

We report here on the methodological challenges of designing privacy for patient-centered social media with and for teenage patients. Because of a lack of literature on teenage patients and online privacy, we implemented in 2011 a study among 20 teenage patients in a children's hospital in Canada [15]. The analysis of the qualitative interviews showed, among other things, that all teens were active on Facebook and implemented a wide range of privacy strategies. Facebook was not used to share or discuss their diagnosis.

In a follow-up study, in 2012, 16 teens participated while receiving treatment in the hospital. We implemented a new version of the 2011 study, this time based on a card sorting exercise. They also participated in the re-design of the visibility of Facebook's privacy settings, using paper prototyping, and were asked to describe their ideal patient social network. Based on these experiences in Canada we are now evaluating the use of a 'cool wall' [7,13] in interviews with Norwegian teens, non-patients and non-hospitalized patients. Those experiences will be used to design a 'cool wall' to be used in a hospital setting.

Research with Hospitalized Teens

Research and design work with teenage hospital patients involves a wide variety of ethical, organizational, and logistical challenges. We focus here on the methodological challenges of working with hospitalized teens and only mention other challenges when they directly affect the choice and implementations of methods.

Limitations imposed by the context of the study

Time: Nearly impossible to have un-interrupted time with the participant.

Space: Participants are often in bed, frequently with one arm connected to hospital equipment. Things used for the workshops need to take into consideration the limited space available: they have to fit a hospital tray table.

Process: Needs to be *flexible* – so that the discussion is easily picked up after the interruption; *privacy aware* – so that private information does not get disclosed accidentally; and *mobile* – so that all the props can be easily picked up and moved whenever necessary.

Choice of materials:

Everything shared between the patients needs to be disinfected. Cards and other paper props need to be plasticized.

Teenage patients receiving treatment in a hospital are often isolated from other teens and are immobile because of intravenous treatment or as an effect of their condition. Contact time with the patients had to be organized between doctor visits, treatments, family visits, visits to physiotherapy, hospital school attendance, and homework. It is almost impossible to have non-interrupted time with the participant. Thus, the context of the study imposes some limitations, as shown in the text box on the left.

Designing Privacy with Teens

During the second study in the Canadian children's hospital we used two methods: card sorting and paper prototyping. In Norway, we are now using the 'Cool Wall'.

Card sorting with thinking aloud

During the second study we wanted to find out what teenage patients think about online privacy by asking them what they share on Facebook and with whom. We created a set of 52 plasticized cards, based on the interviews with teenage patients in the first study. We asked the participants to associate the word on the card with Facebook and to sort the cards over three piles: positive, negative, and neutral. While they sorted the cards, we asked them to think out loud. We then asked them to select the top 3 positive and negative associations. Almost all participants were eager to explain the reasons for sorting cards in a particular way. Of the 16 participants in the card sorting exercise, two were not able to sort the cards themselves. One participant had to lie flat and could therefore not use her bedside table to sort the cards. One participant could not use either arm. Some movements in the card

sorting game easily triggered the alarm from the intravenous system.

Prototyping

The prototyping exercise was based on a set of plasticized cards with design alternatives for the visibility of privacy settings in a social network. We then worked on the personalization of one alternative design, using paper, markers, and a pen on the hospital tray table. The example in the prototyping exercise was based on Facebook. All participants were experienced Facebook users and therefore felt familiar with the task at hand. In order to work on the paper prototype, the participant had to be able to sit up straight in bed in order to have a good view on the paper. This was uncomfortable for some patients and impossible for the participant who was lying flat. In these cases we asked the participants to tell us how they would do it. The researcher would implement it and make sure this was the way the participant had in mind. We felt that this way of working was not particularly inspiring for the participants. The quality of their prototyping was lower than in the case of participants doing it themselves.

'Cool Wall'

Looking for other and maybe more appropriate ways to include teenage hospital patients in design work, we were inspired by the research on 'cool' and the 'Cool Wall' [2,7,13]. We are at the moment testing a prototype, made out of a metal panel, magnets, sticky tacks, and paper icons (see Fig. 1), with a small group of teenagers, non-patients and non-hospitalized patients in Norway. The 'Cool Wall' is used to find out which social media applications are considered cool and what are cool things to do on a patient-centered social network.



Metal board with magnets is used. Extra icons, as well as some blank cut outs are available to teenagers to use on their cool wall. Sticky tacks allow for quick adaptations.



The wall has 4 categories: absolutely not cool, not cool, cool and super cool. Teenagers express the need for a 5th category: neutral.

Figure 1. Figure 1. 'Cool Wall' inspired by [7].

Conclusions and Future Work

Interaction design with teenage patients in the hospital challenges the array of available design methods. Our methodology was further challenged by the topic at hand, designing privacy. Teens have particular privacy concerns, needs, and strategies, but don't necessarily express these in the language of privacy and confidentiality.

From 'cool wall' to 'social wall'

We are at the moment designing the next version of our 'wall', which will be a magnetic white board on a stand, which can be positioned in different ways on a hospital table or above an hospital bed. The white board function makes it possible to quickly change the layout of the 'wall'. After the 'cool' exercises we can thus use the 'cool wall' as a 'social wall' to map the social world of the participants: who play important

roles in a teenage patient's life and who should be able to join the teen in a patient-centered social network.

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References

- [1] Allsop, M.J., Holt, R.J., and Levesley, M.C. The engagement of children with disabilities in health-related technology design processes: Identifying methodology. *Disability and Rehabilitation: Assistive Technology* 5, 1 (2010), 1-13.
- [2] Culén, A.L. and Gasparini, A. Situated Techno-Cools: factors that contribute to making technology cool and the study case of iPad in education. *Psychology Journal* 10, 2 (2012), 117-139
- [3] Alpay, H. Transition of the Adolescent Patient to the Adult Clinic. *Peritoneal Dialysis International* 29, Supplement 2 (2009), 180-182.
- [4] Berwick, D.M. What 'Patient-Centered' Should Mean: Confessions Of An Extremist. *Health Affairs* 28, 4 (2009), 555-565.
- [5] Callahan, S.T., Winitzer, R.F., and Keenan, P. Transition from pediatric to adult-oriented health care: a challenge for patients with chronic disease. *Current opinion in pediatrics* 13, 4 (2001), 310.
- [6] Chira, P., Nugent, L., Miller, K., et al. Living Profiles: Design of a health media platform for teens with special healthcare needs. *Journal of Biomedical Informatics* 43, 5, Supplement (2010), S9-S12.
- [7] Fitton, D., Horton, M., Read, J.C., Little, L., and Toth, N. Climbing the cool wall: exploring teenage preferences of cool. *Human Factors in Computing Systems Extended Abstracts*, ACM (2012), 2093-2098.
- [8] Franck, L.S. and Noble, G. Here's an idea: ask the users! Young people's views on navigation, design and content of a health information website. *Journal of Child Health Care* 11, 4 (2007), 287-297.
- [9] Frost, J., Beekers, N., Hengst, B., and Vendeloo, R. Meeting cancer patient needs: designing a patient platform. *Human Factors in Computing Systems Extended Abstracts*, ACM (2012), 2381-2386.
- [10] Lang, A.R., Martin, J.L., Sharples, S., Crowe, J.A., and Murphy, E. Not a minor problem: involving adolescents in medical device design research. *Theoretical Issues in Ergonomics Science* 0, 0 (2012), 12.
- [11] Mack, R., Giarelli, E., and Bernhardt, B.A. The Adolescent Research Participant: Strategies for Productive and Ethical Interviewing. *Journal of Pediatric Nursing* 24, 6 (2009), 448-457.
- [12] Mazzone, E., Read, J., and Beale, R. Design with and for disaffected teenagers. *NordiCHI* (2008), 290-297.
- [13] Read, J., Fitton, D., Cowan, B., Beale, R., Guo, Y., and Horton, M. Understanding and designing cool technologies for teenagers. *Human factors in computing systems*, ACM (2011), 1567-1572.
- [14] Reis, C.I., Freire, C.S., Fernández, J., and Monguet, J.M. Patient Centered Design: Challenges and Lessons Learned from Working with Health Professionals and Schizophrenic Patients in e-Therapy Contexts. In M.M. Cruz-Cunha, J. Varajão, P. Powell and R. Martinho, eds., *ENTERprise Information Systems*. Springer Berlin Heidelberg, 2011, 1-10.
- [15] Velden, M. van der and Emam, K.E. "Not all my friends need to know": a qualitative study of teenage patients, privacy, and social media. *Journal of the American Medical Informatics Association* 20, 1 (2013), 16-24.
- [16] Waller, A., Franklin, V., Pagliari, C., and Greene, S. Participatory design of a text message scheduling system to support young people with diabetes. *Health Informatics Journal* 12, 4 (2006), 304-318.