

UNIVERSITY OF OSLO
Department of informatics

Sprinklr:
**Designing a ‘cool’ health-
oriented social
networking site with and
for teenagers**

Master thesis
60 credits

Margaret Machniak

1. May 2013



© Margaret Machniak

2013

Sprinkl: Designing a 'cool' health-oriented social networking site with and for teenagers

Margaret Machniak

<http://www.duo.uio.no/>

Trykk: Reprosentralen, Universitetet i Oslo

Abstract

Background: Teenagers with chronic health challenges are not disclosing their health on social media. Yet, social and emotional support has an impact on health. Currently there is no online health community in Norway targeting teenage patients. Initiatives such as Upopolis have failed to generate critical user mass because they were not age-appropriate

Objective: This study examines how a ‘cool’ online health community looks like when designing it with teenagers. The study aims to extend design guidelines from teenager’s perceptions of what is cool online and look at properties of ‘cool’.

Methodology: The study is located within participatory design using qualitative methods to involve teenagers in the decision-making in the design process. With 9 teens a low fidelity but high resolution prototype was developed. The prototype was further evaluated using semi-structured prototyping interviews.

Results: Using the cool wall made it possible to map what functions the teenagers perceive as cool. The analysis demonstrates that ‘cool’ is a situated and gendered concept and that teenagers are not satisfied with how social media are dealing with privacy settings. The teenagers want a health community to be entertaining and provide an option to contact health care professionals. They don’t want the site to be focused on illness and rather provide the users with entertainment.

Conclusion: Cool can be used to design age-appropriate and engaging technology. The concept of ‘cool’ was useful in keeping the focus on what teens need or are interested in. Further research is needed into the concept of cool and involving other actors in the design of an online health community and the cool wall needs to be tested in hospital settings allowing for including bedridden patients.

Acknowledgements

400 words are not enough to express my gratitude to all people who made this happen. First of all I would like to thank my amazing supervisors: Maja and Alma. Thank you, Maja, for being the best supervisor I could ever hope for. Thank you for all the help and giving me wings and motivation each single time you talked to me. A huge thank you goes to the beautiful Alma. Thank you for being an inspiration and sharing your endless knowledge and experience about design with me. Without you two amazing women, this thesis would not exist.

I would like to send a lot of love and hugs to all the teenage participants. You guys were amazing and I feel lucky and privileged that I got a chance to work with you. You are the best designers in the world and it is *you* who created Sprinklr.

I would like to give a huge shout out to my homies on the 6th floor. Thank you for all inspiring lunch breaks, the cake, the support, and giving me a reason to get up and go to school every day. When I'm out in the real world making C.R.E.A.M., I will always remember that it was Dunia who taught me how to eat mackerel and cottage cheese and be a decent human being even when under pressure, Torbjørn that showed me that behind every pair of hipster glasses there is a person, Tina who showed me that you don't lose your soul if you eat oatmeal every day, Eirik that showed me the true meaning of multi-cultured, and Therese who showed me how to dance with the wolves.

To all of my friends – thank you. Thank you for being patient, and tolerating my ups and downs, and listening to my monologues about this thesis. Thank you for not calling me boring and for not pointing out how I became more socially retarded with every passing day. You are truly amazing and I am blessed to have you in my life.

My biggest thank you goes to my mother, Zeberka, and Bjørn. Thank you for reminding me to study and learn every single day. Thank you for always believing in me and giving me a shoulder to cry on when I thought I couldn't do it anymore. Your job is done now. This thesis is for you and Tatuś.

And finally, the love of my existence: Martin. Thank you for being mine and loving me despite my flaws and all. I couldn't ask for a more perfect soul mate. Thank you for putting up with me. I'm glad we survived this and I can't wait to spend the rest of my life with you. I love you.

Margaret Machniak
Oslo 01.05.2013

Table of contents

Table of figures	XI
1 Introduction	1
1.1 Motivation	2
1.2 Research interest.....	2
1.3 Chapter guide.....	3
2 Literature review	5
2.1 Search criteria	6
2.1.1 Inclusion and exclusion criteria.....	6
2.1.2 Analysis	7
2.1.3 Why not Facebook?.....	7
2.1.4 Results of the search.....	7
2.2 Existing interventions	8
2.3 Findings	10
2.3.1 Information.....	10
2.3.2 Support	11
2.3.3 Entertainment	13
2.3.4 Privacy and sharing	13
2.4 Recap	14
3 Theoretical and methodological framework	17
3.1 The concept of Cool	17
3.1.1 Definition of Cool	17
3.1.2 Cool challenges	18
3.2 Designing for Cool	19
3.2.1 Cool as a design requirement for teenagers	19
3.2.2 The wheel of joy.....	20
3.2.3 Hedonic and utilitarian information systems	21
3.2.4 Virtual possessions.....	22
3.3 Participatory Design	23
3.3.1 Why PD in this project?	24
3.3.2 Ethical considerations	24
3.3.3 What can be expected?.....	26

3.4	Recap	26
4	Methods.....	27
4.1	The cool wall as a research tool.....	27
4.1.1	Interviews using the cool wall.....	28
4.1.2	Evolution of the cool wall	29
4.2	Collection of the data.....	32
4.2.1	Consent forms	33
4.2.2	Recruitment	34
4.2.3	Participants	35
4.2.4	Location.....	36
4.2.5	Pilot workshop using the cool wall	37
4.2.6	Interviews via email	37
4.3	Reflections around the method	38
4.3.1	The Cool Wall	38
4.4	Recap	39
5	Data and analysis.....	41
5.1	What do teenagers do online?.....	41
5.1.1	School.....	42
5.1.2	Parents	42
5.1.3	Friends.....	43
5.1.4	Self-presentation.....	44
5.2	What's cool?.....	48
5.2.1	Cool sites	48
5.2.2	Cool functions	53
5.3	Design.....	59
5.3.1	The look and feel of Sprinklr	59
5.3.2	Functionality.....	61
5.3.3	Finding others with the same diagnosis on Sprinklr	61
5.3.4	The informational part of Sprinklr	62
5.3.5	User interface of Sprinklr	63
5.4	Discussion.....	65
5.4.1	Connecting with health care providers.....	66
5.4.2	Information.....	66

5.4.3	Avoiding lurkers.....	68
5.4.4	Cool: situated and gendered	69
5.4.5	Presentation and privacy	69
5.4.6	Implications for the objective of Sprinklr	71
5.5	Translation	71
5.6	The mock-up.....	72
5.7	Recap	75
6	Sprinklr – The prototype	77
6.1	Ease of use	79
6.1.1	Ease of use through decreasing performance load	79
6.1.2	Ease of use through familiarity	80
6.1.3	Ease of use through aesthetics.....	80
6.2	Privacy.....	82
6.3	Sprinklr	83
6.3.1	The prototype	83
6.4	Prototype testing	89
6.4.1	The setup	90
6.5	Results from prototype testing.....	91
6.5.1	Students	91
6.5.2	Teenagers	93
6.6	Implications for future design and implementation.....	94
6.6.1	Design for all.....	94
6.6.2	Openness of the design.....	95
6.7	Recap	96
7	Evaluation of the process	97
7.1	The methodology	97
7.1.1	The cool wall.....	98
7.1.2	Prototyping interviews.	99
7.1.3	Recruitment	99
7.2	Limitations.....	100
7.3	Recap	100
8	Conclusion.....	101
8.1	Contribution.....	102

8.1.1	Cool as age-appropriate.....	102
8.1.2	Cool as a research tool	102
8.1.3	Cool as a quality of technology.....	105
8.1.4	Cool as a design guideline.....	105
8.2	The road ahead.....	106
Bibliography.....		107
Appendix A.....		117
Appendix B		123
Appendix C		128

Table of figures

Figure 1: Map of projections	6
Figure 2: Mind map of the reviewed literature	7
Figure 3: Existing initiatives	9
Figure 4: Fostering optimal benefits	12
Figure 5: The Hierarchy of Cool [50]	18
Figure 6: The wheel of joy [52]	20
Figure 7: Joy in use triangle [52]	21
Figure 8: Cool wall 1.0.....	29
Figure 9: Cool wall 2.0 and the glass-marble magnets	31
Figure 10: Participants	35
Figure 11: Cool sites	49
Figure 12: Cool functions.....	54
Figure 13: First design (male 15 and 16, non-patients).....	63
Figure 14: Second design (male 19, non-patient)	63
Figure 15: Third design (female 18, non-patient)	64
Figure 16: Fourth design (female 17, patient).....	64
Figure 17: Fifth design (male 13, non-patient)	65
Figure 18: What prototypes prototype? [91]	78
Figure 19: Position of Sprinklr in the model for what prototypes prototype	78
Figure 20: "Echo Beach at Dusk".....	82
Figure 21: Login page	84
Figure 22: News feed and the global navigation.....	84
Figure 23: Chat.....	85
Figure 24: Profile page	85
Figure 25: Games	86
Figure 26: Group page.....	87
Figure 27: Privacy settings page	87
Figure 28: Ask a Pro page	88
Figure 29: Inbox page	88
Figure 30: Information page.....	89
Figure 31: Calendar	89
Figure 32: Cool Wall 3.0.....	104

1 Introduction

Social media are becoming a part of our daily lives. The constantly growing number of online health communities and patient blogs indicates that patients are also active online [1].

Because of the unique qualities of Internet such as its availability, affordability and interactivity, much attention has been given to the potential of online health-services. In addition to offering ubiquitous access to information and interaction with others in similar circumstances, virtual communities increase availability for support which is especially valuable for people with chronic health challenges. Children and adolescents are being presented as especially amenable for e-health technologies due to their proficiency in using the Internet [2]. Born in 1988, social media is something I have only used for a couple of years, and I still remember my life without them. Tim Finin [3] goes as far as to stating that for today's teens, "social media is not technology, it's just life".

In her article "Patients and Social Media: If you build it will they come?" van der Velden [1] discusses benefits, challenges, and risks of introducing and using patient-centered social media. The study is a case study of Upopolis, a social network for young patients in Canada. The study demonstrates how despite the benefits of meeting others with the same condition and the opportunity to share about their disease, only a small number of teenage patients are using the offer. The question here is: why?

The population of young patients is small [4], but their need for social connection is high [5]. Currently, there is no online health-community in Norway targeting teenage patients. If there is a need for such a community, how should one go about it designing one? How can we make sure that what we design will be used by teenagers in Norway? Why did Upopolis fail in creating a critical mass in Canada? Are there any lessons we can learn?

In the article, van der Velden writes that Upopolis was designed with age appropriateness in mind. However, the targeted group was young patients age 5-19. And it is obvious that what is age appropriate for a 5 year old is not as appropriate for a 15 year old. What is age-appropriate for teenagers?

1.1 Motivation

When I first found out that I was accepted into the Master program, I knew that I wanted to write my thesis about something that had to do with healthcare and/ or social media. As I browsed through available master thesis proposals I came across a larger research project with the Design group at the Department of Informatics. One of the aspects of this project was designing user interface for a health-oriented social networking site for teenagers with chronic health challenges. The idea for the thesis encompassed all my wishes and dreams. As challenges regarding the collection of the data rose, so did the questions. Every time I was asked to explain my thesis I was faced with questions such as “What’s the point?” and “Why not use closed groups on Facebook?”. At first my answers were based on research my supervisor had implemented in Canada and the literature suggesting that Facebook was not appropriate for health-oriented communication and how the teenagers create different identities online. My answers made many people wrinkle their foreheads in disapproval - as if I was just stuck in front of academic publications without any knowledge of the real world and how social media are being used today.

I got my final answer when I was preparing my first interview guide. I was planning for all the possible answers and ways the interview could unfold and I thought – what if the teenagers I’ll interview don’t have many friends? What if they don’t use Facebook? What if... what if? The answer came to me while browsing different health oriented forums. On the Q&A page for one of the health associations I found an anonymous post:

I'm a 12 years old girl who has had psoriatic arthritis for a year now! I really want to meet others with the same condition as me.

Other posts asked about how many other teenagers had this condition and if it was normal. There it was: my motivation. If I could make life better for just one teenager in reassuring him/her that s/he was not alone, then my thesis had a purpose.

1.2 Research interest

This thesis is part of a project that examines if and how a patient-centered social networking site can support teenage patients. Because the project targets teenagers, it is important to ask what is age-appropriate in the context. How do we decide what is age-appropriate for teenagers?

Based on the literature used in this thesis, ‘cool’ is something that belongs to the teenagers, and may be an indicator for what is age-appropriate. Consequently we must look into teenagers perceive as cool and how we can extend this into design guidelines for a patient-centered social networking site. The research interest for this thesis is therefore

How does a ‘cool’ health-oriented social networking site for teenagers look like and how can we design it with its future users?

The research interest is broad and can cover a large number of design challenges. I have therefore decided to approach the research interest by looking at four specific functions of ‘cool’:

1. Cool as age appropriate: What is the concept of ‘cool’ and can we put an equation sign between cool technology and age appropriate technology? Can ‘cool’ be used as a guideline for what’s age appropriate for teenagers?
2. Cool as a research tool: How can ‘cool’ be used as a research tool?
3. Cool as a quality of technology: What makes technology cool? What does it mean to be cool online?
4. Cool as a design guideline: How can perceptions of cool be translated into design guidelines?

To answer the questions constituting the research interest of this thesis, I aim to focus on the functionality and the look and feel of the designed site as well as already existing social networking sites and their functions.

1.3 Chapter guide

The study’s outcome is a simple prototype developed *with* teenagers as opposed to designing *for* them. The study also presents alteration of a research tool presented by Fitton et al. [6] and using ‘cool’ as a design guideline, interesting for future research with young patients. Before entering the next part of this thesis I would like to present a brief overview of the upcoming chapters:

Chapter 2: Literature review: In this chapter I present an overview of the already existing initiatives towards young patients in order to position myself in the field. I also present findings regarding the needs that health oriented social networking sites are aiming or should be aiming to satisfy, and the implementations these findings have for design.

Chapter 3: Theoretical framework: This chapter presents participatory design which was the methodology applied in this thesis. It also introduces the concept of ‘cool’ with the implications designing for it has for design.

Chapter 4: Methods: Here I will present how I performed the data-gathering using the cool wall during semi-structured interviews, and how I tested the prototype for the site.

Chapter 5: Data and analysis: In this chapter I will present and analyze the data collected using the methods from chapter 4. I am going discuss them against both the reviewed and relevant literature. The reader will be provided with the mock-up which emerged from the gathered and translated into design specifications data.

Chapter 6: Sprinkl – The Prototype: This prototype for Sprinkl will be presented along with justification for the various design decisions based on the interviews with the teenagers and universal design principles. The chapter will also provide the reader with the results of the prototyping interviews followed by implications for future research and design of Sprinkl.

Chapter 7: Evaluation of the process: In this chapter I want to present what the teenagers thought about the methods used in this project while continuously reflecting upon the project and my role as designer. A summary of limitations to this study will be provided.

Chapter 8: Conclusion: In this concluding chapter, I aim to provide a summarizing answer to the research interest presented in this chapter. Further, I will list the contributions of this study for the field. I will also take the opportunity to present some implications for future design and research regarding Sprinkl or any other health oriented social networking site for young patients.

2 Literature review

This literature review provides an overview of previous and current initiatives regarding using social media to offer more support to patients. There exists a tremendous amount of studies regarding existing health-related online communities. However the studies concern already existing initiatives without providing sufficient information about the design process behind these initiatives and more importantly do not target adolescents in particular. The topic of designing a health-related online community for chronically ill adolescents is to the best of my knowledge under researched. Within this I aim to position myself in the field by presenting initiatives most relevant to what the aim of this thesis is and relevant findings concerning health related online communities and the design implications these impose.

The starting point for this review were two articles: ““Not All my Friends need to know”: a qualitative study of teenage patients, privacy, and social media” by van der Velden and Emam, and “STARBRIGHT World: Effects of an Electronic Network on the Social Environment of Children With Life-Threatening Illnesses” by Battles and Wiener [7]. In “Not all my friends need to know”, van der Velden and Emam argue that young patients have multiple needs which results in them having multiple social networks [8]. They discovered that few patients disclose personal health information to all of their Facebook friends. They want to be like their non-sick peers [9]. The STARBRIGHT World (SBW) studies the positive health related outcomes for young patients using SBW. Some of the reviewed literature stems from using the literature list from these articles and the rest is the result of the search strategy explained below.

To enhance the search strategy and because of the many areas where social networking sites can be used, a map of projections was appropriate (Figure 1). Projections here mean additional areas or aspects of online communities that fall under the focus of this literature review. This review concerns online communities being used and designed for not only patients, but for adolescent patients in particular. The projections used to position myself in the field consist of the existing initiatives, findings regarding the use of online communities, and implications these findings have on design.

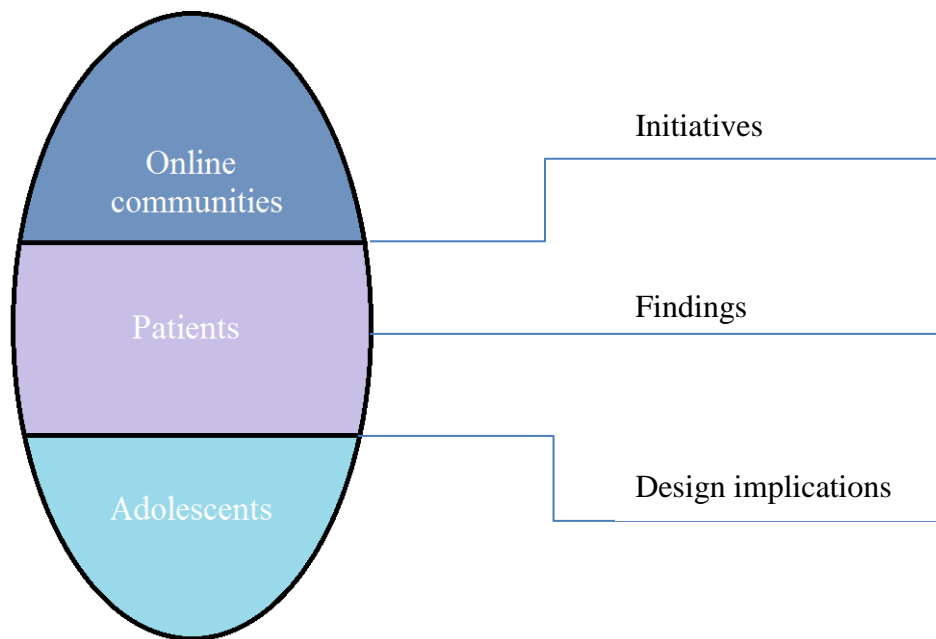


Figure 1: Map of projections

2.1 Search criteria

The search focused on social networking sites/ online communities. In order to separate health related online communities from those with non- health related content as well as cover the various components of the map of projections, the search included the phrases “young patients”, “adolescent patients”, and “teenage patients” in addition to “social networking sites” and “online/ virtual communities”. The search engines used to find relevant literature were Google scholar, BIBSYS, X-port, Scopus, and PRIMO.

2.1.1 Inclusion and exclusion criteria

Inclusion and exclusion criteria were applied to the results of the search described above. The review of published literature includes peer-reviewed full research papers as well as parts of books, reports and websites. In order to be included in the review, the articles had to describe a health care intervention delivered through the Internet with children or adolescents as their target group or part of the intended users. The children oriented initiatives were included due to the fact that adolescents were also grouped with them as a result of organizing them at hospitals. The review of the literature also includes studies describing SNSs that are not Internet-based, yet have the characteristics of a SNS [10]. Since the objective of the prototype is to facilitate information seeking behavior, forums and informational sites were included. The review also includes literature reviews of health-care interventions delivered online, for example [11]. Cited works were prioritized, though it was not itself an inclusion criteria.

2.1.2 Analysis

In some cases, several papers concerned one single intervention, meaning that their main objective was evaluation or performing a follow-up project. Whenever this occurred, the papers were grouped together and were treated as one coherent case.

2.1.3 Why not Facebook?

Before presenting the results of the analysis, I think it is of interest to explain briefly why this review does not include articles presenting Facebook as an arena for health related online communities for adolescents. In “Not all my friends need to know”, van der Velden and Emam argue that young patients have multiple needs which results in them having multiple social networks [8]. In their study concerning teenage patients’ behavior online related to privacy, they used Upopolis as an example of a social networking site and researched if the teenagers already in possession of a Facebook account used the site in addition to it. They discovered that few patients disclose personal health information to all of their Facebook friends [8]. They want to be like their other peers [9]. The young patients created different profiles to cover different needs. In cases where the teenagers chose not to join any online communities beside Facebook, they elaborated that they were not interested in meeting other patients regardless of it was online or offline [8].

2.1.4 Results of the search

After reading through the literature, I organized it with regards to initiatives, findings, and design implications. The findings were organized in the form of key words and sentences using an Xcel sheet in order to organize the articles according to the findings. To structure this review, I decided to create a mind map which chronically ordered the relevant literature and key words and sentences into categories: initiatives, findings, and design implications (Figure 2).



Figure 2: Mind map of the reviewed literature

2.2 Existing interventions

The reviewed literature can be summarized in a list of relevant online health interventions targeting young people. The list is presented in the following table. The categories of the table are the name of the initiative, age of the targeted patient population (age in parentheses mean that the study used this age group in their evaluation of the site, and were not necessarily the targeted users' age group), which illness is being addressed by the initiative, which functions are being provided by the service, whether the initiative was an online source or based on the intranet and the country providing the service. The order of the initiatives does not infer any hierarchy or degree of relevance.

Initiative	Age	Illness	Functions	Internet/Intranet	Country
MyTrack	Young people (18-25)	Cancer	Forum, activity log, photos, list of members' pages, hyperlinks to other sites	Internet	Australia
Upopolis	Young people (12-18)	General	Facebook format, meet other patients, stay wired with school and family + information	Internet	Canada
StarBright World	4-17	General	Communication, entertainment, explore	Internet	North America
Hopkins Teen Central	(Median: 13)	Cystic fibrosis	Post information, quiz, group messaging, diary, messaging	Internet	USA
kTalk	(14-18)	Chronic kidney disease	Community, blog, threaded discussion	Internet	USA
Zora	(11-15)	Organ transplants	Creating virtual spaces	Internet	USA
Diabit	(11-18)	Diabetes	Information, blogs, message boards	Internet	Sweden
Ability online	(Median: 15)	Chronic kidney disease	Chats, discussion boards	Internet	Canada
scoliose-op.info	16-50	Scoliosis	Scoliosis specific community	Internet	Germany
Health 2 website	Not specified	General	Profiles, interaction	Internet	USA
ADMS	8-18	Diabetes	Real-time alerts, trend analysis reports	Intranet	USA

Health 3.0 Patients like me Cure together HealthCentral	Not specified	General	Connecting with other patients	Internet	
--	------------------	---------	-----------------------------------	----------	--

Figure 3: Existing initiatives

The initiatives bearing most relevance to both this thesis and the review are being explained accordingly to the criteria used to position myself in the field.

MyTrac is an online social network application based on the *ning* platform (www.ning.com) intended to support online connection for young patients with cancer. The website offers forums, activity logs, photo sharing and links to other users and hyperlinks to external websites containing information about cancer. In order to be more accessible from mobile devices, the main page also includes an RSS twitter feed. The site was designed by keeping its functionality to a minimum in order to allow the users to give feedback on which functions they wanted implemented in MyTrac.

Upopolis is an online Facebook-like environment with higher level of security and privacy, which helps the patients connect to other patients and invite their friends and family. The website offers chats, discussion forums, photo albums, blogs, email and information delivered in an age-appropriate format. The reviewed literature did not include information about the design process.

STARBRIGHT World is an online resource for ill children including games, activities, education and interaction with peers. The reviewed literature does not offer any information about the design process resulting in the online intervention.

kTalk is an online community driven by peers. Its purpose is to facilitate information sharing, exchange of social and emotional support and distribution of patient education materials. The pilot implementation held functions such as threaded discussions, blogs and lists of members in order to allow the users to interact with each other. In 2011, the pilot concerned young patients entering their earlier adulthood. The website was not designed with the users; something the reviewed article concludes would be beneficial.

Zora is a web-based virtual community which facilitates development of psychosocial support networks for adolescents with organ transplants. The website engages its users in the creation of virtual spaces and functions as a construction tool rather than delivering content in order to teach them about specific issues and topics.

Diabit is an Internet portal for invited patients and parents further developed from the previous design model. The prototype was designed using participatory design methods such as design workshops and interviews using cultural probes and was further developed using user centered design methods. The portal provided users with diabetes centered information and social networking functions such as message boards and blogs. The portal also included text pages, video and online stimulation software.

2.3 Findings

The reviewed literature comes up with a number of relevant findings. In order to use them appropriately, it is justifiable to divide these into three categories: information, support, and entertainment. The first category concerns information seeking behavior while the other reviews the findings related to the support provided by health related virtual communities. The last part of the review of the different findings is entertainment which addresses adolescents need for entertainment.

2.3.1 Information

The Internet has changed how people and especially patients access health-related information and how they seek support [7] [12] [13] [14, 15, 16, 17, 18, 19, 20, 21, 22, 23]. Most of the reviewed literature presents providing information and information seeking as the key aspect of health-related virtual communities. Many patients are satisfying their need for information by using online resources as their primary source of information [24].

After receiving a diagnosis, patients usually turn to Internet in order to find more information on what the diagnosis entails and how the treatment will affect their lives [25]. Studies have shown that having read themselves up on the information online, patients had more courage to ask doctors questions about their condition as well as being reflected on the illness [26].

The special position of teenage patients

Teenage patients are in a special stage in their development. The period they are in can be categorized by dramatic biological, psychological, cognitive, and social changes [27]. All these changes occur simultaneously and when they intersect with health or illness, they present the teenager with additional challenges [28].

Adolescence is a period during which independence is achieved [29, 30]. This happens through balancing who the teenagers are depending on and who they are trying to emancipate themselves from. Adolescents are redefining themselves in relation to others and define others in relation to themselves [28]. Therefore at a time when they are trying to identify themselves with their peers and “fit in”, having or receiving the diagnosis of illness can be particularly stressful [27]. However, the teenage patients tend to be more concerned about how their condition will affect their social life and interfere with schoolwork and after-school activities. Information concerning the impact on these aspects of their lives is often favored over how it will affect their psychological condition [31, 32].

Advantages of online sources

The direct advantage of online sources is that they transcend the clinical environment and are easy to access at any time [14, 16, 20, 33, 11]. Online resources have also an empowering

effect on the patient. Several articles [19, 25, 34] argue that having read through online resources makes it easier to communicate with health care providers as well as being reflected on the illness [26]. The preparation makes it easier to ask questions and talk about their symptoms which the patient didn't perceive as relevant in advance of the information search. Britto et al. [35] argue namely that adolescents fear to reveal information to health care providers, and especially information that in their opinion is not relevant to the treatment.

Medical practitioners use a language that is in many cases too advanced for young people. In some cases they might also not fill the knowledge gaps that the patients have. The claim in this case is that users of health-related online communities might learn more from their peers than from medical practitioners [14, 16, 9]. The arguments behind this claim lay in the fact that patients have a better understanding of each other's' conditions based on the same experiences [22] and can by active participation in virtual health care related communities fill each other's' knowledge gaps [34].

In addition, online communities and informational sites may be a source of information about subjects which teenagers avoid with adults such as sexuality and questions related to the changes they are going through [36]. It is therefore important that the information is accurate and not misleading.

2.3.2 Support

The reviewed literature argues that informational support is the most important form for support provided by virtual communities [22]. However, informational support is not the only form of support provided by virtual communities. Virtual relationships provide emotional [13] as well as psychosocial support, and it is argued that because of the support they provide members superiorly cope with the information [13, 37, 18, 34, 21, 22, 38].

Because of frequent visits to the hospital, many young patients feel isolated [7, 5, 39, 37]. Especially young patients with cancer (YPWC) are referred to as the most disadvantaged and isolated patients in the health care system [39]. The challenge here is that the number of YPWC is low compared to their need for social connection [39].

What much of the reviewed literature suggests is that social media sites help to reduce the feeling of isolation and loneliness many patients experience [7, 5, 39, 37, 22, 11, 38, 40]. Although virtual communities cannot replace real life relationships [13, 5, 41, 18, 11], social interaction with others can improve patients' condition and used together with face-to-face support groups provide strong social support which may help to reduce their suffering [22].

There exists an agreement on the claim that accomplishment of success in the treatment of chronic diseases depends on the patient's self-management and management of his/her own disease by adopting a healthy lifestyle [5, 16]. The degree of self-management is connected to the interplay between initiatives and resources, and resources on the part of patients, relatives and health care providers [16].

Martin et al. [33] describe how the various forms of online communication can reduce symptoms and some of the complications of mental health problems in addition to improvement of the encounters with health care providers. This correlates with the finding regarding social media’s positive effect on patients’ willingness to come back for treatment, reduction of withdrawn behavior and anxiety [7, 37, 34, 33, 22, 40].

Due to the fact that patients are sent to treatment and isolated from other patients, connecting to others with the same condition is challenging [31]. Online communities overcome geographical barriers, access- and communication- related challenges and by providing the social support lower psychological distress and mental health [34]. One of the key aspects of virtual communities is meeting and interacting with others based on connection established by specific needs and interests [13, 14, 41, 30, 42, 23, 43]. Virtual communities that encourage their users to form meaningful relationships with each other are being argued to have the potential to “foster supportive friendships, mutuality and social support among adolescent patients” [37]. By supporting forming of interactions among patients, one can protect them against health consequences springing out of life stress [22].

In order to fully exploit the positive potential of health-related virtual communities, Nicholas et.al [21] suggest that patients who have a desire for peer support and are willing to share their stories, need to find a form of communication where they can identify themselves to other users. The point of connection must facilitate online peer support and will then offer benefits which are social connection, less illness and isolation and better coping (Figure 4).

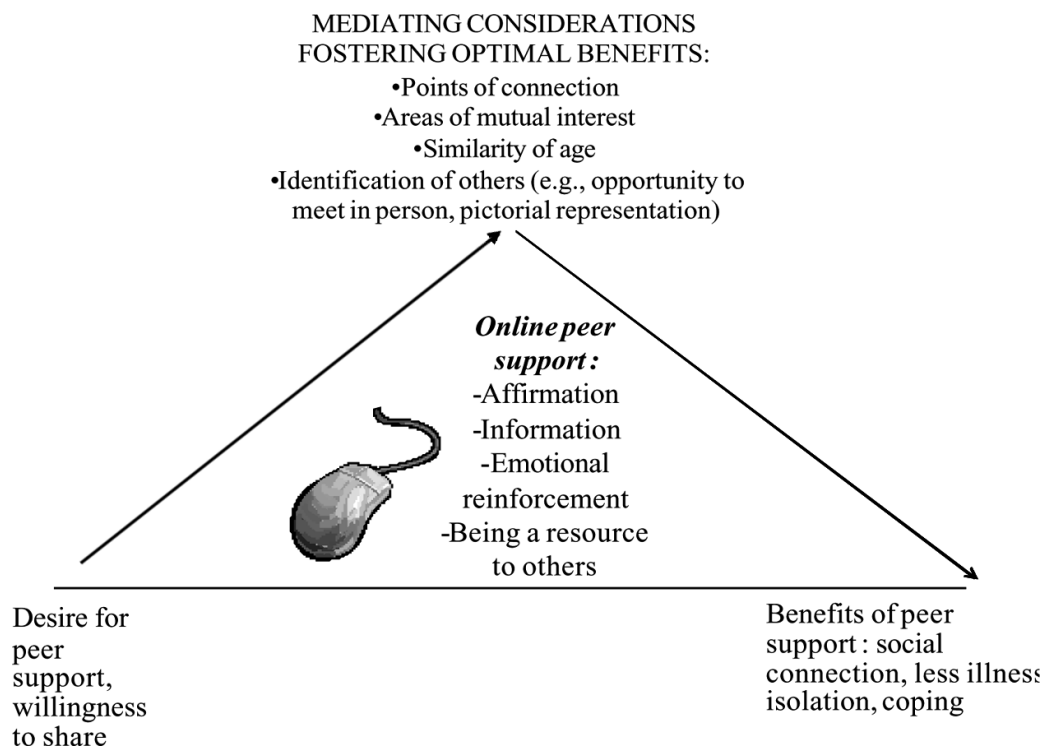


Figure 4: Fostering optimal benefits

Where an opportunity to form social relationships with each other exists, users have shown to use virtual communities as a starting point for communication offline and shared offline activities [5]. Part of the reviewed literature offers findings around what aspects of a social networking site are valued at all. Perry et al. [31] argue that the main conditions that might affect the usefulness of a site are age and diagnosis. Davis et al. [39] find that a lack of critical mass, inadequate resources, physical isolation and psychosocial distress are the key barriers regarding health related virtual communities. This was also the case for Upopolis [8].

2.3.3 Entertainment

Social media are a huge source of entertainment for both children and adolescents [44]. Providing entertaining and engaging content was also drawn forward as important for health oriented online communities by the participants in the study of Zora [5]

In their article evaluating how young patients perceived STARBRIGHT World (SBW), Nicholas et al. [37] argue that the decision to take part in SBW was in addition to factors such as interest in computers, observing other patients and recommendation from health care providers largely influenced by the prospect of accessing games that were perceived as “fun”. They further discuss how SBW became a distraction tool and entertainment for younger patients through the available games. The evaluation of SBW concludes with that the most positive direct outcome of the online network participation was that it gave the participants something to do. While providing another activity and entertainment SBW facilitated interactivity with other patients being according to the parents a better source of entertainment than i.e. TV [37].

Battles and Wiener argue that electronic media can be used as formal interventions or for entertainment [7]. They highlight entertainment as an important source of distraction from boredom and unpleasant experiences. They further justify their argument by referring to the popularity of video games and entertainment related web sites. In addition, Battles and Wiener discuss how anger has been shown to be reduced by distraction. Using entertainment is also widely applied in the reduction of experience of pain in pediatric practice.

2.3.4 Privacy and sharing

In comparison to other online communities, online health communities (OHC) hold their main function in being an arena for patients to share their disease experiences [22]. This context is highly challenging with regards to privacy. Patients are highly emotional around their medical condition and there is a risk associated with loss of sensitive information and privacy [22]. [45] suggest that in order to protect their users’ privacy, the online communities for teenage patients should be equipped with strong *default* privacy settings as well as offer a strengthened and age-appropriate privacy awareness education. When developing a social networking site for young patients, the designer needs to find out how much the users want to keep private and if they want to share some of the stories with non-members [31].

Van der Velden and Emam [8] discuss how users seek privacy based on Burgoon's [46] privacy framework distinguishing between social, informational, and psychological dimensions of privacy. *Social privacy* refers to the control over social interactions with others. The control covers several aspects of interactions such as frequency, length, and content. *Informational privacy* is gaining control over who may access information about oneself and what they can do with it. *Psychological privacy's* function is to protect "the individual from intrusions upon one's thoughts, feelings, and values, and the freedom to decide to whom to disclose certain personal thoughts and feelings" [8, p. 2]. Van der Velden and Emam [8] point out that users benefit from social media in terms of social and psychological privacy, but fear threatened about their informational privacy. Teenagers, however, tend to be more concerned about their social privacy than about their informational privacy.

When it comes to information seeking behavior, this might be strengthened by allowing the users to specify the viewings of the information, provide search capability and allow users to rate the information so that it would offer a peer review mechanism [38]. In addition, [24] suggest that the information presented on OHC should be reviewed by professionals so that the posted information would not be false.

David et al [39] suggest that in order to develop a satisfying OHCs, they should offer opportunities for users to share their stories, be sensitive by facilitating for support in different stages of patient's illness and, be flexible in relation to self-presentation [39, 17]. Burns et al [17] suggest that in addition to flexibility of their personal experience with the site, the OHCs should offer Q&A forums. In order to keep the site alive and attract more activity, [38] argues that the site should push notifications for events, facilitate groups and regularly scheduled group activities.

Somewhat summarizing remarks can be found in [16] who argue the three roles that OHCs should cover: the generator, the gatekeeper and the management tool. The generator's role is to generate more information than users expect. This can be achieved through chat rooms and message boards. In relation to information the management tool is of relevance. The management tool makes it easier for the users to find information. The gatekeepers task is to protect users' privacy and the additional design implication here is to keep the log in as simple as possible. Here Norfeldt et al. [16] point out that the main question in relation to this role to be answered by the future users is how closed the community should be. The claim here is that by keeping the community more open to general public; one can generate more users and thereby more information.

2.4 Recap

In this chapter I have presented some of the works concerning the theme of this thesis. I have described the existing initiatives targeting young patients world- and nationwide that have met the search criteria. What comes clear in the review is that despite that the design and functionality of the initiatives has shown to contribute to improving the patients' condition;

sites like Upopolis offer their services to both children and young people. Because of this, the information, functionality, and the design of these sites are not age-appropriate for adolescents. In addition, the reviewed initiatives do not have Norwegian youths as their targeted audience, and provide information about services and treatments that may not always be available in Norway. These foreign sites require a certain proficiency regarding the English language which Norwegian adolescents may not have. The description of the design process is also almost non-existing. This may seem paradoxical when looking at how much the reviewed literature stresses the specific needs of the teenage patients as presented in 2.3. The design implications regarding privacy and the different roles OHCs should cover for their users contributed to the focus of the questions during data-gathering (see Appendix B).

3 Theoretical and methodological framework

In this chapter I would like to present the theoretical and methodological framework used in this thesis. As discussed in the previous chapter, only four of the reviewed initiatives were directed towards teenagers. The performed review concludes that the initiatives were little age appropriate. Presented with this finding, the first question that came to my mind was: What is age appropriate for a teenager? In this chapter I aim to approach the research interest by focusing on the function of ‘cool’ as age-appropriate for teenagers and can contribute to creating engaging technology for teenagers. I will also present how the literature which makes up the theoretical framework of this thesis describes ‘cool’ as a design guideline. The literature review concludes with that the teenagers were not included in the design process of the reviewed interventions. Based on this, I will present the methodology applied in this thesis which aims to include the teenagers in the design process.

3.1 The concept of Cool

“Either you’re cool or you suck” is a widely spread slang for approval or disapproval among teenagers [47]. In this chapter I will present the concept of cool as it applies to technological products. How do different factors affect our perception of cool? “Cool” is something owned by the teenage community [6], and understanding what is teenagers think is cool may provide guidelines to design engaging technologies.

3.1.1 Definition of Cool

There is no one definition of cool.
There is no one definition of Beauty
Art
Obscenity [47, p. 177]

There is no unambiguous definition of the cool concept. Just the word “cool” can be used as a noun, verb, and an adjective, giving the term paradoxical properties [48]. The phrase “be

cool”, here meaning acting calm and unimpressed, not giving away one’s failure, was created and adapted by the African Americans during the White oppression in the USA. [49] compare this to the African origin and the Yoruba tribe’s usage of it. This particular tribe defined being cool as the “ability to be nonchalant at the right moment”. After being adapted in the jazz circles, it spread to the rest of the world keeping its meaning. The word was translated to “kul” in Norwegian, and as opposed to the current posh feel of the word “cool” in English, “kul” has a hip feel to it and is more “neutral” [49].

Digging more into the linguistics of “cool”, Fitton et al. [6] present how “cool” can be identified with material objects and people. They present a summary provided by Read et al. [50] with the Essential Categories of Cool. The six categories are: rebellious, anti-social, retro (as being clearly from another era; an outdated cell phone is not retro – a vintage bag is), authentic/ the real thing (such as must-have items and brands), rich/ big money (costly items that might represent the individual as being rich), and innovative (here meaning something that surprises people with its unusualness). Read et al. [50] derived a hierarchy of cool from the Essential Categories of Cool.

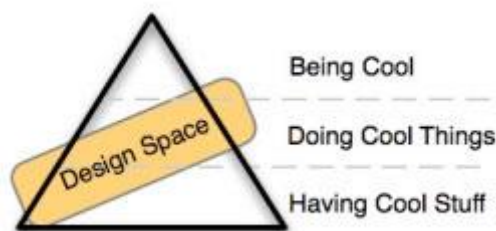


Figure 5: The Hierarchy of Cool [50]

The top of the pyramid consists of what people strive after; namely being cool. Second is doing cool things, and on the bottom exists having cool stuff. Read et al. [50] argue that the coolness at the top is hardest to achieve, but by designing for “cool”, it may be possible to develop cool technologies and artifacts that contribute to doing cool things.

Marketing researchers have understood that people, and especially teenagers strive for being cool. The assumption here is that when branding a product, the consumer must be persuaded into thinking that by owning the cool product or doing cool things provided by the merchandiser, s/he might become cool [49]. This marketing strategy has proven to work both with Gen Y (people born between 1980 and 1995) and Gen (people born after 1995, including “tweens” defined as “too old for toys too young for boys”; aged 8-12).

3.1.2 Cool challenges

Cool as a guideline is difficult to define [51]. Once again turning to the poetic definition of cool presented by Liu, one can say that

It's a sort of
"I know it when I see it"
type of thing. You can argue
'til the cows come home
that this was or wasn't cool,
but it's all pretty subjective. [47, p. 177]

Due to the subjective nature of cool, it is hard to say how cool differs across cultural and social groups. I for instance think that iPhone is the coolest smart phone out there, while some of my friends disagree pointing towards technologies they perceive as much cooler. Is there any consensus on something that is perceived as cool across social groups?

Garber & Geiman [51] argue that when researching 'cool' it is more fruitful to work with a group rather than separate individuals as they tend to represent themselves, while groups give more accurate estimates because they focus on the target. Yet still, the concept of cool is slippery. It cannot be found in objects, but in perceptions of others [51].

In addition, when researching the 'cool' concept, it is possible that especially teenagers describe things that their 'cool peers' find engaging and cool, and in the striving for being cool might describe these things as cool as opposed to viewing their own opinions. The same is true for teenagers who are consciously and actively distancing themselves from the 'popular and cool' peers, guided by political or personal agenda. They might want to avoid 'cool' things and behaviors, or perceiving the opposite objects than their peers as cool. Having 'cool' as a guideline might be challenging when trying to meet the needs and understand the standpoint of the outsiders who do not wish to be on the inside.

3.2 Designing for Cool

3.2.1 Cool as a design requirement for teenagers

Fitton et al. [6] describe how when designing something engaging for a specific group, a developer might first turn to guidelines or heuristics for designing a specific type of technology and then turn to guidelines for what engages the specific group. In the case of this thesis this would impose concentrating on how to design social networking sites and increase their usability and attracting users, and then turning to literature and future users to get feedback and guidelines for how to improve the site in order for them to use it.

However, following the approach presented by Fitton et al., the designer must first determine what engages the specific group he or she is working for and with. In case of teenagers it is "cool". It is something teenagers are and most adults are not, and as Fitton et al. present it, by understanding what is 'cool' from the perspective of teenagers "it may be possible to distill guidelines for the design of engaging products and technologies for this population" [6, p.

143]. This means that the designer turns to what engages the future users and uses this information as a guideline before turning to heuristics and general guidelines.

3.2.2 The wheel of joy

In the article “What Makes Things Cool? Intentional Design for Innovation, Holtzblatt [52] presents *joy* as the absolute center of cool, explaining with it why the experience of cool is so compelling. Further on, she argues that joy doesn’t come from one specific feature, or an attractive design, but emerges when products offer us possibilities to satisfy our motivations, these being: accomplishment, connection, identity, and sensation. She presents the needs in the wheel of joy (figure 6) as a part of life-centered design, where the idea is to pay attention to the chunks of activities that make up larger tasks and how they can be executed more efficiently. The motivations included in the wheel of joy are the ‘*what*’ of cool.



Figure 6: The wheel of joy [52]

While *accomplishment* emphasizes the joy of doing life better than before; *connection* deals with the joy of being able to keep in touch with others. Central to experiencing joy of connection is the way technology makes the relationships manageable. Social networking sites as Facebook make it easier to drop in more frequently, and at the same time provide the users with conversational content such as videos, photos and things to do. As Holtzblatt argues; “relationships are not relationships with nothing to do or talk about” [52, p. 43]. In addition, sites bringing together people based on their interests “create tangible communities where only dispersed people existed before” [52, p. 43].

When describing the *identity* aspect of joy, Holtzblatt stresses adolescents’ quest for self-definition which is most intense during that period of life. Cool tools make it possible to see what others at our stage of life are doing and give us examples of what to do, value etc. in order to become who we would like to be [52]. Like conversations, identities need content and aid. While helping out with defining identities and creating connection, social media profiles are becoming the “living cave wall”. Last but not least, the *sensation* aspect is being presented as a vacation from everyday life. Sensation can be divided into sensory immersion

where a person experiences “time out of time”, and sensual delight. The requirement of paramount importance in design is creating absorbing technologies and making sensation a natural part of experience. Holtzblatt argues that joy is the product of how the factors included in the Wheel of Joy impact life and that the main goal is to be able to evoke the “I can’t go back” experience in users.

In order to fulfill the aspects of joy in life, one must design joy in use [52]. Holtzblatt’s Triangle of Design defines factors which together can increase or decrease the overall experience of cool. Joy in use is a holistic approach, which means that it does not focus on specific functions of the system such as for example heuristics.

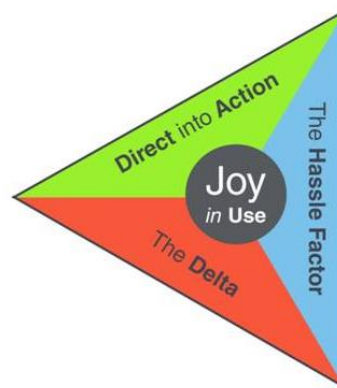


Figure 7: Joy in use triangle [52]

The “Direct into Action” aspect of joy in use emphasizes that all cool products draw their coolness from their ability to help the users to fulfill their core intents in a profoundly better way than previous technologies. The cool technology may thereby remove some of the “Hassle Factor”, but will always create a new hassle. The “Delta” embraces the learning stretch embedded in the technology. It is the context necessary to achieve the first part of the triangle of joy, namely “Direct into Action”. Products that go directly into action without any knowledge are cool. Intuitive is cool.

3.2.3 Hedonic and utilitarian information systems

There are different ways to categorize IT systems. The reviewed literature emphasizes that teenagers have different ways to use the Internet to pursue their interests. Taking consumer behavior under consideration, which distinguishes between utilitarian and hedonic products, it becomes obvious that it is important to look at the use context of the site as well as at the purpose for why the users are using it.

Heijden [53] describe hedonic systems as providing self-fulfilling value to their users, unlike utilitarian systems, aiming to offer instrumental value, such as increasing task performance. In its purest form, interacting with a hedonic system is designed to be the goal, and the most important objective is to encourage prolonged use. Heijden [53] explains that the motivation for using hedonic systems is intrinsic which means that the user is motivated by the benefits

of interacting with the system per se, as opposed to extrinsically motivated users who draw on benefits deriving from expectation of some reward or benefit.

The web then, serves both hedonic and utilitarian purposes and perception of usefulness or entertainment influences the Web use. Users may seek hedonic websites to satisfy their entertainment needs, for so to turn to utilitarian sites in order to satisfy their work or school related purposes. Heijden describes homes as being “the natural habitat of hedonic systems” [53, p. 697] and therefore suggests that systems designed to be used at home should seek to serve the hedonic purposes as opposed to utilitarian systems habituating work places and serving utilitarian purposes. The ease of use is more central to the prediction of intention to use the system than perceived usefulness. The ease of use is one of the main contributors to future intentions of using the system, because it neither enhances nor inhibits the overall entertainment experience. In addition, the hedonic information systems presented and perceived as esthetically more attractive, were regarded as easier to use [53]. In order to increase the user acceptance, Heijden suggests focusing on the nature of the system and the context of use.

3.2.4 Virtual possessions

In their article “Teenagers and Their Virtual Possession: Design Opportunities and Issues”, Odom et al. present that we live in a world increasingly filled with virtual possessions (2011). They investigate how people, and especially teenagers value and form attachment to virtual possessions. Following their argumentation, meaningful attachment can emerge by extending the self, like teenagers who draw on displays of their interests as a way of authoring their space and conveying their values. Social networking sites offer their users personal places where they can design and reformulate experimental selves and keep their virtual possessions in the cloud [54].

On the web, teenagers tended to make presentations of themselves, and wanted all of the technology aspects to represent them. Odom et al. [54] argue that privacy considerations were important so that the presentations of the self could be targeted through permissions. Those permissions were not only important in order to shield the users from embarrassing and regrettable experiences, but they also strengthened a sense of social connectedness.

Through their study of virtual possession, Odom et al. [54] came up with a list of design opportunities and issues. One of the main opportunities is metadata which is a unique quality of virtual possessions, and which over time, may become a virtual possession in itself. Both human and machine produced metadata are dependent of users sharing their possessions with others. Sharing content within a group creates bonds and permitting others to present and edit possessions with others plays the main role in extending individual sense of self through other people. Another opportunity is creation and presentation of self to multiple audiences and that the possessions become placeless, increasing their value through display of these [54]. Presenting the self and possessions which convey who they are and what they stand for is of

paramount importance for teenagers who strive for finding out who they are and their place in the world.

3.3 Participatory Design

Over the past six decades, designers have given more and more attention to the future users of their solutions [55]. Design was moved out of the lab and into the field where the users became the irreplaceable resource [56]. Participatory design (PD) is a design approach aiming to *actively* involve the people designed for and other stakeholders in the design work [57]. By including the future users in the design process, it is possible to expand the space for design ideas, trusting that the solution will not only become functionally superior but also more creative [58]. PD springs out of the idea that those affected by the design should have a say in the design process [59].

PD has its roots in the Scandinavian democratization movement at the workplace, where the focus of democratization is channeled through engaging multiple voices. The pioneer was Kristen Nygaard who not only developed the programming language *Simula*, but also in 1972 involved the Norwegian Iron and Metal Workers Union (NJMF) in the process of system development. By doing so, he took the first step towards moving away from traditional research and system development to working with people, and involving the local unions. This approach spread throughout Scandinavia, and made PD a part of the Scandinavian tradition [60]. That said, PD has undergone many changes; it has moved away from the motivation being empowerment of the workers, but has still preserved the core which is examination of the tacit aspects of human activity, and a belief that the tacit knowledge can be examined ethically and efficiently through cooperation and partnership with the participants [61].

Bratteteig & Wagner [58] argue that using PD approach is appropriate early on in the design process. At this stage the constraints that often follow introduction of a prototype, are often absent. In addition, user involvement early in the design process facilitates for more creative solutions as well as increased user satisfaction. Most of the theories and practices within the PD approach suggest combining different perspectives and disciplines, based on a belief that complex, human problems call for multi-disciplinarian solutions [62] and because all stakeholders need to be involved in the process.

The PD approach offers a number of qualitative methods and techniques for involving the users in the design process. The methods include interviews, observations, future workshops, design workshops, storyboards, role playing, thinking aloud, prototyping and many more. Kanstrup and Christiansen suggest the usage of artifacts or boundary objects [63] to prompt creativity [56]. Star and Greisemer [63] define boundary objects as:

“(...) objects which are both plastic enough to adapt to local needs and constraints of the several parties employing them, yet robust enough to maintain a common identity across sites. They are weakly structured in common use, and become strongly structured in individual-site

use. They may be abstract or concrete. They have different meanings in different social worlds but their structure is common enough to more than one world to make them recognizable, a means of translation.”

[63, p. 393]

They further argue that using boundary objects is critical in developing and maintaining understanding between different social groups. When using boundary objects, users need to feel challenged, but at the same time feel free to innovate [56].

3.3.1 Why PD in this project?

There are many examples of failed initiatives directed towards teenagers in Norway. As Fitton et al. [6] argue, there is an absence of research done with teenagers as opposite to using them as informants and test users. The group targeted by this project have different needs and motivations for using the Internet, and without involving them in the design process, the project could end up completely bypassing what they would find enjoyable. The study examines how to design a ‘cool’ health-oriented social networking site for teenagers, and what is ‘cool’ for me is probably the opposite for the teenage generation. I needed help from the teenagers. Bratteteig et al. argue that users provide “(...) knowledge that makes it easier to solve the right problem the right way” [64, p. 19].

One of the many challenges related to using PD in this project is that the future users are teenage patients. Due to the recruitment challenges, the involvement of future users is limited, but since the focus of the website is on the “cool” aspect, the research can be done with non-patient teenagers presented with the scenarios. Kanstrup and Christiansen [56] faced a similar dilemma in their research, and argued that even though the participants in a PD project are not the future users, they may still represent the web of relationships between user and product. They are potential users with respect to their general attitude towards technology.

3.3.2 Ethical considerations

Brandt argues that there is a considerable agreement around the claim that designing the design process itself within PD is just as important as designing the artifact [57]. Any methodology and method decision is an ethical decision. In her article “The Methods, Politics, and Ethics of Representation in Online Ethnography”, Markham [65] presents important ethical considerations one should address when choosing how to collect and present data:

Every choice we make about how to represent the self, participants, and the cultural context under study contributes to how these are understood, framed, and responded to by readers, future students, policy makers, and the like [65, p. 811].

Löwgren & Stolterman (2004) stress the uniqueness of every design process which imposes ethical considerations. The process itself is always a combination of actions, choices, and

decisions. In order to prompt the creativity and to louden the voices of the participants, one must provide them with appropriate tools [55]. Therefore, I used and further developed certain methods and tools I thought were appropriate and would give me the necessary data needed for development of an appealing product. But already by choosing the tools and methods I was affecting people's lives and possible choices for action during the data collection as well as future usage of the site [66].

Based on the reviewed literature and experiences my supervisor had during her study with teenage patients in Canada [67], I understood that the teenagers seldom identify themselves as patients. The challenge in preparing and executing the data collection was that being patients, the participants could be perceived as victims. I wanted the teenagers to not be involved in the project as victims or a group who needed help in order to master their lives and social connections, but as designers in possession of a different view of technology and social media. During their teenage years, teenagers strive towards being independent, and therefore I did not include the parents in the design process. I felt that in order to fully become my design partners, I had to discard the image of adolescents as being unable to take care of themselves online.

By doing PD, I committed to involving them in the early stage of the design process and tried to evoke mutual learning by making their "tacit" knowledge come into play. My focus had to be widened and the instruments for collecting the data had to embrace it. In order to obtain mutual trust and a feeling of equality I wanted to know as much as possible about what they thought was cool online and why. The design specifications become of lower priority and importance as I figured out that what came out of collaboration with the participants was data and not results, and that it was my job to understand and analyze them. The situatedness of what they thought was cool, where they came from, and how they viewed the Internet, became the focus of the data.

PD, in line with cultural probes and ethnography, recognize the essential role played by the interpreter. It was therefore of paramount importance that I reflected on my own biases in terms of opinions, experiences, and the way I perceived the participants. While not directly useful, this reflection is ethically necessary [65] as I am doing the translation, and that the translation and transcription changes the original data.

Design is also drenched with values and ideals. Every decision related to design moves us either closer or further away from these values. Ethical considerations must also be uttered toward the aesthetic aspect of design and the politics of design. The aesthetics address that in a world filled with artifacts, creation of a new one affects the overall experience of the world where the artifact is placed. When implemented and even when tested, the graphical, artistic expression of the design will affect how the users experience cyber space as a whole. The aesthetics may make the world a more pleasant or ugly place to live in [66]. The political aspect of design cannot be underestimated. Every decision about the functionality and purpose of the design either constrains or facilitate for actions which in itself is a political action [66]. Suchman [68] also stresses how design of technology is not only design of

physical things; “It is the design of practices and possibilities to be realized through artifacts” [68, p. 186]. By allowing for certain actions, promoting specific skills and permitting certain outcomes, we are in a way forcing the user to adapt.

The recruitment of the participants also brings ethical implications; by not being able to access the actual future users in the design process, not all the voices will be heard. Locating the project in Oslo and surrounding area excludes youth from other parts of Norway with different support bases and social environments. It is possible to imagine that adolescents living in less populated parts of Norway have limited access to health and support services and have other needs than the participants from Oslo with easier access and the option of choice of such services.

3.3.3 What can be expected?

One can expect many outcomes by committing to PD. PD is a highly political approach. Even with a social networking site concerning a very specific user group there are a lot of other users. By only including the teenagers in the design process, one can expect that the prototype will not consider other stakeholders like moderators and health care professionals who would administrate the health oriented aspect of the site.

Since PD is a highly democratizing process and demands a divergent approach [69], it may be expected that the participants will lead the design and purpose of the site in an unexpected direction. Giving the responsibility to choose the functions and overall design of the site to the participants may also lead to solutions that are not as easy or possible to implement.

3.4 Recap

In this chapter I have presented the theoretical and methodological framework for this thesis. The theoretical framework of this thesis concerns the concept of cool which is the objective for this study. Following I have described how the literature suggest one should design for cool. I have chosen PD as my methodology. The main reason for choosing this approach is grounded in the motivation for this thesis, namely designing a social network for teenage patients and therefore PD was the methodology of choice.

In the next chapter I will present the methods used for the collection of the data and how they were used. The methods were chosen based on the methodological framework and imply a number of challenges and ethical considerations which had to be taken under account.

4 Methods

Myers and Avison [70] explain how quantitative research methods were developed in natural sciences to study natural phenomena, while qualitative research methods were developed in social sciences to study social and cultural phenomena. The motivation for choosing qualitative research over quantitative is the observation that what distinguishes humans from the rest of the natural world is humans' ability to talk [71]. While quantitative data consists mostly of numbers and measurements analyzed by applying statistic procedures, qualitative data consists of text and photos and are coded or grouped during analysis [72]. Whenever applying a qualitative approach, the researcher seeks to establish the meaning of a phenomenon from the views of participants [72].

Despite the fact that quantitative research methods were originally developed in and for natural sciences, they are now being applied in social sciences without discussing their validity over the qualitative research methods [71]. Upon choosing whether one wants to use qualitative or quantitative research, the most important question is what is being studied and what kind of data the researcher wants to collect [73].

Silverman [73] discusses how research on computer-aided systems has been dominated by survey methods. However he quotes King when explaining why survey methods decontextualize perception of IS: "the surveys do not reveal the context in which tools are used... which... influences the respondents' perceptions" [73, p. 4]. Suchman argues that the design of new IT "must take account of everyday rationalities and avoid treating people as "cultural dopes" preprogrammed by the rules [73, p. 5]. In order to answer the research questions it was appropriate to use qualitative methods. In order to be able to deliver an exciting and attractive product, the users had to be the center of every method chosen for the collection of data.

4.1 The cool wall as a research tool

In order to design something that would be fun to use, my supervisors advised me to look into the concept of cool. I considered collecting the data through focus groups using boundary objects such as enlarged screen shots of popular social media sites and talking about what

made them cool. My supervisor then suggested me to read the article “Constructing the Cool Wall: A Tool to Explore Teen Meanings of Cool” by Fitton et al. [6]. In this article they describe the process of developing and exploration of a tool used to investigate the “cool” aspect of technologies. The authors present a significant absence of published literature from the design community on designing with teenagers. Disregarding the possible reasons for not engaging this part of the population in their research, they highlight that the role of teenagers have for the most part been the role of a tester or a user as opposed to the role of an informant or design partner. In order to design with teenagers, Fitton and others [6] took the idea of the Cool Wall from a popular UK BBS program about cars called Top Gear where the presenters placed pictures of different cars on a so called “Cool wall” according to how cool they perceived the vehicles were. In the show, the wall was divided into four categories: seriously uncool, uncool, cool and subzero. They used the concept as well as the categories in their own study by transporting them onto an interactive touch screen where the users were asked to drag images of things coming from categories like music, fashion, technologies, interests etc. [6].

4.1.1 Interviews using the cool wall

Inspired by the work of Fitton et al. [6], I decided to use the cool wall as a research tool and it became a boundary object during interviews. Wanting to acquire in depth data consisting of detailed views on situated coolness of social media sites and their different features, I decided to conduct individual interviews instead of group sessions. Looking back at Gerber & Geiman’s argumentation concerning rating the target rather than oneself, it becomes obvious that by splitting the informant group into individuals, as opposed to conduction group sessions, the rating would be much more representative. At the same time, it can be challenging to hear all the teenagers during a group session. In case of one participant having stronger opinions or being “cooler” than the other participants, his/hers opinions might become more dominant and influence the answers of the rest of the group. Using the cool wall, would also be challenging in groups. The decision was additionally strengthened by the fact that the purpose of the data-gathering was to rate the ‘cool’ of specific functions and social media sites, and that by having a narrow objective did not require the accuracy provided by group ratings.

The interviews were semi-structured in order to allow a less restricted conversation. I followed an interview guide consisting of questions I wanted to ask the participants while not using the cool wall as a form of introduction to the different stages in the interview. The interviews were divided into three sessions. The first part of the interview concerned what they did online and which sites they perceived as cool and what made them cool. They were asked to place six magnets they felt strongest about with various logos on a metal plate (The cool wall) divided into stages of coolness. During the second part of the interview, the teenagers rated different functions according to their coolness by placing them on the cool wall. When rating the sites and functions, the teenagers were asked to think aloud, and were asked appropriate questions about why they chose the different sites and functions. The last

part of the interview was organized as a workshop where the teenagers were asked, with the first cool wall prototype, to place different functions (magnets) according to where they wanted these on the site. Before working on the placement of the different functions, the informants were asked questions regarding graphical interface of the site, what functionality it should offer and who should administer the site. When the interview was conducted with non-patient teenagers, I used personas. The personas were respectively a boy or a girl at 17 with diabetes facing some daily challenges the teenagers could relate to. I chose diabetes because of it being a condition not perceived as “threatening” as i.e. cancer (Appendix B)

4.1.2 Evolution of the cool wall

In this section I will describe the process of developing the tool used for data collection. While not directly related to this thesis, I wanted to develop a low-fi design tool that could be used in a hospital environment. This meant that all the materials should be easy to disinfect, and could be used even if the patient was bedridden. The developed prototype for the cool wall is still in need of further improvements, but will hopefully be used in future studies with bedridden young patients.

Cool wall 1.0

The cool wall Fitton et.al [6] used in their research was on a simple screen where the participants used buttons in order to place different images of cool objects and concepts in the four categories. Although this would not be difficult to achieve and use as a tool during the interviews, I was advised to use magnets on metal plates to make the wall as simple to use as possible. With the help from the IT department I acquired a couple of PC covers cases which were perfect to place magnets on. I drew on a table divided into the four categories, translating them into Norwegian (ultra kult, kult, ikke-kult, and seriøst ukult). After the pilot interview, I used the second PC case to represent a site, by dividing it into header, left and right block, content area and footer in order to get information on where on the site the participants wanted the various functions to be.



Figure 8: Cool wall 1.0

In order to place different images on the board, I used regular magnets and attached small images and symbols using blu-tack. After asking a couple of co-workers in their late teens at my part time job I got a feeling of what sites and functions I should include in the representations. Using magnets proved itself to be fruitful as we were able to lift the board during the interviews in order to discuss it and move the objects around.

Represented sites and functions

The first part of the interview concerned the sites that the teenagers thought about as “cool”. They were presented with various examples of social websites. Since the purpose was to identify the functions that they thought were “cool”, sites that did not directly fall under the definition of social networking sites presented in chapter 1 were also included. Excluded were sites completely divergent from the definition and that did not include any facilitation for socializing with peers. Based on the assumption that teenagers use Internet sites for dating purposes, a few dating sites targeting youth were included.

In the pilot interview, the second part of the workshop focused on interests that teenagers pursued online. The interests were represented in form of categories, meaning that for example the music category was not represented by standalone artist. Talking about pursued interests was meant to facilitate the discussion in the third part of the workshop concerning functions found and used in the online sites. Because I wanted to include a design session in the interview, I decided to exclude this part in the remaining interviews.

The functions chosen in to the selection were based on those most often offered by social networking sites. Functions such as music or video were presented in order to examine the social aspect of these. The magnets used in this phase of the interview were also used when placing functions on the board representing the future site.

Social Media Sites	Interests (removed)	Functions
Twitter	Wikipedia	Music
Facebook	Food	Video chat
Instagram	Cars	Blog
Chat.no	Body	Chat
Decate.no (added after the pilot interview)	Health	Profile
Nettby.me (removed after the pilot)	Fashion	Email/ messages
Biip.no	Games	Events
Myspace	Books	Like/rating
Skype	Music	Pictures
Blogg.no	Politics	Friends
Flickr	Movies	Hyperlinks (sharing)
Foursquare	Shop	Friend finder (suggested)
Gaysir	Sports	Search bar
Google+	Mental health	Status updates
LinkedIn	Homework	Video

MyOpera	TV	Groups
Snap Chat (added after the pilot)	Travel	Group chat
Pintrest	News	Hashtag
Reddit		Tag (pictures)
Sol.no (removed after second interview)		Places
Tumblr		Invites
Ung.no (removed after second interview)		Games
YouTube		

Table 1: Represented sites, interests and functions

Cool wall 2.0

After I decided to use the cool wall as a tool to design the site during the interviews, I depended on two large boards, which would work poorly in a hospital environment. They were both heavy and would be challenging to disinfect. I acquired a new magnetic board, this time a glass covered, black white board (Figure 9). This gave me an opportunity to use one board throughout the interview as well as enabled drawing on it using markers (the markers could be easily disinfected). During the design phase of the interview, the participants were now able to draw directly on the board in addition to placing the magnets.

Magnets presented me with another disinfection challenge. The blu-tack and small paper images could not be cleaned, and could be a contamination hazard for the patients. I came across an idea for making fridge magnets using glass marbles. The images could be glued underneath a glass marble and placed on a magnet. This proved to be a good solution to the disinfection challenge, and also made the images more presentable and easy to grab.

Moreover, the cool wall 2.0 enabled me to include and test a new category: “whatever” which was requested during the three first interviews. In case the category failed to be of use for this study it would not present any hassle as it was easy to erase. Due to its properties the board can now also be used by others in different ways and settings.

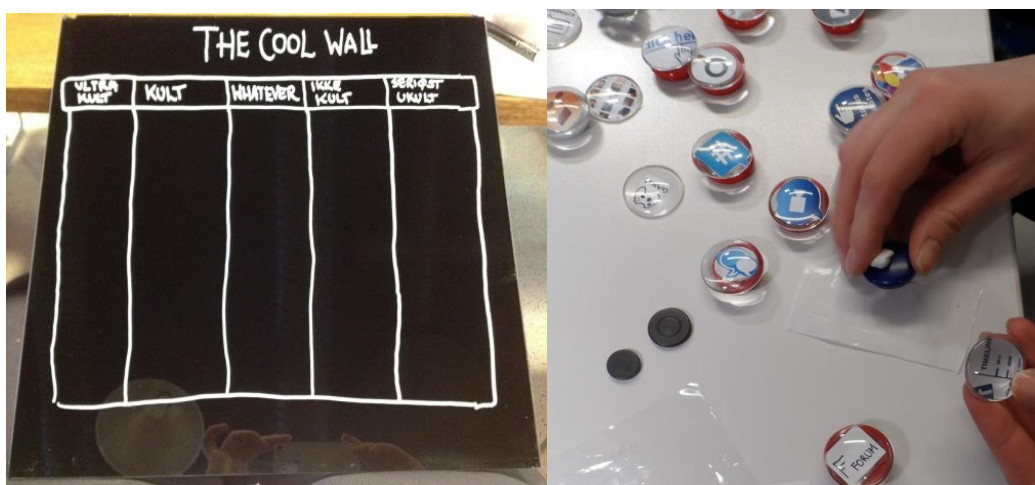


Figure 9: Cool wall 2.0 and the glass-marble magnets

4.2 Collection of the data

In their article about methodological challenges of interviewing teenagers as research participants, Bassett et al. [74] present how to encourage teenagers to expand their answers in semi-structured interviews. Teenagers have long been perceived as passive due to researchers looking at them as lacking of cognitive skills related to decision making and responsibility, and providing untrustworthy answers. I knew that the target group of this study was methodologically challenging, and strived therefore throughout the process of collecting the data to overcome these obstacles by following some of the advices provided by Bassett et.al [74].

The biggest challenges highlighted by Bassett et.al are trust from teenagers' families towards researchers and their agenda and intentions and voluntary participation. Participation requires parental consent, and thereby the recruitment moves out of researcher's control. Adolescents may not have much to say about their participation, and in some cases, the teenagers might feel the need to participate in order to please their parents [74].

In order to create a relaxing atmosphere around the interview, it is important to think about the location where the interviewees feel that they are not being overheard and that they feel comfortable with the recording device. One might for example use a smart phone to record the interview since it is a non-threatening device which they are already used to have around them. When it comes to the interview itself, Bassett et al. [74] suggest that one might avoid some of the silence by stressing the confidentiality of the interview and that the researcher is non-judgmental. They suggest that in order to engage adolescents it is fruitful to have some prior knowledge about them, such as their interest, and use them to start an in-depth conversation as opposed to simple question and answer interview.

Enhancing teens' engagement can also be achieved by disclosing information about oneself in order to create mutual trust. Sharing one's fondness of something that the teenager is also fond of creates common ground and helps the adolescent to see the researcher as a person. Using culture and references to popular culture known to evoke emotions in teenagers can enhance the conversation. Cultural familiarity may be essential for the success of the interview [74]. For example, knowing that Justin Bieber is either loved or hated by the teenagers, one can ask them if they are fans. Expressing the same feelings towards the artist may in my case lead to interesting conversation about what the teenagers think is cool and produce a relaxed atmosphere.

Bassett et.al [74] present that being an insider of the interviewees' culture might be fruitful in terms of connecting with the teenager and understanding their background, but may also lead to neglecting vague concepts and grey zones. Being relatively young and still remembering my teenage years might contribute to me not bothering to sufficiently investigate how they view the world and relate to it.

Expanding focus and avoidance of intrapersonal triggers

Having a relatively defined concept of investigation makes it that much challenging to keep the focus of the interview as expanded as possible. Beyer & Holtzblatt [75] stress the importance of paying attention to intrapersonal triggers that may affect the interview in a less productive way.

When presented with surprises and contradictions such as when a teenager might say that they do not perceive something established as cool by the other teenagers, as cool, it is easy to let it pass and consider the statement as irrelevant. That way important data gets neglected. The right thing to do is to explore the reason behind the statement, keeping in mind that nothing a person does is unique for them and that they represent an important class of users whose need will not be met if the contradiction or surprise is not examined thoroughly [75].

Beyer & Holtzblatt stress that when user communicate something that fits with the designer's assumptions, the conclusion that follows is often that everything that has happened to the researcher has happened to the user [75]. Again, the physical act of the nod and the unspoken conclusion on the designer's side has consequences for the quality of the data. It may also trigger a need in the participant to satisfy what s/he thinks the researcher wants to hear and not what is actually the case.

During interviews, the participants may mention a technical concept that the designer has no knowledge about. It is less humiliating to admit one's ignorance, but is certainly not productive. By asking the participant to explain the concept, not only does the designer get an insight into the new type of technology and how the user understands it, but it gives an opportunity to step away from the role of an expert allowing the interview to continue on more equal terms [75]. During the interviews, the participants were asked to explain how they if they used Internet to do homework. Even though I have used "Fronter" in schoolwork, I asked them questions about how it worked and what they thought of it.

4.2.1 Consent forms

Before starting an interview, the participant was presented with a consent form which s/he had to read and sign before we could begin (see Appendix A). The purpose of having them to sign the form with me present was facilitation for questions and explaining to them how I would use the collected data and what I would gather information about. Due to restrictions laid by NSDⁱ, I did not collect information about the participants' condition, ethnicity, social status, or occupation. The only information gathered was gender, age and the participants were categorized according to whether they were chronically ill/ of the targeted group for the study or not. The signed forms and names were stored in a locked cabinet and destroyed after finishing the thesis.

During the collection of the data and reading up on the existing literature regarding this field, it became clear that including data about the participants' type of illness as well as ethnicity

and social status would provide richer qualitative data. These factors such as the ones mentioned above can have much to say about why and how the teenagers use Internet in their daily lives. Unfortunately I could not use or record these due to the restrictions laid by NSD.

4.2.2 Recruitment

“The people you include in a design process determine the kind of design you get” [75, p. 75]

It quickly became clear that the recruitment would show itself to be challenging. Personally I did not know any teenagers and both my friends and family did not know about any teenagers with chronic health challenges. According to the laws regarding collection of sensitive personal information, in order to get in touch with the targeted group, I had to first go through various institutions such as hospitals, health-organizations and diagnosis-specific associations, gain their interest and perform the recruitment within their premises.

The first idea was to go through children’s wings at hospitals. Thinking it would be easier to recruit in a smaller hospital, I contacted SiV (Central Hospital in Vestfold, Tønsberg). After several weeks, the answer was negative due to the chief doctors at the children’s unit who expressed that they did not have time to help out with research not connected to their own and were doubting if their patients would want to participate in the study. Thereafter I contacted the Norwegian Association for cancer patients and their branch dealing with children and adolescents at Radium Hospitalet. Again the answer was negative due to the low number of young patients using their consultation offers. After contacting another association for young patients, my supervisor made it possible to post information about the study on their website and Facebook page. This helped me to recruit one teenager.

Due to the issues connected to finding chronically ill teenagers, in agreement with my supervisors, I decided to start collection of data and design implications using “healthy” teenagers. The reason for it was not only that this population was easier to find and invite to the workshops, or to find if there were any significant differences between this population and the target group of this research. The main reason was the purpose of the interviews: to find out what young people think is cool online and what functions make the social media sites cool.

Finding the teenagers showed itself to be a very challenging task. Teenagers have tight schedules including school, after school activities and leisure with peers. I found it very challenging to recruit them without offering any compensation for their time. As I struggled with the recruitment, I was considering offering the teenagers gift cards or small rewards for their participation. The idea; which would probably make the recruitment easier, seemed unethical due to the fact that participation was supposed to be voluntary. Offered any rewards it would be possible that the teenagers would feel somehow obligated to participate which would remove the main part of the terms for participation.

The first participant (female 19, non-patient) was asked directly to join the study. The second participant (female 18, non-patient) was recruited through a friend. The second participant in the group of healthy teenagers knew of a couple of teenagers who this study targeted. She got me in touch with them and therefore recruitment of the last participants can be referred to as snowball effect [76].

4.2.3 Participants

The table below summarizes the gender and age of the teenagers participating in the collection of the data. Variables such as race, religion and their location were not directly connected to the focus of the study. Therefore they were not considered nor taken under account under the design process.

Gender	Age	Patient/ non-patient
Female	19	Non-patient
Female	17	Patient
Female	18	Non-patient
Male	19	Non-patient
Male	16	Non-patient
Male	15	Non-patient
Female	22	Patient
Female	19	Patient
Male	13	Non-patient

Figure 10: Participants

In order to avoid confusion and overload of names/aliases, the participants will be referred to as female or male followed by their age, and whether they were patients or non-patients. When presenting the data, I will apply qualitative description as described by Sandelowski [77]. “Such study is especially useful for researchers wanting to know the who, what, and where of events” [77]. The method is appropriate as I want to stay close to the collected data and the structure of the words.

Population sample

While being an enjoyable and highly informational process, data-gathering has to stop somewhere. After deciding the method, the researcher must know what data s/he wants to gather and how and where to gather it, and last but not least when to stop. No matter the objective, the issue of sampling needs to be addressed [78]. After conducting 7 interviews, I was insecure if the sample was large enough to provide me with enough information on how to design.

There are no guidelines for determining nonprobabilistic sample sizes [79]. While Holloway [80] and Wheeler suggest that in order to provide enough data for a purposeful analysis 4-6 data units are sufficient for a homogeneous group and 14-20 samples for a heterogeneous group, the general recommendation in order to determine purposive sample sizes is to reach theoretical saturation. Theoretical saturation can be defined as a point where “no additional data are being found whereby (researcher) can develop properties of the category. As he sees similar instances over and over again, the researcher becomes empirically confident that a category is saturated.” [79, p. 65]

Guest et al. [79] argue that data saturation cannot be achieved if the interviews are unstructured. Interview structure and content must be consistent to a degree where the target would stop moving. Adding a narrow objective and a homogenous population might contribute to the reduction of the sample size. In case of this project, the targeted age group constitutes a fairly homogenous population. With the phenomenon of interest being “cool functions”, it did not take many participants to reach data saturation. “When you’re no longer surprised by what you’re observing, you’ve probably seen enough” [78, p. 132]

When walking into the 7th interview I could predict what would occur, and the predictions showed themselves to be accurate, grounded in Blomberg and others’ argumentation, I decided that I could be secure in believing that I had saturated this category and part of the research and could move on to the next phase of the design process. When it came to the design part of the interviews, I realized that data saturation in relation to user interface could never be achieved due to the unstructured form of their gathering. However, I could see clear similarities across the interviews regarding which functions adolescents thought would be useful and entertaining for the intended health oriented social networking site.

4.2.4 Location

The consensus form informed the interview objects about the possibility of carrying out the interviews wherever it was convenient for the participants. Two of the interviews were conducted in my living room, two at a meeting room at IFI, and one in the hallway at the participant’s school. Except for the interview in the hallway where we were interrupted once by a teacher, the interviews were undisturbed. Since the interviews showed themselves to last more than one hour (in one case over two hours), the participants were offered a short break before starting the design phase of the interview. We filled the breaks with off the record

small talk, and conversations regarding the method and how it could be improved. The participants expressed that the surroundings were non-threatening and that the interview situation was laid back and not as “serious” as they have feared.

4.2.5 Pilot workshop using the cool wall

In order to find out if the method was appropriate for collection of the data for the prototype and this study, I decided to execute a pilot interview. Four teenagers were invited to join the workshop, but only one showed up. Together with the informant (female 19, non-patient) we went through the agenda and the participant was then asked to evaluate the method. What came forth was that the images representing the variables in each phase of the workshop were easy to understand, even though two of the sites represented in the “Existing social media sites” were outdated. However, the participant expressed concern and confusion regarding the coolness categories. She felt that there was no room for objects that were “in the middle” meaning that some things were of a more neutral nature and she wished she could place them on the cool wall without needing to categorize them as not cool.

After observing that the participant placed more than 10 items on the board I decided to be more strict about the number in future interviews, but not make a big deal out of it in order to not restrict the participants as the qualitative data were more important than the quantitative in this study.

4.2.6 Interviews via email

Two of the participants (girls 19 and 22, patients) could not meet me in person due to personal reasons. We decided together that the interviews would be conducted through e-mail. The participants sent me signed consent forms prior to receiving the interview in text format. They received the questions from the interview guide as well as pictures of the cool wall (figure 9). They were then asked to answer the questions and describe where they would have put the different functions and sites and why. Whenever the answers were unclear or I wanted to ask a follow up question, a follow up mail followed. The design guidelines which emerged from these interviews consisted of information about what they thought about the various functions and answers to the questions from the third part of the interview guide (see Appendix B). The emails were deleted and the answers they provided were anonymized and destroyed after transcription.

4.3 Reflections around the method

4.3.1 The Cool Wall

In the article about the “Cool Wall”, Fitton et al. [6] present the limitations of the method. The main limitations presented were the coverage given by the set of images and the interpretation of these. That was proven to be the case during the collection of the data in this thesis. During the first two interviews, I failed to include few functions such as comments and forum. The interviewed teenagers did not suggest additional functions and the failure to include the previously mentioned functions would not be discovered unless I discovered the lack of these myself. However they did suggest other pages that I had not consider as social media sites according to the definition provided by Boyd and Ellison [10]. The participants embraced the social value of both Spotify and Youtube using both as a tool to share their likes and dislikes with their friends.

The advantages of the method were most importantly enabling and encouraging a meaningful conversation. The first two participants (female 19, non-patient and female 17, patient) expressed that they were insecure about what their contribution to the study could be as they regarded themselves as not over average computer skilled. The “Cool Wall” proved itself to be a helpful tool to get the teenagers talking about why they thought things were cool, removing the time and energy it would take to come up with examples of cool social networking sites. In the first phase of the interview, the teenagers were only asked to mention what social networking sites they used and did not come up with as many examples as they put down on the cool wall. The whole purpose was to find out what the teenagers considered to be cool and what they thought was uncool. The method provided a mixture of qualitative as well as quantitative data which made interpretation and using them in design specifications easier.

Personas

Fitton et al. [6] argue that teenagers tend to focus on their own perception and knowledge of the world making them more egocentric. Therefore they may possibly be less able to put themselves into someone’s shoes. However, using personas during interviews with the “healthy” teenagers showed to be a good way to get some information about cool functions and a user friendly UI (Appendix B). At the same time the selection of the functions to be implemented into the prototype may be limited due to the obvious fact that they were not health challenged.

Recording

I recorded the first three interviews using a tape recorder and an iPhone. The tape recorder was placed further away from where the interview and work with the “Cool Wall” was

happening. It was used in order to provide backup in case the iPhone failed to record the interview. After the iPhone proved itself to be sufficient enough to record the interviews, I excluded the tape recorder.

Based on the experiences my supervisor had while interviewing teenagers in Canada I chose to use my iPhone as the main recording device. The teenagers she interviewed had their smart phones near them at all time. Having your own placed on the table proved to not be a distraction. I also took pictures of the “Cool Wall” after each session after carefully informing the participants that they would not be in the pictures. The pictures would only contain the board and in some cases their hands.

Video recording

The use of video cameras is on the increase due to both their affordability and availability. There are many good arguments for why one should use them in the process of data-gathering in design. Blomberg et.al [78] argue that human actions unfold themselves so quickly that it is impossible to capture that complexity by observation alone. Especially during interviews and other methods for data-gathering when the researchers have to take notes and lead the interview situation. One cannot have eyes everywhere and words are often not enough to describe everything that happened during an encounter with participants. Advantages also include being able to analyze the material without the presence of the person who recorded it [78]. This opens for more interpretations of the material.

As there are many advantages related to video recording, there are as many challenges and problems. Video cameras might be intimidating, and what the recordings show is still just a sample of the whole interview situation. The interviewer is still affecting the participant and there are many human activities that are difficult to record on videotape. Last but not least, analyzing videotapes is a time consuming activity and cannot be delegated to others. Insights may only be achieved through careful analysis [78].

During the pilot interview I used a video camera to record what was happening on the cool wall during the interview. The benefit of using it was that I could record which magnets were put on the board first and which were moved around. As I could not videotape the participants except for their hands, and the order in which the magnets were laid upon the board shown itself to be guided by which images were discovered first, this technique proved itself to be redundant for the interview part of data gathering. Instead I took pictures of the cool wall after every phase of the interview and ask the participants to think aloud when placing the magnets on the board. When the participants omitted mentioning which images they placed on the board I commented on it in order to be able to recall it when transcribing the interviews.

4.4 Recap

In this chapter I have presented the method used during the collection of the data. The method was first presented by Fitton et al. [6] and was adjusted to fit the research focus of this thesis. The main contribution of this chapter was adding another category to the cool wall in accordance to participants' suggestions. With future research with hospitalized children and adolescents, the tool, the cool wall, was changed, making it easier to disinfect in hospital environment.

The chapter has also described the recruitment and population involved in the data collection. In the upcoming chapter I aim to present the data collected by applying the method with the participants.

5 Data and analysis

The theoretical framework of this thesis discusses how ‘cool’ can be used as a guideline for what’s age-appropriate technology for teenagers. After applying the methods presented in the previous chapter the following data was recorded. In order to be able to present the data, I decided to split the data into four categories: the data concerning the method which will be presented in chapter 7, data concerning teenagers’ online activity, data about what’s cool focusing on the functions and different features of websites used by the participants, and data collected through the design part of the workshop. A session about interests pursued online was conducted during the pilot interview. The data obtained through this session will not be included due to their little relevance for this study and the fact that the other participants did not rate their interests.

Additional data was obtained through the research conducted by van der Velden [67] as a part of the A3 project. Van der Velden interviewed 16 teenagers (between 14 and 18 years old, 9 girls and 7 boys) with chronic health challenges at the Children’s Hospital of Eastern Ontario (CHEO), Canada, in November 2012. The data from the Canadian teenagers creates a valuable context for the data collected in this study. In addition it demonstrates similarities and differences in perceptions of cool and online behavior among teenagers as well as provides teenage patients’ views on functionality of a health-oriented social networking site.

The data was structured and categorized according to the different phases of the conducted interviews, the questions in the interview guide (see Appendix B) and the themes the guide tried to cover.

5.1 What do teenagers do online?

The interviews did not only provide me with data about what the teenagers perceived as cool, but also gave me information on their general behavior online. This data provides a relevant context for the rest of the data. The data presented in this subchapter give an overview of what adolescents do online, what they value, and how life challenges affect their behavior online.

5.1.1 School

During the interviews, the participants were asked about how they used Internet in their academic work. The main reason behind this question was to map how Norwegian teenagers catch up on homework while away from school. I was interested in if the teenagers still needed to communicate with their peers and class mates in order to be a jour with their homework, as I had to during my teenage years. All of the participants (9/9) responded that the used Fronter as a regular part of their day and work at school.

Fronter, previously known as ClassFronter, is a Norwegian learning platform developed for the educational sector. The platform supports both learning and collaboration in addition to giving students and their teachers a channel through which they may communicate outside of the educational institution. While focusing on collaboration and communication, Fronter also offers a private room for each student which they can use as a working space. This part of the site is only accessible to the teacher.

When asked to further explain how they used Fronter, the participants expressed that everything concerning assignments and homework was on Fronter. Whenever an assignment is given, the students are asked to check their Fronter accounts. They can then upload the finished document to the web and get graded online. In addition, the teachers post behavior remarks on Fronter giving the students a chance to read them and in some cases talk to the teacher if they disagree on the basis of the remark. When wondering about something after school hours, the students have an opportunity to contact their teachers and head masters through Fronter with questions of both curriculum based and personal matter.

After conducting the first interviews, it became obvious that Fronter is now the acknowledged and most widely applied learning and communication platform, and that the Norwegian adolescents no longer need to use other channels to keep track on their academic life.

5.1.2 Parents

As presented in the literature review [30, 29], the teenage years are considered to be a time when teenagers are striving towards independency. Similar observation was found during the interviews. Only three out of nine participants had befriended their parents on Facebook. When asked why they didn't wish to add their parents the responses were as follows.

“I want to separate friends from family. I don't want them to know about my private life. There is a lot of personal content on Facebook. There are many people who post pictures of things that their parents are not supposed to know about or don't wish to know about (male 19, non-patient)”.

All of the participants reported that they had other family members on Facebook.

One of the other reasons for not welcoming their parents into their profiles and social networks was that they did not want their parents to see their photos, especially images

snapped at parties that they were tagged in. The participants also expressed that it is embarrassing when family members leave comments on the content they post online. They also highlighted that one can tell if a person is not cool/popular just by looking at the comments on their content.

I wanted to know if having their parents on Facebook was out of the question by principle or they just did not have enough knowledge about privacy settings available on Facebook. I therefore followed up with the question about whether they had their parents on Facebook or not by asking them if they even didn't have them on limited profileⁱⁱ. Surprisingly, even though they expressed a certain experience and proficiency with the privacy settings, they did not know how having their parents on limited profile would affect what content and information would be visible for them.

When it comes to the participants that had their parents on Facebook, the main reason for having their parents there was that the parents were not obtrusive. One of the participants (male 13, non-patient) uttered that if his parents' presence would become noticeable, they would be removed. The girls who befriended their parents on Facebook believed that their parents knew what was going on in their lives anyway, so it was not a big deal if they saw what they posted online. *"I have both my father and mother on Facebook. That's because they can see what's happening in my life regardless of whether they have a Facebook account or not. I also think it is nice to see what they are doing out there, online."* (female 19, patient).

5.1.3 Friends

During the interview it was important to map who the teenagers connected to through the Internet. I was especially interested in finding out whether they used Internet to maintain their already existing friendships or to establish virtual friendships. Only one of the participants (female 19, non-patient) admitted to actively search for new friendships online. The 22 years old female patient expressed that she did get acquainted with other young patients through patient organizations and their Facebook pages. She also highlighted that this has happened lately.

The participants uttered that the people they felt most connected to through the Internet and especially social media were friends they saw all the time and the ones they rarely met.

Despite their expressed privacy awareness and perceived control over who could see information and the content they put online, it appeared that the threshold to include people in their network was fairly low. When asked about how many friends they had on Facebook the answers varied from four hundred to over a thousand. When confronted with the high numbers and a question of how they managed such a large network, the teenagers explained that they perhaps did not know everybody on their list as well as their regular friends, but that it was almost a custom to add people one have only heard of or met once. As these were only people from their school, neighborhood, and local community, the teenagers expressed no privacy concerns or regrets toward their friend-adding behavior.

One of the participants expressed how he felt that he spent more time with his friends online than in real life (male 13, non-patient). Few of the other participants reported the same impression, having no further remarks on whether this was good or bad – “*That’s just how it is*” (female 19, non-patient).

5.1.4 Self-presentation

During the interviews it became clear that it was important for the participants how they presented themselves online. That being said, how they wanted to present themselves and how much they wanted to share varied. The questions about how much they shared online quickly became focused on how much they shared on Facebook. It was not a planned turn – the teenagers were free to interpret the questions and answer them however they wished. The interpretation of the question as being focused on self-presentation on Facebook was consistent across the interviews. Therefore, the data presented in this subsection are to be interpreted as data regarding self-presentation and privacy settings on Facebook.

Presentation

During categorization of the data collected through the interviews, two trends regarding self-presentation emerged. It was clear and consistent throughout the interviews that the teenagers thought that presenting themselves on social media was important. However how true their online identities stayed to their offline identities was split.

One of the reasons for why presenting themselves online was so important was to show who they were. It was important in order to give people an impression of what they would and would not say or do. “*Facebook represents who you are as a person. I’m politically active and my Facebook profile says that as well*” (male 15, non-patient). The audiences of the presentations are their friends and future employers.

The majority of the interviewed teenagers expressed concerns and conscious strategies concerning the content they posted, because they have all heard stories about people getting fired or not getting a job because of inconsiderately posted content. Just one of the participants argued that although he made conscious decisions about what he posted online, he did not think it had anything to say for his future. He explained that if the employers fired everyone who posted reckless content in social media, the whole country would be unemployed.

When it comes to the other audience for the presentation, the participants uttered that they had friends they did not meet on a daily basis in mind. One of the participants explained that it was because it was the only way they saw him. Since he did not post much content himself, and was mostly tagged by other friends, when meeting upon these friends he was met with their reactions about how they thought that he should ease down on political activities. It namely looked like it was his only activity and interest.

It became clear that in line with the findings in the literature review regarding teenagers' urge to fit in, it was important for the teenagers to be perceived as cool by their peers. This came forward when discussing Spotify, when the participants stressed how important it was that the top played list on their Spotify profiles consisted of music they listened to, and how unreliable it was compared to Facebook where they could decide for themselves which pages and artists they "liked". The participants stressed how music could influence how others perceived them.

The previously mentioned split in the self-presentation trends among the interviewees regarded how much they wanted the others to know about them. While some wanted their friends to know everything about them and thought that they presented themselves online as they did offline motivated by the assumption that their friends would react negatively if they did not stay true to themselves, others thought of themselves as having two identities. Motivations behind this attitude were that it was more important to present themselves in person and that one could easily change their persona online, unlike in real life. While one of the male participants wrote mostly what he called for "bullshit" on Facebook explaining that nobody had a profile that mirrored reality, one of the interviewed teenage patients expressed that she had two identities because she did not share that she was ill on Facebook. The three interviewed patients did not share anything about their disease on social media, arguing that they only talked about it with their closest friends. Another participant imparted that her online presentation portrayed her as being quieter and more reserved than she really was.

Sharing when caring

Because how one perceives one's online identity and self-presentation may differ from how it actually is, I asked the participants about how much they shared online. This brought out interesting and in some cases paradoxical results.

As previously mentioned, presentation of oneself was a major priority among the participants. Statements such as "You have to stay true to yourself", and "It is important to show who you are" were uttered. Moreover, a few of the participants told me that one could say almost everything about a person just by looking at his/her profile. However, when asked about how much they thought they shared, the majority of the participants mentioned that they did not share anything personal online. How could it then be that one could tell everything about someone by looking at his/her profile on Facebook?

When asked about why they did not share anything they defined as personal, the answers pointed in the direction of not wanting to overshare. The teenagers expressed that sharing too much about what one is doing can be annoying and not cool. When referring to the friends who posted too much in form of status updates on Facebook, they argued that instead of spamming their news feeds with pointless updates about their daily life, they could just get a Twitter account. If the statuses were too long or personal, they tended to think that the person in question should rather start a blog. They stressed that they did not see the point in knowing everything about everybody. It often became too much and too personal.

How they perceived these annoying acquaintances' posting-behavior on Facebook to a large extent affected their own behavior. "I don't want to tell about everything I do on Facebook. Sometimes I think to myself "Oh, I must post this on Facebook", but then most of the times I think that people don't need to know this" (female 19, non-patient). They did not want to look uncool and too attention-seeking. One of the participants, who expressed his concern for his own oversharing, did not mean it in terms of giving out too much personal information, but rather that many of the things he said online could not be deleted later on. Especially pictures could be used against him, or seen by a future employer.

Following what they described as personal information, the most personal content they shared were photos and promotion of events. Status updates reported by the male participants for the most part had to do with travel and events that made them unavailable for others. Between the girls, the status updates concerned promoting events, sharing of positive experiences and life events, and expressing things that others could relate to. The teenagers stressed that it was a trend to get as many likes as possible and that several of their peers posted content and status updates without hiding that the main motivation behind it was getting likes. When asked why it was so important to harvest likes on Facebook, the teenagers elaborated that everyone wants others to know more about them. How many likes a person had on their posts and especially their profile pictures was also an indicator for how popular they were.

The interviewees revealed that they did share their name, occupation, where they lived and age online. In addition they shared their interests through liked pages and videos and pictures that they found and shared with their friends. They were also sharing their political and religious views. "*I share very little. I share my interests, but nothing personal*" (male 16, non-patient). When asked why they didn't perceive this information as personal, one of the answers was "You can't say too much about a person based on their interests. You can't really say anything about how they are or how it is to talk with them." (Male 19, non-patient) Again this contradicts what they say about knowing everything about a person based on their profile.

The interviews conducted with the teenage patients revealed, as previously mentioned, that they did not share anything about their illness online. One of the participants elaborated this by saying:

I don't share everything. Like now I feel that I have become so used to feeling normal, so I try to behave as normal as possible to have the strength to do everything the others do, so I don't say anything until I am really exhausted or I'm going to the hospital. I don't feel that it is necessary to say that to anyone.

(Female 17, patient)

This need for being perceived as "normal" by their peers correlates to the data found during research with teenage patients in Canada. However they did state that they would not have any qualms liking a page concerning their condition or about the patient organization they belonged to.

Privacy

In line with literature concerning the psychological developmental stage of teenagers and their struggle towards independency, the participants were very concerned about their privacy. The participants stated that they did feel high control over what their friends could see, and who could access their profiles on social media.

All the participants reported that they have changed their privacy settings both on Facebook and Instagram making their profiles closed for unauthorized audience. The vast majority had also made it only possible for friends of their friends to search them up and add them as friends. Regarding their posted content, they had made pictures and their walls on Facebook only available to their friends.

It seemed at first as if the teenagers were very conscious about the actions they performed in order to obtain their privacy. However they expressed that it was hard to follow all the changes Facebook made in the privacy settings, making them uncertain about what strangers could see about them. *“There is so much new on Facebook that I don’t really have an overview”* (female 18, non-patient). Therefore, two of the female participants created fake accounts and used them to check how much was visible to unauthorized audience. Moreover, one of the participants used the fake account to create accounts on other sites and services such as Spotify and Dropbox in order for them to not be linked with their real account.

When asked about their use of the different friend categories with both default and personalized privacy settings such as “close friends” or “limited profile”, the participants responded that they did not use limited profile grouping. They further elaborated that it was only friends who could see the content they posted anyway, and if they wanted someone to have a restricted insight to their profiles and posted content, they rather blocked or deleted them from their friend list. However they did not show any worries about their posts and comments on their “liked” pages which according to Facebook policies were visible to everyone.

All of the interviewed teenagers were concerned about privacy. However what aspects of their privacy they were most concerned about varied across genders. While the male participants were most worried about Facebook selling their information and stressing that they did not create Google+ accounts because of the fact that Google sells all information they get the hold of, the female participants worried most about who could see their activity and private conversations on Facebook. The female participants shared that they “stalked” people on Facebook. Their biggest expressed fear was what would happen if their ex-boy/girlfriends or friends found out how many times they had visited their profiles. They expressed their anxiety when I asked them if they ever checked their activity logⁱⁱⁱ, and if they feared that Facebook would ever publish that information. They did not notice the feature and showed an immediate urge to check this feature as fast as possible.

One of the female participants imparted that Facebook was full of surprises. She referred to the time when Facebook introduced the timeline and when private messages were visible on

the timeline. When informed that what she referred to were simply wall posts which were the precursors of private chat messages, she expressed her relief, but still stating that you never knew who could access your private conversations and that people should be careful with what they discussed on Facebook.

In line with what I found in the reviewed literature concerning privacy, all of the participants expressed certain powerlessness towards the privacy settings offered by Facebook. One of the participants expressed how she felt that she had to give up on some of her privacy in order to be able to use Facebook, but it was worth it. She elaborated that one had to have a Facebook account in order to be counted among the living.

Therefore it was not as surprising to hear during the design phase of the interviews that the participants wished for better and safer privacy settings on Sprinkl. They wanted an option where they would be able to decide what level of security and privacy they could have on each content type and personal information on Sprinkl. They explained that they thought it would only be obtainable by keeping the site away from commercialization and funding it on a nonprofit organization basis. Commercials had nothing to do on a private sphere as social media.

5.2 What's cool?

The focus of the interviews was to ask the participants about what was cool online and why. It was important to capture the situatedness of the cool [49]. For example a high number of status updates could be cool on Twitter, but annoying on Facebook.

As I discussed in chapter 4, the cool wall used during this phase of the interview was intended as a boundary object [63], a tool to help generate qualitative data, without focusing on the quantitative results. However I would like to present the numbers of participants who perceived different sites and functions according to their coolness to visualize what we talked about and which functions and sites generated most responses and opinions. When looking at the tables with numbers representing the number of responses on each item on the list placed according to their coolness, it is important to keep in mind that especially during the phase when the participants were rating the different sites, some of them placed more than six, and in one case all of the sites on the board. I did not correct that behavior, and I am now using the quantitative data merely as a visualization of which sites and functions we talked about during the interviews.

5.2.1 Cool sites

In this subchapter I aim to present how the participants rated the various sites listed in chapter 4 during the interviews.

Name of the site	Ultra-cool	Cool	Whatever	Uncool	Seriously uncool
Skype	2	3	1		
Twitter		3	2		
Facebook	5	3			
Youtube	5	2			
Snap Chat	1	2	2	2	
Chat.no					3
MySpace					2
Pintrest					2
Geysir				2	1
Reddit					2
LinkedIn	1		2		
Google+		1			2
My Opera				2	
Spotify	4	2			
Flickr		1		2	
Biip					2
Instagram	2	4			
Tumblr			3		
Blogg.no				1	2

Figure 11: Cool sites

Entertainment

The teenagers rated Spotify as cool and ultra-cool. The main reason for it not being ultra-cool was that not all music they listened to was on Spotify. In addition, one of the participants experienced trouble with her premium account. Majority of the participants had premium accounts meaning that they paid a certain amount of money for or received a subscription

removing ads from their telephone operator. Commercials were annoying in general and should be avoided at all cost.

The participants loved the concept of having access to a large music database and being able to listen to it offline on their smart phones. As for sharing, they did not share music through Spotify or even linking to songs on Facebook. Youtube was the site of choice for sharing music with friends and then preferably through private messages on Facebook. However they used Spotify to find new music using the “Now Played” list showing what their friends were listening to. They also followed playlists they found especially cool.

The participants used their profiles on Spotify and especially the “Top played” list and their self-generated playlists to show what music they listened to and to prove their good taste in music. Two of the male participants described the emerging trend of taking screen shots of the automatically generated “Top Played”-lists and posting them to social media often mocking the owners of the profile. As previously described, the list was generated automatically based on which song they listened to the most, but glitches did occur leading to sometimes random and unwanted song titles to appear on their “Top Played”-list.

While Spotify was used mostly as a tool for listening to music, and in some cases self-presentation and inspiration, it was Youtube which the teenagers used the most for the purpose of discovering new music and sharing it with their friends. Majority of the participants expressed their enthusiasm for Youtube, arguing that one could find everything on Youtube.

“You can find everything there; videos from all over the world; everything from music to documentaries. Everything is on Youtube. There is nothing you won’t find there. If you want to find a video of someone banging their head against the wall, you can find it on Youtube; everything from someone pranking people, to people jumping out of planes”

(Female 18, non-patient)

Although they reported that they did use Youtube for finding funny videos and followed internet trends such as “Harlem shake” and “Gangnam Style”-videos, the main function was listening to music and watching music videos. They also subscribed to their favorite channels following their special interests such as football or English panel shows.

As for blogging, the participants did not think that it was something they enjoyed reading. Majority of the participants reported that they had read some blogs, and even started their own just to find out if it was something they could do. Blogging was referred to as uncool and attention seeking. In spite of that they did argue that it was better that people started blogs instead of writing long status updates on Facebook. The main argument against bloggers was that the participants, especially the boys, did not see the point of writing everything about oneself and “forcing” others to read it.

Photos

During the interviews, the participants highlighted the importance of pictures. How many pictures they shared with the world varied across genders and interests. Apart from one participant who was interested in photography, the male participants reported that they did not share as many pictures on social media, but that they found pictures entertaining to browse. The female participants expressed much greater enthusiasm for both sharing and browsing pictures.

“It is true what they say, you know; that a picture can say more than a 1000 words.”

(Female 18, non-patient)

It was also girls who thought that Snap Chat was cool. During the interviews, many female participants both received and sent “Snaps” to their friends.

They explained that Snap Chat was cool because one could instantly and free of charge send entertaining picture messages to their friends which they could only see for a few seconds before the picture disappeared from their phones. While girls thought of Snap Chat as a safe way to share silly pictures, the boys questioned security around the Snaps, elaborating that no one really knew how long the pictures were stored on Snap Chat’s servers and that they could easily be sold or used against the users. They also did not see they point of sending images, sharing their concerns about girls their age sending revealing photos to people they didn’t know.

While Snap Chat received the most scattered ratings of all presented sites and apps, Instagram was liked across genders and ages. Again, while boys were most interested in browsing pictures, girls showed their approval of the possibility to edit photos using the provided filters before sharing them. Pictures of food and celebrities were pinpointed as the coolest and most fun to follow. It appeared at first as if it was the picture sharing and browsing were the most appealing things about the aforementioned sites. However, I found it interesting that Tumblr and Flickr, both photo sharing communities, were not perceived as cool. The participants expressed that Tumblr, although filled with entertaining content had grown too big and it was hard to navigate across the website to find captivating content. Flickr was perceived as a site for particularly interested, meaning that it was only interesting if one was into professional photography. Again the site seemed chaotic and unorganized. How the site was organized and how many of their peers used it had more to say than what content it presented.

Communication

When rating and talking about cool ways to keep in touch with their friends, Facebook was the only option represented on the board that did not receive a negative rating. However it was interesting to see what affected and caused the teenagers to perceive Facebook as cool and ultra-cool. Several participants reported that they joined Facebook because of peer pressure. As it stands in the previously quoted statement, one is not counted among the living

without an account on Facebook. Moreover, the teenagers expressed an anxiety when asked how it would be to deactivate their Facebook accounts. They elaborated that they would no longer know what's going on.

The main advantages and coolness of Facebook brought forward by the participants were that the service was free of charge, everyone were using it making it easy to keep in touch. A few of the participants expressed their pleasure with how entertaining it was to just hang around on Facebook and follow what others their age were doing, while at the same time uttering their concerns about how much time Facebook took away from the time they could spend doing other things such as schoolwork.

Majority of the interviewed adolescents checked their Facebook accounts several times a day using different devices. They all expressed that they did check Facebook before even getting out of bed. Before I included the fifth category (whatever), one of the participants expressed how Facebook had become such a central part of her life that she no longer knew whether it was cool or not. The addictive part of Facebook caused a couple of participants to rate it as cool instead of ultra-cool.

Disregarding the concerns about their extended use of Facebook, when asked about what made Facebook cool, in addition to the previously mentioned attributes, the participants also tended to mention how Facebook had everything. They highlighted that one didn't have to log onto Facebook explicitly to connect with friends. They could also log in just to play games, create events, groups, pages etc., or simply read about and browse pictures of strangers or celebrities.

The participants reported that Facebook had "taken over" SMS. They elaborated that they have been sending fewer text messages since they joined Facebook. They thought that it was cool that whenever wanting to contact someone or simply just talk, one rather did it using chat or private messaging free of charge on Facebook.

In line with the responses concerning photo sharing sites, how cool a site was depended on how many peers were using it and the way the content was presented. While Facebook remained cool and popular throughout the interviews, Google + was nearly butchered by the teenagers. They described Google+ as being lame and awkwardly intimate because of the low number of users. They elaborated that no one was on Google+ and by joining they could risk embarrassment through ending up in the same circle as their parents and family. In addition they felt that the coolness of the site was further reduced because of the fact that Google steals and sells personal data and information. They did not trust it.

When looking at the answers regarding the unpopularity of Google motivated by the absence of their peers on the site, it was surprising to hear their opinions regarding Twitter. Although only two of the participants reported to have ever tweeted (status update on Tweeter), none of the participants regarded Twitter as uncool.

All of the participants had noticed Twitter and thought of it as cool mainly because of all the celebrities who had a Twitter account. The teens explained that they were interested in celebrities and gossip. One of the male participants expressed that it was cool that he felt as if he came closer to his idols because they updated and answered their tweets themselves. The general attitude among the participants was that it was cool to be able to follow celebrities.

Even though the participants described how Facebook has incorporated everything onto their site, they did perceive Skype as cool, arguing that it was a good communication tool when wanting to video chat with their friends. When rating Skype as “whatever”, the participants explained how Skype was just a tool one had to have in order to communicate with friends and family abroad.

Skype did not end up being rated as ultra-cool mainly because the teenagers expressed that they did not want to be seen when talking with their friends. One of the participants deepened this statement by explaining how when he still lived at home, the only computer was placed in the living room making it hard for him to have any privacy and thereby any video conversations. The participants explained that the chat function alone did not make Skype cooler. The function was rather redundant and unnecessary – they had chat on Facebook.

The above described sites are primarily used to maintain already existing friendships. Sites like biip.no and MySpace were reported as uncool and outdated. Few of the younger participants did not even know that these even existed. The teenagers argued that Facebook has replaced the services which are the backbone of these sites.

The interviewees voiced that redundancy was uncool. Similar to the coolness model presented by Read et.al [50], the teenagers reported that for example Geysir which is a Norwegian dating site for homosexuals was outdated and unnecessary highlighting the importance of originality and novelty. “Why do they have their own page when they can use the same as everybody else” (female 22, patient). Same rule applied for Chat.no (an old chatting site) which the participants expressed that no one used and was filled with “old perverts” (female 19, non-patient), and was something “my grandpa could have developed in order to make some money on the side before he went to sleep” (male 16, non-patient).

5.2.2 Cool functions

In this subsection I aim to present how the participants rated the various functions listed in chapter 4 during the interviews.

Function	Ultra-cool	Cool	Whatever	Uncool	Seriously Uncool
Calendar		1	2		
Events	3	1			

Forum		1			
Group chat					
Hash tag	1	1			
Comments	2	1			
Games	1,5	1,5		1	
Search	2,5	5,5			
Link		1		2	
Video	5				
Music	7	2			
Tag		1	1		
Pictures	4,5	1,5		1	
Invites	1	1	1		1
Mail		2			
Video chat			1		
Friend finder		2	3		
Status update	1	2	1		
Like	2	1	3		
Chat	5,5	2,5			
Timeline		1	1	1	
Blog					1
Places		2		2	
Group	2	1			
Profile		4			

Figure 12: Cool functions

Utilities and information

When discussing their thoughts on calendar, the participants uttered that in spite of the fact that it made their life easier; calendar was just one of the functions you just have. At the same time, “events” was a cool function.

Creating events made it easier to plan gatherings and parties, and most importantly gave the teens a chance to assess whether an event was worth attending or not. They shared that they often checked who was attending an event to see if anybody they knew was going or if they were on their own. A couple of informants also joined the discussions on the wall of the event they were invited to in order to get to know the other attendees. Another strategy was checking if the attendees they didn’t know had any common friends with them. This prepared them for interacting with them; having a common friend equals having a common ground and a starting point in a conversation.

To my surprise the search function generated a lot of positive responses and enthusiasm. My predictions were that the search function was one of the “whatever”, something one has anyway. What unfolded itself was that the participants thought that the search was cool and was something they thought every page should have. It gave them an opportunity to search for things they were wondering about, wanted to find, and gave them quicker access to profiles, liked pages, and events. They reported that Google was the search engine of choice.

Every feature that made it easier to find things was cool. Hash tags were cool because they made it easier to find new content on for example Instagram. But this function lost its coolness once transferred to a site where it lost its utilitarian value such as Facebook. The participants told me that whenever they saw endless hash tags in a status update or caption of a photo, they thought to themselves that Facebook was neither Instagram nor Twitter and that the post was out of place and uncool.

Self-presentation

Profile was a popular function. They regarded it as a simple way to present themselves and share who they were. They also liked how fast one could judge who a person is based on his/her profile.

When asked how a cool profile looks like, older teenagers described what they meant was a general preference of profiles across their age group.

“Not so many posts. If you visit their profile and they have many friends and a profile picture with many likes, then you know that a person is popular. And not a thousand pictures of themselves either. Not every second day updates like “Just showered”. That’s not cool.”

(Male 15 & 16, non-patients)

They further explained how the uncool profiles of younger teenagers (13-14 years old) looked like. The boys told me that they didn't have any good profile pictures, but had thousands of likes on their pictures. They meant that they generated these likes by adding other younger teenagers and people they didn't know who liked everything. They also found the presence of the younger teenagers annoying due to the fact that they likes everything and filled their news feeds with things they were not interested in because of their obtrusive activity.

Timeline, being a relatively recent extensive update on Facebook, was not popular with the participants. It was good as they explained for stalking purposes and made it easier to get an overview when visiting other profiles, but they did not appreciate that the information and content they posted was made more available for others. Additionally, they felt that they lost control over their content because when erasing old posts other old posts appeared. This made editing their presentation an ongoing struggle. Only one participant reported that she thought that it was fun just to browse through her previous posts, walking down the memory road and thinking "*Did this really happen*" (female 17, patient).

Status updates were over all rated as cool. The teenagers regarded status updates as an easy way to share their everyday activities and thoughts. As I described in 5.2.2 concerning cool sites, they did highlight how one should not post statuses that were too personal and frequent. They regarded oversharing as annoying and advised their peers to start a blog or redirect the updates to Twitter.

Communication

I was interested in the teenagers' opinions concerning e-mail. The only cool rating of e-mail came before I included the "whatever" category in the cool wall. The teenagers expressed that e-mail was just another function one had to have. The teenagers reported that they had different e-mail accounts for different purposes. With each purpose came a different e-mail address. For more professional purposes such as school, work or sending "serious" e-mails, they used e-mail addresses that had their name in them. When signing up for services, websites, shopping online, or signing up for things they were not sure if would fill their inboxes with spam they used accounts where the address did not necessary match their name.

The participants were enthusiastic towards chat. They used the Facebook chat and private messaging as prior to SMS and e-mail. In general, having free options for services that otherwise cost money was cool. Also the teenage patients in Canada expressed that it was important that online services were free of charge [67].

They did express their mixed feelings towards the Facebook update that shows when a message has been read. They meant that it was better before. After the update they felt pressured to answer people straight away in order to not make them feel neglected or ignored. They did however develop strategies to circumvent this feature by simply not opening the message or the chat window if they considered it not important or urgent based the summary that appeared on the scrolling floater belonging to the inbox tab on Facebook.

Sharing

In the subsection about privacy (p. 51), the teenagers did not think too much about the privacy of their content because it was only their friends who saw the content anyway. When talking about the friend finder function on Facebook the reactions were mixed. Some participants expressed that they liked suggested friends because it made it easier to find acquaintances, while others stressed that there was a reason for why they weren't friends with the suggested people.

They liked groups. They made it easier to organize things like event or simply discuss things without having to post everything on each other's walls. Although none of the participants put down the group chat on the cool wall, the participants explained how it was cool that one could communicate through group chat not only with one person at a time.

When it came to sharing the teens told me that they did not regard links as cool. Despite some of the links shared on their feeds being funny or informative, the teens felt it was often too hazardous to visit. They had all experienced being lead to suspicious websites where they felt their computers were exposed to viruses. They felt that unless the links were shared in a conversation and referred to as safe; they were not worth the risk.

As I described in the previous subsection, image sharing sites were among the teenagers' favorites. Therefore I was not surprised to see the high rating of images on the cool wall. The participants found it entertaining and more meaningful than status updates. In spite of that, they did not care too much for the tag function where one can tag one's friends in pictures on Facebook. There were two trends in arguments regarding tags. The first objection towards tagging was that people were tagging them in pictures they weren't in just to create blast around their own content. In relation to this, the participants found it annoying to get many notifications derived from activity around the photo. The second argument-trend was that being tagged by others removed some of the control they felt they had over their own page. They did not think it was cool that others could see unflattering pictures, or pictures they were not particularly proud of.

Throughout and across the interviews the teenagers stressed the importance of getting noticed on the web and expressing themselves. They stressed the importance of "likes" and "comments". "Comments" were rated as cool because it was an easy way to communicate to someone what they thought was good or bad with the content. The participants thought it was cool that they didn't have to send a personal message or write a post on someone's wall in order to say that they had a cool profile picture or congratulating them on an achievement. They also liked to comment on posts by their idols and pages they liked. At the same time they did express some concerns for the fights that went on in the comment sections. They elaborated that it only took one bad comment to start a fight. In addition comments were often used for bullying and could be a less cool when used for the purpose of making fun of someone.

What the participants thought was good about likes and ratings in general was that it was an easy and a low threshold way to express one's appreciation and acknowledgement of a posted content. When having doubts about what to write in the comment field they just liked it. They were also thrilled that they could like pages representing their interests, idols, activities, etc.

Again, "likes" could be cool and uncool at the same time. When asked to contemplate and elaborate this uncool side, they explained how getting likes had turned into a competition and how people edit pictures of themselves, or post untrue things about themselves just to get likes. They stressed how likes could mark the popularity differences even more. It was easy to tell how popular or unpopular person was by looking at how many likes they had on the content they posted. In their eyes, this opened up for cyber bullying.

Entertainment

All of the participants shared that they liked games. Games on mobile devices such as Angry Birds were popular across the genders. However when it came to playing online and especially on social networking sites, the opinions varied. While the female participants showed more enthusiasm for games on Facebook, the boys stated emphatically that games belonged outside of Facebook and mostly because of all the invites. Except for two participants, the majority of the interviewed teenagers did not like invites. Here the invites referred to invitations to multiplayer games. The resisters of invites argued that invites were annoying, especially when they came as a notification on Facebook, and that they found it very difficult to reserve themselves from them. The two supporters of invites acknowledged the fact that many of their peers regarded invites as uncool, but they meant that they could just block them from their friend list or simply remove the invite. They also shared that playing online with their friends gave them much more than playing alone on mobile devices or Xbox etc.

Music was the overall winner when it came to cool functions. The teenagers revealed that music was a major part of their lives. They said that they listened to music whenever they had the chance and used music to present themselves through it. Every option that offered free streaming of music was a cool one. They admitted to never buying music through for example iTunes, opting for illegal download, but preferably streaming it and creating offline playlist they could listen to when on the move.

Complementary, videos followed music as one of the coolest functions. The teens listen to music by watching videos online. They also used various browser extensions to download music from Youtube. They told me that they did not post many videos themselves, but would post videos on Facebook in case something really funny happened. Asked how they came across entertaining videos, few of the participants said that when their friends liked published videos on Facebook, it appeared on their news feed. But they mostly pursued videos related to their interest such as fashion, sports, favorite movies and TV shows etc. In any case music is a central part of the Norwegian teenagers' lives.

5.3 Design

In this section I aim to describe how the teenagers envisioned the look and feel and functionality of a health-oriented social networking site for teenagers.

The name

After each interview I asked the participants for a non-health related name for the health-oriented social networking site for adolescents. As they did not come up with a name I asked them if the one I found was appropriate. Disregarding all the symbolic meanings of the word like spreading things (love, support, sorrow, information), putting out fire, reacting in emergency situations, I found the Norwegian pronunciation of the word to be fascinating. As far as I am aware of it, “sprinkler” is one of the few words in the Norwegian language which cannot be pronounced without smiling. Being such a positive and special word was a good attribute to the fact that the word itself does not produce any direct association to health or sickness. It was important that the name of the site was not stigmatizing or presuming its users to identify themselves with their condition. The site had to represent the values and activities of the users, empowering them – not victimizing them.

5.3.1 The look and feel of Sprinkl

During our interviews, the participants were invited to be designers. When introducing them to their new occupation, some of them shrugged, and some of them expressed concern for their inadequate skills in creating web sites. To get the mood right, the non-patient teenagers received scenarios (as described in chapter 4). In order to ease into the task, I started the session by asking the participants about their preferences concerning design and what they would like Sprinkl to offer to their users.

The look and feel

Among the answers I quickly noticed a gender difference between the participants. While the female participants were focused on colors and had often specific suggestions to color themes, the boys were interested in stressing the “feel” of the website. The male participants were stressing the importance of the first impression of the site. Consequently, they focused on the ‘feel’ of Sprinkl. Something they couldn’t put their finger on, but as soon as one saw it they could “feel” it. Based on my own prejudices towards boys and them not talking too much about feelings, it was surprising to hear how much they valued and used the feel of a site in their evaluation of if they wanted to use a site or not. Asked about how I could achieve the right feel for Sprinkl, they did not pin point direct specifications. However, they ordered me to give the site a feel of that the site looked serious in terms of a “legitimate” initiative^{iv}. At the same time it was important that the site did not end up looking too “sterile” (male 19, non-patient). The two male non-patient participants aged 15 and 16 emphasized that the site

should not appear childish and thereby not age appropriate. At the same time it should not give a sad impression.

The female participants focused more on colors and direct requirements. They stressed the importance of colors to separate Sprinklr from other sites and also physical locations such as hospitals. The color schemes were not to be similar to those found on Fronter or educational pages, nor should they remind of clinical settings. The colors should be bright and clear. It was also important that the colors should not interfere with the content, and that the background for the content should be as free of colors as possible.

Across the interviews, both female and male participants agreed on that the site should be as simple as possible not having any distracting elements such as flash animation, moving objects and unnecessary decorations. They wished for the site to be as organized as possible. They preferred simplicity over complexity and messiness. As for the font on the written content of the site, all of the participants agreed that it should be clear and easy to read. It should also be consistent throughout the site, meaning that even with personalized profile page; the font should stay the same. They agreed on keeping the font as simple as possible, pointing more towards sans serif fonts such as Helvetica and Ariel (not included casual sans serif fonts such as Comic Sans), than serif fonts.

Familiarity

To get a better insight into what design the participants thought was visually appealing, I asked them if they wanted the site to look like or even have the same functionality as other sites. Here the gender differences presented in previous subsection evaporated leaving behind an agreement on that the site should include familiar features such as chat, profile, groups, and navigation similar to for example Facebook.

One of the participants (female 18, non-patient) uttered that she did not wish the site to resemble any other sites because: *“It’s supposed to be special. This will be a site for those who need it. It will be amazing. Nothing like Facebook, but everything will look like Facebook, because Facebook has everything”*. She further explained that while wanting for the site to become unique and radiate this uniqueness, she felt restrained by the lock in Facebook had created, and felt it was bad. After trying to fight the Facebook layout, she finally submitted to it, explaining that even though she felt that Sprinklr should not become a second Facebook, Facebook did offer some good solutions and everybody were used to it. She then ended up including more and more functionality found in Facebook into Sprinklr, wishing for Sprinklr to become easy to learn.

Another participant (female 17, patient) thought that she liked Fronter and the design found there, but that she did not want it to be the same so she felt that she was not doing homework but just hanging out. It came clear during the interviews that I should search for inspiration in similar pages, and included features people were familiar with.

The 15 years old male non-patient participant beat me to the question about familiarity with other sites by asking if he was allowed to make Sprinklr look like other pages. After receiving a green light he explained that he wanted Sprinklr to look like other pages “Because people get used to how things are. It works.” When I asked him at the end of the interview if there was anything I absolutely shouldn’t do related to design, he answered with: “Don’t do too much. It is important that you can understand it (the site) right away. That’s why people buy iPhone, because they use it one time and understand it right away. It has to be simple (nor.: “enkel”). People buy what’s simple.”

5.3.2 Functionality

At an early stage of this project I came up with an idea of what I thought this site could look like and what it would offer to its users. But by submitting myself to PD, I had to let the teenagers participate in the decision making on what they wanted from a site like Sprinklr.

The trend across the interviews was that Sprinklr should facilitate for contacting other teenage patients, allowing the users to communicate with each other, and offering some information about the various diseases.

All of the participants thought that Sprinklr should not be illness-centered. “*It shouldn’t focus on your illness*” (male, 16, non-patient). The interviewees meant that it was important that the site generated possibilities to talk about interests and regular “stuff” and not only talking about diseases and asking for advice. They explained that by allowing users to discuss daily things and build relations based on same interests, they would not come to the page just to ask a question, get an answer and leave, but would remain to just hang around. The participants argued that a social site like this had to have a lot of active users. Without users and activity the page would not become cool, no matter how cool the design was.

Several of the interviewed teenagers wanted Sprinklr to have games internally on the site. In addition to games, Sprinklr should allow its users to share content like links, videos, pictures, and status updates.

One of the participants (female 22, patient) came with a somehow summarizing suggestion. She suggested me to offer the users the functionalities found in other social media, while at the same time giving them access to appropriate information.

5.3.3 Finding others with the same diagnosis on Sprinklr

What was interesting about the answers gained through the first phase of the interview, compared to the ones gained during the design phase, was that the teenagers expressed no need for finding new friends online. However they felt it was an important feature of Sprinklr to give the users opportunity to find new friends. A wish for the possibility to find other teens with the same diagnosis on a health oriented social networking site was also uttered by the Canadian teenagers [67].

When asked about how the users of Sprinklr should find new friends, the answers varied from use cases where users searched for user names, found friends by joining groups or forums. They did not include i.e. hash tags they thought of as cool during the session with the cool wall. It seemed as if they were so focused on Facebook, which they thought of as the only way to connect with friends that they had hard time to include features from other sites they previously perceived as social networking sites. Never the less, the solutions were focused on group activities and the search bar.

As previously described, the participants were enthusiastic toward the search function of various sites, stressing the value of being able to search for things. They emphasized that Sprinklr should offer a good search engine making it easy to search for things like friends, groups, various conditions, etc.

5.3.4 The informational part of Sprinklr

Except for one, all of the participants thought that Sprinklr should offer possibility for their users to find information about their disease. The motivation behind wanting to include internal information on the site was that a lot of online information might be misleading, and the majority of the participants had previously had some bad experiences with online health information sites giving out wrong information.

One of the suggestions for ensuring the quality of information offered on site was having users rate it. By rating comments on static informational content, it would become easy to see relevant experience based information in addition to disease information generated with help from professionals, which would be a generator for comments.

Despite the fact that they wanted most of the activity to happen on Sprinklr, attracting users to the site, few of the participants suggested that Sprinklr recommend safe links to other health oriented websites and especially patient associations that the users could visit.

Surprisingly, when asked if it would be fruitful to have doctors or other health care professionals on the site available for answering questions, the participants expressed reluctance. They stressed how Sprinklr should be for teenage patients *only*, and having healthcare professionals there would be wrong. However having an opportunity to ask anonymous questions was something they thought would be helpful as long as they didn't have to become friends or share their profile information with the professionals. Asked how they thought it could be arranged, they suggested a sub site for questions only. One of the interviewed patients expressed that she would like to ask a doctor questions without having to book an appointment or go through her parents first.

Despite the fact that they mentioned that having professionals on Sprinklr would be helpful, the participants did not think that this should be the focus of the site. They expressed that Sprinklr should focus on finding friends, connectivity, sharing, and entertainment, and most importantly *empower* its users.

The teenagers stressed experience-based information. They argued that reading about how other people their age solved daily challenges and coped with their condition would be of big help. Two of the older participants (male 19, non-patient & female 22, patient) proposed using forums for both generating and presenting experience based information. On the other hand, the younger participants proclaimed their contempt for forums explicating that forums were definitely not cool and messy, again accentuating the presentation of the content.

The solution they deemed appropriate was having different groups which users could join where experiences and challenges could be shared as posts that could be liked or commented on.

5.3.5 User interface of Sprinklr

In this subchapter I wanted to present the visual part of the design phase of the interviews. The following images present the design created by five participants (the first design was the one created during the interview with the two teenage boys aged 15 and 16). The layout on the boards present the news feed and the first thing a user meets upon entering the site.

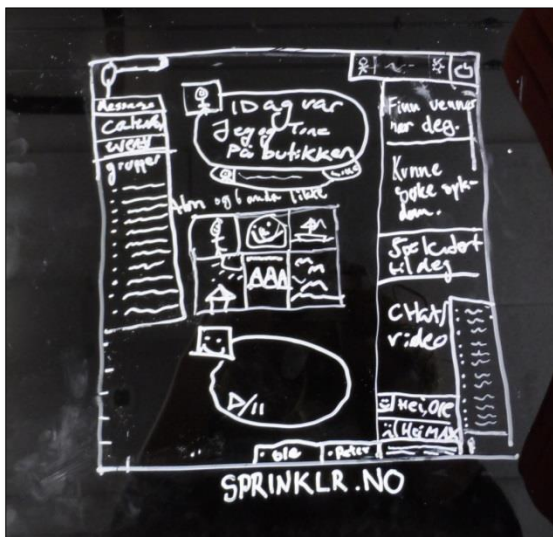


Figure 13: First design (male 15 and 16, non-patients)

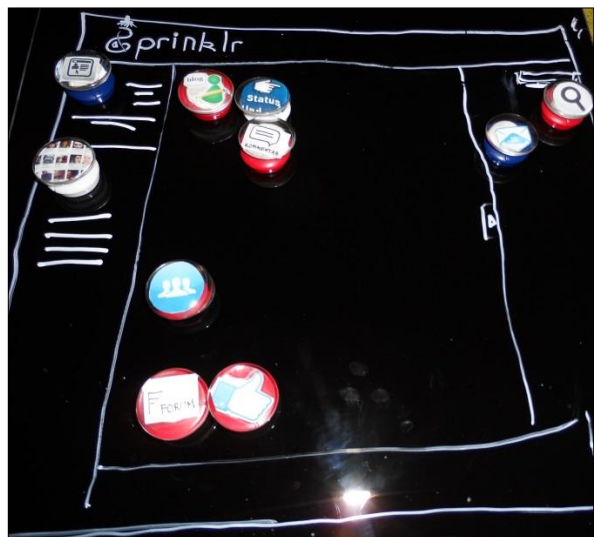


Figure 14: Second design (male 19, non-patient)

The use story of the first image (figure 13) was that after login in the user is presented with his or her news feed showing the activity of his/her friends since the last login. Although the participants expressed that they did not like the friend finder on Facebook, they thought it would be necessary and fruitful on Sprinklr. They also included two types of search fields. The first would be searching for friends in the header while the other would be searching for information about their diseases, followed by an option to find suggested pages.

The news feed should view friend activity such as status updates, videos, and pictures. Newly posted and liked images should be grouped, compressing the amount of new content. The chat

should follow the layout used on Facebook. The left banner is supposed to present a list of groups the user is a member of, a link to a page viewing events, a calendar, and a permanent link to the user's profile page.

After checking the feed, the user could check activity within the joined groups and chat with his/her friends. The list of friends should be presented as a list showing who was online.

The second design (figure 14) developed by the 19 years old boy had also the profile link and abstract in the top left corner. The friends list was unfolded beneath it. The boy wanted the feed to show new activity, but the site was supposed to be more forum-based. He wished to have chat as a removable floater allowing the user to hide it when not needed. Upon login the user was supposed to check the status of his or her posts on the forum and read blog posts that appeared on the news feed.



Figure 15: Third design (female 18, non-patient)

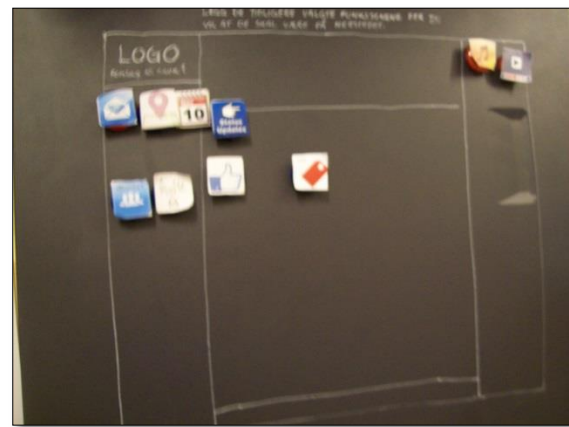


Figure 16: Fourth design (female 17, patient)

In the third design (figure 15), the participant wanted to move as far away from Facebook as possible acting on the uniqueness of Sprinkl.r. She wished for the different links to sub sites to be presented as tabs. When opening the tab, the content from this category would appear in the content area. Search and settings should be placed in the top right corner. She also wanted that Sprinkl.r could offer some engaging and age appropriate games.

The fourth design (figure 16) shows the vision of the 17 years old female patient. She wished to have a news feed presenting status updates, and a separate feed presenting posted and shared music and videos. She did not wish for an integrated music player.

She wished for games and a possibility to invite her friends to join in. Private messages and not e-mail were supposed to be the mean of communication. Tagging people in status updates and being able to “check in” were functions she thought would be cool to include in the final design as she thought that especially “checking” in to hospitals would possibly make it easier to meet other teenagers or just discussing what they thought of the hospital.



Figure 17: Fifth design (male 13, non-patient)

The last of my co-designers (figure 17) unknowingly wished for some functionality and a mixture of the other participants' design. However he did not want any medical information or focus on illness on the website. He elaborated that if he was ill himself, he would probably want to forget about it and come to SprinklR for entertainment purposes only.

5.4 Discussion

In this subchapter I would like to present the discussion of the now presented data from the interviews. The purpose of this thesis is to investigate if, and how cool can be used as a guideline for designing a social networking site for teenage patients. In this discussion I aim to present the gathered data in light of the concept of cool and other relevant literature. During the discussion I hope to be able to show how the data transforms more and more into design specifications which will be the focus of the next subchapter.

In line with the findings among the Canadian teenage patients, the interviewed teens expressed a need for a social networking site for teenage patients, emphasizing that the site should be for teenage patients *only*. While Madan et al. [81] present Facebook as a potential arena for enhancing patient experience and being fit for health-related activity, the data gathered in this study correlate with among other van der Velden and Emam's research [8] and pointed in the opposite direction. The teenage patients expressed that they wanted to connect with other patients but not through Facebook. They didn't feel ashamed, but they wanted to be as normal on Facebook as possible and didn't feel the need to share their condition there. The others didn't need to know everything about them. This trend of not wanting to expose everything about their lives continued throughout the interviews with the non-patient teenagers.

The Canadian teenagers expressed the same reservation toward Facebook. In addition to not wanting to be perceived as attention seeking and be as normal as possible, they grounded their reservation in that they found it difficult to talk about what they were going through with their healthy peers. Communication about their condition was easier with other patients due to the

fact that they were going through a lot themselves and could thereby have more empathy. They felt as if their healthy peers wouldn't know what to say when presented with their daily struggles. Therefore they welcomed the idea of connecting with other patients through a social patient network site.

In their article "The value of values: resourcing co-design of ubiquitous computing", Halloran et al. [82] present the increased importance of and focus on values in design. They argue that by focusing on and embodying values into the design, one can create more successful products. During the interviews I noticed a set of consistent values. The participants sometimes directly, other times indirectly highlighted the importance of cool, privacy, and independency. They expressed how important it was for them to keep their life private especially from parents and other grownups. As presented in the gathered data, the teenagers did not wish for health providers to be a part of Sprinklr other than being available for answering anonymous questions. Also the Canadian teenagers tend to not want health care providers on a health oriented online community [67].

5.4.1 Connecting with health care providers

The responses regarding asking questions to health care providers matched the ones Sands [26] presented in relation to patient-doctor communication through e-mail. However in case of the teenagers considering doctors' busy schedule was not a factor when considering whether they contacted the doctor or not; rather having to go through their parents in order to get an appointment was the issue. The teenagers want to gain more control over their own situation and life.

In addition, e-mail was neither a cool nor desirable way to contact a doctor. The data regarding the coolness of e-mail point in the direction of e-mail being uncool and is used for school or work purposes or in order to register on various sites. E-mail is being replaced by other cool communication tools such as private messaging and chat. Intuitively, this leads towards a conclusion that the teenagers would want to have medical practitioners on Sprinklr in order to be able to send them private messages instead of e-mails. As presented data shows this was not the case which disassociates with the suggestion that health care providers should communicate with their patients via social media [12]. Asking anonymous questions was the preferred way of contacting a health care provider as opposed to what adult informants thought as appropriate in Sands' research [26].

5.4.2 Information

Finkelstein et al. [34] showed how teenagers with atrial fibrillation were not as interested in medical information by health care providers and researchers as they were in experiences of other users. I came across similarities with this when interviewing the teenage patients. They wanted to hear how others dealt with the issues they had. They expressed how information online and information obtained through doctors and their parents did not necessarily cover

what they were interested in. The teenagers, in line with the research by Perry et al. [31], were more concerned with their condition as related to school and after school activities.

Similar to the Canadian teenage patients, the participants wished for static information pages per diagnosis, but mainly to allow organization of user generated experience based knowledge in form of comments which could be rated. This again underpins the patients' needs presented by Finkelstein [34] to fill knowledge gaps. This correlates with findings from the first round of interviews with Canadian teenagers presented by van der Velden and Emam in "'Not all my friends need to know": a qualitative study of teenage patients, privacy, and social media" [8], and differs from the information seeking reported among adult patients by Trobisch et al. [24] and Morris et al. [83].

Yan and Tan [22] argue that while informational support is the most useful and the main reason for patients joining health oriented communities, it was the emotional support that had the biggest impact on changes of patients' health condition. In comparison, the participants of this study expressed that neither informational nor emotional support would be the main factor contributing to them wanting to join Sprinkl. The main focus should be connecting with peers and just hanging around. The teenagers thought it would be cool to find new friends.

In line with the research regarding high school seniors' social network preferences presented by Agosto et al. [84], the teenagers show that they used the Internet to maintain already existing friendships. However Agosto et al. do not elaborate on Facebook acquaintances. As it came forward in the data, the interviewed teenagers added people they had only met once or even only heard of. Then they used Facebook chat, comments, and "likes" in order to get to know them better.

It seemed to me as it was important for them to obtain and maintain a high number of friends, especially among the younger teens (up to 18 years old). Having a lot of friends presents you as popular and cool. It may seem as if by befriending and interacting more with acquaintances made it more OK to have them on Facebook where the privacy strategy was that only their friends could see the content. This threw a new light on how one can understand their statements about how they used social networking sites only to maintain already existing friendships.

Disregarding this, the participants expressed that it would be desirable to befriend strangers on Sprinkl. This correlates with the findings about health-oriented virtual communities and how having something in common is ground for further interaction.

However sharing stories about their diseases is not enough for motivation for interaction or wanting to use the site. As Davis et al. [39, p. 322] argue in their article concerning young patients with cancer, "Individual cancer stories alone are not enough to sustain new connections. Rather we have seen that a shared hobby, passion or interest – as well as shared journeys with cancer – facilitated connections between participants".

As one of the participants expressed, she did not identify herself with her condition. She was trying to be as normal as possible, not talking about her illness on Facebook. Also other participants reported on having a different identity online. This underpins that it may be fruitful to allow users of health oriented online initiatives to create avatars as presented in [17]. As previously mentioned, Sprinklr should not focus on illness and should not be stigmatizing. Offering an account on Sprinklr and facilitating for users' discovering that this online community was not focused on illness and did not stigmatize them as patients could contribute to reducing the distress the teenagers could be exposed to upon considering joining health oriented social websites which van der Velden warns about in "Patients and Social Media: If you build it will they come?" [1].

5.4.3 Avoiding lurkers

The advantages of designing Sprinklr as a hedonic website are among many how being focused on social interactions and entertainment may lower the threshold to take part in the activities.

The participants wanted Sprinklr to focus more on "fun" and the "entertainment" part of the website. That implies focus on the hedonic aspect of the site. It is possible that this was the case because most of the participants were non-patients. Still, one of the participants suggested that this was the only way to get a higher number of active users. By allowing the users to interact on a level not connected to their illness would engage them in the overall activity, thereby lowering the threshold to share and participate in the health oriented activities. This can be understood by using the third principle based on the ecological cognition framework presented by Bishop [42]. The actor will act upon how he/she perceive the environment. Focusing the environment on entertainment and peer-to-peer communication as opposed to the environment to be focused on health and utilitarian information could make it more appealing for the users to act upon their needs and desires.

In the spirit of Bishop's argumentation, creating dissonance based on not posting health related content or identifying themselves as ill will not make the lurkers more active. Instead, accommodating for fulfilling the needs and desires of users will be a more fruitful strategy. Since the teens expressed their need for presenting themselves via their interests, music, and pictures, allowing for that presentation and creating an environment free for illness centration, could make it more attractive to act. Once the user would become comfortable and could show who s/he was, s/he could participate in the informational part of Sprinklr.

That being said, Sprinklr should not make it too unattractive to lurk, as teenagers underlined; the entertaining value of social networking sites was also just hanging around snooping on profiles of other users. Being forced to do something all the time in order to get the joy out of Sprinklr was too much, such as in case of blogging. The participants who had tried blogging explained that they stopped blogging because they didn't have time to write blog posts all the time. And blogs lost their coolness because in order for them to become something cool they had to post all the time.

5.4.4 Cool: situated and gendered

As I understood, being cool online and being perceived as cool offline based on the online profile could only be obtained by doing things the right way. This confirmed Read's hierarchy of cool, where the main design space would be located in the doing cool things [50].

Therefore it was important to find out what was cool to do and how could one do it.

What I found interesting was how coolness of functions and level of usage of these varied across the different sites. While many status updates were regarded as cool on Twitter, too many updates on Facebook were seen as attention seeking and not cool. This correlates with findings regarding techno-cools presented by Culén and Gasparini [49]. Just as techno-cools, different functions' coolness varied across contexts and situations. Different sites demanded different activities and level of openness.

Being in a life situation when they want to fit in may have caused the teenagers to use some sites mainly because everybody else used them. However that did not necessarily affect how cool the sites were. For example while not being active on Twitter; they still perceived Twitter as cool in one case because of the blast around it, in another because of all the celebrities and news. Celebrities' presence on social media sites was an important factor in whether a site was cool or not.

One final thought concerning discussion of cool in the presented data concerns factors affecting perceptions of cool. Gerber and Geiman (2012) argue that cool varies across ethnicities and social statuses- I found that 'cool' also varies across genders. Van der Heijden argues that some consumers tend to be more hedonic and others more utilitarian [53]. This was the case during the interviews. While the overall perception of the coolness of a site and estimation of the desire for future usage was based more on utilitarian value of the site by male participants, girls tended to focus more on hedonic values when rating the coolness of functions and sites. While boys appreciated games outside of social media sites, girls found games online engaging. This finding is an interesting one and worth investigation on a bigger scale in future research because of the lacking discussion around it in the reviewed literature.

In line with highlighting the ease of use in hedonic systems as a factor contributing to future intentions to use the system [53] because of neither inhibiting nor enhancing the user's hedonic experience, the participants expressed that ease of use was cool and an important factor in their intentions of using the technology in the future. Just as iPhone sells because it is easy to understand, Sprinkl should reduce the hassle. This correlates also to Holtzblatt's Triangle of Design. By allowing for the delta to facilitate for the "direct into action" and reducing "the hassle", one can increase the joy and coolness of using the technology [52].

5.4.5 Presentation and privacy

The teenagers had their own perception of what is personal information. This view on what is considered as personal seems vague; more grounded in their understanding of the word

“personal” as being equivalent to the word “private”. Moreover, their perception may easily be perceived as paradoxical when applied to what they did not perceive as personal content and information.

Krämer and Haferkamp [85] explain that users of Facebook are strongly motivated to use this arena for self-presentation. Further argumentation presents the colliding intentions that occur when presenting one online; on one hand a person wants to show their personality and meet other peoples’ expectations, guiding their impression, and on the other hand maintaining privacy. This was the case among the interviewed teenagers.

The teenagers’ privacy strategies were closely related to their presentation. For example decisions around their informational privacy, such as posting factual data and pictures on their Facebook profiles were made in order to look cool. As the two teenage boys explained, in order to look cool on Facebook, one had to have a good picture. This information however was not perceived as personal. Both the interviewed teenage patients as well as non-patients expressed a higher degree of psychological privacy. In case of the non-patient teenagers the strategy was clearly targeted towards their self-presentation – disclosing too much information about their lives, thoughts, and feelings was personal information which when revealed too much or posted too many times could make them look uncool and attention-seeking. The teenage patients expressed that they did not want to share psychological privacy with others than their closest friends and then only through private messages. They wanted to present themselves as normal, and therefore applied this privacy strategy. They did not report on adjusting their social privacy by creating groups with different levels of security.

The strategies used by teenagers were limiting the audience of their posted content to friends or friends of friends. Therefore it was OK to post anything as no strangers would gain access to the content. Even though one feels in control of one’s own privacy settings on Facebook, Facebook gives access to one’s information to third parties. This is being described as *privacy paradox* [86]. The teenagers were well aware of Facebook and other third parties having access to their personal information, in some cases even expressing that they did not like it, but one had to pay, in case of Facebook with factual information. However they did express a feeling of being in control and feeling their privacy settings were satisfying. In line with van der Velden and Emam [8] and Trepte and Reinecke [86] this cognitive feeling of control over one’s privacy when evaluated on such attentive level was not a paradox.

However when presented with SprinklR as a non-profit project where informational privacy could be obtained - where users don’t have to give up their personal information to be able to use the service - they requested much higher degree of privacy and more options for deciding the audience for every bit of content they shared.

By changing who could add them as friend, selecting friends and choosing how much and what content would be visible to who, they were increasing their social privacy. At the same time, by adding people they barely knew in order to get the numbers of their friends up, they were again adjusting their privacy settings to fit with their presentation.

5.4.6 Implications for the objective of Sprinklr

Perry et al. [31] present how a primary objective of health oriented virtual communities should be based on supporting peer-discovery, communication, and information sharing alike. On the contrary the main outcomes of the data gathering on this stage of the design process show that by following cool as a design guideline for age appropriate technologies, a social networking sites for teenage patients should primarily focus on hedonic and communicational aspects with information sharing and seeking as a secondary focus.

5.5 Translation

The title of this subchapter, *translation*, may seem inappropriate as the methodology applied in this project was participatory design. As Sanders & Stappers argue, when approaching the design from a PD point of view, the researcher or designer takes on a role of a facilitator instead of a translator.

After conducting the interviews, assuming the role of facilitator, I stood in front of five different UI designs. I had information on what functionality the users wished for, what level of familiarity they would feel comfortable with, and what would make the site cool for its users. The challenge I faced was not combining the different designs, but translating the interviews as a whole and including the result in a prototype. The designs provided by the participants had to be translated and the translation had to result in a prototype solving functionality challenges like those of how to get to know people or how to ask questions to others than oneself.

O’Leary [87] noticed web directories’ tendency to borrow popular features from each other until they resembled one another. Similarly, during the interviews I noticed how locked the participants were in the Facebook model and how what they wanted Sprinklr to resemble Facebook. After several interviews I noticed that Facebook was what they thought of as a real social networking site, and how they felt that in order to create a new site, it had to follow Facebook’s layout. None of the participants wished for hash tags they previously described as cool or focused so much on sharing pictures. While O’Leary explains the resemblance between the various web directories using his ‘Law of Merging Models’ [87], Thompson and Arsel [88] present the concept of ‘hegemonic brandscape’.

“A hegemonic brandscape is a cultural system of servicescapes that are linked together and structured by discursive, symbolic, and competitive relationships to a dominant (market-driving) experimental brand [which] also shapes consumer lifestyles and identities by functioning as a cultural model that consumers act, think, and feel through.” [88, p. 632]

Thompson and Arsel [88] present hegemonic brandscape as something positive. In their study local coffee shops draw advantages from being similar to Starbucks, but by being not being

global they manage to achieve a “think globally act locally” ethos [88]. Based on the concept of hegemonic brandscape, making Sprinklr resemble Facebook can show itself to be fruitful.

I chose to summarize what the teenagers shared with me about different cool factors and their designs of Sprinklr in a list of requirements. The main translating activity was interpreting which functions should appear on the site and which ones should gain attention based on the collected data.

The list of design requirements

Sprinklr should:

- ✓ resemble Facebook in terms of navigation and some of the functionality
- ✓ be easy to use
- ✓ have the right feel in terms of its visual appearance

Sprinklr should have the following functions:

- ✓ chat (should be able to hide it)
- ✓ groups (plus a list of groups the user is a member of; accessible at all time)
- ✓ calendar (accessible at all time)
- ✓ profile with personalization possibilities (accessible at all time)
- ✓ activity feed (with grouping of content)
- ✓ good privacy settings (accessible at all time)
- ✓ a page where patients can ask questions to health care professionals (accessible at all time)
- ✓ informational pages per diagnosis (accessible through search)
- ✓ games with invitations and an option to turn these of (accessible at all time)
- ✓ search bar with good search mechanism (accessible at all time)

5.6 The mock-up

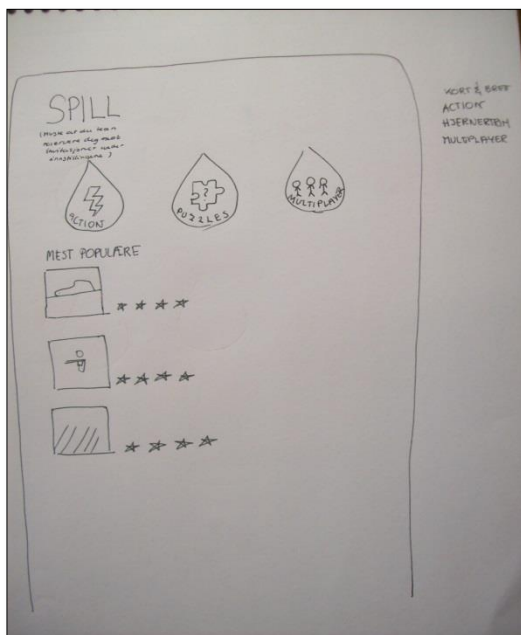
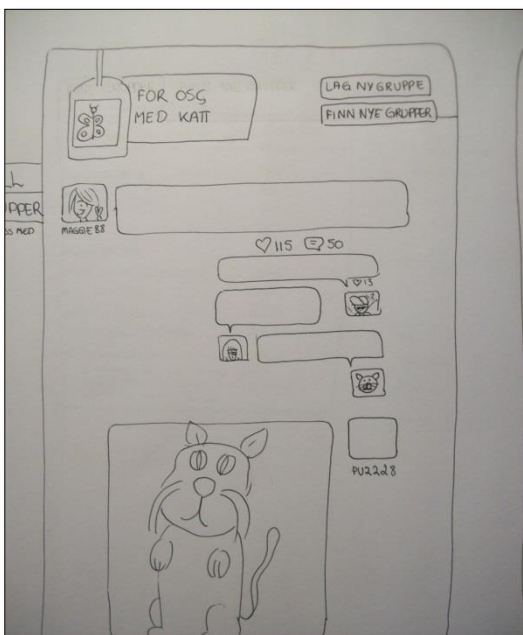
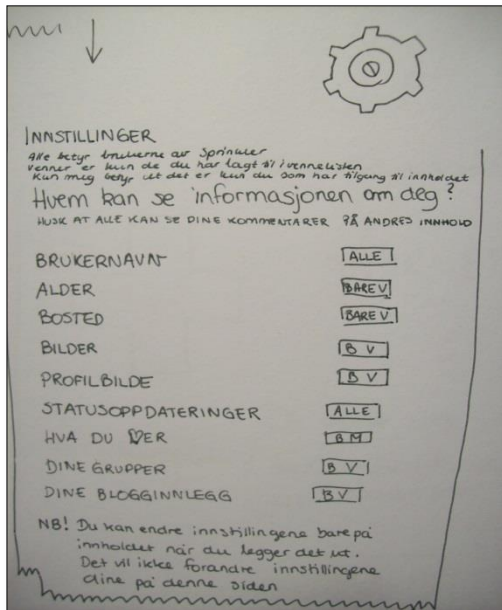
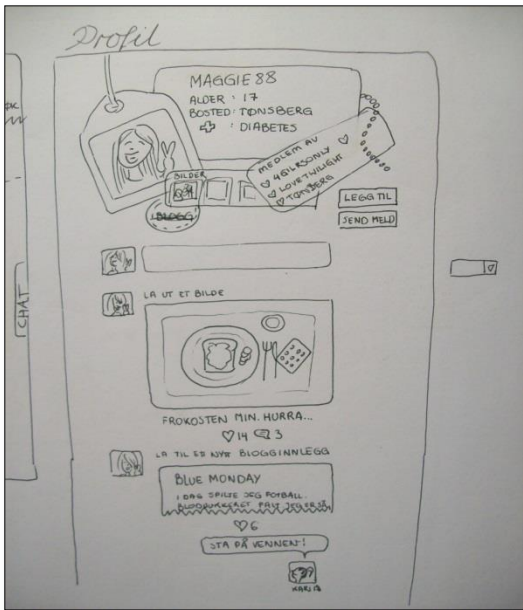
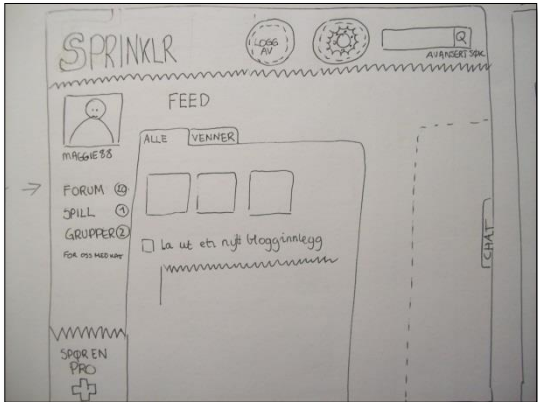
As I argued in 5.1, the design is a highly ethically loaded process. I realized that while making the first sketch as predicted by Löwgren & Stolterman (2004). Designers always work in a minefield filled with restrictions and limitations. I had to fit all the wishes and visions of the

participants while at the same time adjusting them up against their perceptions and opinions about cool sites and functions. The cool concept became both an affordance and a restriction. Affordance in terms of that I was well informed of what, why, and where the teenagers thought different social networking sites and functions were cool, restriction in terms of that I could not include functions I considered as useful or fun myself.

In order to cope with both given and translated design requirements, I needed to externalize my design thinking through a representation. Löwgren & Stolterman (2004) quote Schön when suggesting sketches as tools for thinking and “meditators in the dialectic relationship between the vision, the operative image, and the situation” (2004, pp. 28). Sketches can be used to prompt creative thinking and structure one’s thinking. It was not only these particular assets of sketches that made me choose sketches on paper over digital mockups in Photoshop or other mock-up tools found online. The main reason was that I wanted to skip the technical restrictions of these programs. Whether it is Photoshop where one can draw freely using a drawing pad, or a mock-up tool, there is always a limited space, limited number of tools and a constricted way of discussing the mock-up. As I wanted to use the mock-ups collaboratively, asking my peers for advice, it was preferable to have a tangible mock-up where one could draw freely, erase things and add others without any problems.

As I worked further with the mock-up, I added things continuously following the data from the interviews. I also spent a considerable amount of time trying to decide on the color theme and browsed through various award winning pages trying to find a style and layout that inspired me. I then ended up with the following mock-up.





Sprinklr was conceived and was ready to become a prototype.

5.7 Recap

In this chapter I have presented the data collected through the interviews with the teenage participants using the methods from chapter 4. The data was presented in three subchapters summarizing what the participants thought was cool and how they wanted Sprinklr to look like. The data collected during the interviews concerning what functionality the teenagers wanted in the site complies with the findings presented in literature review. The participants wanted the site to offer informational support in form of information, advices from peers, and opportunity to ask health care professionals. However, they preferred the site to not be health oriented and thereby allowing its users to freely express themselves, share content, and simply hang out for hedonic and entertainment purposes only.

In addition, this chapter presented some significant observations around gender differences regarding how the teenagers understand cool design. Male participants tended to focus more on the utilitarian value of sites when rating them according to the coolness, while at the same time stressing an abstract concept regarding design, namely the *feel* of the site. Female participants focused more on the hedonic values of the different sites, using this as the main motivation for continued use. Simultaneously, they tended to give clear descriptions of how they wanted the graphic design to look like.

I described how I used the collected data in creating the first hand drawn mock-up of Sprinklr. In the next chapter I would like to present the final product of this thesis, namely the prototype. Before demonstrating the prototype I will summarize the process of both graphic and UI design and which design principles I followed when designing the prototype. The method for and the results of the prototype testing will also be provided.

6 Sprinklr – The prototype

In this chapter I aim to present the prototype for Sprinklr, where it came from, how it ended up looking and its functionality. I will also provide the method for prototype testing and the results of it. In the previous chapter I have described how I translated the data from the interviews into design requirements. When it came to designing the prototype itself, I came across a major challenge. By using PD, I was supposed to include the teenagers in the decision-making. However some of the requirements they presented contradicted the universal design principles. Therefore I aim to present how I incorporated teenagers' design requirements into the design while at the same time trying to follow design principles presented in “Universal Principles of Design: 100 Ways to Enhance Usability, Influence Perception, Increase Appeal, Make Better Design Decisions, and Teach through Design” by Lidwell et al. [89] and using the design strategies presented in chapter 3.

Requirements and principles

The main motivation behind using design principles in addition to the requirements obtained through the interviews was that as Donald Norman argues in his book “Design of Everyday Things” [90], by being too focused on the future, or more precisely Sprinklr, it is easy to forget the lessons of the past. As he expresses in the introduction to the book: “As each new technology matures, customers are no longer happy with the flashy promises of the technology but instead demand understandable and workable designs” [90, p. XV]. I did not want to override the teenagers' requirements but rather enhance them and adjust them to design principles in order to provide a good design.

In the following chapter I will present the relevant design principles for Sprinklr focusing on usability and appeal of the site. When developing the prototype I focused on what it prototyped. The purpose of the prototype was to focus on the look and feel of the site, evaluating its coolness. But as I will elaborate in the following section, aesthetics have a more holistic spectrum that cannot only be tested through showing static images of the colors and alignments of different objects. Houde and Hill [91] argue that by focusing on the purpose of the prototype, not only can we build better prototypes but also be able to use them in better ways to think about design.

Houde and Hill [91] present a triangular model for what prototypes prototype (figure x).

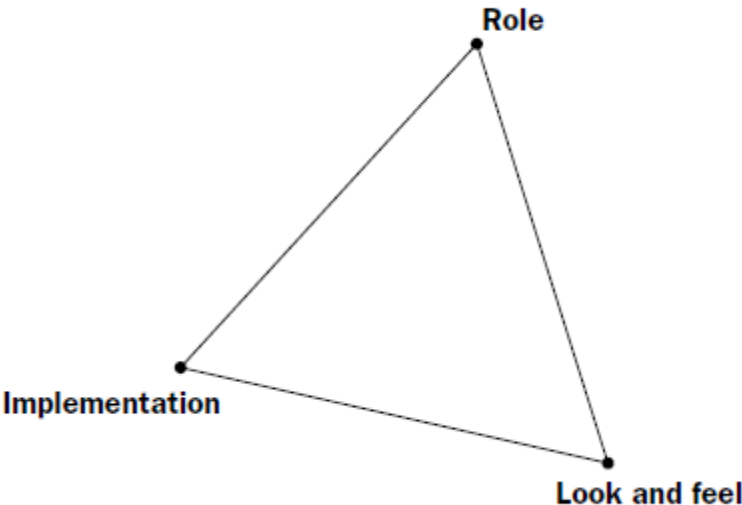


Figure 18: What prototypes prototype? [91]

The three-dimensional space represents design aspects of an interactive artifact, where each dimension corresponds to a class of questions. The ‘role’ refers to the way in which the artifact will be useful for the users, what role it will play. ‘Implementation’ addresses the techniques and components through which the artifact performs its function. The ‘look and feel’ covers the questions about the “sensory experience of using an artifact – what the user looks at, feels, and hears while using it” [91, p. 369].

In the process of designing the prototype, I found it useful to explicitly visualize which dimension I positioned the prototype within. The explorational focus of the prototype was the look and feel of Sprinklr, whether it was cool or not. However being set on the aesthetics implies research of the implementation dimension which was imbedded in the design. As the role of Sprinklr was well understood through the interviews, this positioned both the prototype and the exploration focus between implementation and look and feel on Houde and Hill’s model. The position tilted significantly toward the look and feel dimension (figure x).

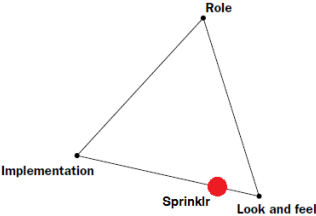


Figure 19: Position of Sprinklr in the model for what prototypes prototype

As Houde and Hill discuss, look and feel prototypes are built to explore and demonstrate options for the concrete experience of an artifact [91]. As they explain, “They stimulate what

it would be like, look and interact with, without necessarily investigating the role it would play in the user's life or how it would be made to work". The questions concern how the look and feel can be improved. As for the implementation prototypes, they are built in order to discover how a future artifact can work. They visualize the technical feasibility of the artifact, and get feedback from the users on performance issues. I will now present the relevant design principles for Sprinklr prototype.

6.1 Ease of use

Ease of use was stressed by the teenagers as an important factor contributing to coolness. As van der Heijden [53] argues, ease of use directly contributes to future intentions of using the hedonic system.

6.1.1 Ease of use through decreasing performance load

One of the ways to increase the experience of ease of use is decreasing the performance load [89]. Successful accomplishment of a task is directly connected to the effort it takes to complete it. The teenagers themselves stressed how the act of posting content should not exceed two steps at the most. This again correlates to the "Joy in Use"-triangle [52]. In order to design a cool website, I had to reduce the hassle factor and increase the direct into action aspect.

During the design phase of the interviews, the participants placed profile information on the left side of the site. The profile information should include a picture, a link to the profile page, and in some cases a brief summary of the user information. Following the wish for a two-step post option, I decided that in order to post content, the user has to go through his/her profile page where a posting option would be provided. The profile information became a handy way to provide a shortcut to the profile page and thereby to the posting option.

In order to reduce the cognitive load of a site, one can eliminate unnecessary objects and information from displays, for example they present chunking [89] as an alternative. The participants indirectly referred to the principle of chunking by expressing a wish for viewing newly posted or liked content as groups of contents instead of several individual posts. This would allow them to get updated and check the news feed more efficiently and eliminate the number of objects on the screen.

Iconic representations

Iconic representations hold the power to reduce performance load by conserving the display and control area in addition to making signs and controls more understandable across cultures. Images of common physical objects can enhance the usability of a site [89]. Accordingly, I used icons on the buttons linking to various sub sites, to represent them and to categorize

groups in terms of the group's category, the designated members (such as girls/boys only, ages, etc.), and whether joining the group required invitation.

In order to attain the optimal performance, all of the buttons shared a common visual motif and were labeled following the 'labeling principle' [89], in order to prevent misunderstanding some of the iconic representations. Norman argues that the need for labeling is a sign of a failed design when it comes to simple things [90]. However, in case of complex technologies explanation is required [90], which was the case here.

6.1.2 Ease of use through familiarity

In line with their Canadian peers, the interviewed teenagers wished for the UI to be similar to for example Facebook. This correlates to the principle of consistency and positively affects the delta aspect of the "Joy in Use"-triangle [52]. In case of Sprinklr, the reduction of the learning stretch could be achieved by transferring some of the familiar features of other cool sites could make it easier to go directly into action. The familiarity can also be connected to the consistency principle. The principle is that the usability of a system improves with expressing similar parts in similar ways.

Lidwell et al. talk about internal consistency in form of aesthetic consistency or functional consistency [89]. While in "The "McDonaldization" of Society", Ritzer [92] tries to draw attention to the rationalization of the American society and adopts a critical attitude towards consistency, hegemonic brandscape argues that smaller undertakings may draw benefits from the resemblance to the global brands. This however requires maintaining a balance between offering the same popular features and branding themselves as different [93].

During the process of making the prototype I used the designs provided by the teenagers, which as they expressed themselves, were very much similar to the UI of Facebook. When implementing the feed showing user activity, the profile with the cover pictures and other functions and their placement I tried to place some of the features on different parts of the site and making it aesthetically differ from Facebook. The reason behind this was that I wanted to create an environment that did not give the users associations toward sites where they due to the social norms and their own need for self-presentation could or would not express themselves freely in fear of being uncool. That being said, I did not only use aesthetics to separate Sprinklr from sites like Facebook, but also to increase usability.

6.1.3 Ease of use through aesthetics

Lidwell et al. argue that aesthetic designs are perceived as easier to use than less aesthetic designs regardless of whether they are or not [89]. Small things like aligning elements of design with one or more elements have much to say for the overall impression of the design.

In the context of the research focus, the aesthetics of Sprinklr are directly connected to coolness. The teenagers did take into account the aesthetics of different sites when rating

them according to their coolness, stressing aesthetics as of paramount importance. Because of time constraints, the planned prototype testing would not be followed by a second iteration. It would therefore not be possible to get an adequate feedback on the ease of use. Consequently, based on the design principle concerning aesthetics presented by Lidwell et al. (2003), I wanted to see how aesthetics could contribute to their perception of usability of Sprinklr.

According to Lidwell et al. [89], using aesthetics as a mean to increase usability does not come without a price in terms of methodical considerations. “Aesthetics have the power to foster positive attitudes towards the design. Evoking feelings of affection, loyalty, and patience through the positive and personal relationship with a design is crucial for the long-term usability and overall success of a design.” [89]. However this positive attitude might lead the teenagers into being more tolerant of design problems creating biased feedback. Lidwell et al. [89] argue that despite the influence of the positive attitude towards a design, it can help to catalyze creative thinking and increases problem solving as opposed to negative attitude which leads towards narrow thinking and stifles creativity.

It is difficult to pinpoint a direct principle to provide an aesthetically appealing design. Aesthetics are of a highly emotional value and therefore operate on a more holistic level. Noble & Kumar [94] argue that “Through an effective combination of various design elements, it is possible for the exceptional product to achieve both functional differentiation and to tap into deeper-seated emotional value.” [94, p. 443].

Colors

One of the first things that come to mind when mentioning aesthetics is colors. It was during the process of choosing colors that I had most difficulties to stay true to the design requirements of the participants. The male participants wished for colors that gave Sprinklr the right feel, while the girls wished for bright, clear colors; instead of baby-blue, they wanted darker blue. According to design principles regarding colors [89], saturated colors (pure hues) should be avoided. Pure hues should only be used when attracting attention is the priority. Ergo I decided to overrule the wish for bright, clear colors in favor of less saturated colors focusing on giving the right feel to the site.

Lidwell et al. [89]advices using maximum 5 colors, of which one is the base color, for the non-user-generated site content. I therefore decided to use Adobe Kuler which is a web-hosted application for generating color themes. One of the themes struck me with its warmth and unobtrusive appearance: “Echo Beach at Dusk” created by the user b_wiebe. The lightest of the five colors, would create a light background for the content area which was important to the users because it would make it easier to read text. The performance is best when contrast levels between text and background exceed 70% [89]. Therefore the content area was white, while the color behind user generated text was light grey.



Figure 20: "Echo Beach at Dusk"

In order to obtain consistency in the aesthetics connected to color, I decided to use the lightest color for making the various “buttons” or icons. Apart from the user generated content font, I used the darkest color from the color theme which was also used in the logo. This created a visual consistency with regards to the site’s colors. In line with the design principles, I used complementary, but saturated colors to the areas of importance, namely privacy.

6.2 Privacy

Since the teenagers uttered their privacy concerns and stressed the importance of being in control of their private information, when designing the site I wanted to put extra focus on the privacy setting Sprinklr would provide for its users.

The users can choose between their posts and information being visible to everyone on Sprinklr, their friends, and themselves which is the default privacy setting on all the privacy options plus the content input field for status-, blog-, and photo posts. Allowing users to create friend groups with varying grade of privacy seemed redundant considering the reported absence of this type of privacy behavior on Facebook. Making strict default privacy settings could motivate the users to read the information and make conscious choices about whom they wanted to share things with. Without making conscious choices about their privacy, nobody would see the content they posted, which is possible that is a desirable option, but when wanting to be active on Sprinklr should be avoided. The users were informed about the fact that all users could see their comments and hearts on others’ posts and in groups, especially open groups.

Micheti et al. [95] present implications for design of privacy policies for young people. Based on their research with Canadian teenagers, they argue that the privacy policies should avoid redundancy and should group the different parts of the policy. This was not necessary in case of Sprinklr in addition to the Norwegian teenagers’ wish for having the ability to control every aspect of their information and content on the site. I therefore provided a list of the various information and content categories they could decide over.

I wanted to visualize the different options while at the same time present clearly which settings the user has chosen. In the research with Canadian teenage patients the participants were presented with images of how colors could be used to visualize different privacy settings. The majority of the participants expressed that colors were a good way to visualize who could see the content they were posting. I therefore used a scroll menu displaying the

three options. There I incorporated psychological constrains such as colors from traffic lights. In spite of the fact that inverting^{vi} creates noise in the design [89] I sacrificed the noise in favor of drawing attention to the various settings. The psychological constrains were based on conventions which influence behavior based on previous experiences.

6.3 Sprinkl

Buchenaus and Suri argue that prototypes are the key activity within the design of interactive systems [96]. For the prototype I decided to use Axure. Axure RP is wireframe software making it possible to generate clickable prototypes. I have previously used the software in generating prototypes and was able to deliver prototypes that users could click on in order to find out if the navigation and functionality of the page satisfied their needs. The tool also makes it possible to design the graphics of the prototype by placing pictures, backgrounds and texts. The graphical part of Sprinkl was created in Photoshop and the functionality was added in Axure.

The logo

When designing the logo I wanted to play with the word Sprinkl. I therefore chose to include the water pipes and connect them to the Sprinkl itself. When placing the name of the site, I applied the ‘figure-ground relationship’ principle from Gestalt psychology. Placing the name beneath the pipes made the name a figure element. By doing so, according to the ‘figure-ground principle’, the name will receive more attention and be better remembered [89].

6.3.1 The prototype

Login page

The login page includes the logo and fields for the user name and password. I did not design the log in procedure in terms of how a teenager can create an account on Sprinkl or how s/he would log into the site. However another student is currently working on the design of the login procedure as a part of the project this thesis is a part of as well.

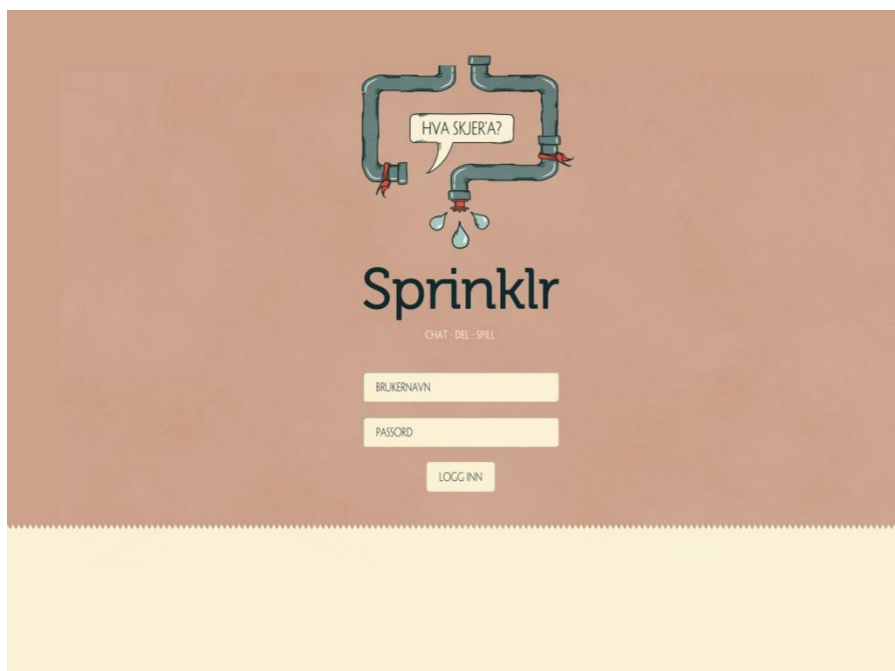


Figure 21: Login page

Homepage/ news feed

After logging in, the user is presented with the activity feed of all users and friends, presented as tabs on the top of the content area. The interaction allowed in this content area are commenting on and “hearting” content posted by others.

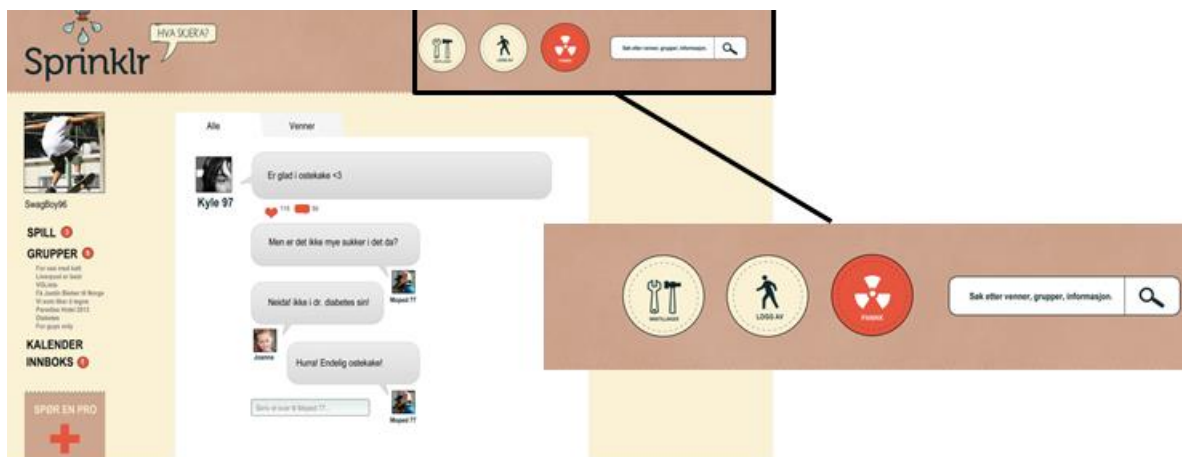


Figure 22: News feed and the global navigation

The global navigation consists of the clickable logo which brings the user to homepage, a shortcut to settings, logout, the panic button and the search field. On the left, the global navigation includes shortcuts to the user’s profile page, games, groups, and inbox placed directly over the “Ask a pro” shortcut. The friend list and chat with reduced opacity is placed in the right corner and can be removed by clicking the arrow.

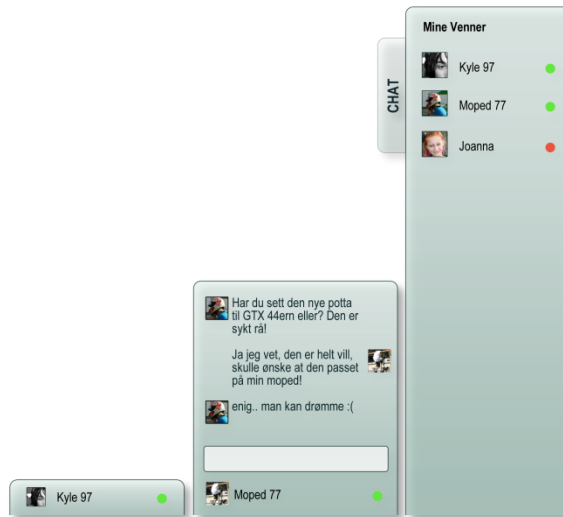


Figure 23: Chat

In the further presentation of the prototype, the navigation field of the site will not be included, showing only the content area where the feed is located (Figure 22).

Profile page

The profile page presents the user; his/her content, and includes the field for posting new content. Others can visit the profile and comment on or heart the content. Even though the participant wished for possibilities for personalized design on their profile page, it would create a decrease of usability, and following Ockham's Razor, given the choice, the simplest design should be selected [89] and in case of Sprinkl'r a Facebook inspired cover photo would provide some degree of personalization without affecting the usability.

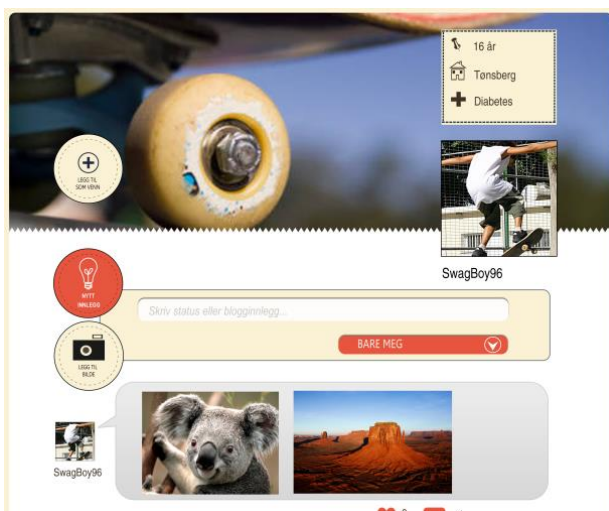


Figure 24: Profile page

Games

Because the participants stressed the importance of critical mass for the coolness of a site, I pursued keeping the users on the site. It was therefore important to create activities they would find engaging over time. One of the principles for creating engaging design is to create immersion, a lost in time feeling [89]. In order to facilitate for immersion I included a page for on-site games in addition to interaction with other users through chat and comments.



Figure 25: Games

The users can choose different types of games according to their preferences and taste. One of the three game categories is multiplayer where the users can invite others to play with them. Due to the split feedback on the invitations to games based on the teenagers' experiences with Facebook, it is possible for the users to reserve themselves from getting invites to games in the setting.

Groups

The groups offer the same degree of personalization apart from the profile picture as the profile page for the administrator of the group. In addition, the group administrator must choose appropriate category for the groups such as i.e. hobby, decide who the group is made for, i.e. everybody, and if the group requires invitation or is open for all the users. This will make it easier to find groups relevant to the users' interests on and off the site.

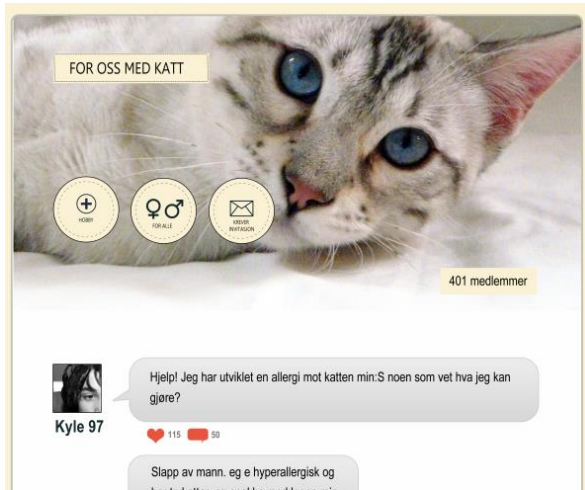


Figure 26: Group page

Privacy settings

The privacy settings are accessible at any time through the shortcut in the top global navigation.



Figure 27: Privacy settings page

Ask a pro and inbox

When accessing the ‘Ask a pro’ page, the user can contact health care professionals and ask them questions. The answers will be transferred to their inbox. The idea is to not make health care professionals a part of the community, and facilitate for communication without them having to know anything about a user. The FAQ will include some of the most asked questions.



Figure 28: Ask a Pro page



Figure 29: Inbox page

For general information about their disease, the users can search the disease and will be presented with general information in form of static text and experience based information presented in form of comments from other users. The comments can be “hearted”, facilitating for the best comments to appear on the top of the list. In the prototype the field transfers a tester to an information page by one-click action instead of keyboard input.

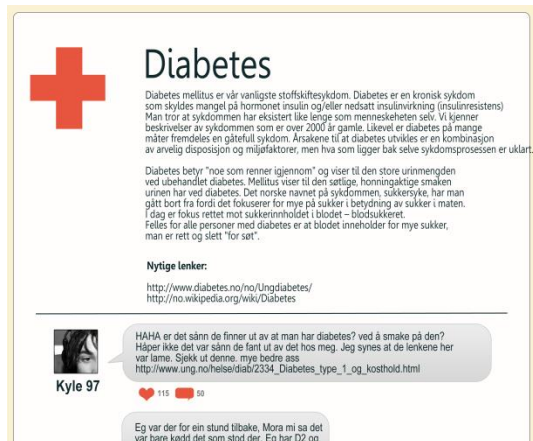


Figure 30: Information page

Calendar

The users wished to have calendar on Sprinkl. Some wanted it to only show different events that a user could be invited to by others, others wished for possibility to be able to out their own appointments in the calendar. The participants did not pinpoint the exact functionality during the interviews; therefore just a simple calendar similar to that found on Google calendar was used in the prototype.

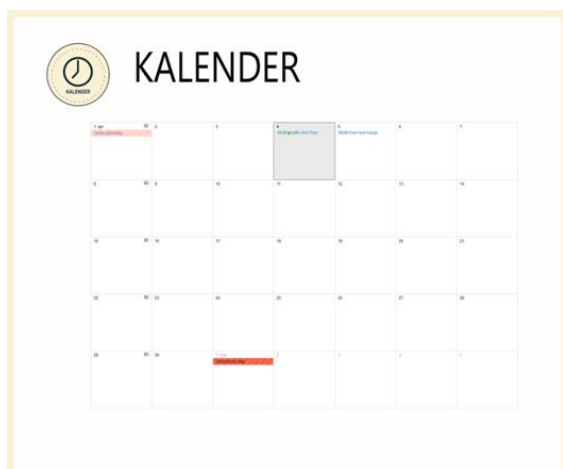


Figure 31: Calendar

6.4 Prototype testing

The method used for the prototyping was prototyping interview. As discussed by [75], prototyping interviews do not differ significantly from regular interviews apart from the logistics. The main objectives of prototyping interviews is probing into the reason for users' actions and generating a sense of shared discovery, co-interpretation and co-design. However, while Beyer and Holtzblatt propose focusing on the structure of a designed system ignoring

the pure UI problems, the main purpose of the prototyping interviews was finding out if Sprinklr was perceived as cool by the teenagers.

When positioning Sprinklr in Houde and Hill's three-dimensional model (see Figure 17), I accepted the questions and exploration focus of the prototype. Therefore, I used the positions when designing the interview guide for the prototyping interviews.

6.4.1 The setup

Beyer and Holtzblatt [75] claim that the best way to collect accurate data from prototype testing is a mixture of old participants and “outsiders”. My main concern while both developing and testing the prototype was the perceived fidelity of the prototype based on the resolution. The developed prototype can be classified as a low fidelity, but high resolution prototype. I did not want the testers to perceive the site as more functional than it was. In consequence, I had to find a way to explain how the prototype is not implemented in order to avoid feedback inaccuracy related to high fidelity prototypes presented by Bødker [97].

Therefore I decided to include participants from the former interviews, but also conduct prototyping interviews with some of the master students studying design at IFI. The reason for including the students was primarily to focus on the implementation dimension, usability, and the technical aspects and the structure of the prototype. With them being aware of the different levels of fidelity and resolution possible in prototyping it would demand less explanation and focus more on the task, namely exploring the implementation possibilities for Sprinklr. The look and feel-questions would also be included, but I was well aware of the fact that cool still belongs to the teenagers, the data collected would rather give an interesting context for the data concerning cool with the teenagers.

Before starting the interview, the teenage participants were asked to confirm their willingness to perform the second interview. I summarized the consent forms from the previous interviews, explaining it was up to them if they wanted to continue our collaboration. The students received consent forms included in the appendix (see Appendix A). I did not tape record the interviews. I notated their responses and suggestions on a notepad.

The testing started off with the presentation of the prototype explaining the role of Sprinklr. An explanation of the level of fidelity and resolution was provided and terminology was adjusted to the age and knowledge they possessed. As the main objective of the testing were the aesthetics, whether the design was cool, and its usability, introducing the participants to personas used during the first round of interviews seemed redundant.

After presenting the prototype, the testers were offered opportunity to interact with the site, click around and get to know the site on their own premises. When ready, the participants were asked to perform several actions while thinking aloud. Corry et al. refer to Preece's definition of thinking aloud when discussing it in their article [98]. In Preece's own words thinking aloud is “a special kind of verbal protocol in which the user says out loud what she is

thinking while she is carrying out a task or doing some problem solving” (Preece 1994 in Corry, Frick, & Hansen, 1997 pp. 69).

We went through the questions presented in the appendix (see Appendix C). Towards the end of the interview, the participants were asked to express what they thought of the method and clearing eventual questions. The prototyping interviews varied in length but were no longer than 30 minutes each.

Location

Due to their short duration the interviews could be performed anywhere. The interviews with the students and one of the teenagers were performed at IFI, while the rest of the interviews were performed at their home and workplace.

6.5 Results from prototype testing

Following the guidelines of Beyer and Holtzblatt, I chose first to conduct four interviews before altering the prototype [75]. Beyer and Holtzblatt argue that one should conduct four prototyping interviews before changing the prototype and the next iteration. Since the master students were chosen to test usability and structure of Sprinklr, I performed the interviews with them first in order to alter the prototype to make it easier to use based on their expertise. I then moved on to the teenagers to probe into the look and feel of Sprinklr.

6.5.1 Students

The overall feedback from the prototype-testing interviews with the students was positive. They expressed that the content of Sprinklr was presented in an accessible way and was easy to read. They expressed their contentment with the static information about the various pages and the consistency of the design. They thought the site looked cool and something adolescents could like. However they did have some comments on the navigation.

One of the student expressed that the different objects in the global navigation on the left bar could be ordered differently. The calendar and the inbox accompanying the “Ask a pro” site could be placed below the profile shortcut in case a user was a member of many groups. The student expressed also that they missed an inbox for private messages. They elaborated that it would perhaps become necessary to have a log with one’s messages in case one receives a link or an invitation.

When it came to the feed, several of the participants suggested framing the various contents and grouping the comments and a possibility for rolling out more comments. The purpose of that was having quicker access to the comment field.

The students liked the idea of having a calendar but suggested having an opportunity to synch it with other calendars. However they expressed concerns for the privacy of the site if the teenagers were to synch the information from the calendar with for example the Google calendar and how it would affect the privacy of the site. They also underlined that maybe this was not something the teenagers had an interest for, but that it was something I should look into. In addition one of the participants suggested viewing weeks instead of months referring to his assumption that teenagers operated more on a weekly basis than on a monthly one.

The icons and the openness of the design

The students expressed that they thought that the various buttons and icons were visually attractive and provided consistency in the overall design. They were enthusiastic about the different categories groups could have and the visualization of these. However, they imparted that the rounded buttons and icons did present a challenge for the openness of the design. By creating categories for the groups, I pre-decided what kind of groups could be created and that the scope of the categories should be rather large in order to cover the various interests of the users. At the same time they communicated that I could only through use discover whether the categorizing was a good idea.

I was surprised to find how much attention the panic button received. As the participants expressed, due to the placement and color of the button, they were drawn to it and curious about what it did. When being transferred to a Norwegian news site, they immediately realized the purpose of the button which was hiding what one was doing to another site. However they expressed a certain concern for the destination of the button. Due to the fact that the news site changes and one cannot control the content, the users could be exposed to distressing information. During one of the interviews, the top news was child abuse in a war dominated area, which led him to a conclusion that the purpose of the button was to show the users that things could be worse. They thought that the purpose of the button was good, but the site it led too should be more neutral, such as Google. In addition not knowing what the button did had a negative impact on the predictability of the site. The suggestion was to include a hover when placing the mouse cursor over the button. At the same time they expressed that as long as the panic button did not cause logging out of the site, this would be learned quickly by the users since the panic button can be found on other sites and it is easy to just go back to the previous page.

Improvements to the design

After the interviews I decided to change where the panic button was leading the users. I chose Google since it is a very neutral site which would not raise any questions from a person standing behind the user. I also moved the calendar under the shortcut to the profile page. I did not move the inbox shortcut in order to find out if the teenagers would understand its connection to the “Ask a pro” site.

6.5.2 Teenagers

All the teenage participants thought that the design of Sprinklr was cool. They liked the colors and aesthetics of the site. However, one of the participants (boy 13, non-patient) asked for possibility to change the colors of the theme of Sprinklr.

Although they did not miss any functions on the site, they communicated a need for an inbox which would contain their personal messages in addition to answers from the “Ask a pro” section of the site. When asked where it should be located, one of the participants suggested having an under-category in the inbox, similar to the list of shortcuts to the different groups. The purpose of the inbox was allowing tracking earlier messages but also sending messages but also sending messages without having to chat. The participants expressed their enthusiasm for separating the chat from private messages as opposed to Facebook where chat and private messages were intertwined. They also liked the transparency of the chat and the possibility of hiding the chat altogether. In addition they underlined that it was important that the chat windows did not pop up and were less intrusive than on Facebook.

Again, much discussion arose from the panic button. The overall responses were very positive. The teenagers were excited about a function which would hide what they were doing from unwelcomed audience and especially their parents. One of the participants uttered however concerns for the fact that only one specific page was being displayed for the incoming parent. He evaporated that this could be suspicious and suggested that this could the user could be redirected to different sites every time the panic button was pushed. Another participant suggested that the users could decide the page they would be redirected to. In addition, it was not clear what the button did without clicking on it. They suggested a hover box explaining the purpose of the button. Other than this, the panic button was a hit.

The fact that the design of the buttons was used to represent the categories in the groups was confusing for the participants. It was not intuitive that the button shaped icons did not do anything. However the categorization itself showed itself to be cool. The teenagers expressed that they wished for more links leading to new information and search results. They suggested that for example the different information fields on the profile could function as links leading to others their age, coming from the same town, or peers with the same disease. One of the testers expressed that she would not wish to contact younger users of Sprinklr, and it would be cool to be able to sift out younger users when searching for new friends.

The teenagers liked the game page. They thought it was cool that Sprinklr would offer different categories of games, and highlighted that it was an important feature of the site. They were very excited about the option to be able to block game invitations. They expressed that they liked the way the water drops from the logo were used to show the different categories.

The feed was divided into two categories (everyone and friends), and the opinions were divided as well. While two of the participants missed more categories, but were uncertain about what they should be, the last participant was not interested in reading about what other

people posted on Sprinklr. One of the teenagers expressed that having a feed for all users of Sprinklr could be challenging. He saw the benefits of having an all-user- feed, however he said that whether this would work depended on the number of users. Should Sprinklr become a large website with a high number of users, the feed would go wild with the high number of updates.

When questioned about what they thought of the posting option, the teenagers expressed their contentment with having a privacy option in the status update form. It was also easy for them to understand where the posting option was placed, namely on the profile. However, they suggested having the option to create new posts in the feed as well. One of the participants suggested posing status updates on the feed, while creating blog post should happen on the profile page. He evaporated that the design should differentiate these better.

The participants liked the informational page for diabetes. One of the participants used some time to read the information and uttered that while he thought the provided information was OK, he thought it would be cool if the information pages gave more information on how life with a disease is. He evaporated that if he met someone with epilepsy on Sprinklr and would like to know more about the condition, he would be interested in knowing what his friend could or couldn't do, if he could for example suggest going to the cinema together or if a video he considered sharing with the person was appropriate. Knowing how life with the specific condition looked like would reduce the changes for him asking inappropriate questions.

6.6 Implications for future design and implementation

In the following subchapter I would like to present implications for future design of Sprinklr. As the prototype testing was done in two iterations, with the first iteration being followed by minor changes to the design, it is important to summarize what the main improvement areas for Sprinklr are and where more research should be done in order to make Sprinklr ready for implementation.

6.6.1 Design for all

Universal design challenges and exceeds user centered design in terms of forcing the designer to consider the needs of people not able to access the whole content due to limitations such as disabilities or environmental constrains (Gibson et al. 2012). The main goal of inclusive design is to avoid social exclusion of people who have difficulties in accessing the online content, communicate with others and create their own content.

In 2009 both the private and public sectors in Norway were obligated to use universal design in structuring their ICT content. The requirements towards the new law will follow a separate regulation. Direktoratet for forvaltning og IKT (Agency for public management and

eGovernment) will execute the law according to the regulation which is at present under hearing. According to the Agency's website all ICT solutions and content as of 2014 will have to follow the requirements, and the existing ICT content will have to be adjusted before 2021.

When the time for implementing the prototype comes it will be crucial to implement solutions according to the WAI 1.0 requirements [99]. Not only will it be important to use universal design because of the incentives from the government, but most importantly because all teenagers in need for the designed electronic intervention shall be included. Following the guidelines will require another form of user testing (specified on the W3C website). W3C informs that even though the content of the site meets the highest level of universal design according to the guidelines (AAA), it will still not be accessible to all individuals. Therefore it will be necessary to seek guidance to ensure that the best practices available at the time of implementation will be used in order to facilitate usage for this community.

6.6.2 Openness of the design

The designer knows when he has reached perfection, not when there is no longer anything to add, but when there is no longer anything to take away.

[100]

As De Laet and Mol present in their article on fluid technology, openness of the design and allowing the users to adopt technology creates successful technologies. It is important to keep the design as simple as possible [89].

The prototype of Sprinklr does not accommodate for such fluidness. Due to its focus on the visual and coolness aspect, the prototype is rich on aesthetics such as rounded buttons for the important functions. Such rounded forms, although visually attractive, do not facilitate for future alterations in way that for example simple titles with hidden drop-down menus do. While the prototype was appropriate for the focus of the prototype interviews, it does not allow for easy changes in the design when this will become necessary after implementation. This has major implications for future design. In order to keep the design open it will become necessary to transform the rounded shapes to textual representations.

The informational part of Sprinklr presents a challenge for the openness of the design. By providing the users with static information, we are deciding on what information they have access to. The only information that is not pre-decided and provided by Sprinklr is the comments. It will be necessary to give a lot of attention to what kind of information is being presented, and as participants expressed connect the information into how the presented disease affects a patient's life. As the reviewed literature argues, teenagers are in a special life position. Therefore they are more interested in information about how their condition will affect their life. This is important to incorporate into the design of the information. In order

for Sprinklr to be age appropriate, the information must contain what they are interested in and be presented in a cool way.

When it comes to “Ask a pro”, the page itself is simple enough to allow for incorporating different infrastructures underneath it, such as redirecting the questions to other question and answer sites such as Klara Klok^{vii}. The teenagers expressed that they thought it would be good to have an opportunity to choose to whom the questions would go to. However, by keeping the page simple and the form open, it will be easy to change the underlying infrastructure and the issue with finding a health care professional who could answer the question would not be as dominant.

The openness of the design is also important for personalization of the site for the younger participants. By allowing the users to personalize how the site is presented for them and how they can present themselves, one can use the openness of the design to facilitate for creation of a virtual possession described in chapter 3. This can make the site cooler to use for the younger users, as well as for the older teenagers who would find this option attractive.

6.7 Recap

In this chapter I have described how I developed the prototype for a health-oriented social networking site for teenagers with chronic health challenges. When designing the site I used the data presented in chapter 5, and especially the design suggestions received from the participants. I gave a lot of thought to the context in which the site would be used in. Further I presented how I planned the prototype testing with both design master students taking on the role of experts, and teenage participants from the data collection interviews.

The developed prototype can be described as a low fidelity but high resolution prototype, developed with look and feel exploration in mind. The feedback from both the teenagers and the students was positive in terms of both usability and coolness. I have also presented implications for future work with Sprinklr based on the feedback. When implementing the prototype, more attention should be given to opening up the design. At a so early phase, Sprinklr should allow for more customization in accordance to use of it. In the following chapter I would like to present the reader with an evaluation of and my own reflections on the process.

7 Evaluation of the process

It is necessary for researchers and designers to integrate diverse theoretical aspects in their creative work, to be able to reflect upon not only activities in the design process, but also upon the multiple intentions and interpretations that build the analytical lens of the research or design project. [101]

During the course of this thesis I was trying to systematically present how I, as Schön [102, 103] described it, reflected in action through ethical consideration and ongoing discussion around my role as a designer. In the following chapter I aim to present an evaluation of the design process in form of a reflection on action. In addition I would like to discuss how this evaluation can contribute to future research and design with teenagers.

7.1 The methodology

Bratteteig et al. [64] argue that involving children or other “weak” groups poses even more challenges to the participation and the representation of the users. The complexity of the system itself as well as the number of actors involved has a lot to say for whose voice and logic will be represented in the final design. Bratteteig et al. further discuss how PD with “difficult” users is particularly challenging. Difficult users mean among others users speaking for others, in case of Sprinklr that were non-patient teenagers speaking for their patient peers.

It was indeed challenging to let the teenagers control the design of Sprinklr. It is possible that the voices being heard in this project did not necessarily represent the end users. However, I investigated how to use ‘cool’ as a design guideline for what’s age appropriate. In addition, in line with the non-patient children used in the presented by Bratteteig et al.’s [64] study of SiSom, when presented with personas, the non-patient participants showed a great deal of empathy and involvement, often referring to their friends with diagnosis. They were not future users, but were brought in to represent a vast majority with respect to the general attitude toward technology [56] and showed themselves to be an irreplaceable and invaluable resource. In addition it was fun for me as a designer to see their reaction when they

recognized their ideas in the prototype. They expressed their excitement and pride over being a part of the prototype.

Bratteteig et al quote Linde [104] when describing design work “as an act of metamorphosing, to create the metamorphoses of the objects of design and to reflect on the effects of the changes is at the core of design work” [64, p. 44]. They argue that every representation is based on a translation which again is an interpretation. The various interpretations add and remove some of the information acquired from the users, strengthening some voices and silencing others. This did happen during the course of the design process behind the Sprinklr prototype. In case of the panic button, I interpreted what the participants said about not wanting their family members to see who they were video chatting with, and translated it into a panic button which would hide their activity from intruders. Nicolini [105, p. 2757] argues that “A large part of the designers’ work is that of inscribing a vision of (or prediction about) the world in the technical content of the new objects”. It is therefore ethically necessary that right now I again highlight how the prototype reflects my situated knowledge and that this has affected the design no matter how much of the participants’ knowledge and design I have used in the prototype.

Mutual learning is being drawn forward as one of the most important aspects of a participatory design process. It is important when different categories of people join in a creative process and usually concerns the future application and use areas of the designed technology [101]. Throughout the interviews, I felt and was further reassured by the participants that the mutual learning did occur. During the process I learned a lot about how the teenagers perceived the technology around them, what they thought was cool and how they thought Sprinklr could look like and function in order to become a resource for teenage patients in Norway. They shared with me the various social norms that I as a non-teenager had no knowledge of. During our conversations I again shared my insights into the technology they used, made them more aware of the various functions on the sites they used on a daily basis and as several of the participants expressed, made them think more about what they were doing online. They also learned that they could design sites, and that designing a site did not only involve coding and sitting in front of a computer. Upon starting the project, I did not anticipate all the laughter, fun, and the tremendous amount of new knowledge I would get through collaboration with the teenagers.

7.1.1 The cool wall

During each interview, I tried to include short discussion around the method, especially the cool wall. The cool wall’s purpose was not to be a data collecting instrument, but rather a boundary object and a tool to get the teenagers going. After conducting the first interview, the participant (female 19, non-patient) expressed that in advance of the interview, she thought that she did not know how she could contribute to the study due to her low IT skills. She felt that by seeing what I wanted to ask her about she could relax and knew that she was

competent enough to answer the questions. The other participants also thought that the method made the interviews fun.

Already during this pilot interview, the girl communicated that she had no problems understanding the categories, but wished that the cool wall gave an option for “should be different”. The motivation behind this statement was that she felt that many sites were neither cool nor uncool, but with a few adjustments could fall under one of these categories. Therefore as explained in chapter 4, I included a new category: “whatever”.

What I found interesting was that the teenagers thought the wall itself was a cool object. One of the participant expressed that he wanted one for himself and asked where the white board was purchased. By using a cool boundary object made it easier for them to focus on cool things. We also discussed what they thought about using the magnets which they found cooler than for example using pieces of paper with pictures or words on them.

7.1.2 Prototyping interviews.

In chapter 6 I described my concern with the fact that the prototype was a low fidelity but high resolution prototype. I was afraid that the resolution of the prototype would limit the evaluation and produce inaccurate data if the participants thought that the site was more finished than it actually was. When discussing this with the participants, they expressed that they liked using a laptop instead of paper prototypes. They did not have any problems with understanding what they could click on. However, by creating the prototype through adding links to static images, some of the resolution was lost and the text belonging to the various buttons and icons got blurry and harder to read. The teenagers thought it was fun to see the prototype in the browser. *“It makes it easier to see how it will look like. I don’t have to imagine how it will look like and I can focus more on the functions. That’s cool.”* (Female 18, non-patient) The participants thought it would be less productive to use paper prototypes since they did not see the connection between the paper prototype and a site.

In line with the guidelines presented by Houde and Hill [91], using a high resolution prototype proved itself to be fruitful when evaluating the prototype in terms of its coolness. However, if the focus of testing would be the ‘role’ or ‘implementation’ of the prototype, using paper prototype would be necessary prior to the introduction of a high fidelity or resolution prototype.

7.1.3 Recruitment

It was challenging to recruit teenagers. Teenagers have tight schedules including school, after school activities and leisure with peers. I found it very challenging to recruit them without offering any compensation for their time. As I struggled with the recruitment, I was considering offering the teenagers gift cards or small rewards for their participation. The idea; which would probably make the recruitment easier, seemed unethical due to the fact that

participation was supposed to be voluntary. Offered any rewards it would be possible that the teenagers would feel somehow obligated to participate which would remove the main part of the terms for participation.

7.2 Limitations

There are a number of limitations to this study. The most important limitation is using the concept of cool as a design guideline for designing age appropriate technology for teenagers. This is due to the fact that “cool” is subjective; it is challenging to design a technology that would be perceived as cool by all its users. In addition, while sufficient for reaching the data saturation for the focus of this study, the population sample used here was not large, so additional study needs to be performed in order to confirm the data presented in this thesis.

Second of all, the participants were informed both in the consent form (see Appendix A) and verbally that the transcriptions of the interviewed would be anonymized prior to the analysis. I therefore had to exclude information regarding their condition, religion, ethnicity, or social status. The purpose of this was not only the restrictions provided by NSD, but also increasing the validity of the self-reported data. However, as van der Velden [1] discusses, culture plays a role in how people perceive and use social media. In addition the data is based on self-reports and could not be checked against how the teenagers actually behaved online.

7.3 Recap

In this chapter I provided my reflections and evaluation of the design process. I have reflected on how it was to use PD as a methodology and how I as a designer affected the design of Sprinklr. I have also presented what the participants thought about the methods used. The presented evaluation may be valuable for future work with teenagers and future research regarding Sprinklr.

As I presented in the section concerning limitations, the population sample was sufficient for the focus of this study which was the concept of cool. However, as Sprinklr moves towards future implementation, I tried to underline the importance of involving more voices of Norwegian teenage patients. When additional teenage patients will be involved in the project, it will become necessary to make changes to the cool wall making it more suited to use in hospital context, adapting it to allow for comfortable interviews with bedridden patients. We are now moving toward the end of this thesis and in the next chapter I will summarize the finding of this study and answer the research question from chapter 1 through a conclusion.

8 Conclusion

The research question of this thesis was: *How does a 'cool' health-oriented social networking site for teenagers look like and how can we design it with its future users?*

I approached this question from a PD perspective using qualitative methods with both patient and non-patient teenagers. In spite of the fact that the use of social media for health oriented activity has increased dramatically during the last decade, little attention has been given to teenagers and age appropriateness of the health oriented online initiatives targeting this specific part of the population. A lot of research has been done on designing health initiatives and online services for children, unfortunately to some degree neglecting the teenagers. Being in a special life position, both with and without a diagnosis, changes what the teenagers think is age-appropriate and what makes them use a site, this has not been given much attention in the researched field. Many of the reviewed initiatives do not describe the design process, and have been designed *for* and not *with* teenagers. Putting an equation sign between cool and age-appropriate made it absolutely necessary to include the teenagers in the design process, not only as informants but also as co-designers due to the fact that they are the only ones with insights into the cool. I found it interesting to see how using the cool concept reflected on the nature of the site, resulting in creation of a prototype for a hedonic rather than utilitarian site.

In the exploration of what's cool and how these insights could contribute to creating a cool social network for teenage patients, I have gained insights to what and why teenagers think is cool in relation to social media. They have shared with me their online strategies related to both privacy and their self-presentation

In order to approach the research question, I have presented an overview of the literature and existing initiatives targeting young patients in chapter 2. The presented overview together with theoretical framework in chapter 3 created the ground for the analysis and discussion of data obtained through the methods introduced in chapter 4. The analysis and discussion of the data together with the designs by the interviewed teenagers provided design specifications which were put against universal design principles and resulted in the prototype presented in chapter 6. The prototype was tested with both previous teenage participants as well as with master student at IFI. The results of the prototype testing interviews together with some of the findings in chapter 5 resulted in a set of implications for future design and suggested areas

that need more research. The process was evaluated in chapter 7 where some main moments of the process were discussed in light of both PD and the cool concept. The main description of the cool wall as it was used in this study was provided in chapter 4. However the evaluation of both the method and the cool wall using the feedback from the participants was presented in chapter 7. My contribution to the field is summarized in the following subchapter.

8.1 Contribution

I approached the research interest by focusing on four specific functions of ‘cool’:

- Cool as age-appropriate
- Cool as a research tool
- Cool as quality of technology
- Cool as a design guideline

8.1.1 Cool as age-appropriate

The study has further strengthened Fitton et al.’s claim that ‘cool’ can be used as a design guideline for designing engaging technology. The data collected during both the interviews and the prototype testing interviews show that when focusing on ‘cool’ the participants easily describe what would be cool to have on the site and how one could create a bigger critical mass. Having ‘cool’ in mind made it easier to design a site that the participants would find engaging. When asking how the information about diagnosis could be presented in a cool way, the participants focused on what they needed. Thereby the study confirms that one can put an equation sign between cool and age-appropriate.

8.1.2 Cool as a research tool

The results of this study have demonstrated how cool can be used as a design guideline, and how one can design for cool. My view is that when designing with teenagers, using cool boundary objects can contribute to better collaboration and communication. In this study I have used the cool wall, which was an altered version of the cool wall used in research presented by Fitton et al. [6]. Instead of using a touch screen, I have used metal plates and later on magnetic whiteboards, and magnets. In addition a neutral category (whatever) was introduced based on the feedback from the first interviews.

By using magnets and explaining the different categories, the teenagers can quickly understand what is expected of them. By using a whiteboard one can facilitate for even more creativity by allowing participants to draw on it. In addition, whiteboard make it easier to

move between different phases of an interview if it's necessary. The magnets look cool and have a practical advantage over pieces of paper; if the interviewee is bedridden, the whiteboard can be repositioned allowing for the interview to be performed without the patient having to get up. In addition, using whiteboard and magnets instead of a touchscreen allows the researcher to add objects to the board, for example if a function the participant think is cool is not included in the provided selection, it can be easily added. Another advantage is that both the whiteboard and magnets (if laminated or covered by glass marbles) are easy to disinfect making the cool wall suitable for research in a hospital environment.

My supervisor and I have continued to work on the cool wall. Our goal was to make the cool wall as safe and as convenient as possible for hospital settings. We were trying to find a magnetic whiteboard that was not too heavy. The white boards used earlier in the study were far too heavy and dangerous to hang over a person's head. The hospitals in Oslo have screens at each bed (Picture 1 in Figure 29). Since the arms holding up the screen are movable, we decided to hang the magnetic whiteboard on the screen allowing for the patient to lay in bed or sit by his/her bed under the interview. We used Velcro straps to attach the board behind the screen as shown in picture 2 and 4 (Figure 29). This allowed for easy attachment and removal of the board. The bed side table can be used for supplying the participant with markers or additional magnets.

Unfortunately because of time constrains I did not get an opportunity to perform an interview with a bedridden teenager. However after trying it out ourselves in a hospital setting using the equipment available there, the wall did not lose any of its functionality and as a bonus facilitated for more comfortable interview situations for the young patients. The cool wall 3.0 will now be used in the larger project this thesis was a part of, and demonstrates how a cool boundary objects can be transferred to hospital settings allowing for more participation.

“Whatever” is a loaded word

I have demonstrated the benefits of including a neutral category on the cool wall. By allowing for this category, I have gained much information about how sites can be improved. It has also contributed to uncovering the often conflicting feelings toward functions and sites that the teenagers use. Therefor I suggest discarding the statistic view on the neutral category as a category providing null variables and suggest rather embracing the neutral category and allowing the teenagers to express why they shrug upon some functions or have doubts about where on the cool wall an object should be placed.

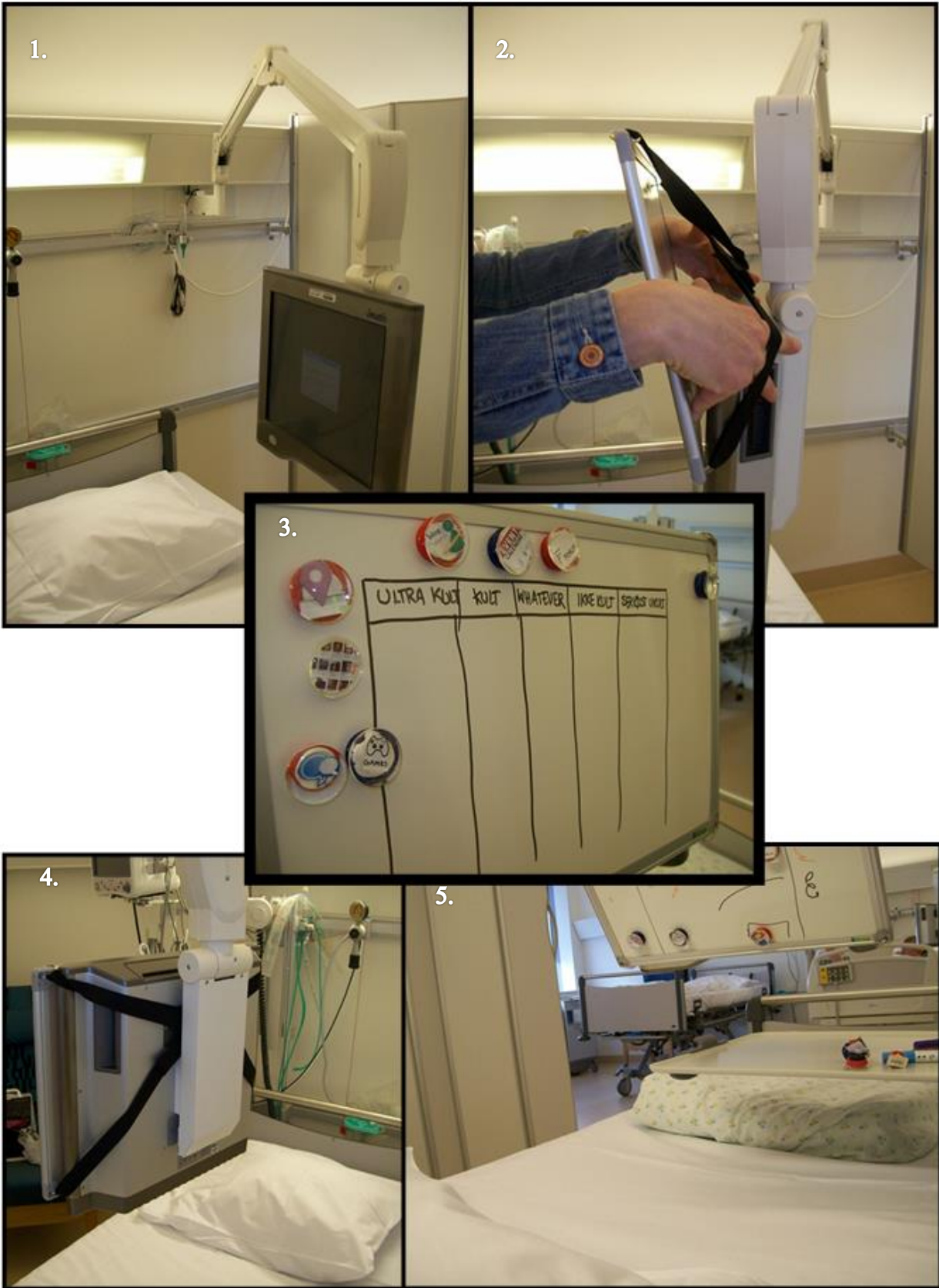


Figure 32: Cool Wall 3.0

Personas

The study has shown that it is constructive to use personas during interviews with non-patient teenagers. Defying the concerns about teenagers being self-centered and having difficulties to walk in someone else's shoes, the participants of this study showed a great deal of empathy. Using a relatively common disease as diabetes makes it easier for the participants to imagine what a patient peer would look for in a health oriented online community. In several cases, the participants reported to know someone with diabetes and used their knowledge and relation while designing Sprinkl. I suggest presenting non-patient teenagers with personas they can relate to and placing them in front of them during the design phase to keep their focus on the targeted group of users.

Low VS high fidelity prototype

Finally when considering what kind of prototype to design, I found it helpful to focus on what I wanted to investigate during the interviews. Cool is much about the visual aspects of a site, and when probing into the coolness of a prototype I found it fruitful to use a high resolution but low fidelity prototype. It helped me learn more about what makes a site have the right feel and level of coolness and what needs to be changed in the prototype.

8.1.3 Cool as a quality of technology

In order to design a cool social network for teenage patients it was not sufficient to only probe into what functions were cool and why, but also where they were cool. The study demonstrates how the interviewed group of teenagers had their own rules for the appropriate level of sharing and using functions on different sites. Many status updates were cool on Twitter, but were considered attention seeking on Facebook. It was impressive to hear about the teenagers' privacy and self-presentation strategies and how much they meant for the coolness of a site. The results of this study show that 'cool' is both a situated and a gendered concept. 'Cool' varied across genders both regarding functions and the aesthetics of the different sites. This is an area which needs further research.

8.1.4 Cool as a design guideline

This study has demonstrated that using cool as a design guideline can in PD contribute to designing engaging and cool technology. It is impossible to explore the coolness of the implemented site or even a high fidelity prototype, but as far as a low fidelity but high in resolution prototype goes, the participants reported the site to be cool. In addition, by collecting information about what is cool elsewhere on the Internet, it is possible to include functions teenagers themselves don't include in a design but regard as cool, and thereby bypass the hegemonic landscape.

8.2 The road ahead

Based on this study, it is impossible to say if Sprinklr can contribute to increasing the support the teenager patients receive and lead to the positive effects presented in the literature review. However the interviewed patients expressed that it would be cool to find others with their condition and feel less alone. This should be investigated after implementation of Sprinklr.

In this thesis PD was applied in order to give voice to the teenagers. Since the research interest of the thesis how to design a patient social network for and with teenagers, only teenagers were included. Using cool as a design guideline for Sprinklr allowed for the participation of non-patient teenagers. As the design and use for Sprinklr develops through further work with the project this thesis is a part of, other actors will have to be included.

The current design of Sprinklr may not be sufficient for the future use cases. However, in line with Franck and Noble [106] the results of this study point in the direction that the look and feel of a site are all important factors for future use and that in order for a site like Sprinklr to become a success, one must understand the design preferences of teenagers. This study has demonstrated that the cool wall can be used as a boundary object [63] during semi-structured interviews with teenagers making it easier to talk about the situated coolness of functions. My view is that in order for Sprinklr to become a site teenage patients would like to use, it will be important to include the cool concept in the design and development of the site. But most importantly, one must include the teenagers, because as Bill Watterson (1990) said “It seems like once people grow up, they have no idea what’s cool.”

Bibliography

- [1] M. van der Velden, "Patients and Social Media: If You Build It, Will They Come?," (Under review) 2013.
- [2] R. M. Baños, A. Cebolla, E. Oliver, S. Q. Castellano and C. Botella, "An E-Health System for Treatment of Childhood Obesity: The Etiobe Platform," in *E-Health Communities and Online Self-Help Groups: Applications and Usage*, Hershey, Medical Information Science Reference, 2012, pp. 24-35.
- [3] T. Finin, "For teens, social media is not technology, it's just life," 13 January 2008. [Online]. Available: <http://ebiquity.umbc.edu/blogger/2008/01/13/for-teens-social-media-is-not-technology-its-just-life/>. [Accessed 14 April 2013].
- [4] H. Skjeggstad, "Ahus får råd av ungdommen," *Aftenposten*, 25 February 2013. [Online]. Available: http://www.aftenposten.no/nyheter/iriks/Ahus-far-rad-av-ungdommen-7129749.html#.UX_qycqr4mg. [Accessed 15 April 2013].
- [5] M. U. Bers, L. M. Beals, C. Chau, K. Stoh, E. D. Blume, D. R. DeMaso and J. Gonzalez-Heydrich, "Use of virtual community as a psychosocial support system in pediatric transplantation," *Pediatric Transplantation*, no. 14, pp. 261-267, 2010.
- [6] D. Fitton, J. C. Read, M. Horton, L. Little, N. Toth and Y. Guo, "Constructing the Cool Wall: A Tool to Explore Teen Meanings of Cool," *PsychNology Journal*, vol. 10, no. 2, pp. 141-162, 2012.
- [7] H. B. Battles and L. S. Wiener, "STARBRIGHT World: Effects of an Electronic Network on the Social Environment of Children With Life-Threatening Illnesses," *Children's Health Care*, vol. 31, no. 1, pp. 47-68, 2002.
- [8] M. van der Velden and K. E. Emam, "'Not all my friends need to know': a qualitative study of teenage patients, privacy, and social media," *J Am Med Inform Assoc*, pp. 1-9, 6 July 2012.
- [9] S. Livingstone and D. R. Brake, "On the Rapid Rise of Social Networking Sites: New Findings and Policy Implications," *Children & Society*, vol. 24, pp. 75-83, 2010.
- [10] D. Boyd and N. B. Ellison, "Social Network Sites: Definition, History, and Scholarship," *Engineering Management Review*, vol. 38, no. 3, pp. 16-31, 2007.
- [11] F. Griffiths, A. Lindenmeyer, J. Powell, P. Lowe and M. Thorogood, "Why Are Health Care Interventions Delivered Over the Internet? A Systematic Review of the Published

- Literature," *Journal of Medical Internet Research*, vol. 8, no. 2, p. e10, 2006.
- [12] N. P. Terry, "Fear of Facebook: Private Ordering of Social Media Risks Incurred by Healthcare Providers.," *Nebraska Law Review*, pp. 703-750, 2011.
- [13] S. Ilioudi, A. A. Lazakidou, N. Glezakos and M. Tsironi, "Health-Related Virtual Communities and Social Networking Services," in *Virtual Communities, Social Networks and Collaboration*, New York, Springer New York, 2012, pp. 1-13.
- [14] J. F. Zrebiec and A. M. Jacobson, "What attracts patients with diabetes to an internet support group? A 21-month longitudinal website study," *Diabetic Medicine*, vol. 18, no. 2, pp. 154-158, 2001.
- [15] A. P. Baptist, M. Thompson, K. S. Grossman, L. Mohammed, A. Sy and G. M. Sanders, "Social Media, Text Messaging, and Email—Preferences of Asthma Patients between 12 and 40 Years Old," *Journal of Asthma*, vol. 48, no. 8, pp. 824-830, 2011.
- [16] S. Nordfeldt, L. Hanberger and C. Berterö, "Patient and Parent Views on a Web 2.0 Diabetes Portal - the Management Tool, the Generator, and the Gatekeeper: Qualitative Study," *Journal of Medical Internet Research*, vol. 12, no. 2, p. e17, 2010.
- [17] J. M. Burns, T. A. Devenport, L. A. Durkin, G. M. Luscombe and I. B. Hickie, "The internet as a setting for mental health services utilization by young people," *MJA*, vol. 192, no. 11, pp. 22-26, 2010.
- [18] J. Versnel, "You're in Charge: Engaging youth in designing and delivering an early preparation self-management program," *Occupational Therapy Now*, vol. 13, no. 5, pp. 28-29, 2011.
- [19] R. A. Bell, H. Xinyi, S. E. Orrange and R. L. Kravitz, "Lingering questions and doubts: Online information-seeking of support forum members following their medical visits," *Patient Education and Counseling*, vol. 85, pp. 525-528, 2011.
- [20] P. Veretilo and S. B. Billick, "Psychiatric Illness and Facebook: A Case Report," *Psychiatr Q*, vol. 83, pp. 385-389, 2012.
- [21] D. B. Nicholas, G. Picone, A. Vigneux, K. McCormick, A. Mantulak, M. McClure and R. MacCulloch, "Evaluation of an Online Peer Support Network for Adolescents with Chronic Kidney Disease," *Journal of Technology in Human Services*, vol. 27, no. 1, pp. 23-33, 2009.
- [22] L. Yan and Y. Tan, "Feel Blue so Go Online: An Empirical Study of Online Supports among Patients," 2010. [Online]. Available: http://papers.ssrn.com/sol37papers.cfm?abstract_id=1697849. [Accessed 10 September

2012].

- [23] G. Eysenbach, J. Powell, M. Englesakis, C. Rizo and A. Stern, "Health related virtual communities and electronic support groups: systematic review of the effects of online peer to peer interactions," *BMJ*, vol. 328, pp. 1-6, 13 May 2004.
- [24] P. D. Trobisch, P. A. Ricart and K. Verma, "Clinical and demographic characteristics of online community members--does it represent reality?," *The Spine Journal*, vol. 11, no. 9, pp. 826-831, 2011.
- [25] Y. Setoyama, Y. Yamazaki and K. Nakayama, "Comparing support to breast cancer patients from online communities and face-to-face support groups," *Patient Education and Counseling*, pp. e95-e100, 2011.
- [26] D. Z. Sands, "Electronic Patient-Centered Communication: E-Mail and Other E-Ways to Communicate Clinically," in *Consumer Health Informatics*, New York, Springer New York, 2005, pp. 107-121.
- [27] R. Mack, E. Giarelli and B. A. Bernhardt , "The Adolescent Research Participant: Strategies for Productive and Ethical Interviewing," *Journal of Pediatric Nursing*, vol. 24, no. 6, pp. 448-457, 2009.
- [28] D. Christie and R. Viner, "ABC of adolescence: Adolescent development," *BMJ*, vol. 330, pp. 301-304, 2005.
- [29] T. Toscos , K. Connelly and Y. Rogers, "Best Intentions: Health Monitoring Technology and Children," *CHI*, vol. 10, pp. 1431-1440, 2012.
- [30] D. Boyd, "Why Youth <3 Social Network Sites: The Role of Networked Publics in Teenage Social Life," in *Youth, Identity, and Digital Media*, Cambridge, The MIT Press, 2008, pp. 119-142.
- [31] E. E. Perry, K. Zheng, M. E. Ferris, L. Torres, K. Bickford and J. H. Segal, "Adolescents with Chronic Kidney Disease and Their Need for Online Peer Monitoring: a Qualitative Investigation of Social Support and Healthcare Transition," *Renal Failure*, vol. 33, no. 7, pp. 663-668, 2011.
- [32] M. van der Velden, "Teenage Patient Pricacy: Self-presentation and self-protection in social media," pp. 1-14, 2012.
- [33] S. Martin, P. Sutcliffe, F. Griffiths, J. Sturt, J. Powell, A. Adams and J. Dale, "Effectiveness and impact of networked communication interventions in young poeple with mental health conditions: A systematic review," *Patient Education and Counseling*, vol. 85, pp. e108-e119, 2011.

- [34] J. Finkelstein, E. Cha and J. Wood, "Use of Social Media for Health Education: An Example of Online Support Group for Individuals with Atrial Fibrillation," in *eL&mL 2012: The Fourth International Conference on Mobile, Hybrid, and On-line Learning*, Valencia, Spain, 2012.
- [35] M. T. Britto, T. L. Tivorsak and G. B. Slap, "Adolescents' Need for Health Care Priva," *Pediatrics*, vol. 126, pp. e1469-e1476, 2010.
- [36] J. P. Calzo and L. K. Suzuki, "The search for peer advice in cyberspace: An examination of online Bulletin boards about health and sexuality," *Applied Developmental Psychology*, vol. 25, pp. 685-698, 2004.
- [37] D. B. Nicholas, J. Darch, T. McNeill, L. Brister, K. O'leary, D. Berlin and D. Roller, "Perceptions of Online Support for Hospitalized Children and Adolescents," *Social Work in Health Care*, vol. 44, no. 3, pp. 205-222, 2007.
- [38] K. B. Johnson, R. D. Ravert and A. Everton, "Hopkins Teen Central: Assessment of an Internet-Based Support System," *Pediatrics*, vol. 107, no. 2, pp. 1-8, 2001.
- [39] H. Davis, F. Vetere, S. Ashkanasy, G. Dyson, P. Schofield, K. Thompson, G. Withers and D. Thomas, "Towards Social Connection For Young People With Cancer," *OZCHI*, pp. 319-322, 2008.
- [40] P. Carlbring, E. Nilsson-Ihrfelt, J. Waara, C. Kollenstam, M. Buhrman, V. Kaldo, M. Söderberg, L. Ekselius and G. Andersson, "Treatment of panic disorder: live therapy vs.self-help via the Internet," *Behaviour Research and Therapy*, vol. 43, pp. 1321-1333, 2005.
- [41] A. L. Williams and M. J. Merten, "A Review of Online Social Networking Profiles by Adolescents: Implications for Future Research and Intervention," *Adolescence*, vol. 43, no. 170, pp. 253-274, 2008.
- [42] J. Bishop, "Increasing participation in online communities: A framework for human-computer interaction," *Computers in Human Behavior*, pp. 1881-1893, 2007.
- [43] G. Holden, D. J. Bearison, D. C. Rode, M. F. Kapiloff and G. Rosenberg, "The Effects of a Computer Network on Pediatric Pain and Anxiety," *Journal of Technology in Human Services*, vol. 17, no. 1, pp. 22-47, 2000.
- [44] G. S. O'Keeffe and K. Clarke-Pearson, "The Impact of Social Media on Children, Adolescents, and Families," *Pediatrics*, pp. 800-804, 2011.
- [45] E. Aïmeur, S. Gambs and A. Ho, "Towards a Privacy-Enhanced Social Networking Site," in *2010. ARES '10 International Conference on Availability, Reliability, and*

Security., Krakow, 2010.

- [46] J. K. Burgoon, "Privacy and communication," in *Communication Yearbook 6*, Beverly Hills, Sage, 1982, pp. 206-249.
- [47] A. Liu, *The Laws of Cool: Knowledge Work and the Culture of Information*, Chicago: The University of Chicago Press, 2004.
- [48] M. Horton, J. C. Read, D. Fitton, N. Toth and L. Little, "Too Cool at School - Understanding Cool Teenagers," *PsychNology Journal*, vol. 10, no. 2, pp. 73-91, 2012.
- [49] A. L. Culén and A. A. Gasparini, "Situated Techno-Cools in a given context of use," *PsychNology Journal*, vol. 10, no. 2, pp. 117-139, 2012.
- [50] J. C. Read, D. Fitton, B. R. Cowan, R. Beale, Y. Guo and M. Horton, "Understanding and Designing Cool Technologies for Teenagers," *CHI '11 Extended Abstracts on Human Factors in Computing Systems CHI EA '11*, pp. 1567-1573, 2011.
- [51] J. P. Gerber and C. Geiman, "Measuring the existence of cool using an extended Social Relations Model," *PsychNology Journal*, vol. 10, no. 2, pp. 103-115, 2012.
- [52] K. Holtzblatt, "What Makes Things Cool? Intentional Design for Innovation," *Interactions*, vol. 18, no. 6, pp. 40-47, 2011.
- [53] H. van der Heijden, "User Acceptance of Hedonic Information Systems," *MIS Quarterly*, vol. 28, no. 4, pp. 695-704, December 2004.
- [54] W. Odom, J. Zimmerman and J. Forlizzi, "Teenagers and Their Virtual Possessions: Design Opportunities and Issues," *CHI*, vol. 7, no. 12, pp. 1491-1500, 2011.
- [55] E. Sanders and P. J. Stappers, "Co-creation and the new landscapes of design," *CoDesign*, vol. 4, no. 1, pp. 5-18, 2008.
- [56] A. Kanstrup and E. Christiansen, "Selecting and evoking innovators: combining democracy and creativity," in *NordiCHI'06*, Oslo, Norway, 2006.
- [57] E. Brandt, "Designing Exploratory Design Games: A Framework for Participation in Participatory Design," *PDC*, pp. 57-66, 2006.
- [58] T. Bratteteig and I. Wagner, "Spaces for Participatory Creativity," *PDC*, pp. 51-60, 2010.
- [59] P. Ehn, "Participation in Design Things," in *Proceedings of the Tenth Anniversary Conference on Participatory Design 2008 (PDC '08)*, Indianapolis, 2008.

- [60] Y. Sundblad, "From Utopia 1981 to Utopia 2008," in *(Re)Searching The Digital Bauhaus*, London, Springer, 2008, pp. 13-41.
- [61] C. Spinuzzi, "The Methodology of Participatory Design," *Technical Communication*, vol. 52, no. 2, pp. 163-174, 2005.
- [62] R. Fowles, "Symmetry in design participation in the built environment: Experiences and insights from education and practice.," in *Proceedings of CoDesigning*, London, 2000.
- [63] S. L. Star and J. R. Greisemer, "Institutional ecology, translations' and boundary objects: Amateurs and professionals in Berkeley's Museum of Vertebrate Zoology, 1907-39," *Social studies of science*, vol. 19, no. 3, pp. 387-420, 1989.
- [64] T. Bratteteig, I. Wagner, A. Morrison, D. Stuedahl and C. Mörtberg, "Research Practices in Digital Design," in *Exploring Digital Design: Multi-Disciplinary Design Practices*, London, Springer, 2010, pp. 17-54.
- [65] A. N. Markham, "The methods, politics, and ethics of representation in online ethnography," *The Sage handbook of qualitative research*, pp. 793-820, 2005.
- [66] J. Löwgren and E. Stolterman, *Thoughtful Interaction Design: A Design Perspective on Information Technology*, Cambridge, Massachusetts: The MIT Press, 2004.
- [67] M. van der Velden, "A Social Networking Site for Teenage Patients: Interests, needs, and functionalities," University of Oslo, Oslo, 2013.
- [68] L. Suchman, "Do Categories Have Politics? The language/action perspective reconsidered," *Computer Supported Cooperative Work (CSCW)*, vol. 2, pp. 177-190, 1993.
- [69] L. Björneborn, "Design Dimensions Enabling Divergent Behaviour across Physical, Digital, and Social Library Interfaces," in *Persuasive Technology*, Berlin Heidelberg, Springer, 2010, pp. 143-149.
- [70] M. D. Myers and D. Avison, *Qualitative Research in Information Systems*, London: Sage publications, 2002.
- [71] M. D. Myers, "Qualitative Research in Information Systems," Living. [Online]. Available: <http://www.qual.auckland.ac.nz/>. [Accessed 1 October 2011].
- [72] J. W. Creswell, *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches*, Thousand Oaks: Sage Publications, Inc., 2003.
- [73] D. Silverman, "Qualitative research: meanings or practices?," *Info Systems Journal*, vol. 8, pp. 3-20, 1998.

- [74] R. Bassett , B. L. Beagan, S. Ristovski-Siljeppevic and G. E. Chapman, "Tough Teens: The Methodological Challenges of Interviewing Teenagers as Research Participants," *Journal of Adolescent Research*, vol. 23, no. 119, pp. 119-130, 2008.
- [75] H. Beyer and K. Holtzblatt, *Contextual Design: Defining Customer-Centered Systems*, San Francisco: Morgan Kaufmann Publishers Inc., 1998.
- [76] D. Krackhard and L. W. Porter, "The snowball effect: Turnover embedded in communication networks," *Journal of Applied Psychology* , vol. 71, no. 1, pp. 50-55, 1986.
- [77] M. Sandelowski, "Focus on Research Methods: Whatever Happened to Qualitative Descriptions?," *Research in Nursing & Health*, vol. 23, pp. 334-340, 2000.
- [78] J. Blomberg, J. Giacomi, A. Mosher and P. Swenton-Wall, "Ethnographic Field Methods and Their Relation to Design," in *Participatory Design: Principles and Practices.*, Hillsdale, Lawrence Erlbaum Associates, 1993, pp. 123-156.
- [79] G. Guest, A. Bunce and L. Johnson, "How Many Interviews Are Enough?: An Experiment with Data Saturation and Variability," *Field Methods*, vol. 18, no. 59, pp. 59-82, 2005.
- [80] I. Holloway and S. Wheeler, *Qualitative Research in Nursing and Healthcare*, Oxford: John Wiley and Sons, 2010.
- [81] G. Madan, M. E. Stadler, K. Uhrich, C. Reilly and A. Drake, "Adolescents with thacheostomies - Communications in cyberspace," *International Journal of Pediatric Otorhinolaryngology*, vol. 75, pp. 678-680, 2011.
- [82] J. Halloran, E. Hornecker, M. Stringer, E. Harris and G. Fitzpatric, "The value of values: resourcing co-design of ubiquitous computing," *Journal of Co-Design. International Journal of CoCreation in Design and the Arts*, vol. 5, no. 4, pp. 245-273, December 2009.
- [83] M. E. Morris, S. Consolvo, S. Munson, K. Patrick, J. Tsai and A. D. Kramer, "Facebook for health: opportunities and challenges for driving behavior change," *CHI EA '11 Proceedings of the 2011 annual conference extended abstracts on Human factors in computing systems* , pp. 443-446 , 2011.
- [84] D. E. Agosto and J. Abbas, "High School Seniors' Social Network and Other ICT Use Preferences and Concerns," *ASIST*, pp. 1-10, 2010.
- [85] N. C. Krämer and N. Haferkamp, "Online Self-Presentation: Balancing Privacy Concerns and Impression Construction on Social Networking Sites," in *Privacy Online*,

- Berlin, Springer- Verlag, 2011, pp. 127-141.
- [86] S. Trepte and L. Reinecke, "The Social Web as a Shelter for Privacy and Authentic Living," in *Privacy Online*, Heidelberg, Springer - Verlag Berlin, 2011, pp. 61-74.
- [87] M. O'Leary, "Web Directories Demonstrate an Enduring Online Law," *Online*, vol. 22, no. 4, pp. 79-81, 1998.
- [88] C. J. Thompson and Z. Arsel, "The Starbucks brandscape and consumers'(anticorporate) experiences of glocalization," *Journal of Consumer Research*, vol. 31, pp. 631-642, 2004.
- [89] W. Lidwell, K. Holden and J. Butler, *Universal Principles of Design: 100 Ways to Enhance Usability, Influence Perception, Increase Appeal, Make Better Design Decisions, and Teach through Design*, Gloucester, Massachusetts: Rockport Publishers, Inc., 2003.
- [90] D. Norman, *The Design of Everyday Things*, New York: Basic Books, 2002.
- [91] S. Houde and C. Hill, "What do Prototypes Prototype," in *Handbook of Human-Computer Interaction 2*, Amsterdam, Elsevier Science B., 1997, pp. 367-381.
- [92] G. Ritzer, "The "McDonaldization" of Society," *Journal of American Culture*, pp. 100-107, 1983.
- [93] M. van der Velden, "Organising Development Knowledge: Towards Situated Classification Work on the Web," *Webology*, vol. 5, no. 3, pp. 1-18, 2008.
- [94] C. H. Noble and M. Kumar, "Using product design strategically to create deeper," *Business Horizons*, vol. 51, pp. 441-450, 2008.
- [95] A. Micheti, J. Burkell and V. Steeves, "Fixing Broken Doors: Strategies for Drafting Privacy Policies Young People Can Understand," *Bulletin of Science Technology & Society*, vol. 30, no. 130, pp. 130-143, 2010.
- [96] M. Buchenau and J. F. Suri, "Experience prototyping," *DIS'00*, pp. 424-433, 2000.
- [97] M. Bødker, "Artifactual Relations in UCD," *Nordes*, vol. 3, pp. 1-4, 2009.
- [98] M. D. Corry, T. W. Frick and L. Hansen, "User-Centered Design and Usability Testing of a Web Site: An Illustrative Case Study," *ETR&D*, vol. 45, no. 4, pp. 65-76, 1997.
- [99] W. Chisholm, G. Vanderheiden and I. Jacobs, "Web Content Accessibility Guidelines 1.0," W3C, 5 May 1999. [Online]. Available: <http://www.w3.org/TR/WCAG10/>. [Accessed 3 March 2013].

- [100] M. De Laet and A. Mol, "The Zimbabwe Bush Pump: Mechanics of a Fluid Technology," *Social studies of science*, vol. 30, no. 2, pp. 225-263, 2000.
- [101] C. Mörtberg, T. Bratteteig, I. Wagner, D. Stuedahl and A. Morrison, "Methods That Matter in Digital Design Research," in *Exploring Digital Design; Multi-Disciplinary Design Practices*, London, Springer-Verlag, 2010, pp. 105-144.
- [102] D. Schön, *Educating the reflective practitioner*, San Francisco: Jossey-Bass, 1987.
- [103] D. Schön, *The reflective practitioner: how professionals think in action*, New York: Basic Books, 1983.
- [104] P. Linde, *Metamorphing - The transformative power of digital media and tangible interaction*, Karlskrona: Blekinge Institute of Technology, 2007.
- [105] D. Nicolini, "The work to make telemedicine work: A social and articulative view," *Social Science & Medicine*, vol. 62, no. 11, p. 2754–2767, 2006.
- [106] L. S. Franck and G. Noble, "Here's an idea: ask the users! Young people's views on navigation, design and content of a health information website," *J Child Health Care*, vol. 11, no. 287, pp. 287-296, 2007.

Appendix A

Participants Information and Consent Form

The participants were presented with different consent forms depending on whether they were teenage patients, non-patients, or master students. The consent forms did not vary in the information about the study or information about what data would be collected, the storage and treatment of the data or information regarding withdrawal. I did however change information regarding what I wanted to obtain through information. In the consent forms for teenage patients and non-patients, the participants were informed that I was interested in what was cool online and that I needed their help to design a cool social networking site for teenage patients. The consent forms for the master students stated that I was interested in testing the usability. No new consent forms were provided for the teenagers for the prototype testing interviews as their consent for further collaboration was asked for in the previous form.

Consent form for the teenage patients

Forespørsel om deltagelse i masteroppgave Lukket sosialt nettsted for langtidssyke ungdommer

1. Bakgrunnsinformasjon

Jeg er en masterstudent ved Institutt for Informatikk, Universitetet i Oslo, og holder nå på med den avsluttende masteroppgaven. Målet mitt er å lage et lukket sosialt nettsted for langtidssyke ungdommer i Norge. Jeg ønsker å finne ut av hva ungdommene selv vil at et slikt nettsted skal inneholde.

For å finne ut av dette, ønsker jeg å intervju ca. 5 personer i alderen 12-20 år. Spørsmålene vil dreie seg om hvor mye langtidssyke ungdommer deler om tilstanden sin på allerede eksisterende nettsider, hvor de finner informasjon om sykdommen sin og hva de kunne ha tenkt seg at et nytt nettsted kan tilby de.

Studien utføres av meg og min veileder Maja van der Velden som er forsker ved Institutt for Informatikk, Universitetet i Oslo. Oppgaven skal være ferdig i mai 2013.

1.2. Hva innebærer studien?

Jeg ønsker å invitere ungdommer med langtidssykdom til et intervju for å høre hvordan de synes at et lukket sosialt nettsted skal være. Jeg ønsker å høre din mening om hvordan jeg kan gjøre dette nettstedet kult og nyttig for brukerne.

Intervjuet vil ta mellom en halvtime til en time, og vi blir sammen enige om tid og sted.

Mulige fordeler og ulemper

Det vil ikke være noen direkte ulemper ved å delta i dette prosjektet utover eventuelt ubehag knyttet til intervjusituasjonen.

Indirekte fordeler ved å delta i dette studiet er at du kan bidra til at det sosiale nettstedet jeg skal utvikle kan hjelpe andre ungdommer i liknende situasjon som deg.

Det er frivillig å delta i dette studiet. Du kan når som helst trekke deg fra studiet uten å oppgi noe grunn til dette. Dersom du ønsker å delta, er det fint om du kan undertegne den vedlagte samtykkeerklæringen.

Hva skjer med informasjonen om deg?

Under intervjuet noterer jeg på en papirblokk og bruker en båndopptaker. Jeg renskriver notatene ved hjelp av lydopptaket. Etter dette sletter jeg filen på lydopptakeren og papirene blir makulert. Opplysningene som er direkte personidentifiserende erstattes med et referansenummer som viser til en navneliste. Denne listen oppbevares låst og adskilt fra øvrig datamateriale. Filene med notater og lydopptak er passord beskyttet og vil ikke bli lagret på et PC-nettverk.

Om deltakerne opplyser jeg navn, kjønn, omtrentlig alder og et generelt problem eller diagnose. Jeg skal også opplyse om religion eller etnisitet dersom det er relevant for analysen. Jeg kommer ikke til å registrere adresseinformasjon, fødselsnummer eller andre direkte personidentifiserende opplysninger – alle disse erstattes med et referansenummer.

Det er ingen andre enn meg og min veileder som vil få tilgang til de personidentifiserbare opplysningene. De er underlagt taushetsplikt og vil bli behandlet konfidensielt. Det er ingen enkeltpersoner som vil kunne gjenkjennes i den ferdige oppgaven.

All informasjon vil kun oppbevares så lenge det er behov for det; det vil i praksis bety at all informasjonen blir slettet når oppgaven er ferdig innen 30. mai 2012. Det er imidlertid mulig at det vil bli aktuelt å gjennomføre et oppfølgingsintervju når prototypen for nettstedet er ferdig. Du vil da motta ny informasjon og ny forespørsel om å delta.

Forskningsprosjektet er meldt til NSD (Norsk Samfunnsvitenskaplig datatjeneste), personvernombudet for alle norske universiteter, høyskoler og flere sykehus og forskningsinstitusjoner.

Rett til innsyn og sletting av opplysninger om deg

Dersom du sier ja til å delta i studien, har du rett til å få innsyn i hvilke opplysninger som jeg har registrert. Du har også rett til å korrigere feil i disse opplysningene. Dersom du trekker deg fra studien kan du kreve at de innsamlede opplysningene blir slettet

Kontaktinformasjon

Hvis du har noen spørsmål angående studien eller hvis du har senere lyst til å trekke deg, kan du kontakte meg på tlf. xxxxxxxx eller sende en epost til xxxxxxxx@ifi.uio.no. Du kan også kontakte min veileder Maja van der Velden ved Institutt for Informatikk på xxxxxxxx eller xxxxxxx@ifi.uio.no.

Med vennlig hilsen
Margaret Machniak
(adresse)

Consent form for non-patient teenagers

Forespørsel om deltagelse i masteroppgave Lukket sosialt nettsted for kronisk syke ungdommer

Bakgrunnsinformasjon

Jeg er en masterstudent ved Institutt for Informatikk, Universitetet i Oslo, og holder nå på med den avsluttende masteroppgaven. Målet mitt er å lage et lukket sosialt nettsted for langtidssyke ungdommer i Norge. Det sosiale nettstedet skal først og fremst være kult å bruke, og jeg trenger derfor å finne ut av hvordan jeg kan få det til.

For å finne ut av dette, ønsker jeg å intervju ca. 5 personer i alderen 12-20 år (alene eller i små grupper). Spørsmålene vil dreie seg om hva ungdommer synes at er kult på nettet.

Studien utføres av meg og min veileder Maja van der Velden som er forsker ved Institutt for Informatikk, Universitetet i Oslo. Oppgaven skal være ferdig i mai 2013.

Hva innebærer studien?

Jeg ønsker å invitere ungdommer til et intervju for å høre hva de gjør på nettet og hva de synes er kult. Jeg ønsker å høre deres mening om hvordan jeg kan gjøre et sosialt nettsted for kronisk syke ungdommer kult og nyttig for brukerne.

Intervjuet vil ta mellom en halvtime til en time, og vi blir sammen enige om tid og sted. Intervjuet kan gjennomføres der det passer best for dere (hjemme, på kafè eller liknende). Jeg kommer til å dekke eventuelle reiseutgifter.

Mulige fordeler og ulemper

Det vil ikke være noen ulemper ved å delta i dette prosjektet utover eventuelt ubehag knyttet til intervjusituasjonen.

Fordelene ved å delta i dette studiet er at du som deltaker kan bidra til at det sosiale nettstedet jeg skal utvikle kan hjelpe ungdommer mer kroniske sykdommer.

Det er frivillig å delta i dette studiet. Du kan når som helst trekke deg fra studiet uten å oppgi noe grunn til dette. Dersom du ønsker å delta, er det fint om du kan undertegne den vedlagte samtykkeerklæringen.

Hva skjer med informasjonen om deg?

I intervjuet noterer jeg på en papirblokk og bruker en lydopptaker. Jeg renskriver notatene med hjelp av lydopptaket på PC, deretter makuleres papirene og filen på lydopptaket slettes. Om deltakere opplyser jeg bare kjønn og alder. Jeg opplyser ingen informasjon som kan direkte knyttes til deg.

Ingen enkeltpersoner vil være gjenkjennelige i den ferdige oppgaven.

Det er imidlertid mulig at det vil bli aktuelt å gjennomføre et oppfølgingsintervju når prototypen ("kladden" eller første utkast) for nettstedet er ferdig. Du vil da motta ny informasjon og ny forespørsel om å delta.

Forskningsprosjektet er meldt til NSD (Norsk Samfunnsvitenskaplig datatjeneste), personvernombudet for alle norske universiteter, høyskoler og flere sykehus og forskningsinstitusjoner.

Rett til å kunne se og slette opplysninger om deg

Dersom du sier ja til å delta i studien, har du rett til å få innsyn i hvilke opplysninger som jeg har registrert. Du har også rett til å korrigere feil i disse opplysningene. Dersom du trekker deg fra studien kan du kreve at de innsamlede opplysningene blir slettet.

Kontaktinformasjon

Hvis du har noen spørsmål angående studien eller hvis du har senere lyst til å trekke deg, kan du kontakte meg på tlf. xxxxxxxx eller sende en epost til xxxxx@ifi.uio.no. Du kan også kontakte min veileder Maja van der Velden ved Institutt for Informatikk på xxxxxxxx eller xxxxxxx@ifi.uio.no.

Med vennlig hilsen

Margaret Machniak
(adresse)

Consent form for students

Forespørsel om deltagelse i masteroppgave

Lukket sosialt nettsted for kronisk syke ungdommer

Bakgrunnsinformasjon

Jeg er en masterstudent ved Institutt for Informatikk, Universitetet i Oslo, og holder nå på med den avsluttende masteroppgaven. Jeg har utviklet en prototype for et lukket sosialt nettsted for langtidssyke ungdommer i Norge. Det sosiale nettstedet skal først og fremst være kult og enkelt å bruke, og jeg trenger derfor å finne ut av hvordan jeg kan få det til.

For å finne ut av dette, ønsker jeg å invitere ca. 5 personer (alene eller i små grupper) til et prototype-intervju. Spørsmålene vil dreie seg om brukervennlighet og generelle tekniske aspekter av prototypen.

Studien utføres av meg og min veileder Maja van der Velden som er forsker ved Institutt for Informatikk, Universitetet i Oslo. Oppgaven skal være ferdig i mai 2013.

Hva innebærer studien?

Jeg ønsker å invitere deg til et intervju for å høre hva du synes om brukervennligheten og strukturen av prototypen. Jeg ønsker å høre din mening om hvordan jeg kan gjøre et sosialt nettsted for kronisk syke ungdommer kult og nyttig for brukerne.

Intervjuet vil ta mellom et kvarter og en halvtime, og vi blir sammen enige om tid og sted. Intervjuet kan gjennomføres der det passer best for deg (hjemme, på cafe eller liknende).

Mulige fordeler og ulemper

Det vil ikke være noen ulemper ved å delta i dette prosjektet utover eventuelt ubehag knyttet til intervjusituasjonen.

Fordelene ved å delta i dette studiet er at du som deltaker kan bidra til at det sosiale nettstedet jeg skal utvikle kan hjelpe ungdommer mer kroniske sykdommer.

Det er frivillig å delta i dette studiet. Du kan når som helst trekke deg fra studiet uten å oppgi noe grunn til dette. Dersom du ønsker å delta, er det fint om du kan undertegne den vedlagte samtykkeerklæringen.

Hva skjer med informasjonen om deg?

I intervjuet noterer jeg på en papirblokk Om deltakere opplyser jeg bare kjønn og alder. Jeg opplyser ingen informasjon som kan direkte knyttes til deg.

Ingen enkeltpersoner vil være gjenkjennelige i den ferdige oppgaven.

Forskningsprosjektet er meldt til NSD (Norsk Samfunnsvitenskaplig datatjeneste), personvernombudet for alle norske universiteter, høyskoler og flere sykehus og forskningsinstitusjoner.

Rett til å kunne se og slette opplysninger om deg

Dersom du sier ja til å delta i studien, har du rett til å få innsyn i hvilke opplysninger som jeg har registrert. Du har også rett til å korrigere feil i disse opplysningene. Dersom du trekker deg fra studien kan du kreve at de innsamlede opplysningene blir slettet.

Kontaktinformasjon

Hvis du har noen spørsmål angående studien eller hvis du har senere lyst til å trekke deg, kan du kontakte meg på tlf. xxxxxxxx eller sende en epost til xxxxxx@ifi.uio.no. Du kan også kontakte min veileder Maja van der Velden ved Institutt for Informatikk på xxxxxxxx eller xxxxxx@ifi.uio.no.

Med vennlig hilsen

Margaret Machniak
(adresse)

Appendix B

Interview guide for teenage patients

How much time do you spend online per day?

Does your condition affect your attendance at school? Do you then use Internet to catch up?
How?

Do you use Internet to find information about your disease?

Do you use Internet to connect to other patients with your condition?

Are you a member of a disease specific group on Facebook?

Do you use patient organizations to find other teenagers you can communicate with?

Which social media sites do you use?

Do you use the Internet to find new friends?

Who are the most important people to keep in touch with through Internet?

Do you have your parents on Facebook?

How much do you share about your condition online?

How important is it for you to present yourself online?

Will you say that your Facebook profile represents who you are?

Part one: Other social media sites (time: MAX 10 minutes)

Place 6 magnets on the board.

Which functions make this site cool?

How do you use this website?

Part two: Cool functions

Choose 10 functions and place them on the boards. Think aloud when you place them.

Why did you choose...?

How often do you use this function?

What makes this function cool?

Is there anything that could be better about this function?

Part three: Designing the site

If you could decide how a social networking site for teenage patients should look like, what would you do?

Should it look like an already existing page?

What colors would you choose?

Is font important?

What would you use it for?

Who should run this site?

Is it important to have profile pages?

How important is personalized design?

Where should one find information about one's condition?

Should there be a group for girls- or boys only?

Should there be groups for teenagers with the same diagnosis?

Username or real names?

How would you find friends on this site?

Should parents have access to the page?

How would you prefer to receive information about this page?

Who should be allowed to have an account on this site?

How about health personnel?

Activities?

Place the magnets on the board, draw. Think aloud.

Why did you place this function here?

Where do the user go from here?

How should posts be presented?

Which settings should be included?

Interview guide for non-patient teenagers

How much time do you spend online per day?

What do you do when you're online?

Do you use Internet to do homework? How?

Which social media sites do you use?

Do you use the Internet to find new friends?

Who are the most important people to keep in touch with through Internet?

Do you have your parents on Facebook?

How much do you share about your condition online?

How important is it for you to present yourself online?

Will you say that your Facebook profile represents who you are?

Part one: Other social media sites (time: MAX 10 minutes)

Place 6 magnets on the board.

Which functions make this site cool?

How do you use this website?

Part two: Cool functions

Choose 10 functions and place them on the boards. Think aloud when you place them.

Why did you choose...?

How often do you use this function?

What makes this function cool?

Is there anything that could be better about this function?

Part three: Designing the site

(presenting personas)

If you could decide how a social networking site for teenage patients should look like, what would you do?

Should it look like an already existing page?

What colors would you choose?

Is font important?

What would you use it for?

Who should run this site?

Is it important to have profile pages?

How important is personalized design?

Where should one find information about one's condition?

Should there be a group for girls- or boys only?

Should there be groups for teenagers with the same diagnosis?

Username or real names?

How would you find friends on this site?

Should parents have access to the page?

How would you prefer to receive information about this page?

Who should be allowed to have an account on this site?

How about health personnel?

Activities?

Place the magnets on the board, draw. Think aloud.

Why did you place this function here?

Where do the user go from here?

How should posts be presented?

Which settings should be included?

MARTIN LARSEN:

TENÅRING MED DIABETES

ALDER: 17

SKOLE: SOFENBERG VGS

LINJE: ALLMENN FAG

DATAFERDIGHETER: GJENNOMSNIITTLIGE

SYKDOM: DIABETES

MARTINS ØNSKER:

MARTIN BRUKER DE SAMME NETTSTEDENE SOM DU, MEN HAN KJENNER INGEN ANDRE MED SIN DIAGNOSE. DET ER MANGE TING SOM HAN ER FOR FLAU TIL Å SPØRRE FORELDRENE SINE OG LEGEN OM. HAN ØNSKER SEG ET LUKKET SOSIALT NETTSTED HVOR HAN KAN KOMME I KONTAKT MED ANDRE TENÅRINGER MED DIABETES OG ANDRE KRONISKE SYKDOMMER. HAN ØNSKER OGSÅ Å LERE MER OM SYKDOMMEN SIN OG HVORDAN HAN SKAL TAKLE HVERDAGEN. PÅ DENNE SIDEN VIL MARTIN VÆRE SEG SELV OG KUNNE DELE TING OM SYKDOMMEN SIN UTEN Å MÅTTE TENKE PÅ HVA ANDRE KOMMER TIL Å TENKE OM HAM.

MARTIN HVERDAG:

MARTIN FIKK DIAGNOSEN DIABETES FOR ET HALVT ÅR SIDEN. SIDEN DA MÅ HAN DRA TIL KONTROLL PÅ SYKEHUSET EN GANG I MÅNEDEN OG MÅ TIL REGELMESSIGE SJEKK HOS LEGEN. HAN GÅR I ANDRE KLASSE PÅ VGS. NESTEN INGEN AV HANS VENNER VET AT HAN HAR DIABETES.

HANS DAG STARTER MED Å DRA PÅ SKOLEN. ETTER SKOLEN SPILLER MARTIN VOLLEYBALL, MEN HAN MÅ ALLTID PASSE PÅ BLODSUKKERET SITT. HAN SYNES AT DET ER FLAUT AT HAN MÅ SJEKKE BLODSUKKERET OG ALLTID HA MED SEG MAT.

NÅR MARTIN DRAR HEIM, SITTER HAN MYE PÅ FACEBOOK OG CHATTER MED VENNENE SINE. I HELGENE TØR HAN IKKE Å FESTE MED DE ANDRE KLASSEVENNENE SINE. HAN ER REDD FOR HVA SOM KOMMER TIL Å SKJE HVIS HAN DRIKKER OG TØR IKKE Å SPØRRE LEGEN SIN OM DET FORDI HAN ER BARE 17 OG IKKE GAMMEL NOK TIL Å DRIKKE.



Appendix C

Prototyping interview guide for students

What is good/bad about this site/prototype?

Is it easy to understand what is the objective of Sprinklr?

Do you understand what kind of content you can generate on the site?

Is the site predictable?

What about navigation?

Do you understand the different icons? Should I have text only?

Do you understand what you see in the feed?

What can be done to make the prototype more user-friendly?

Is the prototype consistent in terms of the visual aspect?

Do you miss anything?

Do you think it's cool?

How about the colors in relation to readability and visibility?

Is there anything that should be placed somewhere else?

Do you have any suggestions for where the panic button should be located?

Do you see anything that doesn't work at all?

Prototyping interview guide for teenagers

Tasks:

Where would you go to find information about diabetes?

Where do you go to post a status update?

Do you know what you can post?

How would you find your friends?

Can you explain what you can see on your profile?

What can you do with the calendar?

How can you change your privacy settings?

Questions:

What do you think about the prototype? Bad/good?

Is it easy to understand what is the objective of Sprinklr?

Do you understand what kind of content you can generate on the site?

Is the site cool?

What is not cool?

Do you understand what the panic button does?

Do you understand the icons?

Do you think the colors are cool? What other colors can I use?

Would you use this site?

ⁱ NSD (Norsk samfunnsvitenskapelig datatjeneste) is a competence center regulating data dissemination. Its main activity is guiding researchers and students in Norway during collection and analysis of the data, research ethics, privacy policies, and methods. (www.nsd.uib.no)

ⁱⁱ The limited profile functionality is a variant of friend list. On Facebook, the users have the possibility to organize their friends into different categories with various levels of privacy settings. The privacy settings rolled out by Facebook in 2011 make by default all content inaccessible to people listed under limited profile. Still, the user can customize what content the people on the limited profile list can see and which content is not visible to them.

ⁱⁱⁱ Activity log is a log containing all user activity. The log is accessible through the user's profile. The activity log is currently only visible to the user and shows when he/she posted content, what he/she searched for in the search field, what the user liked, and so on. The meaning behind this feature was providing the user with an overview of his/her own activity, making it easier to detect eventual hacker attacks. It is yet unknown whether this log will be in future visible to others than the user him-/herself.

^{iv} The participants used the word legitimate in this context meaning that the initiative was provided by serious actors and was not a scam.

^v Check in here was described as similar to the check in function available on Facebook. Users tag themselves at various locations by 'checking in'. The update or post then contains information about their location based on either input or GPS tracking.

^{vi} Adding a box or/and color background for a content to draw attention to it. This is done to add priority to the object or a task. For examples see [89, p. 127]

^{vii} Klara Klok is a Norwegian Q&A site for young people (ages 10-25), equivalent to Agony Aunt. The site is sponsored by the Ministry of Health and facilitates for asking questions about health, drugs, additions, family relations and sex. The site is not meant to be a substitute for health and mental health services, but rather a supplement and a service guiding the visitors to the right instances.