Colourful Privacy

Designing visible privacy settings with teenage hospital patients

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Abstract—**The paper reports from a qualitative study based on the analysis of semi-structured interviews and Participatory Design activities with hospitalised teenagers with chronic health challenges. We studied how teenage patients manage their online privacy, with a focus on the design and use of privacy settings. We found that the majority of participants preferred to visualise privacy settings through the use colours and to personalise access control. They also considered these necessary on more secure patient-centred social media. As proof of concept, we implemented some of the findings in a patient social network setting. We conclude that visualising and personalising privacy settings enable young patients to have more control over the sharing of personal information and may result in a more effective use of privacy settings. In addition, privacy-aware default settings may prevent teens from unintended sharing of personal information.**

Keywords-Facebook; participatory design; patient social media; privacy settings; teenage patients; visualisation of privacy

I. Introduction

From a developmental perspective, the teenage years (12-18 years old) are characterised by a quest for identity, independence, and autonomy [1]. New digital technologies, such as social media and mobile phones, are described as supporting this quest [2], [3]. These technologies are therefore now also explored as platforms to provide support to teenagers who are dealing with chronic health challenges, such as diabetes, asthma, cancer, chronic organ diseases, rare diseases, etc. There is a growing interest in the design and development of new applications, and several initiatives actively involve young patients in the design process [4]–[9].

Chronically ill teens are born with a medical condition or they develop such a condition during their childhood or their teenage years. More and more children born with chronic diseases survive into their adult years [10]. As a result, the teenage years are seen as a transition period, in which teens begin to take more responsibility for the treatment and other activities required by their diagnosis [11]. They may therefore have additional information and communication needs and interests because of their chronic diagnosis and treatment.

In Participatory Design, new interactive technologies are not only designed for young patients – they are designed with them [9], [12], [13]. Designing with young patients and other vulnerable users is perceived as difficult as additional ethical issues may arise because of particular circumstances [14], [15], or it may be difficult to include teenage patients because of self-esteem or identity issues [16]–[18].

In our study, we met teenage patients while they were receiving treatment in the hospital. This decision was based on our earlier experiences in research with teenage patients. In a 2011 field study, we looked among other things at the use of a closed social network for young patients in Canada [18], which was often only accessible from a computer inside the hospital. An user account could only be obtained from hospital staff. In order to meet some of the users, we needed to implement the study in one of the participating hospitals.

We were especially interested in understanding how teenage patients *practice* privacy on social media. The practice of privacy can be understood as an expression of their autonomy [19]. We found that many teens don't discuss their diagnosis and treatment with their friends and followers on social media. The reason for this was that they often tried to be "normal" or "regular" teens [18], [20]. Being chronically ill wasn't something they would discuss in social media or sometimes not even outside the physical surroundings of the hospital or the security of the direct family:

"*I guess I just pretend I am normal and I don't have it when I am outside the hospital.*" (girl, 17 yrs.)

"*I like to be as regular as I can, so I don't want to talk about it.*" (boy, 13 yrs.)

We explained this as a form of self-protection and self-presentation [19]. For the outside world, the teens separate their identity as patient from their identity as teenager. Thus, we decided to implement the new study again in the Children's Hospital of Eastern Ontario (CHEO). In order to meet the teens as patients, we needed to meet them where they felt secure to talk from a patient perspective.

This study is part of a larger research and design project called KULU [21]. The objective of KULU is to support young patients (12 – 25 yrs.) with chronic health challenges in their autonomy. One of the KULU projects is the design of a closed social network for teenagers with chronic health challenges. In this paper we present and analyse the design of privacy settings for such a social network. The rest of the paper is as follows: In the next section, we briefly discuss some of the research done on this topic. In Section III, we describe our methodology, methods, and some of the challenges we encountered. In Section IV, we present our

findings, which we discuss in Section V. In Section VI, we implement some of the findings in a prototype for a closed social network for teenage patients. In the final section we present our conclusion and future work.

II. BACKGROUND

The use of personal health information is regulated by national policies and guidelines in order to prevent inappropriate use. Social media and other online sites seriously challenge this regulation: patients voluntarily share their health information online to gain advice and support, or to support others [22], while some medical personnel post images of patients or discuss particular cases with colleagues [23]. Insufficient use of a system's privacy settings, or the copying of information to a site with a less restrictive privacy policy, may unwantedly disclose sensitive health information. This may affect the patient's access to work, insurance, and relationships [24].

A. Design of privacy settings

There is a large body of literature reporting on privacy management, privacy practices, and privacy settings on social networking sites, e.g., [25]–[28], but only a small portion has the design of privacy settings as its focus [29]–[33]. Privacy settings on social networks are the customisable options and technologies that regulate the accessibility of personal data to other users and to third parties. In this context, privacy can be defined as "a set of practices in negotiating the public and private divide" [29]. The design of privacy settings of social networks thus refers to the design of options and technologies that enable users to negotiate this divide. Existing patient social networks, such as Upopolis, PatientsLikeMe, and Mayo Clinic Connect don't use (customisable) privacy settings.

B. Visualising privacy through use of colours

Only a few studies address the use of colours to visualise privacy levels to users of Internet services [34]–[36]. PrivacyDefender, now discontinued, introduced as a Facebook app in 2010, helped Facebook users to understand their privacy settings, but is no longer available [34]. C4PS, now discontinued, was a Firefox browser plug-in using colours to help represent privacy settings on Facebook [32].

III. METHODOLOGY

This study takes a qualitative approach towards the study of teenage patients, social media, and privacy and is guided by the following questions:

- Can design interventions support teenage patients in managing their privacy settings?
- Does a closed social network for young patients need privacy settings?

A. Participatory Design

This study is based on Participatory Design principles [37], [38]:

- Those who will use the technology should have a voice in the design

- Mutual learning between users and designers based on their respective skills, interests, values
- Starting the design process in the practice of the users

We build forth on the teens' existing social networking experiences and skills by using examples from Facebook.

B. Ethical challenges

In the study we adhered to the research ethics and privacy requirements stipulated by the Norwegian Data Inspectorate and the Research Ethical Board of CHEO. There were two additional ethical challenges we needed to deal with, on-going consent and parents. On-going consent is especially important in situations in which the participant is not able to leave the research setting without help. Secondly, most of the teens were accompanied by a parent or other adult relative. The Youth Council of CHEO reminded us to ask the teens if they wanted their parent(s) present or not.

C. Logistical challenges

The particular way in which hospital patients were recruited for the study had an important effect on the design of the study. It was known from the onset that we could not count on more than 30-40 minutes contact time with a patient and that we would meet each teen individually. The majority of meetings took place in a treatment room in the polyclinic or a patient room on one of the wards. In all these cases, the teens were lying in bed and the majority was receiving intravenous treatment while participating in the study. This means that they weren't mobile and had minimal use of one arm.

The rooms were furnished with hospital tables, which could be used for design activities. The size of the tables was 40 x 80 cm and could be installed over the bed. The tables had to be used for the audio equipment of the researcher, to record the session, and storage and use of design materials. The table had to be movable at all times, in order to make room for hospital staff. The design materials themselves needed to be made of materials that could be disinfected when they were used by different patients.

TABLE I. SEMI-STRUCTURED INTERVIEW

Interview themes
1. Technology used in the hospital (mobile phone, laptop, etc.)
2. Favourite sites or things to do on the Internet
3. Age when starting to use Facebook
4. Do you know your privacy settings?
5. Does a closed social network for young patients need privacy settings?

D. Methods

The limited contact time, small workspace, and the need to be flexible in terms of being able to pack things up quickly, if needed, affected our choice of methods. We used semi-structured questions and re-design activities based on paper prototypes as our main methods:

1) Semi-structured interviews

The interview was based on a set of questions that would support the analysis of the paper prototyping (see Table I).

2) Paper prototyping

We based the prototyping activities on the example of an existing social network site (Facebook). The first activity was the comparison of three options for locating privacy settings. The first one was the existing situation and the two others presented possible new situations. The comparison was presented as a game (see Fig. 1), which was used to elicit a discussion about the visibility of privacy settings.
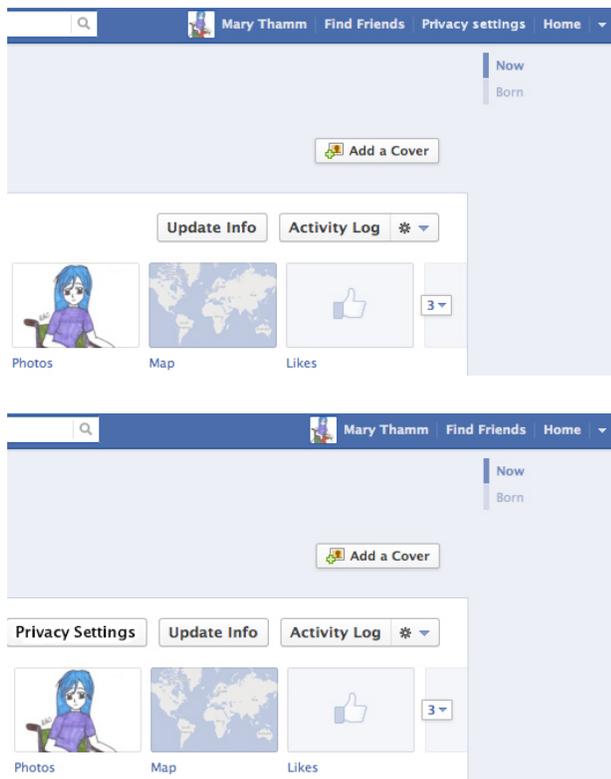

Figure 1. Spot the difference

The second activity was prototyping privacy settings, with a focus on access control: *Who on Facebook can see your status update?* The participants were introduced to using colours to make privacy settings visible. They were given a box with 12 colours and a paper-based image of a status update window. The first image showed the status update window in Facebook. The second image showed the status update window in which the privacy settings were made visible through colours and through self-assigned levels of access. The colours were based on the colour scheme designed by [32]. The participants could use the same colours or personalise the colour scheme.

This prototyping exercise was used to investigate if colours and groups could support the management of their privacy settings. The teens could use Facebook's existing accessibility settings (e.g., 'friends-only', 'friends-of-friends' etc.) or customise these settings so they would better fit their own preferences. We also discussed the need for privacy settings for a closed social network for young patients.

E. Recruitment and participants

The recruitment of the teenage patients participating in the study was undertaken by the Child Life Specialists of CHEO. They knew the teens personally or they could consult their doctor or nurse. Teens were recruited from the wards and from the medical day clinic. They needed to be well enough to participate in a 30 to 40 minute meeting with the researcher. They would receive a leaflet with information and a consent form. The leaflet mentioned that the interview is anonymous, that the teen's diagnosis is not a topic in the interview, and that the researcher has no access to the teen's medical file. Both participant and researcher would sign the consent form. If the teen was younger than 16 years old, a parent also had to sign the consent form.

F. Sample size

In qualitative research, sample sizes differ widely. It is perceived as acceptable to have a small sample size, between 4 and 10 in studies with participants with impairments or other vulnerabilities [39], [40]. In this study, sixteen teenagers participated in the study: nine girls and seven boys. Their ages were between 14 and 18 years old. They participated in the study in the autumn of 2012, while receiving treatment in the hospital.

IV.   RESULTS

A. Technology and Internet use in the hospital

All participants brought their personal technologies to the hospital. In addition, some patients used equipment provided by the hospital (see Table II).

TABLE II.   TECHNOLOGIES IN USE

Technology	Owned by patients	Owned by CHEO	Used for Internet
Mobile phone	16		15
Laptop	6	2	2
MP3/4 player	6		1
Tablet	1		1
Video game	1	2	
Computer		1	1
DVD player	1		

Facebook and Twitter were the most popular social media. All 16 teens were active on Facebook and nine had a Twitter account. Fifteen out of the 16 Facebook users used their smart phones to receive Facebook notifications and to check their Facebook account while in the hospital.

In order to start a Facebook account, the user needs to confirm that s/he is 13 years old or older. Eight of the 16 teens answered they lied about their age when they registered for their Facebook account. Four of them said they were 13

years and four teens said they were adults, i.e. over 18 years old, while they were all 11 or 12 years old.

B. Privacy settings

Most teens changed their privacy settings only after they started using Facebook. The majority has *Friends-only* as privacy settings (11), while 3 teens have *Friends-of-friends* and one teen had *Public*. One teen had closed down her Facebook account, and was using her boyfriend's account.

Many of the teens were concerned with having the right privacy settings. They would check regularly or find had other tactics to make sure they knew what they were:

"*I've set them up, but I've heard you can make it much more complicated and complex and I read this article about it and it seems very difficult and hard to understand. I don't really find it easy to use [them]*" (girl, 14 yrs.)

"*It is not difficult to get your privacy settings the way you like*" (girl, 16 yrs.)

"*I only post if it is for everyone to see and I just keep everything I post on Facebook to a minimum so if everyone sees it it's not like I'm showing like myself to the entire world*" (girl, 14 yrs.)

C. Making privacy visible

Many teens needed some time to spot the difference between the real situation and the two designed options for locating privacy settings. All but one participant preferred a more visible privacy settings button on all Facebook pages:

"*I already have my privacy settings done, but if I was joining a new social networking program and it had that button, I would definitely click on it*" (boy, 17 yrs.)

"*Because it makes people more aware of their privacy and makes them take initiative I guess you could say instead of it being an afterthought*" (boy, 18 yrs.)

In the case of prototyping privacy settings, all but one participant wished to use colours to make their privacy settings more visible and to dedicate one colour to one particular group of Facebook contacts. One teen was satisfied with how Facebook provided privacy settings for status updates.

Fifteen teens chose to customise their privacy settings: "*That would be cool to set them yourself. […]. I really do like the idea of personalising those colours*" (girl, 17 yrs.). They created between 2 and 5 categories to organise their Facebook contacts: two participants created 2 categories; five participants created 3 categories; seven participants created 4 categories, and one participant created 5 categories.

Fourteen out of 15 teens created a *Public* category and two teens created an *Only me* category. Most diversity was found in organizing friends. Eight teens created a *Close friends* category and eleven teens created a *Friends* category. Five teens had a *Family* category while one teen created a *Friends without family* and a *Friends with family* category. Five teens created a *Custom* category. This category allows the user to select names from the list with all friends. This customised list would change, depending on the content of the message (status update, photo, etc.) (see Table III). None of the teens used the colour scheme of the example; all preferred to personalise the colour scheme. The most popular colours were the same colours as used in the example, but they were used in combination with other colours.

TABLE III.   CATEGORIES

Participants	Categories
14	Public
11	Friends
9	Close friends
5	Family
4	Custom
4	Friends of friends
2	Only me
1	Friends and family

D. Are privacy settings needed?

Eleven of the sixteen participants were asked about the need for privacy settings in a closed social network for teenage patients. Ten mentioned that such settings were needed, "*Oh, of course, there are some things you shouldn't share obviously*" (boy, 18 yrs.).

V.   DISCUSSION

Studies have shown that most teenagers with chronic health challenges don't like talking about their experiences outside their direct family and best friends environment [18], [20]. It isn't cool to be different. Teenage patients are careful sharing their personal health information in social media [18]. This was not different with this group of patients:

"*Last time I was in the hospital, I really didn't want anyone to know what was going on because I didn't want rumours to spread*" (girl, 17 yrs.)

The participants in the study were all interested in more immediate access to privacy settings (a large button) and simpler and transparent privacy settings. Several of the teens were not able to locate the privacy settings on Facebook, which (at that time) only became visible after selecting a very small triangle at the top of the page.

Using colours to have an immediate and visible indication of one's privacy setting before sharing a status update was perceived as very helpful and easy to understand. The chosen colour scheme could be used for a variety of purposes, such as visualizing access to one's profile information, photos, etc. Many teens mentioned that they would like the option to personalise their Facebook page, which is not possible at the moment. Choosing one's own favourite colours for privacy settings was therefore perceived as *cool*. Many of them wanted the same colour scheme for use in a closed patient social network.

Although all 15 colour schemes were different, red, yellow, green, and blue were the most used colours. Interestingly, the colours red (5x) and green (6x) were both used to indicate the *Public* setting. In [32], which builds forth on the traffic light colour combination, the colour green is used to indicate *Public*. Some of the participants in our study

indicated that green meant 'safe', i.e. the opposite of *Public*: you know exactly who can read your posting. Some of the participants, who used the colour red for *Public*, understood this colour to mean 'attention': "*I kind of see red as, eh, it's something you should be a little more careful about*" (g/16).

There is a clear need for privacy-friendly default settings. Many of the teens lied about their age when they first started using Facebook. New Facebook users have to confirm that they are 13 years or older, and then provide their date of birth in the account settings. Users who were 13-18 years old, had *Friends-of-friends* as default settings and could changed this only into *Friends-only*. The Public setting was not available to this age group (this has changed in 2013). Those who used an age over 17 ended up with *Public* as default privacy settings. In addition, several of the participants have made mistakes on Facebook, sending a status update or photo to the wrong person(s).

A. The meaning of colours

Red, green, blue, and yellow, the four most popular colours for privacy settings, are chromatically unique colours and universal in terms of their colour terms [41], [42], but the associations with these colours differ widely [43]. The traffic light colour scheme (red, yellow, green) may have gained universal meaning in the context of traffic, but fails to do so in other contexts. The study made clear the contradictive meaning of the colours red and green in the context of the design of privacy. Colours should thus always be accompanied with a textual indication of their meaning in the particular context.

B. Limitations of the study

The particular context of this study, teenage patients in an hospital setting, marks the findings. The study offers meaningful insight into the privacy understandings and needs of this particular group of social media users.

VI.   PROOF OF CONCEPT

We have implemented the findings of the study in one of our prototypes of a closed social network for teenagers with health challenges. Only three categories and three colours were used: *Public, i.e. all users of the closed social network,* (green), *Friends* (yellow), and *Only me* (red), see Fig. 2. The default privacy setting for all users is *Only me*. Users can configure these settings by selecting the large 'Settings button', visible on every page (see Fig. 2). The default setting for all status updates, photos, etc., always remained *Only me*, forcing the user to make a choice every time something new is shared with other users. The different settings can be applied to all types of content on the site as a response to higher privacy demands on a closed social network as opposed to Facebook.

The prototype was evaluated by a group of teenagers in Norway, patients and non-patients. The teens appreciated the possibility to alter the privacy settings for each new piece of information. They especially liked the combination of overall settings, which could be altered using the 'Settings button', and the flexibility to choose the audience for each post in situ.
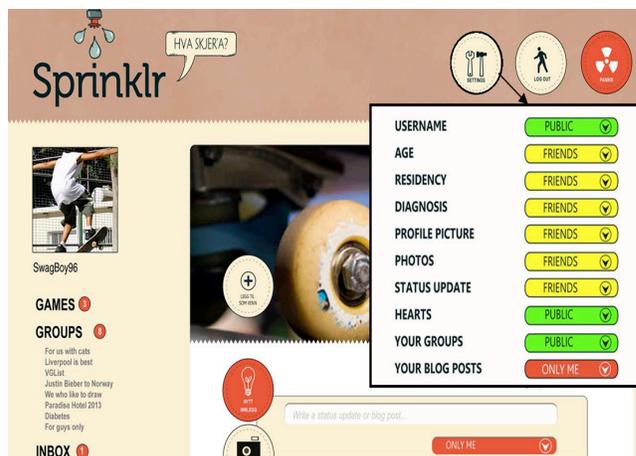

Figure 2. Proof of concept

The teens appreciated that all default settings were set to *Only me*. They elaborated that this was *cool* and gave them the feeling of control: they didn't have to share anything about themselves if they didn't feel like it. The participants thought that the choice of colour was appropriate, as the red colour indicating the *Only me* setting was more prominent and drew their attention to it. This applied only because the default setting was *Only me* and had to be changed in order for others to see the post. The teens also suggested that the *Only me* settings could be used to expand the functionality of the site – the posts marked as *Only me* could for example function as a diary.

VII.   CONCLUSION AND FUTURE WORK

The combination of the participants' Facebook experiences and skills and the researchers' design skills resulted in privacy-aware designs for a closed social network for young patients:

- A large button for configuring privacy setting
- Privacy-aware default setting for sharing new information (status update, posting, photo)
- Use of colours to visualise privacy settings

Personalisation, being able to choose one's own colours to visualise privacy settings, may motivate teens to use privacy settings more effectively.

In our on-going research on the design of privacy settings, we focus on the use and meaning of colours.

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