Hälsokollen - An adaptable eHealth technology for children with long-term illnesses

Exploring ways to enhance children's involvement in their own health care

Master's thesis in Interaction Design and Technologies

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Abstract

The aim of this project was to explore a way of enhancing children with long-term illnesses' involvement in their own health care through technology, and to provide new insights to the field of interaction design and children. The project was conducted together with Sahlgrenska University Hospital in Gothenburg, Sweden. Along with the UN Convention on the Rights of the Child, which recently has become a law in Sweden, the request from the hospital was to create a digital tool that can be used as the child's own communication channel with the nursing staff, with the objective of an increased active participation among the patients. Similar work within this area has been done previous to this project, but they are either created specifically for certain illnesses or cognitive impairments, or have a different objective than this project. To meet the aim of this project, the research question *What design guidelines should be taken into consideration when designing an adaptable eHealth technology for 5 to 18 year old children?*, followed by the sub-question *What is a plausible design suggestion of such an eHealth technology, to be used by 5 to 18 year old children with long-term illnesses within Swedish health care?*, was created. The research questions were answered by performing an iterative and user-centered design process, were methods such as ideation sessions, interviews with stakeholders and usability tests of different prototypes of the digital tool, which came to be called Hälsokollen, were performed. The overall result showed that the general idea of Hälsokollen, as well as its design, was widely appreciated and accepted by the majority of people who evaluated it, including the different stakeholders. The 12 guidelines created for future designs of adaptable eHealth technologies for children, concludes a set of interesting findings made in this project, related to themes such as content, design, interaction and experience of using an adaptable eHealth technology like Hälsokollen. There are however still room for improvement and many suggestions of alternative solutions, which fosters potential future development of Hälsokollen and the design guidelines created.

Keywords: interaction design, young children, adolescents, long-term illnesses, adaptable interfaces, eHealth technology, web-tools.

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Stina Vestergren Kilborn, Emma Nordqvist, Gothenburg, June 2020

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Introduction

January 1st 2020, the UN Convention on the Rights of the Child, UNCRC, became Swedish law [65]. In short, it affirms that all children from 0-18 years old have equal rights and that all decision making regarding a child should consider the child's best interest by involving his or her own opinions and thoughts related to the subject [67]. Simultaneously, the Children's Department of Neurology at Queen Silvia's Children's Hospital in Gothenburg is working for an increased patient participation in the patient's own health condition and in treatment of it, in order to adapt health care in accordance with individual needs and desires. Since the department treat patients that are between 0-18 years old, diagnosed with different long-term or chronic neurological diseases [11], there are special circumstances which affects the way communication of the patient's individual needs can be done. Young children are especially dependent on their parents doing some of the communication for them, and due to the neurological diseases, some might have certain cognitive and/or motoric difficulties.

Along with the UNCRC, the Children's Department of Neurology (CN) and the Play Therapy at Queen Silvia's Children's Hospital in Gothenburg are requesting a digital tool that can be used as the child's own communication channel with the nursing staff, that can be adapted after those special circumstances and needs, with the objective of an increased active participation among child patients. Some children that are or have been patients at the CN have expressed a need to express thoughts and feelings related to their health condition and treatments. The Play Therapy have tried to encounter this by helping children create their own flip book, to be used as a supporting communication tool during doctor's appointments. Starting from this, the CN and the Play Therapy are now requesting a design prototype of an expanded and digital version of this tool. More specifically, it should be designed as a digital tool used on the patient's or caregivers' computers, smart phones or tablets. Patients should be able to enter and edit information, with support from their caregivers if wanted or needed, whenever they are not seeing their doctor, or show the information that has been entered, during doctor's appointments. During doctor's appointments, nursing staff should also be able to enter certain types of information directly through the patient's or caregivers' devices. The digital tool should also be adaptable, by offering children to choose between three different interfaces of varying complexity, to enable the tool to suit the wide age span of 5 to 18 year old children and the various cognitive and motoric difficulties among patients.

1.1 Stakeholders

The stakeholders of this project are first and foremost the end users of the digital tool that this project is aiming to create a design proposal of. The end users are children between the ages of 5-18, diagnosed with different long-term or chronic neurological diseases, their caregivers and their nursing staff. These user groups will however have different roles when it comes to how they will interact with the digital tool. The main users are the children, who are supposed to be able to post information about themselves, their thoughts, feelings and questions related to their disease and the treatment of it, in the digital tool. The caregivers' role will be to support their child in the different aspects of using the digital tool, as much as needed or requested by the child depending on age, cognitive and/or motoric difficulties and the child's individual preferences. The nursing staff will mainly view the information posted in the system, and adapt the doctor's appointments and treatments accordingly. The nursing staff will also have the possibility of posting relevant information related to the individual child's disease and/or treatment, such as information about medication, for the child and his/her caregivers to view whenever they are not seeing their doctor.

The second stakeholder is the Children's Department of Neurology (CN) and the Play Therapy at Queen Silvia's Children's Hospital, which are part of Sahlgrenska University Hospital in Gothenburg, since they are the initiators of this project and its main requirements. The CN are treating the children that are part of the end user group in this project, and the Play Therapy is a department where all patients at Queen Silvia's Children's Hospital can come to play, create and relax whenever they are visiting the hospital.

The third stakeholder is the Centre of Digital Health at Sahlgrenska University Hospital. This department works with questions regarding digitalization of the hospital and are responsible for the delivery of the design proposal that is being created in this project, to the CN and the Play Therapy.

The fourth stakeholder is Chalmers University of Technology, in which this project is part of the master thesis course in the master's programme Interaction Design and Technologies.

1.2 Aim of the project

The aim of this project is mainly two things. The first aim is to provide new insights to the field of interaction design and children. The second one is to explore ways of involving children with long-term or chronic diseases in their own health condition and in treatment of it through technology. Meeting these aims could have several implications. Firstly, it could allow health care to be better adapted for each child's individual preferences and needs. Secondly, children could be better prepared for taking responsibility of their own health condition and treatment the day they turn

18 and are expected to manage their health condition themselves. Thirdly, children could be encouraged to practice their rights in accordance with the UNCRC, and fourthly, it could help children to be empowered because they could make their voice heard without indirectly having their message forwarded through their caregivers.

Two different approaches will be used to meet the aims discussed above. The first one consists of doing an investigation of what design guidelines seem to be of importance when designing these types of eHealth technologies for children. This includes doing a literature review of children's abilities and development, of existing GUI guidelines within the field of interaction design and children, as well as an exploration of new guidelines through evaluation of the design prototypes created in this project. The second approach is to create a design proposal of a child-friendly, digital tool for children with long-term or chronic neurological diseases. However, the aim is to design a digital tool that potentially also could be used by children with other types of long-term or chronic diseases. This approach includes application of the findings from the literature review as well as from prototype evaluations, in a high-fidelity design prototype.

1.2.1 Research questions

To meet the aim of this project, the following research questions were created:

1. What design guidelines should be taken into consideration when designing an adaptable eHealth technology for 5 to 18 year old children?
    (a) What is a plausible design suggestion of such an eHealth technology, to be used by 5 to 18 year old children with long-term illnesses within Swedish health care?

1.3 Limitations

There are a several factors that limits this project in different ways. Firstly, the authors have limited knowledge of the research areas related to this project. Since the project is also bound to the contexts and circumstances provided by the stakeholders, which are an academic institution (Chalmers University of Technology), health care instances (the Children's Department of Neurology, the Play Therapy and the Centre for Digital Health) and end users (children, caregivers and nursing staff), the outcome of the project is also limited by external factors in these contexts. On the academic side, the project needs to consider academic and research correctness as well as the amount of time and resources provided by the master thesis course responsibles and supervisors. On the health care side, the project needs to consider regulations related to patients, their security and rights as well as limitations related to resources and time offered by these stakeholders. Limitations related to the end users include factors such as their availability and willingness to participate in different parts of the design process, as well as whether caregivers give their consent for their children to participate in these parts of the process. Furthermore, the project is limited by the covid-19 pandemic that emerged during the realization of this project, on the spring of 2020. The pandemic caused the Swedish government and Sahlgrenska University Hospital to put up different types of recommendations and restrictions, such as physical distancing and visiting restrictions on the hospital, which affected the way prototype evaluations and other types of contact with stakeholders could be done.

1.4 Delimitation

In relation to the above stated limitations, several delimitations have been established. As mentioned in the introduction of this report, the aim is not only to allow nursing staff to *view* information that their patients have entered in the digital tool when they meet, but also for them to *enter* certain information themselves during doctor's appointments. However, since this project is an exploratory study investigating in which ways technology can be used to enhance children's involvement in their own health care, focus will be on gathering thoughts and opinions about the digital tool from children and their caregivers. Thoughts and opinions from nursing staff will only be gathered from informal discussions with the staff at the Children's Department of Neurology (CN) and the Play Therapy, that are requesting the digital tool. Similarly, the contexts of use considered in this project will be delimited to a hospital setting and a home setting, hence not consider other settings where the digital tool might be used.

Due to fact that the CN and the Play Therapy are requesting a prototype of a digital tool, in the shape of a website to be used on a computer, tablet or smart phone, ideas about other types of tools, such as for example tangible systems, will not be considered.

The combination of varying neurological impairments and the broad age span of the child end users (5-18 year olds) creates numerous parameters that ideally would be considered when designing for this user group. For this project, taking all those parameters into account would however be a challenge too big for the scope of the project. Therefore, a delimitation has been decided to only review design guidelines based on age-related abilities and skills in typically developed children, without taking the abilities in children with cognitive or motorical difficulties into consideration. To fit the different age groups, three interfaces of varying complexity will be designed, where the least complex interface will be designed based on guidelines for children between 5-8, the medium complex interface on guidelines for children between 9-12, and the more complex interface on guidelines for children between 13-18. However, to account for individual differences and preferences, among them cognitive and motorical variations, the aim of the final product is to enable the users to choose themselves which version of the interface he or she want to use, and offer the user to further customize the background in the interface.

Since the child end users in this project are diagnosed with different neurological diseases, there is an occurrence of children with both severe, mild and no cognitive and/or motorical difficulties, as mentioned above. To be able to get insights about the usability, usefulness and user experience of our design, formative evaluations will only be conducted with patients that have the cognitive and motorical ability to use a digital tool on a computer, smart phone or tablet, as well as patients that are able to understand and follow the instructions given during the evaluation sessions. Further on, it was planned to recruit evaluation participants face to face during visits at the CN, to make it easy for patients to apply for participation. Due to the ongoing covid-19 pandemic and the related visiting restrictions, this was no longer possible. Therefore, it was decided to also contact children in the ages of 5-18, that were not patients at the CN and that did not have a long-term illness, to increase the amount of possible evaluation participants.

Finally, due to this project being carried out in Sweden, together with a Swedish hospital, the language used in the digital tool will also be Swedish. Therefore, the prototype evaluations will only include participants that understand the Swedish language.

1.5 Ethical considerations

In this section, all ethical considerations taken in the project are presented. When involving children in research projects, there are many ethical aspects to take into account. The ones that will be presented in this section are considerations that need to be taken when involving children in the design process, and when children are using the web, where personal and/or confidential information about them as patients are shared.

1.5.1 When involving children in the design process

What is important to bare in mind is that the children in our target group have not yet reached a legal age of 18. This in turn means that they cannot independently agree to participate in research projects. Mack et al. discusses ethical aspects of involving adolescents in research, where they mention that a researcher must obtain informed consent from the parent/guardian before involving the adolescent in the research [49]. Although, Pool and Peyton also emphasizes that children and adolescents may be very vulnerable to be convinced to participate in studies by their adult family members [56]. Precautions should therefore always be made to assure that a child actually wants to participate, by informing the participant about the study and his/her right to withdraw their consent of participation at any time.

1.5.2 When children are using the web

The target group in this project consist of both young children and adolescents, and therefore, the amount of experience from using the web likely differs between the two age groups as well as between individuals. Budiu and Nielsen [25] writes that older children often have enough experience from using the web to understand the concept of authentication and the use of passwords on websites. However, they argue that this is not always the case for younger children (under 6 years of age) or children that are new to using the web. Since most of the child end users are older than 6 years of age and authors will have limited insights on the amount of web-experience among evaluation participants, the authors will inform all participating children and caregivers that if the digital tool proposed in this project actually would be implemented in the future, it would preferably accessed through the Swedish e-service Healthcare Guide 1177, which is protected by the citizen identification solution BankID. This consideration will be taken to inform participants that it would be as “safe” to use this digital tool as any of the other e-services offered by the Swedish Healthcare Guide 1177.

1.5.2.1 Sharing personal information

When websites ask children to share personal information, Budiu and Nielsen [25] argues that designers should encourage children to protect their personal information. Even though the objective of using the digital tool proposed in this project is for patients to share personal information with parents and/or nursing staff, such as their thoughts, feelings and questions related to their health condition, using the digital tool will be optional as well as the type and amount of the information to be entered. Therefore, this message should be forwarded to the users if the tool actually would be implemented, to make sure they feel that they always have power over their own information. In an article by Lewis, he describes that adolescents ability to consider risks and consequences regarding hypothetical situations are increasing in the ages of 11 to 18 [47]. Therefore, it is of even more importance to get this message across to the younger children.

1.5.2.2 Patient regulations

Much of the information to be entered in the digital tool by patients, their caregivers and nursing staff is confidential and object for different patient regulations. For example, all Swedish health care providers must apply the Law of patients’ data, which includes regulations such as that only the nursing staff that are involved in the care of a certain patient are allowed to view data about that patient [12]. This message should also be forwarded to users to remind them about the security measures taken for the technology that is provided by Swedish health care instances.

1.6 Terminology

In this section, the terminology that will be used throughout the report will be described.

Children: The term will refer to all children in the ages between 5 to 18. Within this term, both the term *Young children* and *Adolescents* are included.

Adolescents: The term will refer to children in the ages between 13 to 18. This is due to the fact that the *Swedish Healthcare guide 1177* states that these are a child's teen ages [1].

Young children: The term will refer to children 5-12, thereby all children younger than adolescents within our target group.

CN: The term will refer to Children's Department of Neurology, at Queen Silvia's Children's Hospital (Sahlgrenska University Hospital).

CDH: The term will refer to Centre of Digital Health at Sahlgrenska University Hospital.

Digital tool: This term will refer to the tool that was designed in this project.

Hälsokollen: This is what the tool that was designed in this project came to be called. In English, the name means approximately "The health tracker".

2

Background

In this section, research and information will be presented to state the background and problem area of the project. The topics to be presented are long-term neurological illnesses in children, eHealth technologies for children, children and the web, children's participation in decision making, acceptance and adherence of technology, and adaptable interfaces. Lastly some similar and related work will be presented.

2.1 Long-term neurological illnesses in children

Every year, the children's Department of Neurology at Queen Silvia's Children's Hospital in Gothenburg treats approximately 2000 patients with suspected or verified long-term or chronic neurological diseases, and another 1000 children are on the waiting list [16]. Neurological diseases causes disorders in the central nervous system, and among the most common neurological diseases are Epilepsy, Multiple Sclerosis (MS), Stroke, Parkinson's disease and Amyotrophic Lateral Sclerosis (ALS) [45]. Neurological diseases can cause cognitive, motoric and/or sensoric disruptions of varying severity, for example communication-, concentration-, intellectual- and problem solving difficulties, mobility impairments and paralysis [45, 53].

People with long-term or chronic neurological illnesses often have continuous contact with health care and have regular doctor's appointments to keep track of the disease and how it is manifested, to discuss treatments and other things related to the disease [16]. When it comes to children, and adolescents in particular, Mack, Giarelli and Bernhardt [49] argue that it can be even more stressful having or receiving the message of being ill during a child's teenage years, where great developmental changes already occur. Additionally, Mack et al. [49] argue that it is of particular importance for adolescents to feel that they “fit in”, and that the occurrence of visible impairments can take a serious turn on their self esteem. Moreover, until a child turns 18, their caregivers' decisions weight more than the child's when making decisions related to the child's care [3]. However, Holmbeck et al. [39] argue that there are indicators suggesting that children with chronic diseases sometimes feel overprotected by their caregivers.

2.2 eHealth technologies for children

According to van Gemert-Pijnen, Kelders, Kip and Sanderman [68], eHealth has become an increasingly popular way of communicating, nursing staff and patients in between, since Internet was introduced to society. van Gemert-Pijnen et al. descibe eHealth as ”*the use of technology to support health, well-being and healthcare.*” [68] (p. 7). They argue that eHealth can have many beneficial properties. For example, it can increase the access to or quality of care, but also empower patients to be more involved and make more informed decisions regarding their health, which is discussed in more detail in the section “Patient participation” below. When it comes to children’s health care specifically, a study by Thabrew et al. [66] showed that patients and their caregivers among other things desired eHealth technologies to support their psychological needs, such as to reduce anxieties related to being diagnosed with physical long-term illnesses. There have also been studies investigating ways of enhancing patients’ engagement through the use of gamification in eHealth technologies, but it is argued that there is not enough empirical evidence of what impact this might have on patient engagement [58].

2.3 Children and the web

Today, almost all children in Sweden are introduced to Internet before entering elementary school. The organization Internetstiftelsen [43] have investigated Swedish children’s (0-19 years olds) digital habits during 2019. They found that 77 % of 0-5 year olds use the Internet to watch video clips, play games or visit educational applications and websites at home, through their families’ mobile devices. They also report that since July 2019, Swedish pre-schools have a commitment to educate pupils in digital competence (which is further developed through the same commitment throughout elementary school), even though the use of Internet in pre-schools yet is quite uncommon. Children between 6-10 years of age still use their caregivers’ or families’ tablets while 54 percent of the children also receives their first own mobile phone. During this age, 60 % of children also start sending text- and picture messages, and 50 % use the Internet for school purposes. Among children between 11-13, almost all have their own mobile phone, but the use of computers also start to increase due to the fact that 63 % have received their own computer. 77 % of children this age also start to create a digital identity through the use of social media. Additionally, they use Internet on a daily basis as a part of their education. Moreover, children in the ages 14-16 follow the same trend as the younger ages by showing an increased use of Internet, both in their private and educational life, preferably through their own mobile phones but also through computers. The habits in the age group 17-19 are approximately the same as the 14-16 year olds, with the exception that the use of Internet is perceived as more important for educational rather than private purposes. In summary, the use of Internet through mobile devices and computers is a natural part of Swedish children’s lives, even though Internetstiftelsen [43] argues that people’s digital competence requires continuous re-evaluation and improvement along with the digital development in society.

2.4 Children's participation in decision making

Until children turn 18, caregivers are the main responsibles for their children. However, that does not mean that children's opinions, thoughts and feelings are overlooked. In this chapter, children's rights and participation in decisions regarding their health will be presented and discussed.

2.4.1 United Nations' Convention on the Rights of the Child

The United Nations' Convention on the Rights of the Child (UNCRC) is an international agreement between countries to protect and fulfill children's rights [67]. Since the 1st of January 2020, the convention is also part of the Swedish law [65]. Because this project has children as its main stakeholder, the UNCRC will naturally pervade all the work in this project.

The UNCRC contains 54 chapters stating all children's rights and the governments' responsibilities in sustaining them [67]. Even though all chapters generally are equally important, some are of particular relevance for this project. These include chapter 1, 3, 5, 12-16, 23-24 and 42-45, which in summary covers the importance of considering children's best interests in decisions that will affect them and in society as a whole, adult's responsibilities in relation to children's rights, such as helping children to exert them and protecting them against forces that threatens their rights, and the importance of spreading the word of the UNCRC among children and adults.

2.4.2 Patient participation

According to Street, Gordon, Ward, Krupat and Kravitz [62], active patient participation in decision making regarding their health can improve the care's outcome and quality. Since the amount of patient participation varies among individuals, they investigated which factors might affect patient participation and found that both personal-, communication- and contextual factors can play a role.

As discussed in the section "eHealth technologies for children" above, eHealth technologies can also be used to increase patient's participation in their own health care [68]. There have been studies on the design of eHealth technologies for children's health specifically. Hung and Stones [41] compared eHealth technologies used in the east and west parts of the world, but many technologies seems to be designed to be used mainly by the children's caregivers. On the other hand, there have been studies about children's involvement in decision processes related to their health. One study by Coyne and Harder [27] shows that children's preferences regarding their own involvement is dependent on the specific situation, and that the situation also have an impact on the amount and type of support they want from their caregivers.

Research has been carried out to get insights on what type of eHealth technology-features potentially could make children's attitude towards health related issues more positive. A study by Høiseth, Giannakos, Alsos, Letizia Jaccheri and Asheim

[42] investigated the use of healthcare games for toddlers (1-3 year olds) before, during and after nebulizer treatments, but argues that the findings should be useful in other pediatric healthcare situations as well. They found that healthcare games used by this age group for example could make patients' attitudes more positive by allowing the user to explore treatment-related activities through play, offer rewarding elements and age-appropriate information about treatments. Another study by Svedberg, Arvidsson, Larsson, Carlsson and Nygren [64] got insights on how the implementation of the eHealth application *Sisom* could increase patient participation among children, as well as what implications this might have for children and their care. For example, they report that children found it easier to communicate about their thoughts and feelings when they could use the application and a written version of their inner feelings as support, that they felt proud over their accomplishment of entering this information into the application and that they dared to ask more questions related to their health condition and treatment. However, the study also showed that implementation of eHealth technologies that aims at increasing child-participation also require the organization, in which the technology is to be implemented, to be willing and prepared to make changes in the way they are currently working with children.

2.5 Acceptance and adherence of technology

The term *acceptance* refers to the decision of a user on how, if and when they would use a technology, as stated by Gemert-Pijnen et al. [68]. As they continue to describe, just starting to use an eHealth technology is usually not enough for the technology to give the intended impact. One need to both stick with the technology and use it as intended by the developers. This in turn is called *adherence*. Ludden et al. [48] talks about the huge potential of web-based technologies in health today, but also about the problem of non-adherence that is often the case in these technologies. It has therefore been made clear that acceptance and adherence are two important concepts in creating effective eHealth technologies that are used in an optimal way [68].

2.6 Adaptable interfaces

The term *adaptable interfaces* refers to interfaces that can be customized by users themselves to fit their own criteria, Wolfgang et al. says [63]. Further on, they state that the term should not be confused with the relating term *adaptive interfaces*, which refers to interfaces that change their appearance automatically according to an algorithm. Moreover, previous comparisons between the two types of interfaces have shown that users prefer interfaces that they can customize themselves over interfaces that does this for them.

Along with the development of technology and user interfaces, applications are becoming more complex with a growing number of features, Wolfgang et al. states. Adaptability can be said to be one solution to this problem, by allowing a user to customize the application and thereby optimize their screen space. A possible negative aspect of using adaptable interfaces, Wolfgang et al. mentions, is that it requires extensive work for programmers to implement.

Designing interface adaptability can, according to Hourcade [40], also be used as a way to account for differences in needs and desires among individual children. He mentions that this can be done by adjusting the complexity of an interface as well as by allowing children to select their preferred look and feel. When a tool is being used by children for long periods, sometimes several years, the needs and desires in an individual child will likely also have changed after a couple of years of use, as discussed by Joyce and Nielsen [44]. In these situations, interface adaptability could also be an important feature.

2.7 Related work

In this section, products and research that are similar or related to this project will be presented. For every work presented the differences to this project will be made clear. Different tools used for different types of communication and information exists within healthcare or are being created today. Blackstone and Pressman are two authors who have created a handbook with collected resources and tools within effective communication in children's hospitals [24]. Both a similar resource from their handbook and other applications will be presented below.

The Hospital Communication Book
This is a physical book, created by the *Clear communication people Ltd*, which is meant to make communication easier between health care providers and patients [5]. With the handbook, health care providers are for example to be able to explain procedures, check consent and enable the patient to express symptoms, needs and feelings. Overall, this book has some similarities to the physical flip book, called "Delaktighetsboken" ("the book of participation"), that has been used in some cases at the children's Department of Neurology and the Play Therapy, at Queen Silvia's Children's Hospital [16]. How the Hospital communication book differs from the aim of this project is that it takes form as a physical book instead of an digital tool, and that there seems to be less room for "freedom" for a patient or healthcare provider to add their own information, in the form of text or images.

Barncancerappen
The application was created at the Children's Department of Oncology, with support from Karolinska University Hostpital and Barncancerfonden [2]. The aim of the app is to give parents and children, that are hospitalized for cancer at Astrid Lindgrens children's hospital, the information they need. What differentiates Barncancerappen from this project is the fact it is specialized for children diagnosed with cancer, that it seems to be aimed for the parents as main users and that it seems to be more of a digital information book rather than a digital tool meant for communication and increased participation.

Genia
Genia is a mobile application made for young people with long term illnesses [6]. Today the application is made for people with *cystic fibrosis* (CA) and *juvenile idiopathic arthritis* (JIA). The application for example allows the user to log symptoms, reflect about daily activities, keep track of medicines, learn about some selected news about CF and JIA, send reports to their doctor, invite family members to their account and keep in touch with others with the same illness [7]. The application differs to this project in that it is specifically aimed at two diseases, it does not seem to be designed for children under 12 years of age and it seems to incorporate more complex logging of symptoms than what is necessary for this project.

mySugr App
The application mySugr Junior is a digital tool made to teach young children how to handle their own diabetes [10]. The app uses a child friendly “diabetes monster” and also works as a communication tool between parents and their children. What differentiates the application to this project is the fact that it, as with Genia and Barncancerappen, is specifically aimed at a specific diagnosis, here diabetes. Furthermore, it seems to be a communication tool between children and parents, rather than between children and their health care providers.

Sisom
Sisom is an application developed to help empower children in the ages between 6 to 12, that are diagnosed with cancer, to become more involved in their own health care [19]. Further on, the application aims to help the children communicate easier with their health care providers. The application does this though an interactive animated environment where the child visits five “islands” and answers different questions about themselves. These questions can then be discussed during meetings with a health care providers. There are a lot of similarities between this application and the aim of this project, but what differs between them are that Sisom is specifically designed for children with cancer and that it seem to be more constrained in how much text and drawings one can add. Moreover, Sisom does not seem to be adapted for children in the ages of 12 to 18 and it seem to be more complex (over 80 questions) than this project’s digital tool aims to be.

Rättvisat
This is an application created by Bräcke Diakoni, with the aim to enable people to always be encountered in a correct way [4]. The target group of the application is adults and children who have communication difficulties [13]. The aim of the application is to display information of how for example the user wants to be encountered, how they communicate and what they need help with. What differs between Rättvisat and this project is that it is aimed for people with some sort of cognitive impairments or communication difficulties and that the focus of the app is to not to only communicate with the doctor, but with everyone the child might encounter.

TellMe
TellMe [26] is a mobile application to be used in special education schools in Sweden. The application consists of a diary, to be used by the children, and a contact book, to be used by parents and teachers. By enabling children to write a diary about their day in school, they can practice both reflection and to do self-reports, Börjesson describes. The difference between TellMe and this project is that it is designed to be used in a school contexts and that this application, as with Rättvisat, is designed specifically for children with cognitive impairments or communication difficulties.

Kind
The application Kind is made for communication and data sharing between patients and health care providers [9]. While using the application, the patient is able to send messages, videos/images and files back and forth to their health care providers. The differences between the application and this project is that Kind is created to enable communication between patients and health care providers at a distance, through messages and videos etc.

2.8 Summary

In Sweden, at the CN at Queen Silvia's Children's Hospital, there are around 2000 children with suspected or verified diagnoses with long-term or chronic illnesses. When patients are diagnosed with neurological diseases, it means that they have some type of disorders in the central nervous system. Further on, these patients often have continuous contact with health care. Since the UNCRC recently has become part of the Swedish law, considering children's best interests in decisions that will affect them is an important matter. As discussed in the section "eHealth technologies for children" above, eHealth technologies can be used as a way to increase patients' participation in their own health care. One reason that this might be possible is because the use of Internet through mobile devices and computers is a natural part of Swedish children's lives today.

By viewing the similar and related work that has been done previously, similarities and differences with this project were identified. A general and simple communication tool to be used between children (in the age span of 5 to 18 years) with different long-term illnesses and their health care providers, where the tool is meant to be used during and between appointments, does not yet seem to exist. Similar work has been done, but they are either specific to certain illnesses or cognitive impairments, online distance communication tools or solely informational tools. Neither have a similar work been found that is suitable for such a wide age span. This exploratory study therefore has a possibility to add valuable knowledge to this research area.

3

Theory

In this section, theory related to the project will be presented and concluded in a summary. Firstly, theories about child development will be presented. Secondly, children's participation in the design process will be presented and include the differences between children's and adults' participation in research, the different roles of children participation, and considerations to take when involving children in the design process. Thirdly, design guidelines will be presented on how to design for web- and app interfaces as well as how to design for system acceptance and adherence.

3.1 Child development

To meet the aim of designing an eHealth technology that is appropriate for children as users, one should have an understanding of children's abilities and how they develop as they age [40][23].

Hourcade [40] mention Jean Piaget and Seymond Vygotsky as two of the experts on child development, that has had a clear impact on the field of children-computer interaction. According to Hourcade [40], Piaget proposed a theory about children going through a set of developmental stages as they grow to become adults, where each developmental stage take place during an estimated age span, in which children are showing a set of typical behaviors. Furthermore, Hourcade [40] writes that Vygotsky instead proposed the importance of social aspects in child development, where he thought the use of language, signs and external tools could be seen as an augmentation of cognitive processes.

Even though Piaget's theory about developmental stages have been highly criticized and there have been many contributions to the field of child developement since, most of them have evolved from Piaget's and Vygotsky's above mentioned theories [40]. However, Bekker and Antle [23] argues that it sometimes can be difficult to interpret and apply theories of child development effectively throughout a design process, when designing children's technology. Therefore, Bekker and Antle [23] have developed a collection of information cards (so called DSD cards) on children's cognitive, physical, social and emotional development, to be used as a supporting tool for designers in the design process. The DSD cards focuses on the age groups 5-6, 7-9 and 10-12, where the content is based on literature reviews on child development, Bekker and Antle's own experiences of designing and teaching about designing for children, as well as interviews with design students and practitioners. Based on the DSD cards (can be downloaded as a PDF here: http://antle.iat.sfu.ca/research/developmentally-situated-design/), a summary of the abilities children are practicing in the two first mentioned age groups can be found below. Since children up to 18 years of age are also part of the end users in this project, the age group 10-14 will be summarized based on findings from both the DSD cards (age 10-12), and the work by Dahl [28] and Mack, Giarelli and Bernhardt [49] (age 10-14). The last age group, 15-18, are summarized based on the findings reported by Dorn, Dahl, Woodward and Biro [30] and the Swedish Healthcare guide 1177 [15].

3.1.1 Age 5-6

Children in the ages 5-6 have normally reached a physical developmental level where they practice basic movements during both gross and fine manipulation of objects. Their cognitive abilities lies within doing one thing at a time, for example follow simple instructions and do simple reading and problem solving, step-wise and with a caregiver's support. Socially, they begin to be aware of other people's perspectives and to cooperate with others. On the emotional perspective, they are practicing expressing and regulating their own strong emotions, as well as to understand others' [23].

3.1.2 Age 7-9

Between the age of 7-9, children are normally practicing more complex physical movements. Their cognition starts allowing them to independently focus on several tasks and instructions at the same time, as long as they are closely related, as well as to read longer sentences and multi-syllable words. They also begin to understand and solve more complex problems, with an occasional support from caregivers. They start to develop confidence and practice their social skills by considering other people's perspectives, and how to adjust their own behavior to be able to cooperate and build trust with others. Their emotional development has reached a stage where they begin to be able to interpret both verbal, non-verbal and conflicting emotional cues in others. Furthermore, they begin to consider social conventions for expressing and regulating their own strong emotions [23].

3.1.3 Age 10-14

Around the years of 10-12, children normally practice doing sequences of more complex movements during both gross and fine manipulation, with accurate coordination and repetition. They have reached a cognitive level where they practice simultaneous focus on several or sequential tasks of varying difficulty, sometimes intertwined with decision making. They also practice reading of complex words and sentences, as well as independently comprehend and solve problems. Their social abilities enable them to consider multiple perspectives and needs of others, to practice loyality and intimacy. They also begin to build confidence from skills obtained in various domains. Emotionally, children in this age group take other people's emotions, as well as their own, into account then making decisions. They also express and regulate strong emotions in complex social situations based on skills obtained from previous experiences [23].

According to Mack, Giarelli and Bernhardt [49], children between 10-14 develop the cognitive ability to answer questions of more abstract and hypothetical character and to plan for the future, including reflecting over the impact their behavior will have on it. Dahl [28] also argues that sensation-seeking and risk-taking behaviors are common.

3.1.4 Age 15-18

When children enters this age group, Dorn, Dahl, Woodward and Biro [30] argues that risk-taking typically decrease due to improved judgement of risk-taking behaviors and improved self-regulation in general. According to the Swedish Healthcare guide 1177 [15], children in this age group start to have more nuanced thinking in their late teenage years, in which they can better understand consequences, compare alternatives to each other and analyse relationships. Although, they also mention that the brain is usually not done being developed until a child is 20 to 25 years old.

3.2 Children's participation in the design process

This section will describe different considerations to take when involving children in the design process.

3.2.1 Children's versus adults' participation

It is only relatively recent that children have become involved in the design process when technologies are being created for them, as stated by Fails et al. [33]. They continue to describe that involving children in the design process is an important and valuable aspect since children are experts in what children wants. Börjesson mentions that adults do not just have a hard time remembering how it was being a child, being a child today is also very different from being a child just a few years ago [26]. Faber et al. also states that involving children with disabilities in the design process may be even more important, since this perspective is even harder for a non-disabled adult to understand [34].

Even though children can participate in the design process as adults do, they do need different support because of their developmental differences [33], which was described in the section "Child development". Some differences, that Fails et al. mentions, may be that children need more breaks than adults do, due to their shorter attention span, and that methods need to be modified to be more suitable for children. Another difference can be that children are more open minded than adults, which can enable them to come up with more creative ideas. In the next section, a description of the different levels of involvement a child can have in a design process will be described.

3.2.2 Children's roles in the design process

When involving children in the design process, they can have different levels of involvement. In her work, Druin describes a framework where she divides children's involvement into five different roles: *users, testers, informants*, or *design partners* [32]. She defines each of these roles based on the three underlying dimensions: relationship to adults, relationship to technology and the goals for inquiry, see Figure 3:1.

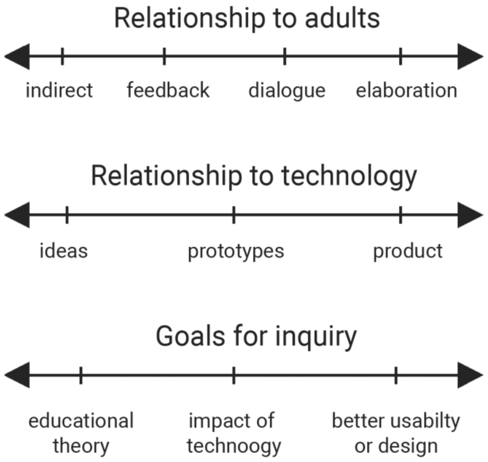


Figure 3.1: The underlying dimensions to each role, as described by Druin [32].

Druin describes that when a child has a role as a *User*, he/she is a user of a technology while adults try to understand the child's activities using different methods. With this role, the technology is not being developed or changed continually. The purpose can instead for example be to better understand children's process of learning. When a child has a role as a *Tester*, Druin states, children test prototypes of technologies under development, to help shape them before they are released. In this role, children are not involved until the first prototypes have been made. Furthermore, Druin states that in the role of an *Informant*, the children can be involved in various stages of the design process, depending on when researchers believe children can inform them. Children in this role can therefore be providing information and feedback both before and after a product is created. Lastly, Druin talks about the role of children as *Design partners*, where children's and researchers' input are considered equally important. Children can for example help perform certain methods together with the researchers.

Today, there are several design approaches which are created to involve children in the design process in different ways [33]. Large et al.[46] describes seven of these approaches and places them on a scale from low to high, based on the level of involvement of the children. To name some of the approaches, *user-centered design* receives a low score on the scale. This is due to the fact that users typically have little or no control over the design process itself, except for providing design feedback. The involvement of the children in this approach could perhaps be said to be testers or users.

On the higher end of the scale the approach called *cooperative inquiry* receives the highest score. This approach involves children as design partners and aims to involve them throughout the whole design process [31]. *Bonded design* [46] is the design approach with the second highest score. This approach is inspired by, among others, the cooperative inquiry, but instead aims to involve children as a mix between informants and design partners. *Informant design* is the approach that is placed in the middle of the scale and involves children as informants [46]. Scaife et al. [59] says that by involving children as informants, one might get answers to what is not known, rather than just confirming knowledge. Further on, he believes that the role of informants is a good approach since one should not treat children as full design partners, as they do not have the knowledge, expertise or time for that.

Among the approaches and thereby roles of involvement of children, the role of children as informants was chosen for this project. This is both due to the fact that this design approach has been shown to be beneficial [59]] and due to constraints in time and resources to involve children at a higher level.

3.2.3 Considerations when involving children in the design process

In this section, some aspects to take into consideration when involving children in the design process will be presented. First, some general considerations to bare in mind when involving children will be presented and later some considerations specifically aimed for adolescents.

As mentioned above, adults have a hard time remembering how it was to be a child [26]. This implies that one needs to bare in mind that, when designing for children, adult researchers' memories might unintentionally bias their work [56]. Another aspect to bare in mind is the balance of power between children and researchers [52]. Hourcade states that since a power imbalance can disrupt the gathering of important information in research with children, researchers must focus on empowering them [40]. An example of this, he mentions, could be to tell the children how important their input is and how they are experts at being children, which the technology is to be designed for.

Accessing participants' meanings could also be more difficult when talking with children than with adults, Morgan et al. describes [52]. They continue to say, that it is therefore important to probe and clarify questions, to make sure that the children properly understands them. Further on, children might sometimes not want to answer questions if they think that the adults already know the answer to it. Morgan et al. states that one strategy to counter this could be for the facilitators to use a stuffed animal to talk to the children. Further on, they mention that when involving shy children in the design process, using a combination of activities such as drawing and role playing could help the child to participate more easily.

The social context is also important to bare in mind when performing research with children, since it could influence how children respond to questions, Morgan et al. says [52]. Two examples they mention one could bare in mind is the seating arrangements and to include warm-up activities. Hazel [38] also discusses that researchers could dress informally and try to refer to popular culture when discussing with the children.

Alper et al. [17] discusses in their article about how to design for children with special needs and emphasize four important aspects to reflect upon throughout the design process. They are *deep engagement*, to understand which needs are special for this target group; *interdisciplinarity*, where designers need to extract knowledge from several domains that are related to children with special needs (for example special education); *individuality*, where the technology to-be-used need to address individual rather than general needs and preferences within this target group; and *practicality*, where designers need to consider other artifacts that might be used along with the technology, and hence might impact the use.

3.2.3.1 Specific considerations when involving adolescents

Talking more in particular about considerations for adolescent-focused research, there are some specific aspects to bare in mind when involving them in research processes. Poole and Peyton mentions that adolescents can be temperamental about their involvement in research [56]. This meaning that they might drop out of a research project or just not actively participate when it is ongoing, even though the potential benefits are high for them or they were excited at the beginning of the study. Mack et al. states that it might be even harder to make adolescents participate if they have a chronic illness or other special needs [49]. They say that adolescents might even reject to participate if the research title reminds them of their illness and how they are “different” from other children. Therefore, as Poole and Peyton says [56], one needs to present the study in a thoughtful way so it can be accepted by adolescents.

3.3 Design guidelines for graphical user interfaces

When designing graphical user interfaces, there are numerous of design guidelines to help designers create adequate designs. Many of these also applies when designing for children, though sometimes, the recommendations vary. As children are a developing user group with differing needs and desires between young children and adolescents, the guidelines also differs between those age groups [44]. This section will discuss the general design recommendations when designing graphical user interfaces for children, websites and mobile applications as well as for for technology acceptance and adherence, and in which ways they differ from design recommendations for adults.

3.3.1 Designing web and app interfaces

When it comes to the design of web and app interfaces for children, Sherwin and Nielsen [60] argues that designers should stick to the general user interface conventions and recommendations about simplification of designs, that is being used when designing for adult audiences. Since some guidelines are specific for the design of interfaces intended for young children, and some for adolescents, they will be discussed separately below.

3.3.1.1 Age 3-12

In the age group 3-12, the guidelines presented by Budiu and Nielsen [25] as well as by Sherwin and Nielsen [60], whose work builds on Budiu and Nielsen's, relate to topics such as navigation, literacy, sizing, type of content and the use of images, animations and sound effects. Some of the recommendations when designing for this age group, that differs greatly from those for adults, include the use of real-life metaphors such as spatial navigation, animations and sound effects.

3.3.1.2 Age 13-18

For the age group 13-18, Joyce and Nielsen [44] present guidelines that in some ways are more alike the recommendations used for adults, and in some more alike the guidelines used for younger children. For example, they argue that some adolescents appreciate the use of animations and sound effects, as long as it they are used to a limited extent. Additionally, they prefer not being required to read loads of text. Furthermore, the adolescent guidelines that are more similar to the adult ones include ways of accessing more information, such as through scrolling. Moreover, there are guidelines that seem to be of more importance for adolescents than for adults and young children, because opposing them seem to have more negative consequences on how they view a design than on the other two user groups. For example, adolescents prefer information to be presented in smaller chunks to avoid distraction. Designers should also think about using an age-appropriate wording (preferably more simple than advanced), as well as to balance the amount of interactive and static content.

3.3.2 Designing for acceptance and adherence of technology

There are different strategies today that aims to tackle non-adherence of technology. *The Persuasive Systems Design Model* (PSD model) by Oinas-Kukkonen and Harjumaa [54] is one of them, and Gemert-Pijnen et al. [68] states that it is an important model for increasing engagement and adherence of technologies that has the aim to change behaviors. They also mention that the PSD model provides a framework to help decide what kind of persuasive features could be added to an eHealth technology. Oinas-Kukkonen and Harjumaa presents four different categories of persuasive system principles, thereby Primary task, Dialogue, System credibility and Social support [54]. Within each category, design principles are presented together with examples of requirements and implementation.

Another strategy for acceptance and adherence is described by Ludden et al. in their article [48]. They discuss three design approaches, namely Personalization, to use Ambient information and to use Metaphors.

When designing for acceptance and adherence, it could also be of value to keep users' goal of visiting a website or application in mind. Young children typically visit websites and apps for entertainment [60], whereas adolescents' approach is more goal-oriented, even if it sometimes include being entertained as well [44].

3.4 Summary

In summary, many changes occurs in children's physical, cognitive, social and emotional abilities as they age. This in turn needs to be taken into consideration when designing technologies for children, as well as a few other considerations related to them being involved in design processes. There are also many design guidelines available for designing technologies for children, where the work by Sherwin and Nielsen is one example. To make children accept a technology and continue using it, there are also certain strategies one could use as a designer, such as the Persuasive System Design model. Depending on the design approach, children can also be chosen to be involved in a design process in four different ways, thereby as users, testers, informants or design partners.

4

Methodology

This chapter aims to give an introduction to the design approach used in this project, as well as to describe all scientific methods that were considered. A short description of possible advantages and disadvantages for using a method in this project is also provided per each method. The methods are divided into two categories, which are "Methods aimed for children" and "Other relevant methods". The methods are also separated into two subcategories, which are methods for ideation and methods for evaluation and iteration. Worth mentioning is that the methods placed in the section with "methods aimed for children" contains all methods that might be suitable for designing with children. The section therefore also includes some methods that could be used with adults as well.

4.1 Design approach

Due to the fact that the aim of this project is to explore and create a first design proposal of a digital tool, the design process will not include any summative evaluations. Instead, focus will lie on methods for ideation, prototyping, iteration and formative evaluation. Since the project addresses a wicked problem, which is often the case in design research [35], the aim is also to use methods that can help create theories of *what might be* a good design rather that *what is* a good design, as described by Zimmerman and cited by Gaver [35].

Rittel and Webber (cited in Gaver [35]) describes wicked problems as complex problems that are not pre-defined, and therefore, there are no pre-defined or "correct" answers or solutions. The Interaction Design Foundation [8] argues that these types of problems, that are complex and ill-defined, benefits from using the lifecycle model *Design Thinking.* There has, however, been earlier proposed lifecycle models within the closely related field of software development, one of them being The Waterfall model. Markopoulos, Read, MacFarlane and Hoysniemi [50] writes that this model presents a process that is divided into a distinct set of steps, where each step is completed before proceeding to the next. The process also proceed forward towards the next step and does not revisit already completed steps. The Design Thinking life cycle model on the other hand, as described by the Interaction Design Foundation [8], is iterative, meaning that the different stages are revisited as new insights about the problem to-be-solved arises. They also argue that there are different views on which stages the model should contain, but the version presented by the Interaction Design Foundation consists of the following five stages: *Emphasise, Define, Ideation,* *Prototyping* and *Test*. This model is based on a proposition from the Hasso-Plattner Institute of Design at Stanford, which The Interaction Design Foundation mention is one of the most successful universities when it comes to teaching about design thinking. The five stages and how they relate to each other are shown in Figure 4:1.

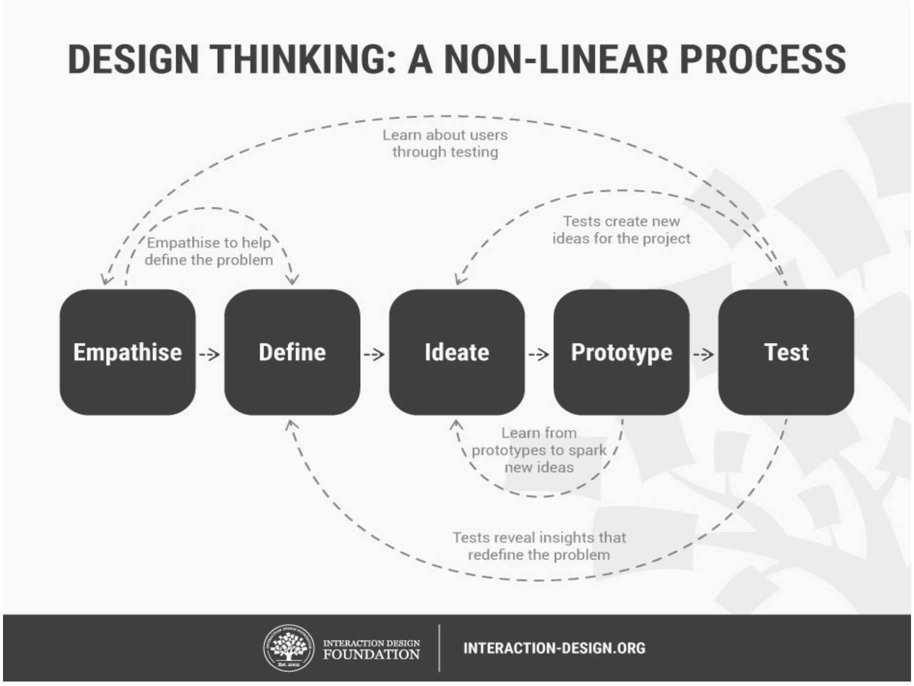


Figure 4.1: The five stages of the Design Thinking life cycle model, as described by the Interaction Design Foundation [8].

4.1.1 Design thinking process

The Interaction Design Foundation [8] describes the *Emphasise*-phase as the stage where the design team try to understand a given problem. Putting their own assumptions and prejudices aside, they try to understand the potential future users of an interactive technology and the context where it will be used. By immersing themselves in the physical environment where these people act, and investigating their thoughts, feelings and behavior, design partners can get an understanding of the needs and desires among users. The *Define*-phase is where the design team put together and analyze the information gathered in the Emphasize-stage, to find potential patterns and trends among user needs and behaviors. The findings are then used to define the problem space, which serves as a base for all decision making throughout the design process. In the next stage, the *Ideation-phase*, the design team try to come up with innovative ideas on how the identified problem could be solved. By evaluating how well the ideas meet user needs and desires, one or more ideas can be selected for further investigation in the upcoming stages. The next stage is the *Prototyping*-phase, where each idea is actualized into one or more simple versions of the final idea, in the form of low- and medium fidelity prototypes. People in and/or outside the design team can test and provide feedback on the prototypes, which is used to inform design choices for upcoming prototypes. The fifth and final stage is the *Test*-phase, where a more high-fidelity prototype is tested and evaluated by the user group. Since the design thinking process is iterative, this stage often take design teams back to one of the previous stages, depending on the findings made.

4.2 Scientific methods

In this section, the scientific methods that were considered to be used in the project are discussed.

4.2.1 Methods aimed for children

4.2.1.1 Problem definition and ideation methods

Observation
The method, in which researchers observe children and adults, is a common and practical method to use when working with children [40]. A good reason for using the method in this project is because children in young ages sometimes can have difficulties in describing verbally what a technology designed for them needs [31]. On a more negative note, Hanington et al. mentions the importance of not falling into the trap of only trying to find “what you are looking for” during observations [37].

Interviews
There are a a lot of different types of interview techniques today that have been used for gathering both qualitative and quantitative data from children, as described by Hourcade [40]. Mack et al. [49] discusses in his article, about interview techniques with adolescents, that depending on a child’s developmental level and level of nervousness, one might need to rephrase interview questions several times to make them more understandable. The opinion, of the authors of this report, is that it could possibly be both a negative and a positive aspect for using interviewing as a method. It is negative since it might require a lot of time and effort to ask appropriate-leveled-questions to children. At the same time, the fact that one can rephrase and tailor questions during an interview is also a very positive matter, which makes it a useful method for this project that aims to design for different children in different ages.

Mission from Mars
The Mission from Mars method is a method for requirements gathering and brainstorming [40]. The method, which is created by Dindler et al. [29], leads children to believe that they are talking to a martian that wants to learn about their lives. An advantage of the method, described by the creators, is firstly that it is a playful method for both children and designers. Secondly, due to the shared narrative space, the method also makes it possible to ask questions that might be weird to ask in a more normal setting. The opinion of the authors of this report is therefore that the method could be useful in this project to spark interesting ideas and thoughts

from the children during the early phase of the design process. The creators of the method however mentions that a possible negative aspect is that it has only been tested to work with children in a limited age span, around the age of 10. This fact, and that it seems to require quite some time to perform, are negative aspects that needs to be out-weight by positive ones, for the method to be used in this project.

Child-persona technique
In the Child-persona technique, designers create “fictional children” whom they can reference to in the design process [33]. Fails et al. further describes that the method is a good supplement in design research when there is no possibility to involve real children in the design process. Antle [18] describes in her article that, even though it might be better to use personas than no child-involvement at all, there is still a risk that the designers create an incorrect conceptualization of how the child-user will really be. The decision, on whether the method should be used in this project or not, is then mostly dependent on how many children that can be involved in the design process.

KidsReporter
The KidsReporter method is also a method for requirements gathering and brainstorming [40]. In this method, the children themselves gather information by playing the role as a journalist [29]. The creators of the method, thereby Bekker et al. [22], mentions that a possible disadvantage of the method might be that it requires a lot of planning. Although, they do mention that this is outweighed by the benefits of the method. The benefits, which Bekker et al. mentions, are that it is appealing and fun for children and that it combines many techniques for retrieving information. For this project, the time available for requirement gathering and ideation with children will help decide how suitable this method is.

Bags of Stuff
Bag of Stuff, also called *low-tech prototyping*, is a brainstorming method with a primary goal of creating many ideas and possible solutions [33]. Fails et al. further describes that the method includes providing children and adults with bags of low-tech art-supplies, which they should use to brainstorm solutions to a specific problem. Further on, he mentions that within Cooperative inquiry, the method has mostly been used with children in the ages of 7 to 11. Regarding the use of the method in this project, the opinion of the authors is that, time available for both picking out creative material and performing the method will decide if it will be used.

Comicboarding
Comicboarding is a version of Storyboarding [37] that is created for children aged 6 to 13 who might need support when brainstorming, Moraveji argues [51]. Moraveji further describes that it is a participatory design method that uses comic books that are specially created to spark engaging brainstorming sessions. The time available to create comicboards in this project, will decide whether the method will be used.

Mixing ideas
The Mixing ideas technique is a method used for merging individual brainstorming ideas and solutions into bigger, collaborative ones [36]. The method also aims to support younger children that might need more support when ideating and combining ideas [33]. The availability of several children and parents to participate at the same time will determine if the method can be used in this project.
Focus groups
Focus groups as a method is valuable for gathering views and experiences of children and adults, according to Morgan et al. [52]. Furthermore, they state that it is a great complementary to interviews. When conducting focus groups, there are a few things that need to be taken into consideration, such as location, environment and group composition [33]. As with the Mixing Ideas method, the availability of several children and parents to participate at the same time will determine if focus groups can be used in this project.

4.2.1.2 Iteration and evaluation methods

Layered Elaboration
Layered Elaboration, created by Walsh et al. [69], is a brainstorming and iteration method that is suitable to use when designing screen-based prototypes, when combining different ideas and when time and space are limited [33]. Fails et al. continues to describe that the technique involves placing a see-through paper on top of a design, where a new iteration can be made without ruining the previous design. Several groups can then iterate on the same design. Fails et al. also mentions that this method evolved from the observation that children don't usually like to "ruin" other peoples designs. Due to the fact that this method is to be used with several children and parents, the availability of participants to participate at the same time will determine if the method can be used. Further on, one might consider tweaking the method into only letting one pair of children-caregiver perform the method at a time.

Sticky notes critiquing technique
The method is an evaluation method that is a part of Cooperative inquiry, where children and adults together critique a technology or prototype [33]. The aim of the method, as described by Fails et al., is to get feedback for improvements of the prototype. The method can also be adapted for children in several ages, from young children in the ages of 4 to 6, to adolescents [34]. A possible disadvantage of the method, expressed by the authors, is that it might be too easy for children to just copy what their parents say. This then needs to be considered when performing the method.

Contextual inquiry
Contextual inquiry is a method that involves both observing and interviewing children and adults while they perform certain tasks with a technology, in their natural context [40]. The one being observed and the observer can also switch roles. The method is used to identify positive and negative aspects of a technology as well as

suggestions of improvements [40]. The positive and negative aspects of this technology can be said to be approximately the same as for observation and interviews as separate methods, with the addition that it will require more time perform this method. This will have to be considered when selecting methods for this project.

Fun toolkit and the This-or-that method
The Fun toolkit is a method for iteration and evaluation, made by Read et al. [57], to measure the level of fun with children aged between 5 to 10. The tools described by the creators, include the Smileyometer, the Fun-sorter and the AgainAgain table. Shortly, they mention that the Smileyometer is a likert scale to measure how fun something was, the Fun-sorter involves comparing/sorting what was most fun and AgainAgain involves stating if they would like to use the product again. The creators mention that this method has been proven to be easy to use by children, but more research could be needed to compare the method to more traditional metrics. This will have to be taken into consideration when deciding if the method should be used in this project.

The *This-or-that method* is an iteration and evaluation method that also derives from the idea to ask children to do pairwise comparisons [33]. Sim and Horton [61] has compared this method with the Fun toolkit method when tested with children in the ages of 7 and 8. Sim and Horton further describes in their article that the main advantage of the This-or-that method is that is requires little cognitive load, but that the Fun toolkit offers more flexibility in its answers. Regarding the possible usage of the methods in this project, the opinion of the authors of this report is that it depends on how it could be adapted to fit children in the ages between 10-18. Furthermore, these methods would probably be used together with some other methods, such as interviews.

Usability testing with Think aloud-protocol
Usability testing is, according to Hourcade [40], an evaluation method that involves asking participants to complete a set of tasks with a technology that are representative of how the technology is to be used. If possible, Hourcade also mentions, it could be combined with letting the participants Think-out-loud. This could enable the researchers to gain useful information of the thought processes of the participants. Hourcade also mentions that there has been different discussions regarding if children should participate alone or together with other children. Further on, the usability test often ends with a questionnaire or an interview. A possible negative aspect of using the method in this project is due to the fact that younger children may have a hard time expressing what they think verbally [31]. This will have to be taken into consideration when deciding if the method should be used in this project.

Picture cards method
The picture cards method is, according to Barendregt and Bekker [20], a data gathering method where children use physical picture cards as support when expressing usability issues of a design. The method can be used when children have a hard time expressing their thoughts verbally, as well as to remind children of what type

of feedback the facilitator is looking for. The authors thoughts about a potential negative effect of using this method, which is partly discussed by Barendregt and Bekker as well, is the potential risk of children associating what the pictures represent differently than intended.

4.2.2 Other relevant methods

4.2.2.1 Problem definition and ideation methods

Literature review
Literature review is a method used to extract information from previous credible and published research or projects, that are relevant to lay a foundation and context to the current project [37]. The method is an integral part when writing academic papers, which makes it an important method to use in this project. The opinions of the authors are that Literature review is an effective and inexpensive method but that one needs to be careful of what to embrace from previous research. This since previous research may not always fit the current project or target group perfectly.

Competitive assessment
Competitive assessment is a method for investigating how existing technologies, which accomplish similar goals as the current project, comply with the requirements set by the design team [40]. Hourcade [40] decribes that the method can gather insights into what current technologies do to fulfill or not fulfill certain requirement and if there are any requirements that might be missing. The opinion of the authors are that while this method might help notice requirements that are missing, attention should also be taken to not gather requirements that might be unnecessary for this project's stakeholders.

Kano analysis
Kano Analysis is a method for eliciting requirements and product attributes, that are most important to ensure user satisfaction [37]. The method sprung from the fact that the “more is better”-approach is ineffective. Regarding the usage of the method in this project, it might not be the most suitable method to use with young children even though it can be an effective method to use with adults. This is due to the fact that many questions are quite hypothetical. If the method was to be used, one would need to tweak the method to become more suitable for children.

Crazy eights
Crazy eights is a method for ideation with the aim to create creative suggestions and ideas by quickly sketching eight different ideas on paper, in eight minutes [21]. Further on, Bavendiek et al. [21] mentions that the ideas are briefly presented and discussed in groups. The opinion of the authors is that the method works well by “forcing” people to write down creative ideas which they might otherwise have scrapped. A negative aspect might be that a lot of unusable ideas, that are a bit too creative, might appear during this type of ideation.

Method 635

The method made by Rohrbach and cited by Petersson et al. in [55], is an ideation method used to gather creative ideas from participants. Further on, the idea is that six participants write three ideas on a paper and pass it to a neighbor. After that, as Petersson et al. continues to decribe, the neighbor contributes three ideas and developments before it is passed to the next neighbor etc. A positive aspect for using the method in this project is due to the fact that one design participant can be inspired by the other participants. Another opinion of the authors is that the method might be more difficult for participants who do not prefer expressing themselves through writing.

Content analysis
Content analysis is a method for systematically describing qualitative data findings, in form of themes, patterns and counted occurrences, as Hanington and Martin describes [37]. Further on, Hanington and Martin mentions that a content analysis can be either inductive, where the codes are established during the analysis, or deductive, where the codes are established prior to analysis. A possible negative aspect, expressed by the authors, can be that content analysis might show misleading results if the amount of participants are too low or if they happen to be a bad representation of the target group.

4.2.2.2 Iteration and evaluation methods

Card Sorting
Hanington and Martin [37] say that Card Sorting is a participatory design technique that is usually used to let users evaluate categories, help organize content or identify terminology that might be hard to understand. Moreover, during Card Sorting, participants are provided cards with for example concepts or features on them, which they are asked to sort in different ways. Regarding the usage of the method in this project, it might be a quite time consuming method to use since one might probably need to make several sets of cards, adjusted to different age levels.

Parallel prototyping
The method Parallel prototyping, described by Hanington and Martin [37], is a prototyping and evaluation method for investigating and testing several design ideas simultaneously. Further on, they describe that the idea of the method is to prevent designers from fixating with designs and instead explore a wider range of options. Although, a negative aspects, in the opinion of the authors, might be that it requires more time to make several parallel prototypes instead of one.

Questionnaires
As Hanington and Marting[37] describe, Questionnaires are used to collect information from participants such as thoughts, behaviours and feelings. Further on, he also mentions that the method is often used together with another method, such as observation, but that i can also be used in isolation. A positive aspect of using questionnaires, he mentions, is that they are usually quite easy to make and administer. A negative aspect, on the other hand, is that one has to be careful when phrasing questions, choosing response options and making the design etc. since it will affect

the result and analysis. These aspects need to be considered when deciding if the method should be used in this project.

Scenario
Scenario is a method in which designers describe a believable narrative to a user from a user's point of view, Hanington and Martin describes [37]. He also mentions that the aim of the method is to concretize ideas so that designers can investigate the future usage of a product. The opinion of the authors of this report is that this could be a good method to use together with the Usability testing method. A possible negative aspect to bare in mind, is that the scenarios need to be made very simple and concrete to enable young children to understand them.

Expert reviews
Hourcade describes that Expert Review is an informal evaluation method which involves letting experts identify problems with an interface instead of the actual users [40]. As Hourcade continues to describe, the evaluation is usually performed by comparing the interface to a set of heuristics. He also mentions that this could be a great method to use when real users, such as children, are not available for evaluation. Although, as expressed by the authors of this report, one should still bare in mind that the results/feedback given might not cover everything that a real user could have identified as problems.

Wizard of Oz
When using this method, as described by Hanington and Martin [37], participants are led to believe that they are interacting with a fully working product while it is actually "faked" by a hidden researcher, the "wizard". Hanington and Martin continues to describe that the aim of the method is to enable designers to iteratively test their product ideas before a more costly higher-fidelity prototype is made. A possible negative aspect, expressed by the authors of this report, is that some prototype features might be more difficult to fake than others. Therefore, the decision to use this method could depend on how the prototype is created.

5

Planning

In this section of the report, the time plan of the project will be presented. Both a short description of what activities are to be included in the process, as well as expected execution time for the activities, will be presented.

The project, which is a 30 credit master thesis project, is expected to take about 20 weeks to complete. The aim for this project is to perform it within 19 weeks but to work extra days and hours to manage the same amount of work expected. The time plan and activities to be performed are presented in table 5.1.

5.1 Changes in the original time plan

During the project, a few things appeared that affected the time plan. The changes made to the time plan was to make more time for both the creation of the medium fidelity prototype and the planning of its evaluation, i.e. one week instead. Less time was then given to the analysis of the medium fidelity prototype as well as the improvement of the high fidelity design.

Week	Description of process
1-5 *(5w)*	* Literature study and writing of the planning report * Learning about research design with children through literature research and a meeting with a researcher in the field * Meetings with the stakeholders at the hospital for requirements gathering * Initial categorization of requirements * Find and preliminary book participants for future prototype evaluations
6 *(1w)*	* Planning and performing interviews of the main end users (gathering thoughts of the project idea and its initial requirements) * Participate in a doctor's appointment at the children's Department of Neurology
7-8 *(2w)*	* Analysis of interviews * Ideation session based on interview analysis. * Creation of medium-fidelity prototype (wireframes). * Planning of usability test 1
9 *(1w)*	* Performing usability test 1 (medium-fidelity prototype) with target groups.
10-12 *(3w)*	* Analysis of results from usability test 1. * Improvement of design into a high fidelity prototype.
13-15 *(3w)*	* Planning of usability test 2 * Performing usability test 2 (high fidelity prototype). * Analysis of results from usability test 2.
16-19 *(4w)*	* Writing the final parts of the report and prepare for oral presentation

Table 5.1: A table displaying the planned process and time plan of the project.

6

Process

This chapter describes the execution of this project, from background research, requirements elicitation, ideation, prototyping, evaluation to analysis of the results. Furthermore, the way design decisions and scientific methods were applied throughout the project will also be discussed.

6.1 Background research

As this project was initiated, a background research was conducted to gain knowledge about the problem area and its related fields. The background research included literature reviews of research within fields such as long-term neurological diseases, eHealth technologies, children's web habits, children's participation in decision making and related work. The literature review was used to lay the foundation for the project as well as the introduction-, background-, theory- and methodology chapter of this report.

6.1.1 Designing with children

Since this project is about designing an adaptable eHealth technology for children with long-term illnesses, there was a specific need to gain as much knowledge as possible about children in general, as well as how to design interactive technologies for and with children. This was done mainly by focusing the literature review on research with children specifically, which apart from the above mentioned research fields also included child development, design guidelines when designing for children, research methods specifically aimed for children, and different ways of involving children in a design process. Furthermore, there was a need to get better insights on the specific considerations to take when working with children with special needs. Therefore, an informal interview was conducted with a PhD student from the Interaction Design division and Department of Computer Science and Engineering at Chalmers University of Technology, who has experience from designing and teaching about designing for this user group.

6.2 Requirement elicitation from stakeholders

Simultaneously with the background research, the requirements of this project were elicited. This was done both through an informal interview with the project initiators at the Children's Department of Neurology (CN) and the Play Therapy, and through semi-structured interviews with patients and their caregivers. Both types of interviews and their result will be discussed in more detail in the sections below.

6.2.1 Interview with project initiators

This project was first initiated by a nurse and a play therapist, at the CN and the Play Therapy at Queen Silvia's Children's Hospital in Gothenburg, who contacted the Centre of Digital Health (CDH) at Sahlgrenska University Hospital, to find suitable candidates to carry out the project. The project description and its initial requirements were first described in an email conversation between the project initiators and the CDH, which was shared with the authors in the beginning of the project. From this email conversation, the requirements were extracted and sorted into a list describing how the end users (patients, with occasional support from their caregivers, and nursing staff) would interact with the digital tool to-be-designed, that was later to be called "Hälsokollen". What other features and functionality Hälsokollen should offer was also listed. The user interactions were also divided into two categories, namely what users should be able to do respectively view in Hälsokollen. The full list of initial requirements can be found below.

What users should be able to do:

- **Describe oneself.** Who I am, what I like/dislike, my idols etc, by building my own avatar and answering frequently asked questions about me, my diagnosis and my treatment.
- **Describe one's everyday life.** What I do on a daily basis.
- **Describe one's diagnosis.** What diagnosis/symptoms I have, why I have it, how it affects me and what things I should keep in mind.
- **Express one's wishes related to doctor's appointments routines.** How I wish to be communicated to and treated by nursing staff, how I wish medical procedures to be carried out etc.
- **Express one's questions** related to the diagnosis and/or treatment.
- **Edit/update** previous entered information.
- **Access games or websites** where I can learn more about things related to my diagnosis.

What users should be able to view:

- **Information about my medication.** What medication I take, why I take it and how it affects my body.
- **Information about my hospital departments.** What departments I usually visit, which nursing staff I usually meet, what their contact information is etc.
- **View** previous entered information.

Additional requirements:

- **Hälsokollen should be designed so that all children in the target group can use it**, regardless of diagnosis/cognitive abilities, age and individual preferences. In more detail, it should allow children to express and interpret information in different ways, by allowing them to read/write, speak/listen and draw/view images and drawings conveying different information.

- **Hälsokollen should be web-based** and designed to be used on computers, tablets or smartphones.

During the interview with the project initiators, the project's background, requirements, execution and aim was discussed and validated. Some basic characteristics of the end users were also introduced, such as that the patients being treated at the CN are between 0-18 years old, that they usually have doctor's appointments 1-4 times per year, and that common diagnoses are epilepsy and diseases that cause cognitive difficulties. Moreover, the currently used communication strategies used by nursing staff and patients/caregivers during doctor's appointments were described as being mainly verbal, in some cases supported by a book called "delaktighetsboken" ("the book of participation"). The book was explained as a physical communication tool that could help patients express their thoughts and feelings related to their diagnosis and/or treatment in a non-verbal way, hence creating a greater opportunity for children to actively participate in their own health care. Since the book had been used by a limited number of patients, the project initiators' vision was that Hälsokollen would be a digital version of the book, serving the same purpose but with an expanded functionality, to be used continuously and by a wider group of patients. Furthermore, considering that the time for the project was limited, it was discussed what type of device Hälsokollen would be designed for, i.e. computer, tablet or smart phone. It was decided to focus either on designing a tablet interface or a smart phone interface, since these devices were said to be more commonly used by the patients at the CN.

Moreover, it was discussed how Hälsokollen could be designed so that all patients can use it, regardless of diagnosis/cognitive abilities, age and individual differences. It was considered too big of a challenge to base design decisions on usability guidelines both for children with typically and atypically developed cognition. Therefore, it was decided to create a design prototype from guidelines for children with typically developed cognition alone, because of the authors limited knowledge of cognitive abnormalities in children and its corresponding usability guidelines. Furthermore, it was also decided to focus on designing for children above 5 years of age. Therefore, it was agreed to design the interface in three different versions of varying complexity, where Version 1 could be based on guidelines for children between 5-8, Version 2 on guidelines for children between 9-12 and Version 3 on usability guidelines for children between 13-18. However, it was of importance to balance complexity and maturity in each version so that none of the versions were perceived as too childish or too mature, since all versions might be used by all ages depending on the user's cognitive ability and/or individual preferences. One solution to this that came up was to separate content from look and feel, so that information could be easily explained without being childish. This way, users could still select the version that best meet his/her needs, regardless of their legal age. The interface would also allow the user to change version whenever wanted or needed, for example as the user develops or wants to learn more about his/her diagnosis and treatment. Hence, it was still to be determined exactly how the look and feel of each version could be designed to fit those different needs.

6.2.2 Interviews with patients and caregivers

In this section, the interviews performed with patients at the Children's Department of Neurology (CN) will be presented. Thereby a presentation of the aim of the interviews, of the preparations made before the interviews, of the people that participated, of how the interviews were performed and of the results.

6.2.2.1 Aim of the interviews

Firstly, the aim was to learn more about the patients' communication habits with their nursing staff. More specifically, to learn how they communicate with their nursing staff today and what they think works better or worse with that way of communication. Moreover, also whether the participants had any suggestions of improvements themselves. A second aim of the interviews was to hear the patients' and caregivers' opinions of the potential digital tool that this project suggests. Questions were therefore asked about whether there is a need of such a product and what components the product should contain. The purpose of this was to get insights on whether there was room for improvement in the communication habits used today, and ultimately, how the project would proceed.

6.2.2.2 Preparations

Before the interviews were performed, a few preparations were done. Firstly an information poster was created and put up at the CN and secondly a physical artifact was created as a help tool to be used during the interviews.

Information posters
To spread information about this project at the CN, where patients were to be asked to participate in interviews and evaluations throughout the project, an information poster was created and put up. The poster contained information about the project and that it is a collaboration between the CN the Play Therapy, the CDH and Chalmers University of Technology. Moreover, contact information of the two project initiators, at the CN and the Play Therapy, was provided. The poster also contained a picture and information about the two authors of this project.

Sticky note sketches
To allow the participants to more easily understand and discuss the product idea, sketches on sticky notes were created by the authors to be used during the interviews. The point of the sketches was to help make the project description less abstract, which might otherwise make it difficult to discuss, especially for younger children.

The sketches, that can be seen in Figure 6.1, consist of two pieces of paper with 10 sticky notes. Further on, a piece of paper with a picture of a tablet on it was also included. In Figure 6.2, one can see an example of five sticky notes/components that one participant choose as their favourites.

On the sticky notes, the 6 possible components, suggested to be included in the product by the project initiators, were drawn with both text and an image. Thereby the components: This is Me (det här är jag), My history (min historia), My Diagnosis (min diagnos), My Medicines (mina mediciner), My questions to the doctor (mina frågor till doktorn), My nurses and doctors (mina sjuksköterskor och doktorer) and Games to learn (Spel för att lära sig). The three green sticky notes to the right represent three different ways of entering information into the product. Either by writing (skriva), drawing (rita) or talking (prata). During the interview, the artifact was placed in front of the participant who was also encouraged to look and move around the stickers while answering the questions.

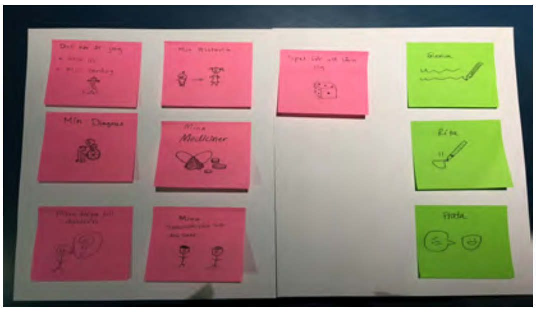


Figure 6.1: The sticky note sketches that were used during interviews.

Figure 6.2: An example picture of components that one user chose as their favourites.

6.2.2.3 Participants and environment

Both the recruiting of participants as well as the interviews were performed at the CN, during the time span of two days. The interviews were performed in a private and quiet examination room and as a compensation for participation, the participants were given chocolate after their interview. Patients who had come to the department for an appointment were asked to participate in the interview by one of the project initiators, who is also one of their nurses who knows them well. Since some of the patients at the department also have cognitive disabilities, which the authors have no expertise about, the project initiator also made a heuristic assessment of those patients' "experienced age". This assessment was based on the children's developmental levels, thereby their ability to read, talk and understand conversations and problems for example. This information was later to be used to inform the design decisions for the three interface versions.

In total, 11 groups of participants agreed to participate in the interviews. Out of these groups, six of them contained children in the target age of 5 to 18 years of age and five of them were groups of parents with children younger than 5 years of age. The age span of the six children in the target age were between 7 to 16 years of age.

Three children were in the age span between 5 to 8 years of age and three children were in the age span between 13-18 years of age. Two of the children that were categorized in the lower age group were children with cognitive disabilities that had an experienced age within that age span. The sex distribution was equal between the child-participants, and none of the participants were known by the facilitators personally.

6.2.2.4 Interview procedure

Firstly, a brief introduction of the project was made, in which a consent form was handed out for the participants to sign (see Appendix A). The participants were provided a copy of the consent form to take home with them, which included contact information for the two authors. On the backside of the consent form, a few demographic questions were asked, including the child's name, age, gender and diagnosis.

After the consent form was signed and the audio recording had started, the interview began. All questions asked during the interview can be seen in Appendix B. All interview questions were adapted to fit both children with a legal or experienced age of around 5 to 8 years, as well as children with a legal or experienced age around 9 to 18 years. To do this, two different versions of the interview questions were made. The version for the 5-8 group had more simple follow up questions, in case the child did not seem to understand the question or know what to answer. If some questions seemed easy enough and straightforward, the same questions were asked for all ages. During the interviews, two types of physical artifacts were shown to the participants - three "books of participation" borrowed from the department, and the sticky note sketches that was previously described.

After the interviews were finished, the findings were sorted and analysed through a content analysis, to later be summarized per interview question and age group. Lastly, an overall summary of the interview results was made.

6.2.2.5 Interview results

In this section a summary of all the findings will be presented, one question at a time. A more comprehensive summary, per interview question and age group, can be found in Appendix C.

How often do the patients at the Children's Department of Neurology have doctor's appointments?
Most of the groups of participants that participated in the interview reported having doctor's appointments at the CN a few times per year.
Take from this: The frequency of use of Hälsokollen would probably be limited to a few times per year or month.

How do the patients communicate with their nursing staff today?
The majority of groups said that they mainly communicate with their nursing staff

verbally, without the support of any tools. The majority had never heard about or seen a “book of participation” either.
Take from this: Since most participants do not use any tools today, there might be room for a tool like Hälsokollen to be integrated in their communication with nursing staff. But it could also be the opposite, that patients does not want to use any additional tools in their communication.

What do patients think works well with their way of communicating with their nursing staff today?
Groups of participants in all age groups said that they thought it was easy to communicate with their nursing staff verbally, and many praised their nursing staff’s ability to communicate with and listen to the child as patient.
Take from this: There are aspects of the communication that the participants value and that should be retained in the case of an implementation of Hälsokollen.

What might patients think works less well with their way of communicating with their nursing staff today?
Only two groups of participants received the question about whether there was anything that worked less well with their way of communicating with their nursing staff, who belonged to the age group 5-8. One response was that it could be troublesome remembering and interpreting information that is told verbally, while another response said that nursing staff’s communication style sometimes was a bit old fashioned by using physical toys rather than tablets and digital games that children are more used to play with today.
Take from this: There are aspects of the communication that potentially could be helped from an implementation of Hälsokollen.

What are the patients’ thoughts about the “book of participation” and the use of such communication supporting tools?
Generally, all groups of participants, regardless of age group, were positive towards the idea of the “ book of participation”. In all age groups except for the 9-12 group, there were groups of participants that either thought the book could be useful for them personally, or for other patients at the department that might have special needs. In the same age groups, there were groups of participants saying that they liked features that would help them prepare themselves for doctor’s appointments, such as being able to include pictures or write down questions they wanted to discuss when meeting their doctor. In the age group 9-12, the book was said to be especially useful for children that have trouble expressing themselves verbally, are shy or tired of repeating information when being introduced to new nursing staff. This was also mentioned by a participant in the age group 13-18. There were also two groups of participants, one from the age group 5-8 and one from the parents’ input group, that said that they would like to have a digital solution, before hearing about Hälsokollen.
Take from this: The participants generally seem to have a positive attitude towards having access to or using a tool that could help them in their communication.

What are the general perceptions and opinions of Hälsokollen?
The general opinion of Hälsokollen was positive within all groups of participants, regardless of age group. Some of the opinions that came up within the age group 5 to 8 were that Hälsokollen could help support your memory, help children that are not very talkative and help empower children to ask their own questions. The group of participants in the age group 9 to 12 mentioned that they valued a digital tool higher than a physical tool, since it can be more easily adjusted as the child ages. Some opinions gathered from the age group 13-18 were that it would be more efficient in situations when meeting new nursing staff and that it could be good for patients with different impairments. One group of participants mentioned that it was a bit unclear what the drawing- and games features was in Hälsokollen. Parents of younger children mentioned, among other things, that Hälsokollen could be calming for parents during critical events.
Take from this: The participants generally seem to have a positive attitude towards having access to or using Hälsokollen, which aside from helping them in their communication also could support their memory, be adaptable and calming in difficult situations.

Is there a need for a digital tool, like Hälsokollen?
On the question whether there is a need for a digital tool like Hälsokollen, groups of participants in all age groups had positive responses. Two groups (one from age group 5-8 and one from parents' input) especially mentioned that they would prefer their child to use a digital tool before a physical. In all age groups, groups said that they thought such a digital tool could help them improve the communication with their nursing staff as well as help patients understand their diagnosis better. Only one group said that they currently did not have a need for a digital tool like Hälsokollen, due to their child's varying cognitive difficulties.
Take from this: The participants generally seem to have a positive attitude towards having access to or using a tool that is digital rather than physical, that could help them in their communication and understanding of their diagnosis.

Which of the features presented are wanted or considered most important to include in Hälsokollen?

- **All features:** All features were perceived as equally important by at least one group of participants per age group. It was mentioned by a total of 6 groups of participants.
- **Questions:** Writing down questions to ask your nursing staff was perceived as specifically important by all age groups, mentioned by a total of 7 groups of participants
- **Games:** Playing games to learn more about your diagnosis was perceived as specifically important by a all age groups, mentioned by a total of 6 groups of participants
- **Medicines:** To be able to see your medicines was considered specifically important by all age groups, except for the age group of 9 to 12-year-olds. A total of 5 groups of participants mentioned this
- **Diagnosis:** To be able to read and learn about your own diagnosis was con-

sidered specifically important by all age groups, except for the age group of 9 to 12-year-olds. A total of 4 groups of participants mentioned this
- **My page:** To have a page where patients can write about themselves, their thoughts and feelings related to their illness and treatment was perceived as specifically important by the age groups 5-8 and 13-18, where a total of 3 groups of participants mentioned this
- **My history:** To be able to view your history of things entered in Hälsokollen was perceived as specifically important by the age group 5-8, where a total of 1 group of participants mentioned this specifically
- **My nursing staff:** To have all your main doctors and nurses gathered in the same place was perceived as specifically important by the age group 13-18 and by caregivers alone, mentioned by a total of 3 groups of participants

Which of the features presented are unwanted or considered less important to include in Hälsokollen?
- **No features:** No features were considered as unwanted by any groups of participants. There was however some features that were perceived as less important among all age groups except for the age group 13-18, mentioned by a total of 4 groups of participants
- **My diagnosis:** One group of participants, in the age group of 5 to 8-year-olds, thought that the page “My diagnosis” could be more difficult to make. This since she does not think one should put focus on a child’s diagnosis in such a young age
- **Games:** Two groups of participants, within the group of parents, thought that games might be either less important than the other components or more difficult to incorporate in a good way
- **My doctors:** The one group of participants within the age group 9-12 mentioned that having a list of all their doctors might not be as important for them personally, since they only meet a few

What new ideas of possible features are mentioned?
The new ideas of possible features and components to include in Hälsokollen, that were mentioned by participants in all age groups, included ideas that the authors either saw potential to include in the design developed in this project, or as potential future work. The evaluation of which ideas to leave for future work was mainly based on the limited time and resource aspect, as well as that some ideas were considered more relevant to take into consideration further ahead in the product life cycle, such before implementation, rather than during early conceptualization and development. The specific ideas and the amount of groups mentioning this idea specifically are listed below.

Ideas that were considered to be included in Hälsokollen:
- Being able to view slide-shows of different medical procedures (2 groups)
- De-dramatize “My diagnosis” (1 group)
- Being able to write about your progress (1 group)
- Being able to estimate and express feelings related to different topics through

- smileys alone (1 group)
- Being able to view information about different medical departments (1 group)
- Being able to write about your fears (1 group)
- Being able to write a diary (1 group)
- Re-name “Min sida” to “Det här är jag” (1 group)
- Receive suggestions of social activities for children with special diagnosis (1 group)
- Being able to get in contact with other children that have the same diagnosis (1 group)

Ideas to consider for future work:
- Being able to send messages to nursing staff directly (2 groups)
- Ensured security, where the information entered to Hälsokollen by all types of users is protected by passwords, the Swedish Healthcare Guide 1177 or similar (2 groups)
- Ensured quality, where the information entered to Hälsokollen by professionals is objective and based on facts (2 groups)
- Being able to change the language used in Hälsokollen (1 group)
- Include a chat bot, to which users are able to verbally talk or ask questions about their diagnosis or treatment (1 group)

Other findings from the interview
Some other general findings, not necessarily related to a question asked, were taken notes of during the interview. One group of participants in the age group 5 to 8 mentioned that Hälsokollen could be useful for explaining his daughter’s unusual diagnosis to others. Another group of participants mentioned that it is easy to put children with a diagnosis in a box, which one should be careful to promote with Hälsokollen. A parent, to a younger child with cognitive impairments, also mentioned a similar existing digital tool called “Rättvisat” which this project could be inspired by.

Interviews with special circumstances
Two of the interviews held with patients and caregivers were carried out or analyzed a bit differently from the others. The audio recording of the first one of the interviews had failed and the authors had to rely exclusively on the notes taken during the interview. Since the audio recordings were only used to clarify or fill out missing pieces in the notes, the data that had actually been written down in a clear way could still be used and analyzed together with the rest of the participants’ data.

The second one of the interviews was carried out a bit differently. This was due to the fact that the participant, already in the beginning of the interview, explained that his child would currently not be able to actively participate in his health care or use any type of tools to improve his communication, due to his severe cognitive difficulties. This made it difficult to ask all interview questions that were asked to the other participants, that did not have this type of cognitive difficulties. However, the questions that were answered were analyzed together with the interview responses from the other participants. Moreover, since children with serious cognitive difficulties are also patients at the CN, and therefore, potential future users of Hälsokollen, getting insights from this perspective was still considered valuable. Therefore, the responses from this participant was decided to be included in the result.

6.2.3 Participation in a patient's doctor's appointment

In this section, the participation in a patient's doctor's appointment at the Children's Department of Neurology (CN) will be presented. Thereby a presentation of the aim of the participation in the appointment, of the preparations made before, of the people that participated, of how the observation and interview at the appointment were performed and of the results.

6.2.3.1 Aim of participation

The main purpose of taking part in a patients doctor's appointment was to be able to observe and learn more about how an actual appointment could take form. This was considered valuable since this is one of the main environments were Hälsokollen would be used. By observing the appointment, a few detailed questions could therefore be asked afterwards. An interview, identical to the previously held interview's session, was also performed after this. The reason for doing this is because it was considered valuable to gather another participant's opinions of those same questions as well. This participant was also the only child in the "middle" age span of 9 to 12 years of age.

More specifically, the aim of the observation was to get answers to a few questions regarding how doctor's appointments usually go about. The questions were about whether an appointment can contain different phases or parts and what type of questions or topics that could be discussed. Further more, they were about who asks questions and to whom the questions are asked. Whether the child do not understand certain questions or if the parents help the child answer questions for them, were also taken notes of. Moreover, the authors wanted to see if there were any situations during the appointment were the digital application could be useful.

6.2.3.2 Preparations

All preparations made for the interviews with the patients, as described above, were also made to be used for the interview in this appointment. Further preparations made were to create an observation sheet for note taking during the observation part of the appointment. In the sheet, six different columns were made for writing down: the question or topic being discussed, in what part of the appointment the discussion took part and from whom to whom a question was asked. Further more, the other three columns were created for taking notes of: whether a question seemed difficult for the child to understand, if the parents helped answer a question for the child and lastly if any situation came up were the projects digital application could be useful.

6.2.3.3 Participants and environment

The participants in this interview were an 11 year old child with an epilepsy diagnosis and her two parents. The participants agreed to let the authors join the appointment after their nurse, and this project's initiator, asked them. The observation and interview was held in one of the appointment rooms at the CN. The participants were provided chocolate after the appointment, as a compensation for their participation.

6.2.3.4 Procedure

Firstly a brief introduction of the project was made. After that the appointment started and the two authors of this project started their observation and note taking. The main questions to be answered during the observation were if the appointment contains different parts, who asks questions to whom, who talks the most and what type of questions there are. Further on, to see if there are any situations where Hälsokollen could be useful. Due to the fact that the doctor wanted to start the meeting on time, the consent form could not be signed until after the observation part was finished. The authors made sure that the participants knew that their observation data would not be saved in case they wanted to stop participating at that point. The consent form looked identical to the one for the previous interviews (see appendix A), except for a part about the collection of observation data. After the consent form was signed and the audio recording had started, the interview began.

The interview questions were also the same as for the previous interviews (see Appendix B), except for a few questions. These questions were about how the child usually discusses her epilepsy with others. Thereby with who, at what times, how often and in what way. Further more, if the child usually discusses certain areas/topics related to epilepsy more than others, such as treatment and medicines for example. Lastly, a question was also asked regarding if the child has any specific topics they think are more difficult to talk about than others, without needing to say what the specific topic is. If the child answered no, a follow up question was asked regarding if the child thought the communication and discussion about certain topics could be made even more easy by using any kind of tool, such as a book or mobile application to write in for example. If the answer was yes, a follow up question would also be asked whether the topics were more difficult to discuss because the topics themselves were sensitive or because they felt like they could not express themselves in an easy and clear way.

6.2.3.5 Results

This section presents the findings from the observation and the follow up-interview.

Observation results
The findings from the observation will be presented below, summarised within each main question. A more detailed overview can be see in the table in Appendix D.

Did the appointment contain different parts?
Overall this appointment can be said to have contained four different parts/phases. The first part included the doctor asking routine questions and the second part included the doctor encouraging the family to ask questions of their own. The third part of the meeting can be said to have been a concluding part, were the doctor asked if there were any final questions as well as decided upon the next date for an appointment. The fourth part included the participant taking samples in the lab, which were not observed by the authors.

What type of questions are asked and to whom?
The type of questions that the doctor asked in the first part of the appointment were aimed to the patient herself and could be said to be routine questions. Some examples of questions asked regarded when the patient's last epileptic seizure was and how school is going. The caregivers also filled in and asked the daughter which school subject it was that she received extra support in. During the next part of the appointment, the caregivers asked the most questions. The questions, which were prepared in beforehand, regarded their daughters diagnosis, medicines, changes in medicines and sample taking. The caregivers also asked the daughter if she was okay with the new prescription of medicines. After this, the doctor asked the whole family if he should write down the new change in medicine for them. In the third part of the interview, the doctor and the caregivers asked if there were any final questions. Then the doctor asked about the date of a return-visit.

Who talked the most?
Generally, the doctor and the caregivers talked the most during the appointment. The patient was still quite talkative and answered ever question directed to her. Although, her caregiver usually added information to her answers. There was one occasion when the caregivers supported the patient in her answer by asking additional questions. Questions directed to the whole family were usually answered by the caregivers alone. Only the caregivers had questions that were directed to the doctor.

In which cases could Hälsokollen potentially be useful?
The observation of the appointment showed that Hälsokollen could be useful in different ways during the whole time span of an appointment. The main themes of what it could be useful for are within documentation of things related to a patient's diagnosis, writing down information related to their diagnosis, writing down questions and as a decision support. Within documentation, Hälsokollen could for example be used to document every time a patient has had a seizure. For information, it could for example be used to present information about how the seizures affect the patient's brain. Within the theme decision support, the digital tool could for example be used to store information about previous medicines and how they affect the patient. This could in turn help the patient become more involved in the decision making of changing his/her medicines.

Interview results

The results from the interview questions in summary showed that the patient seldom talk about her diagnosis at home, since she dislikes talking about it. She and her family mostly talk about it after she has had a seizure. She also said that there are no specific topics about her diagnosis that are more difficult to talk about. The reason that she does not like to talk about the diagnosis is because she does not like the subject at all, rather than it being difficult for her to express herself. Therefore, she reasoned that a possible new digital tool like Hälsokollen might not help her to talk more about the diagnosis in that sense. Lastly, she also mentioned that they mostly use verbal communication when talking about her diagnosis within her family, without any supporting tools.

6.3 Low fidelity prototype

This section describes the creation of the low fidelity prototype, from ideation to paper prototype.

6.3.1 Ideation session

Based on the background research and the requirements elicitation, an ideation session was carried out to explore design ideas of the tool, that was later to be Hälsokollen, in a more concrete manner. This was initiated by writing down the features that were found desired during the requirements elicitation (content and functionality), on sticky notes that were pasted on a piece of paper. Seeing the main features concretely, the authors individually began brainstorming and drawing simple sketches of design ideas for each feature on a Crazy eight's folded paper, as can be seen in Figure 6:3. When the authors had drawn sketches of all features, the designs went through an unstructured evaluation where the sketches served as a tool for the authors to communicate around the different ideas and solutions. By comparing them, discussing their pros and cons and how they could be improved or combined, the ideas that seemed most promising for each feature were pasted on a piece of paper, as shown by Figure 6:4. At this stage, an idea that came up that had not been found in the requirements elicitation, was to include a background theme feature. This idea came to be extra important, since it would allow the user to further personalize the interface, regardless of which version of the interface the user had selected. Hence, including this feature would hopefully solve the problem of making all versions attractive to use, regardless of the user's age, diagnosis/cognitive abilities and individual preferences.

All the features and ideas were discussed with the academic supervisor at Chalmers, where it was decided that there were still too many features for the scope of the project. Therefore, it was decided to leave games, medication reminders and social activities and contacts for future work. Games were left for future work since finding appropriate games to link to from Hälsokollen was considered to be outside the scope of this project. Furthermore, medication reminders was also not part of the fundamental requirements. The same applied to social activities and contacts, where

Figure 6.3: Overview of how the main features were represented by sticky notes and used to label the initial ideas and design sketches related to each feature.

Figure 6.4: An example image of the ideas that were considered as promising for the feature “My page” after the unstructured evaluation.

the design of those pages and consideration of its security implications also was estimated as quite time consuming. It was also discussed what type of device the prototype would be designed for, i.e. tablet or smart phone. After having reasoned that all patients probably have access to a smart phone (as most people today) but perhaps not to a tablet, it was decided to create a prototype of a smart phone interface.

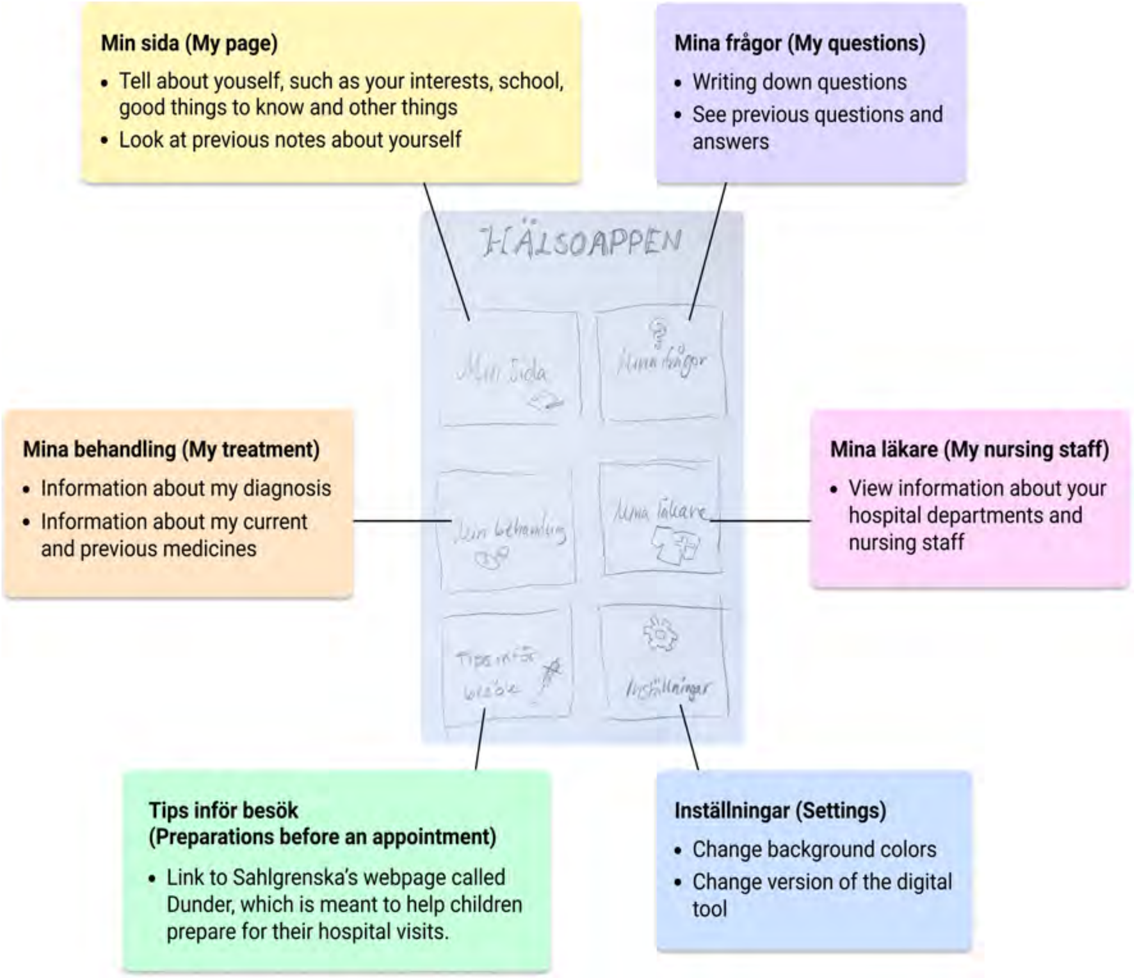
6.3.2 Creation of low fidelity prototype

Three different versions of each page in Hälsokollen were drawn as paper sketches. The aim of making paper sketches was to quickly and easily be able to concertize and iterate on the design of the digital tool. The main features decided to be included in Hälsokollen, at this stage of the project, were as follows:

- *Start page:* The main page of Hälsokollen, where all the six main features are presented and reached through separate buttons
- *My page (Min sida)*: A part of Hälsokollen where the child can write down things about themselves which they later can show to the nursing staff. What could be written down on these pages are things such as personal interests, how they are doing in school and what they want the nursing staff to be mindful of for example. They can express this by writing or by adding drawings, smileys, images and audio recordings. They are also able to view the information they have entered about themselves previously.
- *My questions (Mina frågor)*: On this page, children can write down questions or other things they are wondering about regarding their diagnosis or treatment. They bring their questions to their doctor’s appointments and are able to write down the responses together with their nursing staff. Just like at My page, they can express their questions by writing or by adding drawings,

smileys, images and audio recordings. They are also able to view previously entered questions and their answers.
- *My treatment (Min behandling)*: In this part of Hälsokollen, the children can see information about their diagnosis and their medicines. This information should be written down by the nursing staff or parents during an appointment.
- *My nursing staff (Vi på sjukhuset)*: In this part of Hälsokollen, information about the users nursing staff should be presented. This information should be added by the users themselves, preferably together with a caregiver or nursing staff.
- *Preparations before the appointment (Tips inför besöket)*: In this part of Hälsokollen there is a link to the web page Dunder, which is created by Sahlgrenska University Hospital. On this webpage, users can learn more about how doctor's appointments and different medical procedures are carried out on different departments, in a child-friendly way.
- *Background themes (Bakgrundsteman)*: In this part of Hälsokollen, the user should be able to change the color or theme of the background.
- *Settings/Parents' page (Inställningar/Föräldrarsidan)*: On this page, users would be able to change between the different versions of the interface. At this stage of the process, the page was mostly intended for parents/caregivers so that their children would not change version unintentionally.

A visualisation of all the main features in Hälsokollen and how they related to the start page can be seen in Figure 6.5.



Min sida (My page)

- Tell about youself, such as your interests, school, good things to know and other things
- Look at previous notes about yourself

Mina frågor (My questions)

- Writing down questions
- See previous questions and answers

Mina behandling (My treatment)

- Information about my diagnosis
- Information about my current and previous medicines

Mina läkare (My nursing staff)

- View information about your hospital departments and nursing staff

Tips inför besök (Preparations before an appointment)

- Link to Sahlgrenska's webpage called Dunder, which is meant to help children prepare for their hospital visits.

Inställningar (Settings)

- Change background colors
- Change version of the digital tool

Figure 6.5: A visualisation of all the main features in Hälsokollen and how one can reach them from the start page.

Further on, the final paper sketches made were to be clear and detailed enough to easily be made into digital wireframes. In Figure 6.6 and Figure 6.7 one can see a few examples of the final sketches made.

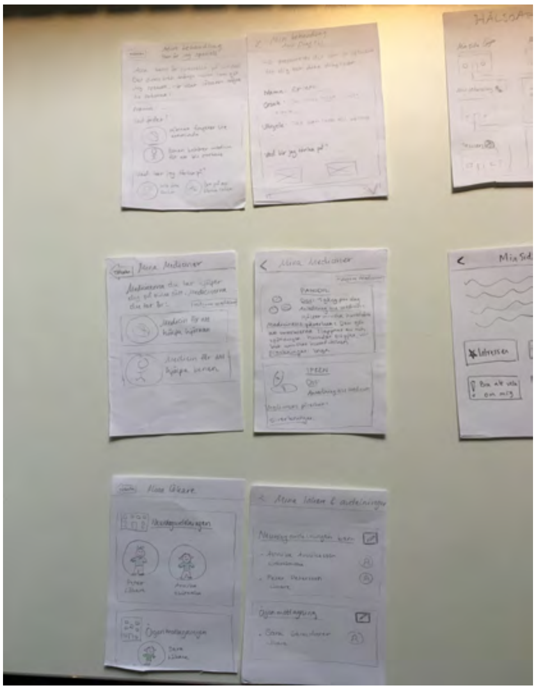


Figure 6.6: Final paper sketches displaying the pages “My treatment” and“My nursing staff”.

Figure 6.7: Final paper sketches displaying the start page and the page called“My page”.

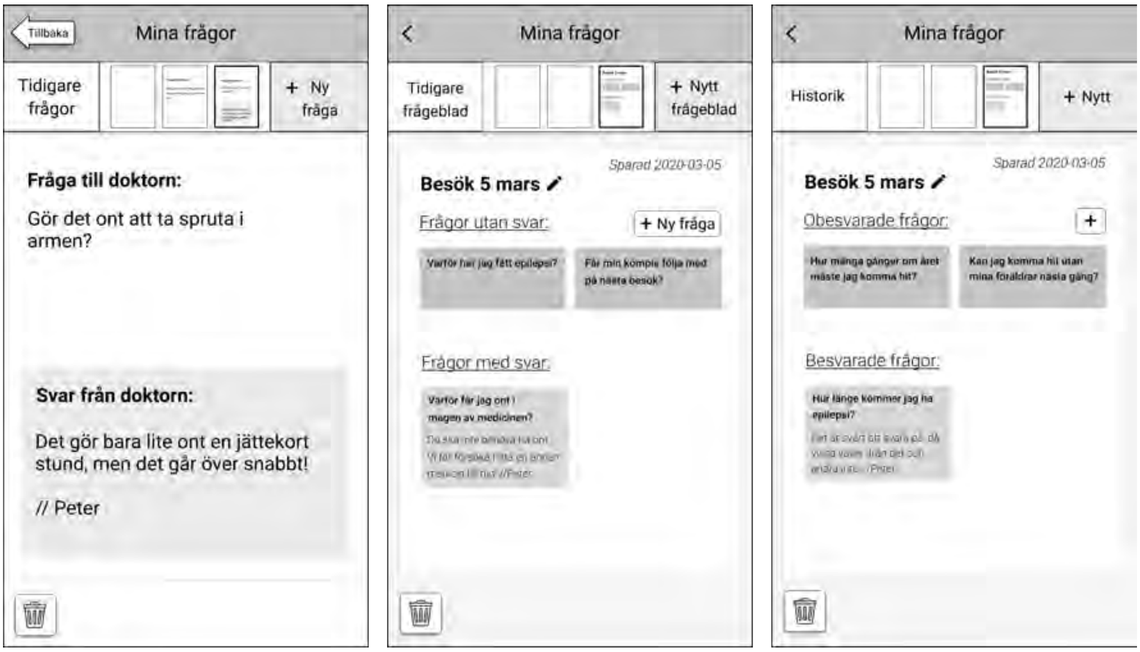
6.4 Medium fidelity prototype

This section describes the process of creating, evaluating and analysing the medium fidelity prototype of Hälsokollen. Furthermore, the results of the evaluation and its implications are discussed.

6.4.1 Creation of the medium fidelity prototype

The development of the medium fidelity prototype was initiated by creating a work sheet in the online design tool Figma. This tool was chosen mainly because it was familiar to the authors and because it allows several people to collaborate around and edit a design from separate computers simultaneously. In the work sheet, titles of the six main features/pages that had been decided to include in the prototype were created. Underneath each title, all the pages that belonged to the feature were created in three different versions, in accordance with the three complexity levels/age spans that the versions were decided to be based on. Three versions were also created for the start page, which acted as the main screen from which all the six main features would be reached. On the first page for each main feature, the user would also be able to reach more pages that belonged to that feature.

All pages except the start page shared the same basic structure in all versions: a header containing the title of the feature (with a subtitle on all the pages that belonged to the feature, but were not its first page) and a back button, followed by cards conveying page-specific information, and page-specific buttons conveying navigation to the other pages that belonged to the main feature. The screens were created in a iPhone 8 resolution, since this was the resolution on the smart phone that was planned to be used during the evaluation of the prototype. The design was also made quite detailed with real icons/images and examples, as an attempt to avoid the problem of young children not yet having developed the cognitive ability of understanding more abstract or hypothetical concepts, such as that prototypes are representations rather than “the real deal”, as discussed by Mack, Giarelli and Bernhardt [49] in the theory chapter about children’s development. Since the aim of testing the medium fidelity prototype was to get participants input on the design and its elements rather than the interaction, screens with dialog boxes and different types of feedback were saved for the high fidelity prototype. Examples of screens from the medium fidelity prototype and the divergence between versions of a page are shown in Figure 6.8 and Figure 6.9.



Fråga till doktorn:

Gör det ont att ta spruta i armen?

Svar från doktorn:

Det gör bara lite ont en jättekort stund, men det går över snabbt!

// Peter

Varför har jag fått epilepsi?

Får min kompis följa med på nästa besök?

Varför får jag ont i magen av medicinen?

Hur många gånger om året måste jag komma hit?

Kan jag komma hit utan mina föräldrar nästa gång?

Hur länge kommer jag ha epilepsi?

Figure 6.8: Example screens from the medium fidelity prototype, which are the first page you see when entering the main feature “My questions”. The screens show the three versions of the page, that were designed for the three different age groups (5-8 year olds to the left, 9-12 in the middle and 13-18 to the right).

Figure 6.9: Example screens from the medium fidelity prototype, showing the four different start pages designed.

6.4.2 Expert reviews of the medium fidelity prototype

This section describes the findings from the expert evaluations of the medium-fidelity prototype and how the evaluations were performed.

6.4.2.1 About the reviews

The expert reviews were conducted with three different groups of experts. The first expert was a PhD student at Chalmers University of Technology who had experience working with interaction design for children. The second expert worked at the department CDH at Sahlgrenska University Hospital and had experience with interaction design in general. The third group of experts were the two project initiators working with children at the CN and the Play therapy at Queen Silvia's Children's Hospital. The aim of the expert evaluations were therefore to get feedback and insights from these three different areas of expertise, which are all relevant for this project.

During the evaluations, the expert was shown each of the screens in the medium fidelity prototype one at a time and asked for their opinions and feedback. The first expert was shown three versions (difficulty levels) of the prototype, thereby version 1, 2 and 3. After each review, changes were made to the prototype according to the feedback provided, before continuing with the next expert review. Since the feedback from the last expert review was more relevant for the high fidelity prototype and for potential future work, no changes were made to the prototype after this review (before the evaluation with potential users). One example of feedback from the first expert review stated that version 2 and 3 were too similar in this level of fidelity. It was therefore advised to only evaluate 2 versions in the following evaluations of the medium-fidelity prototype. The two following expert evaluations were then only shown version 1 and version 3 of the prototype, the one with the lowest and highest level of difficulty (Version 1 and Version 3). The feedback, to be considered for both the high fidelity prototype and for future work, was analysed and converted into a summarised list. All feedback that had not yet been implemented from the first and second expert review was also included in this list.

6.4.2.2 Results from the expert reviews

In this section the results of the expert reviews will be presented. First the feedback from the first and second expert review, that were both changed before the next expert review, will be presented. After that, the changes to be made for the high fidelity prototype will be presented, stating both feedback from the third expert as well as feedback that had not yet been implemented from the first and second expert review. Furthermore, feedback that were considered but not changed will be presented as well as future work. Lastly, the positive feedback, to be kept for the next prototype, will be presented.

Feedback that was changed between the expert reviews

First expert review

As mentioned in the section above, the feedback received from the first expert review was used to iterate the design before the next evaluations. The main critical feedback provided during that expert review, that was also changed before the next review, were as follows:

- *Miscellaneous:* Instead of showing three different versions of the application, with the second and third version being very similar, it was advised to only have two versions in the evaluation of the medium fidelity prototype with potential users (version 1 and 3). More differences between the second and third version might be possible when creating a high-fidelity prototype. It was therefore suggested to let 5-8 year olds evaluate version 1 and the rest of the children, 9-18 year olds, evaluate version 3, during the up-coming evaluation with potential users.
- *All pages:* Descriptions of Hälsokollen’s main features should be placed within an information icon in the header. Add a sound-icon/-function for the users to be able to listen to text on the page.
- *Settings:* Add a short explanatory text in the settings view regarding how the three application versions differ from each other.
- *Start page:* Make the house-icons on the start page look more different, for them to be easier for children to differentiate.
- *My page:* Add the function to be able to include and record your own videos when editing things in the application. Add some example questions of what one could write on these pages. Replace the history bar with a page displaying an overview and history of your previous notes (the changes made after this feedback can be seen in Figure 6.10 and Figure 6.11).
- *My questions:* Similarly to “My page”, the history bar should be replaced with a page displaying an overview and history of your previous questions. Each page of question(s) could be connected to a certain doctor’s appointment as well. Further on, add a preview of the text written in the questions, to more easily find certain questions in the overview.

- *Background colors:* Due to copy rights, the background themes that would be included in Hälsokollen would have to bee self made. Therefore, only the possibility of changing the color of the background should be kept, and themes should be saved for future work.

Jag går i klass 5B och här är en bild på oss:

Figure 6.10: Image showing how the history bar/view, placed in the top of the screen, looked like before it was changed.

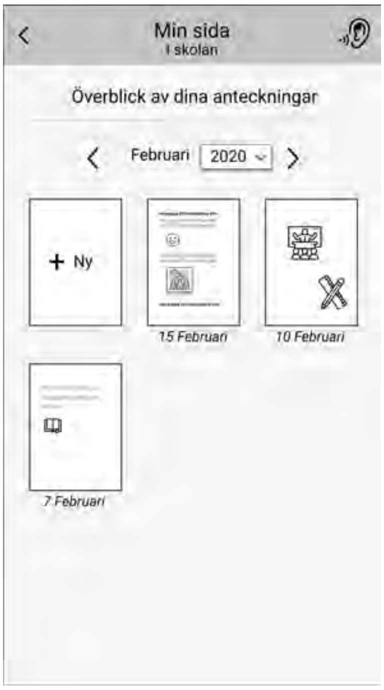


Figure 6.11: Image showing how the new history view/page looked like after the design iteration.

Second expert review
As mentioned in the section above, the feedback received from the second expert review was used to iterate the design before the next evaluations. The main critical feedback provided during that expert review, that was also changed before the next review, were as follows:

- *All pages:* Do not use the word “doctor” as the only name for nursing staff, also use other words such as “nursing staff” and “nurse”.
- *My treatment:* Enable nursing staff to edit “My treatment” without having to log in to the page or similar. Only include previous medicines in the history view, not the current medicines as well.

Changes to be made for the high fidelity prototype

First expert

- *My page:* For version 1, include a picture of the child themselves on the button “My page”, instead of an icon.
- *Start page:* For version 1, the page “Background colors” should be placed underneath the “Settings” page.

Second expert

- *Start page:* Include a picture of the child themselves on the button “My page”, instead of an icon.
- *My nursing staff:* Include an example picture of a nursing staff and a department.
- *My treatment:* Remove the stated fact “How much medicines should I take” as an example from the page. It should be optional if one would like to include that information since it is very important for it to be updated and correct. If it were to be included, a warning text should be displayed encouraging the user to make sure that the medicine information is updated. Add information of why a medication was removed, in the history section. Add information about the nursing staffs’ titles.

Third expert

- *Settings page:* The word “komplexitet” (“complexity”) might be too difficult to understand for younger children. The words “annat utseende” (“other appearance”) or “mer utförligt” (“more detailed”) are suggested as better options.

Feedback that were considered but not changed

First expert:

- *My page:* Consider if it is good to have images etc. to appear in fixed positions on the editing page or not.
  - This was tested, but it seemed to make it more difficult for the user to express themselves more freely and was therefore not implemented.
- *My questions:* Consider if “My questions” might be connected to specific departments and therefore should be placed under the page “My nursing staff”.
  - This was not implemented due to the fact that “My questions” is a function that might be used a lot by the users, according to previous findings in this project. If it would be placed underneath the page “My nursing staff”, it would be more of a hassle every time a user would want to use the function.

Feedback considered as future work

First expert:

- *Settings:* Make small previews of the different versions, to help further clarify the difference of them for the user. For the users to be able to best fit Hälsokollen to their personal level, it might be good to have a setting where they could be sent to the suitable version of Hälsokollen based on a few questions about their age, their reading skills etc. Alternatively, there could be a setting for the caregivers to fully customize the application to fit their children. This could for example mean that the parents could choose the amount of text on each page or how big buttons should be.
- *My treatment:* Enable the nursing staff to add general explanatory videos of patients’ diagnosis.

Third expert

- *Settings page:* Display a preview of the different versions to help users get a more concrete sense of how the versions differ.
- *My questions:* A chat bot could perhaps be implemented to answer the more

simple and common questions asked by the children. Investigate whether it could be beneficial to be able to sort the questions into themes or categories instead of appointments/dates, for the user to easier find questions related to certain topics.

- *My treatment:* Not just show information about medication, but also other types of treatments such as conversational therapy or physio. Possibly add a reminder feature for taking you medication, doing your therapy exercises etc.
- *Preparations before the appointment:* Remove the word “tips” (“preparations”) from the title of this page. If you do this, you could include information about when and where the next doctor’s appointment is being held, which nursing staff the patient will meet and what will happen during the appointment. Depending on what activities will be carried out during that appointment, you could provide links to slideshows about those specific activities.

Positive feedback to keep for the high fidelity prototype

The first and the third expert focused more on providing constructive feedback while the second experts, the project initiators, also focused on providing feedback of what was good with the design and what requirements had been fulfilled. Therefore, some of the positive feedback provided by the second experts/project initiators were as follows:

- *Start page:* The analogy of having a dwelling area with a road leading to different houses in version 1 was considered a fun, playful and easily understandable idea, that definitely could speak to children. That there were small differences in the design of the three versions was also considered to be appreciated by users when switching between versions. Furthermore, the icons used for the different main features were liked.
- *My page:* This page and its navigation structure was perceived as easy to understand. The design of the “overview of your previous notes”-page was very appreciated and said to meet the idea that the project initiators initially had in mind very well. That users are able to express how they want to be treated during doctor’s appointments was considered a very important feature. It was perceived as a good idea to include this feature on “My page”.
- *My questions:* It was considered a great idea being able to provide responses to questions through images, audio recordings etc.
- *My treatment - My diagnosis:* The appearance of both version 1 and 3 of the page was liked. It was considered wise to include the page “My diagnosis” within the page “My treatment”. It was also appreciated to use the word “diagnosis” of the page since they want the child to be aware that they have a diagnosis and be proud that they know things about it.
- *Preparations before the appointment:* The appearance of the page was liked a lot. The fact that you arrive at a general page of the different departments at Sahlgrenska when clicking on the button was appreciated as well. It was considered wise to have the same base for version 1 and 3 but with small differences in the design.
- *All pages:* It was appreciated that children’s tendency to accidentally delete or edit information was considered throughout the design, and that this prob-

lem was encountered by requiring the user to go through several steps before something is deleted/can be edited.

- *Miscellaneous:* It was a good choice to create the prototype to be used on a smart phone, in this initial design phase of Hälsokollen.

6.4.3 Evaluation of the medium-fidelity prototype with potential users

In this section, the evaluations of the medium-fidelity prototype will be presented. Thereby a presentation of the aim of the evaluation, the preparations made, the people that participated, how the evaluations were performed and the results.

6.4.3.1 Aim of the evaluation

The aim of the evaluation was firstly to gather insights of which types of difficulty levels that possibly fit the different levels/ages of the children. Further on, the evaluation was supposed to gather both negative and positive feedback of the prototype, such as ambiguities and things that were especially good. Lastly, possible suggestions of improvements were gathered during the evaluation.

6.4.3.2 Preparations

As a preparation for the medium-fidelity evaluations, a few pictures inspired by the *picture cards method* (see the methodology section) were created. The cards were created to aid both the younger or the older children with difficulties to communicate verbally for different reasons. The pictures displayed 6 images representing “Good/I like”, “Neutral”, “Bad/I do not like”, “I am confused”, “Too simple/childish”, “Too difficult/made for an adult” and could be pointed at by the children instead of speaking. The pictures used can be seen in Figure 6.12.

Figure 6.12: The pictures were created for children having trouble communicating verbally, to be used during the evaluation of the prototype.

Pilot test

A pilot test was performed with a mother and her 5 year old son, that were not patients at the CN. After the pilot test, a few changes were made to the evaluation process. Due to the evaluation taking too long to conduct, a few screens were removed from the evaluation. Some of the main screens removed were regarding "Background colors", "Preparations before an appointment" and "My diagnosis". This due to the fact that they were either less important to get feedback on due to their simplicity or because they were similar enough to other screens included in the evaluation. Apart from removing these screens, no other changes were made to the evaluation procedure.

6.4.3.3 Participants and environment

Due to the ongoing situation of the covid-19 pandemic during this part of the project, a lot of restrictions were made made for visitors at Sahlgrenska University Hospital. The government also advised people to stay home as much as possible. The environment for the evaluation of the medium fidelity prototype was therefore changed to the online video conference call application Skype. The strategy to gather participants was also changed from asking people at the CN in person, to sending out letters of information. The letters shortly explained the ongoing project, how the evaluation would go about and that children between the ages of 5 to 18 were welcome to participate, with or without their caregivers. The letters were either sent out by email or by post together with patient's invitations to appointments.

Due to the lack of participants joining from the CN, the advisor from the Centre of Digital Health (CDH), at Sahlgrenska University Hospital, sent out the information letter within his department as well. The fact that the children at CDH did not necessarily fit the main target group of the project (children with long term illnesses) was not considered a significant issue. This due to the fact that the evaluation was mainly about testing Hälsokollen's appearance and different levels of difficulty, rather than the actual content.

A total of 9 participants, including the pilot test, participated in the evaluation of the medium fidelity prototype. Six of the groups were recruited from the CDH. Within these groups, two groups included children in the age span of 5 to 8 years of age, two children in the age span of 9 to 12 years and two children between 13 and 15 years of age. Two groups of participants were currently patients at the CN, aged 5 and 15 years, and one group had children that were former patients at the department, aged 15 (with an experienced age of 5-8) and 25. This last group included one person working at the CN and one working with children with rare conditions. They were currently working with a similar project and can therefore be said to have provided a slightly different angle of feedback than the other participants. Among the children who participated or had their caregiver to participate, 3 were boys and 6 girls. Furthermore, all child-participants except for one said that they used a smart phone every day. Among the most used type of device, it was an almost equal distribution between smart phones and tablets, where a few participants said to be using a smart phone approximately as much as a tablet. The most commonly used operating system was iOS, which was said to be used by 8 participants, while 2 participants mainly used Android.

Just like in the interviews with patients and their caregivers during the requirement elicitation phase in the beginning of the project, one of the project initiators made a heuristic assessment of the participants', that are currently patients at the CN, experienced age. This showed that all of those participants' experienced and legal age were the same. In total, this resulted in 4 groups who mainly evaluated Version 1, and 5 groups who mainly evaluated Version 3, as suggested during the previous expert reviews.

6.4.3.4 Evaluation procedure

Each evaluation session was initiated by welcoming the participants and by giving a brief introduction of the facilitators and the aim of the evaluation. The facilitators then started an audio recording and asked the participants whether they could give their verbal consent of wanting to participate in the study and that they were OK with their responses being audio recorded. After this, some short questions about their demographic information and mobile habits were answered, followed by an instruction of what the participants were expected to do during the evaluation. Furthermore, a presentation of a short scenario describing the purpose of Hälsokollen and how it would be used by patients was given.

After the scenario, the evaluation of the prototype began by introducing the correct version of the start page (version 1 for 5-7 year olds and version 3 for 8-18 year olds) and by giving an explanation of what one can do on that page. This was done by sharing the computer screen of one of the facilitators' computers, which had the Figma work sheet with the medium fidelity screens to-be-evaluated ready. After this, the interview questions regarding what the participant liked and disliked with the page, what their suggestions of improvements were and what they thought about the page's difficulty level were asked (See Appendix E). This was followed by the facilitators showing the other version of the same page (version 3 for 5-7 year olds and version 1 for 8-18 year olds), thereby taking inspiration from the *This-or-that-method*, to get feedback on which of the two versions the participants thought was the best and would prefer to use. Lastly, a question about whether there was anything surprising or unexpected with the main feature or its belonging pages was asked before moving on to the next main feature. This procedure was then repeated for all the screens that were included in the evaluation. The evaluation session was then finalized by thanking the participants for their participation before moving over to the next group of participants. As a thanks for the participants participation, they were included in a lottery in which one group of participants won two movie tickets.

Throughout the whole evaluation session, one of the facilitators took notes of the participants' responses while the other held the interview and led the evaluation forward.

6.4.3.5 Data analysis and results

The data collected during the evaluation was analysed in several different steps. Firstly, the authors read through each others' notes that were taken during each evaluation session, while listening to the audio recording of the participant's interview responses, to clear out ambiguities and gaps. Thereafter, each group of participants' responses were color coded and gathered under the page in Hälsokollen and the interview question that each response belonged to. Moreover, the responses were sorted so that those that belonged to the age group 5-7/that evaluated version 1 was gathered, and the responses belonging to the age group 8-18/that evaluated version 3 was gathered. The participants in the pilot test and the two nurses that also were parents to children that were former patients at the CN was also sorted into the age group 5-7, since this was the age of their children. However, since these two groups of participants differed somewhat from the other groups, their responses also differed more heavily from the others'. Therefore, these responses were not weighed as much as the other participants' at this stage of the process, even though some responses was considered important to add as potential future work. When all responses were sorted accordingly, the content analysis (as described in [37]) was applied to find themes and commonalities in the data. Furthermore, the general themes and findings of what the groups of participants liked and disliked with the pages, what their suggestions of improvements were, what they thought about the pages' difficulty levels and what was surprising or unexpected with the interface, was summarized for each age group. The full summary of the findings can be found in Appendix F.

The results of the evaluations with potential users showed that the groups of participants in general were positive to the design of Hälsokollen, including its difficulty level, features and components. Therefore, many of the findings collected suggested that certain components and features should be kept as they are. Some examples of these components and features, that were reported as extra likable by participants, are as follows:

- *All pages:* All pages that were shown, both from Version 1 and 2, were perceived as aesthetically pleasing by participants from both groups.
- *Start page:* Participants in both the Version 1 and Version 2 group appreciated the "Background color" page and the ability to write about yourself on "My page". Many participants also appreciated that the different main features in Hälsokollen were presented in a clear way on the start page.
- *My page and My questions:* Several participants mentioned that the different editing buttons, to include information in form of video, images etc, were good to have.
- *My treatment:* Many participants mentioned that it was good to include pictures on the page explaining their medicines. The specific questions/topics brought up on the page, such as "how the medicine affects your body", were also appreciated.
- *My nursing staff:* The nursing staff icons used on the page were appreciated by several participants. Many participants also appreciated the idea to be able to include real pictures of the nursing staff and the departments.

The additional findings from the analysis were translated into a list of priorities. This list contained all things that was disliked or needed to be adjusted for the high-fidelity prototype, sorted according to their level of priority (high-, medium- and low priority). As only version 1 and 3 were part of the evaluation, some of the adjustments also applied to more than one version (e.g. both version 2 and 3 in some cases, and version 1 and 2 in other cases). Moreover, there were also certain adjustments that were of priority for all versions. A summary of all findings can be found in Appendix F. Some of prioritized features were as follows:

All versions

High priority

- *All pages:* Add an icon on all pages displaying that the user can have the text on the page read to them out loud.
- *Start page:* Discuss whether the page "background color" should be placed on the Start page or underneath the "Settings" page.
- *My page:* Change the look of the edit note-page, since it looked like the example questions belonged to the editing buttons. Also, change the circle-icon on the "Other"-button to an icon that shows a number of different things.
- *Me treatment:* Show example photos of medicines of different formulas, i.e. pills, effervescent tablets, injections etc.
- *My questions:* Discuss how it can be made more easy to sort out questions that are answered or unanswered.
- *My nursing staff:* Add a screen displaying information about a certain department, such as address, opening hours, telephone hours and telephone number.

Medium priority

- *Start page:* Try finding another icon for the "background color" button, that better resembles with this feature.
- *My questions:* Change the text "Questions without answers" to "Unanswered question".
- *My treatment:* Place the edit-button underneath the information-button.
- *My nursing staff:* Add an example photo of both a department and a doctor/nurse.

Version 1

High priority

- *Start page:* Make the page look like the previous house-design, but with influences from the button-design.
- *My questions:* Add dates to all the questions on the different screens.

Medium priority

- *All pages:* Shorten the amount of text as much as possible.

Version 2

High priority

- *Start page:* Make the page look like either the button-design or the roundabout-design.

- *My questions:* Let this page have the same design as version 1.

Version 3
High priority
- *Start page:* Make the page look like either the button-design or the roundabout-design.
- *My questions:* Change this page to look more like version 1 while keeping the idea of having several questions collected in one sheet.

What was actively chosen not to be included and why
Not to include
- *All pages:* Icons from the start page should be displayed somewhere on the page you are at, to make it easier for children that have limited reading skills to understand on which page they landed. This was experimented with by adding the respective icon on different positions at the top of the page and in the header, but it was difficult to find a solution that did not clutter or ruin the balance of the page. Therefore, it was decided not to include this feature.

Future work
- *My questions:* Include a FAQ-section, apart from being able to write your own questions.
- *My treatment:* Add links to other digital tools that can help patients track their diagnosis in more detail, when needed. An example could be for patients that have diabetes.

6.5 High fidelity prototype

This section describes the process of creating, evaluating and analysing the high fidelity prototype of Hälsokollen. Furthermore, the results of the evaluation and its implications are discussed.

6.5.1 Creation of high fidelity prototype

The creation of the high fidelity prototype consisted of an iteration of the medium fidelity prototype and was mainly based the findings from the evaluation with experts and potential users in the previous phase. More specifically, the list of priorities created in this phase served as a checklist while doing alterations to the design, where the bullet points were implemented in the prioritized order (from high to low). Furthermore, screens with dialog boxes and different types of feedback, that was supposed to appear when the user interacted with different elements in the interface, was created. Additionally, an Introduction page which provide information about Hälsokollen's background and aim and require the user to select which version he/she would like to use, before being able to start Hälsokollen, was created. Moreover, a look and feel that was inspired by VGR's visual profile was implemented, where their blue standard color was added to the headers of the interface, including a version of their logotype on the Introduction page. The background colors, on some of the pages, were made in a different lighter blue color. The icons and images used in the interface were also updated to colored versions. An example of how the interface was changed from medium fidelity to high fidelity can be seen in Figure 6.13. All the final screens of the prototype can be seen in Appendix G.


Det här är jag
I skolan

Här kan du skriva lite om skolan. Du kan även lägga in teckningar, smileys, foton, ljud, eller video!

Vilken klass går du i?

Vilket är ditt favoritämne?

Vad heter dina bästa klasskompisar?

Tycker du det är kul i skolan?

Finns det något med skolan du tycker är svårt?

Det här är jag
Vad jag tycker och känner

Jag tycker det är jobbigt när...

Jag vill att ni...

Jag vill inte att ni...

Figure 6.13: An example of how the My page - editing page was transformed from medium fidelity (left) to high fidelity (right).

When all the screens were finished according to the list of to-do's, interactivity was added to the prototype by making certain elements in the interface clickable. This was done by using the prototype-feature integrated in Figma, where one easily can drag and drop connections between different screens or design elements. Some of the design elements were also set to play a small animation when they were clicked, as an attempt to create playful effects. Since there are three versions of the interface, the end result also consisted of three different versions of the prototype.

6.5.2 Expert review of the high-fidelity prototype with project initiators

This section describes the findings from the expert evaluations of the high-fidelity prototype and how the evaluations were performed.

6.5.2.1 About the reviews

An informal expert review was conducted of the high-fidelity prototype with the project initiators (working with children at the CN and the Play therapy at Queen

Silvia's Children's Hospital). During the evaluations, the experts were shown each of the screens in the high-fidelity prototype one at a time and asked for their opinions and feedback. They were also shown all three different versions of the prototype.

6.5.2.2 Results from the expert review

The overall feedback from the project initiators was that they were very happy with the end result. Some things that were specifically pointed out as positive were as follows:

- *All pages:* That users are able to listen to the text content in Hälsokollen was good. It is also wise to make the text more difficult/more suitable for older kids in the higher versions. The texts about what each page is about (that is displayed when pressing the information-button in the header) are very well-written and easy to understand without being childish.
- *Introduction page:* The page looks nice and professional with the VGR logo included.
- *Start page:* The idea to include the feature "Background colors" on the start page for Version 1 but hiding it behind the button "Settings" for Version 2 and 3 is a good idea.
- *My page:* That users has a place to express thoughts and feelings that are not tied to a specific category or topic on the "Other things I'm thinking about"-page is good. Further more, that users see examples of what he/she can write or talk about related to the different topics (interests, school etc), which appears each time a new note is created. The editing page looks very good in general.
- *My treatment - My diagnosis:* The topic "what should I think about regarding my diagnosis" is very good to include.
- *My treatment - My medicines:* It is wise to include a warning text encouraging the users to make sure that the information is updated. It is wise to place the edit-button underneath the information button in the header, to minimise the risk of children accidentally pressing it.
- *My nursing staff:* It is good to be able to add your own pictures of the departments you are a patient at. It is a good idea to fetch contact information etc about the departments from VGR databases, to make sure it is updated.

Apart from the positive feedback, some suggestions of improvements were also provided by the project initiators:

- *My treatment - My medicines :* Underneath the information button, a text states that nursing staff can edit this page. This should be changed to state that both nursing staff and caregivers can edit the page.
- *My nursing staff:* One should be able to add new departments, regardless of whether they are part of Sahlgrenska University Hospital or other hospitals that the user might be a patient at. Moreover, nursing staff are not allowed to give out their private email and phone number, so this should be removed from the page.

6.5.3 Evaluation of the high-fidelity prototype with potential users

In this section, the evaluations of the high-fidelity prototype will be presented. Thereby a presentation of the aim of the evaluation, the preparations made, the people that participated, how the evaluations were performed and the results.

6.5.3.1 Aim of the evaluation

The aim of the evaluation was firstly to gather insights about the usability of the high-fidelity prototype. Thereby to check if the layout and navigation of the prototype were intuitive, check if the functions and features included were understandable and check if Hälsokollen felt usable and useful. Further on, the aim of the evaluation was also to gather insights about the user experience of the prototype as well as suggestions of improvements. This was done by performing a *usability test* where users, after hearing different *scenarios*, was supposed to complete a set of tasks that were representative of a normal usage of Hälsokollen, while *thinking out loud*. For the children that evaluated version 1, they also had the opportunity of using the *picture cards method* to aid their thinking aloud.

6.5.3.2 Preparations

A specific preparation made for the evaluation of the high-fidelity prototype was to try find a good video conferencing application where one could share the screen of a mobile device. The aim of this was to enable evaluation participants to interact with the high-fidelity prototype on their mobile devices, as it was designed for, while at the same time sharing their screen with the facilitators. The application Zoom showed to fulfill these requirements. After some informal tests using the application, the authors found that one were unable to see the finger movement of the person interacting with the screen of the mobile device being shared. One could not either see where the person clicked, if they clicked on an non-interactive place in the screen. It was therefore decided to let the users share and interact with the prototype on their computer screens, to enable the facilitators to see the movements and interactions of the computer mouse.

Pilot test
Two different pilot tests were performed to try out the evaluation procedure. The first pilot test was performed with a 25-year-old woman that did not belong to the target group of the evaluation and project. The aim of this pilot test was to test things such as execution time of the evaluation, possible technical issues and the layout of the evaluation process script. The findings of the pilot test showed that the evaluation procedure was working well, only minor clarifications of the script were made, such as which one of the facilitators should start the interview recording.

A second pilot test was made, with a participant within the target age, to also test the tasks and questions in the evaluation. The participants were a mother and her 5 year-old daughter that were not a patient at the CN. No changes needed to be made to the evaluation procedure after this pilot test, meaning that the findings could be analysed together with the rest of the evaluations.

6.5.3.3 Participants and environment

Like the medium fidelity prototype evaluation, this evaluation was restricted by the ongoing covid-19 pandemic and the government's recommendations in relation to this. The evaluation of the high-fidelity prototype was therefore also planned to be carried out remotely, through the online video conference call application Zoom. Zoom was chosen rather than Skype (as used in the medium fidelity prototype evaluation) because it allows the web camera and screen sharing to be activated at the same time. This was of relevance for the data gathering, where participants' facial expressions were planned to be used in case there were ambiguities in relation to their way of interacting with the prototype. The strategy of gathering participants by sending out information letters to the patients at CN and staff at CDH, explaining the ongoing project, how the evaluation would go about and that children between the ages of 5 to 18 were welcome to participate with or without their caregivers, was also kept for this evaluation. Furthermore, a similar letter was also sent out to the staff at the Interaction Design department at Chalmers University of Technology, as an attempt to recruit more participants.

In total, 8 groups of people participated in the evaluation, including the second pilot test group. Three of the groups had or were children that are currently patients at the CN. One of these groups consisted of a mom who had a 4, soon to be 5 year old son (which had cognitive difficulties and did not participate), one of a mom and her 12 year old son, and one of a 16 year old girl. One group of participants were recruited from the Interaction Design department at Chalmers, which consisted of a mother and her 10 year old daughter. The rest of the groups were recruited from the CDH, which included one group consisting a mother and her 5 year old daughter (which were also the second pilot test participants), one group consisting of a 17 year old girl who participated without her caregivers, one group consisting of a mother and her 9 year old son, and one consisting of an 11 year old boy who participated without his caregivers. Questions regarding the child-participants mobile habits showed that all participants used a smart phone every day, except for the two youngest participants who barley had used a smart phone but used a tablet regularly instead. The distribution between the most used device, out of smart phones, tablets and computers, there was an almost equal distribution, including the participants who said to be using one or more of the devices equally much. Like the results in the medium fidelity prototype evaluation, the majority of participants mainly used the operating system iOS, which was found for 6 of the participants, while 1 participant said to be using Android and 1 Windows.

To be able to explore potential usability and user experience issues, the participants were only to evaluate the interface version that was designed for their experienced age. Like the previous evaluations, one of the project initiators again made a heuristic assessment of the current patient-participants' experienced age, to determine which of the interface versions would be best suited for each participant. This assessment showed that none of the patient-participants had an experienced age that differed from their legal age, hence, all participants evaluated the interface version that corresponded to their legal age. In total, this resulted in 2 groups of participants who evaluated Version 1, 4 groups of participants who evaluated Version 2, and 2 groups of participants who evaluated Version 3.

6.5.3.4 Evaluation procedure

Just like in the medium fidelity prototype evaluation, the evaluation sessions for the high fidelity prototype began with welcoming the participants and by giving a brief introduction of the facilitators and the aim of the evaluation, followed by a background description of Hälsokollen's objective. The facilitators then started an audio recording and asked the participants whether they could give their verbal consent of wanting to participate in the study and that they were OK with their computer screen and responses being recorded while interacting with the prototype. Further on, it was made clear that their data would only be used anonymously in this project. After this, some short questions about their demographic information and mobile habits were answered, followed by an instruction of what the participants were expected to do during the evaluation. The participants were asked to open the prototype version that the facilitators had linked in the Zoom chat, and then to share their computer screen so that the facilitators could see how the participant would interact with the prototype.

Having the prototype in front of them, participants were asked to interact with the prototype in accordance with a set of tasks provided by the facilitators, while thinking out loud. The tasks were created so that several different types navigations were tested, i.e. the participants were navigating from the start page to different main features, between different pages belonging to the same main feature, and from certain pages back to the start page. In total, there were tasks and interview questions on the *Introduction page*, *My page*, *My questions*, *My treatment - My medicines* and *My nursing staff*. These pages were selected to be tested both due to lack of time during the evaluation sessions to test all pages and due to the remaining pages either being quite simple (such as background colors) or being similar enough to the ones chosen for testing, After the tasks that were related to a certain main feature had been carried out, a set of interview questions regarding this feature and its belonging pages were asked. Furthermore, after the all the tasks were completed, the evaluations ended by getting the participants' input on Hälsokollen and all its pages as a whole. All the tasks and interview questions asked can be found in Appendix H.

Throughout the whole evaluation session, one of the facilitators took notes of the participants' interaction with the prototype and interview responses, while the other presented the tasks, held the interview and led the evaluation forward.

6.5.3.5 Data analysis

The data collected during the evaluation was analysed in several different steps. Firstly, the authors read through each others' notes that were taken during each evaluation session, while listening to the audio and video recording of the participant's task performance and interview responses, to clear out ambiguities and gaps. Thereafter, each group of participants' interview responses were color coded, gathered in a unified document and sorted according to their age (and thereby the version of Hälsokollen they tested). Participants' performance on each task was also sorted into one of the three predefined completion categories: Immediately and without support, With delay but without support, and With delay and support. The results from both the task performance and the interview responses were summarised in a document, including examples from the raw data to exemplify specific findings.

Two of the children in the groups from CDH (the one with a mother and her 9 year old son, and the one consisting of an 11 year old boy who participated without his parents) were also participants in the medium fidelity prototype evaluation. This could potentially have affected their perception, responses and way of completing the tasks during this evaluation, and therefore, these participants' results will be presented separately.

Furthermore, the mother of a 4 year old son with cognitive difficulties were also analysed a bit differently, since neither her or her child belonged to the target age group at the moment of the evaluation. However, the child is still a patient at the CN and will belong to the target age group in a couple of years, and therefore, it was valued to get input from his mother anyway. Since the aim of having participants performing a set of tasks in the interface was to discover usability issues among the target age participants (i.e. 5-18 year olds), only the mother's comments expressed during the performance of the tasks and during the interview was analysed for this participants, and not her way of completing the tasks.

6.5.3.6 Results

The participants' task performances showed that the majority of tasks were completed immediately and without support, among the participants who evaluated version 1 or version 3. For the participants who evaluated version 2, there were greater variance between the three levels of completion (Immediately and without support, With some delay but without support, and With some delay and support), where it was mainly one participant who needed extra time and support to complete the tasks. The task performances on each interface version is presented in Table 6.1.

Furthermore, all groups of participants, regardless of version evaluated, were generally positive towards Hälsokollen and either said that they would use it themselves or thought that other children with long-term illnesses would. Moreover, the general opinion about the design and the look and feel of Hälsokollen, including the ability to adjust the background color, was appreciated, even though some suggestions of improvements were mentioned. Further on, all groups of participants said that they thought the navigation was easy to understand and use. Next, a few examples of the observation notes and interview responses found during the evaluation will be highlighted per each main feature evaluated. A summary of all the high fidelity prototype evaluation findings can be found in Appendix I.

Task	**Version 1**	**Version 2**	**Version 3**
Introduction page 1	**I:** 1/1	**I:** 3/4 (1 PB) **D:** 1/4 (1 PB)	**I:** 2/2
My questions 1	**D:** 1/1	**I:** 3/4 (1 PB) **D:** 1/4 (1 PB)	**I:** 2/2
My questions 2	**I:** 1/1	**I:** 3/4 (1 PB) **DS:** 1/4 (1 PB)	**I:** 2/2
My page 1	**I:** 1/1	**I:** 3/4 (1 PB) **DS:** 1/4 (1PB)	**I:** 1/2 **DS:** 1/2
My page 2	*	*	*
My page 3	**I:** 1/1	**D:** 3/4 (1 PB) **DS:** 1/4 (1 PB)	**I:** 2/2
My treatment 1	**D:** 1/1	**I:** 4/4 (2 PB)	**I:** 2/2
My treatment 2	**I:** 1/1	**D:** 1/4 **DS:** 1/4 **I:** 2/4 (2 PB)	**I:** 2/2
My nursing staff 1	**DS:** 1/1	**I:** 4/4 (2 PB)	**I:** 2/2
My nursing staff 2	**I:** 1/1	**I:** 3/4 (2 PB) **D:**1/4	**I:** 1/2 **D:** 1/2

Table 6.1: A table displaying how well the participants managed to complete the tasks during the evaluation. The different levels of completion of the tasks were Immediately and without support (I), with some delay but without support (D) and with some delay and support (DS). Participants who participated before are marked 'PB'. The '*' next to the task "My page 2", which was a bit different than the other tasks, represents that the task was accomplished.

Introduction page

Version 1

- The participant chose the interface that was designed for the age group she belonged to.

Version 2

- All participants except for one in this age group chose the versions that were designed "for them". The one participant that chose version 3 instead of 2 was a 12 year old boy.

Version 3

- Only one of the participants chose the version that was designed for the age group she belonged to (Version 3), the other chose Version 2. The participant who chose Version 2 explained that she interpreted Version 1 as too simple and Version 3 as it would require the user to read and do too much.

My questions

Version 1

- The start page was said to be aesthetically pleasing and the buttons to different main features clearly distinguishable
- It was discovered that the mark informing the user that a question has a response could be made more prominent

Version 2

- One could make the distinction between answered and unanswered questions even more clear by adding headers.
- One participant said that the page was easy to understand and one said that it could have been made clearer on how one could see the answers from the nursing staff (which was mentioned by one of the participants who had participated before).

Version 3

- The feature was liked in general, even though one participant would have appreciated being able to ask questions and receive responses in between appointments, as well as during appointments.

My page

Version 1

- The overall purpose, functionality and content of the page was correctly interpreted and explained.

Version 2

- The participants hesitated regarding how they should close the drawing-button (including the participants who had participated before).
- One could add a function to be able to sort out specific notes based on themes or similar. This could be beneficial if you have many notes.

Version 3

- Due to the fact that the “previous month”-button in the calendar view and the back-button in the header were mixed up, they could be made more distinguishable.

My treatment - My medicines

Version 1

- To make it even more easy for children to find their way, it was suggested to consider changing the icon used on the “My treatment”-button on the start page to a tablet icon instead.

Version 2

- The feature to be able to add your own image of the medicine is good to include but it could be made more clear.
- The previous-medicines-button could have been made more clear and prominent (which was mentioned by one of the participants who had participated before), as one participant initially thought that the second medicine presented on the page was a previous medicine.

Version 3

- The informal way of presenting information about medicines was appreciated as well as being able to have pictures of the tablets.

My nursing staff

Version 1

- It was suggested to add a map-feature to this page to make it even easier to find the location of different departments.

Version 2

- The participants thought the page looked good and was easy to understand. Although, the participants did mention that it could have been made clearer that one could click on the card to receive more information (which was also said by one of the participants who had participated before).
- One of the participants suggested that the page could include a short information of every department and what one can do there.

Version 3

- To help users understand that contact information is presented when pressing the department-card, it was suggested to add an arrow button and/or a text saying for example “press here to read more!”. One participant first thought that contact information was presented on the “preparations before an appointment”-page.
- The appearance of the page was appreciated, except from the cartoon-icon, which were to be used for nursing staff which lacked real photos of themselves, in Hälsokollen, that was perceived to decrease the seriousness of the page.

Final interview questions

Version 1

- It was suggested to consider changing or removing the house icon from the buttons on the start page that does not have a clear connection to a certain place or building, such as “Background colors” and “My questions”
- Hälsokollen as a whole was perceived as useful, and the participants said they would definitely use it as long as the data entered was safely stored

Version 2

- One of the participants thought the amount of hierachies used in Hälsokollen was appropriate.
- A name suggestion that came up was “Hälsokollen”, which came to be the winning name suggestion. One participant thought the original name “Hälsoappen”, that had been used up until this phase of the project, was good.

- One of the participants (that had participated before) said that he would not have liked to navigate in any other way than the one used in Hälsokollen now.

Version 3

- That you are able to change the background color in Hälsokollen was perceived as an appreciated and important feature by one of the participants, since it allows users to choose whether they want to get a "hospital-vibe" from using the tool (which this participant associated with the blue color used in the prototype), or not.

6.5.4 Creation of guidelines

All findings from the evaluations throughout the project, together with the requirement elicitation, were analysed and combined to create a list of guidelines that could possibly aid the future designing of adaptable eHealth technologies for children between 5 to 18 years of age. When specific findings, from the three phases where potential users provided feedback, were observed as recurring or perceived as specifically salient, these findings were noted and saved as bullet points. From the bullet points that were supported by several findings, the points that were considered most interesting and important to consider when designing similar eHealth technologies in the future, were sorted out and re-formulated into a collection of twelve design guidelines. The full list of guidelines is presented in the upcoming Results chapter.

7

Results

In this part of the report, the results of the project will be presented, displaying both the final design prototype of Hälsokollen as well as the design guidelines created. To connect back to the research questions of the project, the section called "Design guidelines" aims to answer the question: *What design guidelines should be taken into consideration when designing an adaptable eHealth technology for 5 to 18 year old children?*, and the section called "Design prototype" aims to answer the sub-question: *What is a plausible design suggestion of such an eHealth technology, to be used by 5 to 18 year old children with long-term illnesses within Swedish health care?*.

7.1 Design prototype

In this section, the final design prototype will be presented together with a summary of the feedback from the last evaluation. Each of the six main features, together with the introduction page, start page and settings, will be presented in individual sections below. The full prototype can be seen in Appendix G. An interactive prototype of version 1 of Hälsokollen can be found on this link:
`https://www.figma.com/file/GkWrZJU53nitsXS8Q6n0ML`.

General feedback of the whole idea of Hälsokollen and its features
Some of the general feedback from the final evaluation that could be considered for further development of Hälsokollen are firstly that all participants, regardless of age, were positive towards Hälsokollen and either said that they would use it themselves or thought that other children with a long term illness would. It was also appreciated to include the feature of being able to listen to text content in Hälsokollen, if one for example have trouble reading. Lastly, the fact that the text content was made simple to understand, yet not too "childish", was also appreciated.

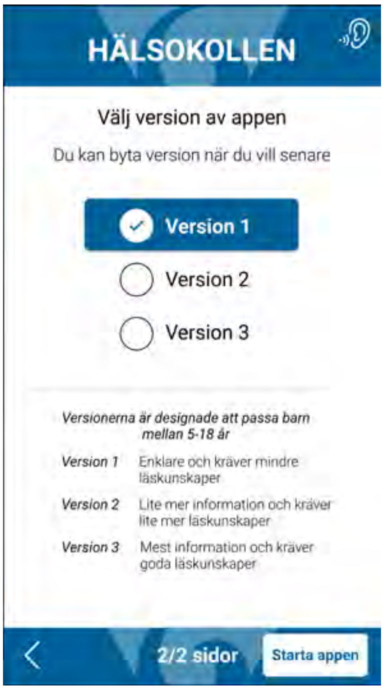
7.1.1 Introduction page

This is the first page that a user encounters when starting up Hälsokollen for the first time. The user is then presented with an introduction of Hälsokollen and its purpose, see Figure 7.1. After that, the user is asked to choose between three versions of Hälsokollen, see Figure 7.2.

Denna app är en del av ett förbättringsarbete som syftar till att göra barn och ungdomar med långvarig sjukdom mer involverade i sin egen hälsa och behandling. Projektet är ett samarbete mellan Sahlgrenska Universitetssjukhuset samt Chalmers Tekniska Högskola i Göteborg. Appen är speciellt framtagen tillsammans med neurologmottagningens patienter som är mellan 5-18 år gamla.

Målet med appen är att patienter, genom kontinuerlig användning av appen, ska få en bättre förståelse för sig själva, sin diagnos och behandling av den redan från tidig ålder. Många barn är idag vana app-användare, men eftersom alla barn är olika och kan behöva olika stöd och hjälp har vi skapat tre versioner av appen. På nästa sida kan du eller ditt barn själv välja den version ni gillar bäst!

Figure 7.1: Image displaying the first screen displayed when starting up Hälsokollen for the first time.



Välj version av appen

Du kan byta version när du vill senare

☑ Version 1
○ Version 2
○ Version 3

Versionerna är designade att passa barn mellan 5-18 år

Version 1 Enklare och kräver mindre läskunskaper
Version 2 Lite mer information och kräver lite mer läskunskaper
Version 3 Mest information och kräver goda läskunskaper

Figure 7.2: Image displaying the second screen displayed when starting up Hälsokollen for the first time.

Some of the feedback from the final evaluation that could be considered for further development of Hälsokollen are firstly that the page was said to look nice and professional with the VGR logo included. A majority of the participants also reported that the page was easy to understand with a good explanation of the difference between the three versions. A possible improvement that did arise was to possibly make it even more clear what the different versions contain.

7.1.2 Start page

The start page displays the different features Hälsokollen contains. Thereby “My page”, “My questions”, “My treatment”, “My nursing staff”, “Preparations for an appointment”, “Background color” and “Settings”. In Version 2 and 3, “Background color” lies underneath “Settings”. The three different versions can be seen in Figure 7.3, 7.4 and 7.5 below.

Some points of feedback that were stated during the final evaluation and that could be considered for further development of Hälsokollen is firstly that the idea to include the feature “Background colors” on the start page for version 1, but hiding it behind the button “Settings” for version 2 and 3, was a good idea. The navigation in Hälsokollen was also considered to be easy to use by all participants, with an appropriate level of hierarchies. Two suggestions of improvements stated was firstly to consider removing the house icon from the buttons on the start page, in version 1 (Figure 7.3), that does not have a clear connection to a certain place or building, such as “My Questions”. Further on, one participant evaluating version 3 (Figure

7.5) stated that the roundabout lines connecting the buttons could be left out, which then needs to be considered during future developments.

Figure 7.3: The start page of version 1 of Hälsokollen

Figure 7.4: The start page of version 2 of Hälsokollen

Figure 7.5: The start page of version 3 of Hälsokollen

7.1.3 My page

On the page "My page" (Swedish: Min sida), the user can tell things about themselves, which they later can show to the nursing staff. They can also use the notes to help them keep track of their life and diagnosis. What could be told on these pages are things such as personal interests, how they are doing in school, what they are feeling or thinking of or anything else that comes to mind, see Figure 7.6 and 7.7 below. They can express this by writing or by adding drawings, smileys, images, audio and video recordings, which can be seen in Figure 7.8 below. Example questions are also presented to help guide the user of what he/she could tell about. The descriptive text is transferred to the information icon when interacting with the page.

Jag heter Alva. Jag är 7 år gammal. Jag har en mamma, en pappa och lillasyster.

Jag vill även berätta om...

Figure 7.6: The first screen of the page "My page" of version 1 of Hälsokollen

Figure 7.7: The second screen of the page "My page" of version 1 of Hälsokollen, showing an overview of your previous notes.

Här kan du berätta om vad du tycker, känner och hur just du vill ha det när du träffar doktorn. Svara på meningarna nedan eller skapa dina egna genom att klicka på de runda knapparna!

Jag tycker det är jobbigt när...

Jag vill att ni...

Jag vill inte att ni...

Figure 7.8: The third screen of the page "My page" of version 1 of Hälsokollen, showing the editing screen when creating a new note.

Some of the feedback from the final evaluation that could be considered for further development of Hälsokollen are firstly that it was wise to include the page "Other things I'm thinking about" (Swedish: Annat jag tänker på) for the users to have a place to express thoughts and feelings that are not tied to a specific category or topic. It was also appreciated to include example questions of what a user could write or talk about on this page. The overall purpose, functionality and content of the different screens of the page were correctly interpreted by a majority of the participants, regardless of the version they evaluated. The appearance of the page, such as icons, images and amount of text, was also stated to be appreciated. Some possible improvements that were stated were firstly to add a feature to be able to sort out specific notes based on themes or similar, which referred to the overview screen in Figure 7.7. Secondly, a suggestion was stated to make it more clear that "My page" is a place where users get the opportunity to express their own thoughts, opinions and feelings, regarding both things related to their everyday life and things related to their treatment at the hospital. Due to the fact that some participants had trouble closing the editing buttons on the editing page, Figure 7.8, these should be improved in future work as well.

7.1.4 My questions

On this page called “My questions” (Swedish: Mina frågor), the user can write down questions or other things they are wondering about regarding their diagnosis or treatment. They bring their questions to their doctor’s appointments and are able to write down the responses in Hälsokollen together with their nursing staff. Just like at the page “My page”, see Figure 7.9 and 7.10, they can express their questions or answers by writing or by adding drawings, smileys, images, audio and video recordings. They are also able to view previously entered questions and their answers.

Mina frågor

Mina tidigare frågor

Februari 2020

+ Ny fråga

Besök 15 Februari

Obesvarad fråga

Hur länge kommer jag vara sjuk?

?

Fråga:

Gör det ont att ta spruta i armen?

Agneta har svarat

Figure 7.9: The first screen of the page “My questions” of version 1 of Hälsokollen

Mina frågor

Besök 15 Februari

Sparad 2020-02-14

Ta bort allt

Fråga:

Gör det ont att ta spruta i armen?

Svar:

Det gör bara lite ont en jättekort stund, men det går över snabbt!

// Agneta, doktor

2020-02-15

Figure 7.10: The second screen of the page “My questions” of version 1 of Hälsokollen, showing how an answered question could look like.

Some of the feedback from the final evaluation that could be considered for further development of Hälsokollen are firstly that the appearance of the page, in form of icons, color and images for example, was appreciated by a majority of the participants, regardless of which version they evaluated. Further on, the screens on the page were also found to be easy to understand by a majority of the participants. The page and feature “My questions” was appreciated by the participants but some of them also mentioned that they would like to be able to communicate with the nursing staff outside appointments as well. Another possible improvement suggested could be to make the distinction between answered and unanswered questions even more clear, by for example adding headers.

7.1.5 My treatment

In this part of Hälsokollen, called “My treatment” (Swedish: Min behandling), the user can see information about their diagnosis and their medicines, see Figure 7.11, 7.12 and 7.13. This information should be written down by the nursing staff or parents during an appointment to make it easy to understand for the child. It is also possible to see a history of your previous medicines and why they were changed.

Namn på diagnos: Epilepsi

Hur kan det påverka mig?: Du som har epilepsi har bara besvär under den tiden då anfallet pågår och en stund efteråt. Anfallen kommer plötsligt och är vanligtvis korta och liknande varje gång. En del epileptiska anfall kan tex ge symtom i endast en kroppsdel.

Varför har jag det?: Epilepsi kan orsakas av bland annat medfödda skador och sjukdomar men ibland vet man inte riktigt anledningen. När hjärnan fungerar som den ska så finns en balans mellan nervcellerna. När man har epilepsi så blir balansen ibland rubbad.

Vad borde jag tänka på?: Några tips man kan tänka på är att sova bra, inte stressa för mycket och att inte utsätta sig för blinkande ljus.

Figure 7.11: The page “My Diagnosis”(Min diagnos) underneath “My treatment” in version 2 of Hälsokollen.

Medicin: Ipren

Hur ska jag ta medicinen?: Tabletten sväljes med vatten

Varför tar jag medicinen?: Medicinen är till för att hjälpa så huvudet inte gör ont

Hur påverkar medicinen mig?: Medicin stoppar skapandet av det i kroppen som gör att det gör ont i huvudet

Datum medicinen gavs ut: 12 mars 2020

Medicin: Alvedon

Hur ska jag ta medicinen?: Tabletten löses upp i ett glas

Figure 7.12: The page “My Medicines” (Min medicin) underneath “My treatment” in version 2 of Hälsokollen.

2020

Februari

Alvedon

2019

December

Ipren

Hur ska jag ta medicinen?: Tabletten sväljes med vatten

Varför tar jag medicinen?: Medicinen är till för att hjälpa så huvudet inte gör ont

Hur påverkar medicinen mig?: Medicin stoppar skapandet av det i kroppen som gör att det gör ont i huvudet.

Varför ändrades medicinen?:

Figure 7.13: The screen showing previous medicines on the page “My Medicines”(Min medicin), in version 2 of Hälsokollen.

Some of the feedback from the final evaluation that could be considered for further development of Hälsokollen are firstly that the topic “what should I think about” (Vad bör jag tänka på) on the page were information about the patient’s diagnosis is presented, is very good to include. It was also said to be wise to place the editing button on both the page “My diagnosis” and “My medicines” underneath the information button in the header, to minimize the risk of the younger children accidentally pressing it. To include a warning text on the “My medicines” page encouraging the users to make sure that information on the page is updated was also appreciated, which among other things were presented when clicking the information icon. Further on, it was mentioned that the informal way of presenting information about medicines was appreciated as well as being able to have pictures of the tablets.

The overall look and feel of the page was appreciated, but a suggestion of improvement, made by participants evaluating version 1 and 2, was to change the icon representing the page “My treatment” on the start page into one that is more intuitive what it represents, e.g. a tablet icon. Apart from the icon on the start page being unclear, the page was perceived to be relatively easy to understand by a majority of the participants, regardless of which version they evaluated. One other aspect that might be worth pointing out was that some participants at first had trouble finding the previous medicines button, due to it having the same color (white) as most of the components on the page. An improvement could then be to make the button more prominent. Lastly, another suggestion of improvement was to make the text on the previous medicines page in a larger size for the younger children.

7.1.6 My nursing staff

In the part of Hälsokollen called “My nursing staff” (Swedish: Vi på sjukhuset), which can be seen in Figure 7.14 and 7.15, information about the user’s nursing staff should be presented. This information should be added by the users themselves, preferably together with a caregiver or nursing staff. Further on, information about the departments the user visits should also be presented.

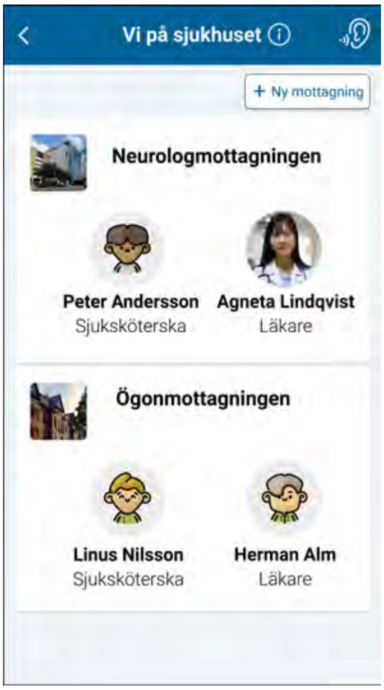


Figure 7.14: The first screen of the page “My nursing staff” (Mina vårdkontakter) in version 3 of Hälsokollen

På neurologmottagningen jobbar jag med att undersöka barn med nedsatt känsel. Där ingår det att undersöka bl.a. reflex, kyla- och värmekänslighet.

Figure 7.15: The second screen of the page “My nursing staff” (Mina vårdkontakter) in version 3 of Hälsokollen, displaying more information about a department

Some of the feedback from the final evaluation that could be considered for further development of Hälsokollen are firstly that the appearance of the page was appreciated by a majority of the participants, who for example mentioned that it was good that you could add your own images of nurses and departments. The people icons were, on the other hand, appreciated by most of the participants but not by one participant evaluating version 3, who instead thought they decreased the seriousness of the page. It could therefore be important to note that the people icons should be optional to use. Further on, the project initiators mentioned that it is a good idea to fetch contact information etc. about the departments from VGR databases, to make sure it is updated. They also said that one should be able to add new departments on this page, regardless of whether they are part of Sahlgrenska University Hospital or other hospitals that the user might visit.

A majority of the participants thought that the page was easy to use and understand but a critical feedback provided was to make it more clear that you could click on the different “department cards” to go to a page with more detailed information about that department and your nursing staff. Participants, evaluating both version 1 and version 3, also stated that it might be difficult to differentiate between this page and the one called “Preparations before an appointment”. It might therefore be of important to change the name or icon for the pages, on the start page, to make this more clear. Some further suggestions of improvements mentioned were to possibly add a map-feature on the page and to include a short description of each department and what one can do there.

7.1.7 Preparations before an appointment

In this part of Hälsokollen, called “Preparations before an appointment” (Swedish: Tips inför besöket), there is a link to the web page Dunder, which is created by Sahlgrenska University Hospital. On this webpage, see Figure 7.16, users can learn more about how doctor’s appointments and different medical procedures are carried out on different departments, in a child-friendly way. No specific feedback for future development are stated here due to the fact that the page was not evaluated during the final evaluation.

7.1.8 Background color

On the page called “Background color” (Swedish: Bakgrundsfärg) the user should be able to change the color of the background, see Figure 7.17. One point of feedback from the final evaluation that could be considered for further development of Hälsokollen was that this feature was perceived as an appreciated and important feature by 1 of the participants, since it allows users to choose whether they want to get a serious and professional “hospital-vibe” from using Hälsokollen (which this participant associated with the color blue), or a more playful and fun vibe. This feature was not specifically evaluated by participants, but one group of participants mentioned that they would have liked to add more fun images of animals etc. in the background, which could point towards that including background themes in future developments of Hälsokollen could be a good idea.

Vill du veta mer om hur ett besök på sjukhuset kan gå till och förbereda dig?

Klicka på mig för att gå till Dunders barnsida!
Du kommer att lämna appen.

Figure 7.16: Page called "Preparations before an appointment" ("Tips inför besök") from version 1 in Hälsokollen.

Figure 7.17: Background color (Bakgrundsfärg) selection in version 3 of Hälsokollen.

Figure 7.18: The first screen of the "Settings page" of version 3 of Hälsokollen. The two alternatives "Version of the app" and "Background color" can be chosen.

7.1.9 Settings

On this page,"Settings" (Swedish: Inställningar), users are to be able to change between the three different versions of Hälsokollen, see Figure 7.18. In version 2 and 3 of Hälsokollen, the feature "Background color" is placed here as well. No specific feedback for future development are stated here due to the fact that the page was not evaluated during the final evaluation.

7.2 Design guidelines

This section proposes a set of guidelines that, based on the findings in this project, seems relevant to consider when designing an adaptable eHealth technology for 5 to 18 year old children. Throughout the project many promising findings were found but only the most important ones were translated into guidelines and presented in this section. The list of guidelines are, as described in the section "Creation of guidelines", a combination of guidelines found in this and in previous studies. Some of the guidelines are based on the features that were implemented in the prototypes, while some are based on features that were desired to be implemented in case Hälsokollen became real, which therefore might need to be investigated further to check their relevance. Moreover, the guidelines found relates to two main topics, namely what type of content and features was found as relevant to include in this type of technologies, as well as some main considerations to take when designing the interface, the interaction and the experience of using such technologies.

7.2.1 Content

1. *Enable children to tell about themselves, to write down questions and to play educational games, as well as to view information about their medicines, their diagnosis, their nursing staff, how different medical procedures are carried out and their own history, to make them more involved in the various aspects of their illness and treatment.*

   Based on findings from the three phases of the process where potential users and stakeholders were involved (requirement elicitation (section 6.2.2.5), medium fidelity prototype evaluation (section 6.4.3.5) and high fidelity prototype evaluation (section 6.5.3.5)), all of the above mentioned features received positive feedback. For example, in the interview with patients and caregivers during the requirement elicitation phase, none of the groups of participants thought that any of these features were unwanted, even though some were reported as more or less important to integrate in a tool like Hälsokollen. In all age groups, there were also groups of participants that, among other things, said that they thought a tool with such features could help them improve the communication with their nursing staff as well as help children understand their diagnosis better. Moreover, apart from the findings in this project, the inclusion of these features could potentially also be supported by the *The Persuasive Systems Design Model (PSD model)* presented by Oinas-Kukkonen and Harjumaa [54]. This model explains that a system that allows the user to keep track of their progress or status helps them achieve their goals or perform target behaviors. Since one of the goals of using Hälsokollen is to increase children's knowledge and involvement in their own health care, the possibility for them to track their health care-related subjects (i.e. their medicines, diagnosis, nursing staff and self-status) could potentially help them reach these goals. Therefore, all the features mentioned were considered relevant to include in similar eHealth technologies. Furthermore, the features were also implemented and kept as main features in Hälsokollen throughout the process, except for educational games that was excluded during the ideation phase, due to the time available for the project being limited.

2. *Enable children or their caregivers to customize the tool in different ways, such as to choose between different difficulty levels and appearances, to better fit the varying personalities, diagnosis and ages among children.*

   In the two last phases where stakeholders and potential users were involved, i.e. medium fidelity prototype evaluation (section 6.4.3.5) and high fidelity prototype evaluation (section 6.5.3.5), the findings showed that several groups of participants liked the idea of being able to choose between different background colors in Hälsokollen, which was implemented in the prototype (see Figure 7.17). Additionally, participants mainly evaluated one of the interface versions, i.e. the version that corresponded to each child participant's experienced age, during the medium- and high fidelity prototype evaluations. In these evaluations, participants were asked about the difficulty level of the version they were shown to, where the majority of participants said that they thought the difficulty level of that version was good. Further on, there were a few cases where participants chose or preferred a version that was not designed "for them". There were also explicit comments about the benefits of being able to adapt a digital tool depending on childrens' age, even though these comments were few and came mostly from caregivers and expert reviewers. Moreover, apart from the findings in this project, previous research by Oinas-Kukkonen and Harjumaa [54] states that according to their persuasive features, a system is more likely to be persuasive if it is visually attractive to its users. They also mention that people can be more easily persuaded if a system reminds them of themselves in some meaningful way. These two points could then possibly be achieved by enabling personal customization of a tool. The prototype of Hälsokollen can be adjusted by selecting background colors (see Figure 7.17) and by selecting one out of three versions, thereby difficulty levels (see Figure 7.2 and7.18). This feature could then be further expanded in future work to allow even further customization. Based on these findings, it seems relevant for similar eHealth technologies to enable children to customize the tool based on different parameters, to better fit the varying needs.

3. *Create space for children to share thoughts, feelings and experiences that are not obviously tied to pre-defined categories or topics, or to the illness itself, since more perspectives than initially expected could be important for their health care.*

   One of the findings from both the requirement elicitation phase (section 6.2.2.5), the medium fidelity prototype evaluation phase (section 6.4.3.5) and the high fidelity prototype evaluation phase (section 6.5.2.2) was the appreciation of including a space where children (and potentially also their caregivers) can express things that, at first sight, might not be perceived as relevant for a patient's diagnosis or treatment or fit within commonly related topics. At least one group of participants in the two first phases, and the experts in the third phase, said that they thought it would be or that it was a good idea to offer children such a space. For example, one of the participants in the medium fidelity prototype evaluation explicitly asked about the purpose of being able to tell about your interest or school on “My page” (see Figure 7.6). When explained that it was realized during the interview with patients in the requirement elicitation phase, that children sometimes have wishes of doing certain things that they have difficulties performing due to their illness but might be able to do with the right treatment, this participant immediately agreed that those things could be important to highlight in eHealth technologies like the one designed and implemented in this project.

4. *One should not be afraid of using the word “diagnosis” or to include information about a user’s diagnosis, as long as the information is optional and presented in an objective way. On the contrary, users should be encouraged to learn more about their diagnosis and to be proud of their knowledge.*

   In the interviews with potential users during the requirement elicitation phase (section 6.2.2.5), a few caregivers mentioned that it might be difficult to include a page about children’s diagnosis in a tool like Hälsokollen, especially at young age. This was said to be due to the fact that children do not want to focus on their diagnosis or be put in a box. Simultaneously, a total of four groups of participants representing all age groups except the 9-12 group, especially mentioned this feature as one of the most important ones to include in Hälsokollen (not counting the groups of participants that considered all features presented as equally important). Since the purpose is to let each user decide if and how much information they want to be written about their diagnosis as well as their medicines, this feedback was encountered by combining these two features into one main feature - “My treatment” which was implemented (see section 7.1.5). By using this title on the start page instead (see Figure 7.3, 7.4 and 7.5), one could avoid children from seeing the word “diagnosis” and getting reminded of it every time they open Hälsokollen or go to the start page. This way, they can choose to view information about their diagnosis if or when they want. In the expert reviews during the medium- and high fidelity prototype evaluation phases (see section 6.4.2.2 and 6.5.2.2), this was also considered a good solution, where the project initiators that were part of one of the expert reviews said that they thought one should inform children that they have a diagnosis, and make them feel proud that they know things about it. There were also many internal discussions about alternative wordings, which was also brought up to discussion during one of the high fidelity evaluations, where the term “diagnosis” was found to be the correct medical term and therefore considered as the best one to use. Therefore, it seems relevant to include information about a child’s diagnosis in similar eHealth technologies, as long as individual users’ feelings are respected and accounted for.

7.2.2 Design, interaction and experience

5. *Enable users to express and acquire information through several different modalities, such as by writing/reading or talking/listening to text, and by adding/viewing different types of images and icons.*

   From the start of this project, one of the requirements was to make it possible for users to express themselves and acquire information in different ways in Hälsokollen (section 6.2.1). This was important due to the fact that Hälsokollen would be used by many different types of users - children in various ages, with varying diagnosis and difficulties, their caregivers and various nursing staff, along with all those users' individual preference of how to express themselves or acquire information. To account for this, multiple ways of adding information (writing, drawing, adding smileys, images, audio- and video recordings (see example in Figure 7.8) was implemented to meet those different needs, along with the ability to read or listen to text and to view images, icons and slideshows. This was found to be appreciated by groups of participants both during the requirement elicitation (section 6.2.2.5) and the medium fidelity prototype evaluations (section 6.4.3.5). Moreover, apart from the findings in this project, previous research can be said to support this guideline as well. For example, Budiu and Nielsen [25] suggests that when designing for children in the ages of 5-12, one should use images as a supplement to text and that the images used should resemble things that children are familiar with in the physical world. The use of real-life metaphors is also discussed as an advantageous feature, especially for children that do not know how to read yet, by Sherwin and Nielsen [60]. Furthermore, Ludden et al. [48] argues that the use of metaphors is successful because they are interpreted intuitively. Moreover, Ludden et al. [48] also promotes the use of metaphors due to the fact that they add fun, meaningfulness and engagement, which fosters motivation for goal achievement. Therefore, this guideline could be good to consider when designing similar eHealth technologies.

6. *Help users complete activities in the tool by breaking them down into smaller tasks and by providing concrete examples and hints.*

   That children sometimes have a hard time expressing themselves was something that was both experienced by the authors themselves and mentioned by several groups of participants, especially during the interviews with potential users in the requirement elicitation phase (section 6.2.2.5). In the medium fidelity prototype evaluation (section 6.4.3.5), both with potential users and experts, it was suggested to make it easier for children to express things about themselves on "My page" if they received concrete examples of things to tell, such as example questions to answer or pre-made sentences with gaps to fill in. Another example of where tasks in the interface were divided into several steps was on the two introduction pages implemented, where users only could read about the interface versions on the first page (see Figure 7.1), and select version on the second page (section 7.2), which all groups of participants in the high fidelity prototype evaluation said was easy to understand (section 6.5.3.5). Moreover, this guideline could also be said to be supported by previous research by Oinas-Kukkonen and Harjumaa [54] and their PSD model. They argue that when a system breaks down more complex activities, such as users being encouraged to“tell about themselves", into smaller tasks, such as answering specific example questions like “Do you have any fears related to your doctor’s appointments?", it aids users in completing their target behavior because they come to see progress (even if it is smaller) faster. Based on these findings, helping children performing tasks by dividing them into several small ones seems to be a guideline worth considering in the design of similar eHealth technologies.

7. *Help users judge the credibility of the tool by providing a serious impression, without being boring.*

   During the requirement elicitation (section 6.2.2.5), several participants mentioned the relevance of having credible content in a digital tool like Hälsokollen. To enhance the credibility of Hälsokollen, apart from allowing nursing staff entering truthful information, the Introduction page of the Hälsokollen was made to display information about the background and founders of Hälsokollen in a professional and trustworthy way, as well as incorporating the logo of VGR (see Figure 7.1 and Figure 7.2). The project initiators also mentioned, during the high fidelity expert review (section 6.5.2.2), that the implemented page looked good and professional with the VGR logo included. Something noted during the medium fidelity prototype evaluation (section 6.4.3.5) was that many participants complained about the colorlessness of the prototype, even though it was mentioned that more colors would be included later in the process. One participant even stated that a page looked “old”. Moreover, this guideline could also be said to be supported by previous research. Oinas-Kukkonen’s and Harjumaa’s [54] PSD model explains that a system have greater persuasive powers if users perceive it as trustworthy, and that the perception of trustworthiness increases if users get a good first impression of the system, and/or if the people/organization behind it is presented. Due to these findings just mentioned, it was considered important to highlight this guideline for future work.

8. *Use a simple navigation structure, such as a start page and a back button from which all main features can be entered and exited.*

   The navigation that was implemented in Hälsokollen was mainly evaluated in the high fidelity evaluation (section 6.5.3.5), due to the prototype only being interactive at this stage. All participants stated that the navigation was good and easy to understand in Hälsokollen and one participant even said that he would not have liked the navigation to have worked in any other way. Further on, when observing the participants performing the tasks in the evaluation of the high fidelity prototype and navigating around Hälsokollen, the overall finding was that the participants had no trouble understanding how to navigate. The previous literature by Budiu and Nielsen [25] also discusses that you should make the navigation easy and non-redundant, to not confuse the children. Children will most probably use common ways of navigation that they have learned before. Further on, Budiu and Nielsen mention the importance of presenting the breadth of a digital tool's content already on the start page. This could help children see what the tool has to offer and were to find those features. This has been pursued in the final prototype of Hälsokollen (see section 7.1.2), but due to the fact that some misinterpretations still occurred, this could probably be made even more easy and clear for the children. Therefore, it was considered important to highlight this guideline for future work.

9. *Do not structure features or information in more hierarchies than necessary - the fewer the better.*

   One finding from the final evaluation, of the high fidelity prototype (section 6.5.3.5), was that the implemented level of hierarchies seemed to be appropriate. One participant mentioned this specifically and also said that Hälsokollen was easy to understand and perspicuous. Further on, the overall findings from observing the participants while they performed their tasks in the evaluation of the high-fidelity showed that they had no trouble understanding how to navigate around the different hierarchies. Thereby, they did not seem to get confused or “get lost” in the hierarchies. Further on, all participants stated that Hälsokollen and its navigation was easy to understand. The guideline could also be said to be supported by the previous work of Budiu and Nielsen [25]. They stated in their book that you should not use deep and circumstantial navigation in digital tools for children. One example they bring up is that a child that clicks on a buttons saying “games” expect to find a game on the next page. This has been accounted for in the final prototype of Hälsokollen, by keeping the level of hierarchies to a minimum. Although, some hierarchies in Hälsokollen, such as the three hierarchies related to the feature “My page”, might still need to be investigated if they are clear and intuitive enough to be kept (section 7.1.3. Therefore, this guideline could be relevant to emphasize in future work.

10. *Increase users' perception of security of using the tool such as by protecting the information entered with login systems like passwords, BankID, and/or integration in the personal pages on the Swedish Healthcare Guide 1177 website.*

    A login system has not yet been implemented in Hälsokollen, both due to lack of time and because it belongs more to the next step in the development process. However, feedback has been collected from participants, both during the requirement elicitation (section 6.2.2.5) and high fidelity evaluation (section 6.5.3.5), stating the importance of data security in tools like Hälsokollen. One participant did for example say, during the high fidelity evaluation, that she would not even consider using a digital eHealth tool if it did not ensure data security. When mentioned that a login system would be planned to be implemented in potential future work of Hälsokollen, it was appreciated by participants. Due to the stated importance of security in a digital tool like Hälsokollen, this was considered to be a valuable design guideline.

11. *Make it simple for nursing staff to enter and edit information, as their time might be limited.*

    This was a fact that has been discussed between the authors of this report and the project initiators throughout the project, even though focus was on designing the children's interface and features addressing the specific needs among nursing staff were not fully implemented in the prototype made in this project. The project initiators have stated that the nursing staff needs to be able to read and write down information in Hälsokollen during appointments in an easy and effective way, due to their restricted time. They do not have time to use Hälsokollen outside of appointments or to perform complex authorisations when entering data into the tool. Although, they could, together with the patient, use the patient's or his/her caregiver's phone when entering information during an appointment. Due to the fact that some information in Hälsokollen are only meant for the nursing staff to enter and edit, such as information about medicines and a patient's diagnosis, these were suggested by the authors of this report to be protected by a password-lock. Although, due to the reasons stated above, this was not considered a good solution by the project initiators, as can bee seen in section 6.4.2.2. The activity to make sure that a digital tool like Hälsokollen is simple for nursing staff to use was therefore considered important to include as a guideline for future work.

12. *When designing for children in the ages of 5-8, make it a bit tricky and less attention-catching to edit and delete information that has been entered to the tool, if they are not supposed to edit and/or delete it.*

    After having read a lot about children and child-computer interaction, one take away was that young children like to explore and click on things they see, even things they are not supposed to interact with. This is something that has been discussed between the authors of this project and the project initiators throughout the project. Due to the fact that some information in Hälsokollen is not meant for the children to edit themselves, such as information about medicines and their diagnosis (see Figure 7.12 and Figure 7.11), the edit button of that information should not be as prominent to children. A simple solution, that could possibly fit many digital tools within this domain, could for example be to implement a password-lock on certain information. Although in this project, the project initiators requested a tool without any passwords and similar, to make it as easy as possible to use for all the different types of users (children, caregivers and nursing staff). Furthermore, a participant that evaluated the medium fidelity prototype (see section 6.4.3.5), a caregiver to a 7-year-old, commented that he would prefer edit buttons, that were not meant for children to interact with, to be hidden. Therefore, a solution in this project was made by placing the edit button underneath the information icon button in the header, on those pages were the information was not to be changed by children themselves. This was inspired by the previous guidelines presented by Sherwin and Nielsen [60], which for example states that one can “hide” certain links or buttons, that is supposed to be used mainly by adults, in places that children are unlikely to click. Additionally, Budiu and Nielsen [25] discusses that caregiver’s usually prefer sites where children can play around themselves without needing help from an adult all the time. Further on, except from “hiding” the button, the idea was also to let at least one modal pop-up appear on the screen if the child would still reach the button, although this feature was not implemented or evaluated in the prototypes of this project. However, the idea of this solution was stated to be appreciated by the project initiators, during the high fidelity prototype evaluation (see section 6.5.2.2), and could therefore be suggested as a solution to projects where a password-lock is not suitable or desired. It was therefore also concluded that this might be an important guideline that similar projects could be inspired by.

8

Discussion

In this chapter, the results of the project will be discussed in accordance with the research questions and previous studies within the related fields. Furthermore, a discussion of the process and the methods used in the project will be presented. Lastly, a set of examples of potential continuous and future work is proposed.

8.1 Results

The aim of this study was to investigate in which ways eHealth technology could be used to enhance children's involvement in their own health care, and to provide new insights to the field of interaction design and children. This is in line with the UN's Convention on the Rights of the Child, which recently has become a law in Sweden, as well as the CN's aim of increased active patient participation. More specifically, this study was to investigate what design guidelines should be taken into consideration when designing an adaptable eHealth technology for 5 to 18 year old children, as well as how a plausible adaptable eHealth technology, created for 5 to 18 year old children with long-term illnesses within Swedish health care, could be designed. The results consists of a high fidelity prototype of an adaptable eHealth technology, as well as a set of design guidelines to consider when designing for children between 5 to 18 years old with long-term illnesses, that will be discussed separately and in more detail in the sections below.

8.1.1 Design prototype

The sub-research question of what a plausible design suggestion of an eHealth technology, to be used by 5 to 18 year old children with long-term illnesses within Swedish health care is, have been answered in this project by creating a design prototype of such a digital tool, through literature studies and empirical research. The high fidelity prototype created in this project was evaluated by people that qualified for one or more of the end user characteristics, where the general response showed that Hälsokollen and its interface was widely accepted and appreciated. The project initiators in particular were very satisfied with the end result.

Hälsokollen is however still in an early design phase, with many suggestions of improvements from expert reviewers, evaluation participants and the authors themselves. There were also some usability issues found during the high fidelity prototype evaluation which need to be worked on further. For example, during the task completion phase, users seemed to mix up “My nursing staff” and “Preparations before the appointment” and had trouble understanding that one could press the card displaying information about a certain department on the “My nursing staff”-page, which they also mentioned. Therefore, some examples of improvements were to consider how “My nursing staff” and “Preparations before the appointment” could be differentiated, or perhaps how they could be combined, as well as to add some sort of signifier on elements that were not obviously clickable. Another feedback that came up regarded the fact that children could ask their nursing staff if they could take a picture of them to include in the “My nursing staff”-page in Hälsokollen. An ethical aspect that one would need to consider in future developments of the tool is to make sure that the nursing staff do not feel guilt tripped into letting patients include a picture of them in their tool, if they do not actually want to. Moreover, the fact that two of the participants in the high fidelity prototype evaluation also were participants in the evaluation of the medium fidelity prototype was considered a potential issue, especially for the task completion phase, due to the fact that they were already a bit familiar with the different pages included in Hälsokollen and therefore might have performed better. However, this did not seem to be the case as one of those participants performed approximately as well as the other participants, and the other one generally needed more time and support to complete a higher frequency of tasks than the other participants. That these participants had participated before might still have affected their interview responses however, but it is impossible to tell either, especially considering the small sample size.

Additionally, many suggestions of features and qualities that are more relevant for a potential future development and implementation of Hälsokollen have been proposed and will be discussed further in the future work section at the end of this chapter. The design prototype made in this project should therefore both be considered a suggestion and an inspiration of how such eHealth technologies could take form, as well as form a basis for future work of Hälsokollen within Sahlgrenska University Hospital, who requested the project.

By viewing the similar and related work that has been done previous to this project, as mentioned in the background chapter of this report, several similarities and differences with Hälsokollen can be identified. The special aim of this project, thereby to be a general and easy to use communication tool between children (in the age span of 5 to 18 years) with different long-term illnesses and their health care providers, where the application is meant to be used during and between appointments, was not found in any other products found while performing this project. A lot of similar work has been done, but they are either specific to certain illnesses or cognitive impairments, online distance communication tools or solely informational tools. Neither have a similar work been found that is designed to be suitable for such a wide age span. This exploratory study therefore has a possibility to add valuable knowledge to this research area and possible future work. Moreover, it could be of value for similar future studies to even further investigate and take inspiration from the related work.

8.1.2 Guidelines

Based on the research question of what design guidelines should be taken into consideration when designing an adaptable eHealth technology for 5 to 18 year old children, a collection of 12 design guidelines have been created as a suggestion of considerations to take when designing similar technologies in the future. As described in the "Creation of guidelines" section in the Execution chapter, the guidelines are based on a combination of valuable insights received from the requirement elicitation and the medium- and high fidelity prototype evaluations. Some of the guidelines found are also supported by previous literature, as brought up in the Results chapter. Although, some of the guidelines found did also provide a slightly different perspective or suggested alternative solutions to previous guidelines. These will be discussed below in this section. Furthermore, this project also proposes guidelines that potentially could be new within the domain of eHealth technology for children, since no similar existing guidelines was found during the literature review.

Due to the fact that this study needed to be adjusted according with the ongoing covid-19 pandemic, where both the performance of evaluations and the type of participants involved were different than originally planned (which will be discussed further in the "Process" section below), an important note is that the guidelines created in this project might not be as accurate as they could have been. Since this study was already highly explorative, trying to find *one* solution to a problem rather than the "correct" one, the guidelines created under these uncontrollable circumstances should rather be viewed as suggestions of what *could* be considered when designing similar eHealth technologies.

Four of the guidelines, number 1, 3, 4 and 11, have been found to be the most innovative of the ones presented in this project, considering that no similar guidelines have been found in the literature that has been reviewed in this project. That being said, it does not mean that similar guidelines could have been found and presented in other literature. The mutual topic for these guidelines is that they are all closely related to the health care domain, that this project is part of, where guideline 1, 3 and 4 are mostly related to what type of content one should include and guideline 11 more to the practical circumstances of using an eHealth tool like Hälsokollen. Guideline number 1 and 3 relates to the findings that were considered most salient for this project, while guideline 4 and 11 relates to topics that needed much discussion and careful contemplation of their advantages and disadvantages, as there were findings speaking both for and against them.

Guideline number 2, regarding customization of the tool, could be said to be both supported and challenged by other guidelines from the literature. For example, Sherwin and Nielsen [60] and Joyce and Nielsen [44] talks about the fact that you need to design for narrow age groups, which they say is a minimum of young children aged 3 to 5, mid-range children aged 6 to 8 and older aged 9 to 12. They say that one cannot simply "Design for children" in general. This is partly achieved in this project, with the three different versions of Hälsokollen being designed for the age groups of children aged 5 to 8 years, 9 to 12 years and 13 to 18 years. Although, the aim of Hälsokollen is not only to fit children in certain age groups but also children with different difficulties that might need to use an easier version of Hälsokollen than their age suggests. Therefore, it was concluded to exclude things such as childish text and images in version 1, so that older children using an easier versions of Hälsokollen could still experience it as age appropriate. Further on, even children who are the same age and does not have any specific difficulties can have different preferences in a design. Therefore, as mentioned above, the ability to be able to customize a digital tool could be very important, and should be expanded as much as possible. Furthermore, allowing users to select what is “visually attractive” to them, might increase their willingness to use the tool, as described by the persuasive features presented by Oinas-Kukkonen and Harjumaa [54].

Regarding guideline number 7, that is about providing a serious impression to help users judge the credibility of the tool, there are both guidelines from previous literature that supports it and opposes it. For example, it is supported by Oinas-Kukkonen and Harjumaa [54] PSD model, as described in the Results chapter. However, Joyce and Nielsen [44] argues that children in the ages of 5-12 care more about being entertained and less about credibility, while teenagers have a hard time determining the credibility of a system. Since Hälsokollen is based on three different interface versions where each version can be used by children in all ages, it was considered important for all versions to provide a serious impression, such as by including an introduction page that included information about Sahlgrenska University Hospital being the main organization behind it. Moreover, as it is probable that children’s caregivers would be present during the first time of use of Hälsokollen, and this project had findings suggesting that credibility was considered important among caregivers, this was considered a relevant guideline to include.

Guideline number 10 regards the increase of users’ perception of security. Joyce and Nielsen [44] discusses in their study that children in the ages of 5 to 18 are hesitant to enter private information. To achieve the goal of this project, thereby making children more involved in their own care, it could therefore be important to help children become less hesitant of this by showing the different security measures taken. This could possibly be done, as the guideline states, by including a login system. Using authorized login like BankID would be the safest choice, however, children need to be at least 13 years old and have their caregivers’ consent for using BankID before the age of 18 [14]. This could lead to the children under 13 years of age, or the under-aged children that does not have their caregivers’ consent to use BankID, feeling excluded if their caregivers need to login for them. Therefore, other types of login systems might be needed. However, Budiu and Nielsen [25] argues that children under the age of 6 and children with little web experience can have a hard time understanding concepts like login systems and passwords. This could mean that caregivers still would need to manage the password for those children. Using passwords as a means for data security therefore need to be carefully balanced with the goal of UNCRC and empowerment of children, which might be partly violated if passwords need to be managed by caregivers. Furthermore, the use of passwords could also be discussed in relation to the form a tool like Hälsokollen has, i.e. whether it is implemented as a mobile application or a webpage. In the shape of a mobile application, the data could be stored locally on the device used, which might make it less important to include a login system. However, this could potentially still be a desired feature, especially in case the device gets lost. What could also be done, which might also be quicker to implement than a login, is to emphasize in a digital tool like Hälsokollen that the entering of information is voluntary and that it is the children themselves that choose what to include. Further on, it could also be made clear that the children do not have to present all information entered in the tool to a nursing staff, but can keep some things private if they want to. It could therefore be interesting to investigate how one could present this in the best way possible in a digital tool like Hälsokollen.

Guideline number 12, about making it more difficult for children to edit/delete certain information, is supported by several existing guidelines presented in previous literature, for example the work by Sherwin and Nielsen [60] and by Budiu and Nielsen [25]. As mentioned in the Results chapter, requiring the user to enter a password to be able to edit and/or delete certain information would be another way to make sure children do not edit/delete things they are not supposed to. However, requiring passwords that only caregivers have access to, at least when their children are young, partly takes away the aim of empowering children to have a voice within their own health care, since it would restrict them from deciding what information they want to be able to share or view in the tool. One should not forget that Hälsokollen is meant to be a place where the children themselves are in focus. Restricting this would therefore also be questionable considering the UN Convention on the Rights of the Child. Furthermore, there might be issues when children are turning 13 and are expected to use the Swedish Healthcare Guide 1177 themselves, but might not have access to the password used in the digital tool. Because of this, hiding buttons to make it harder but not impossible for children to edit/delete certain information, seemed to be the right way to go in this project. That being said, it allows future work to investigate this further and to explore other possible solutions as well.

8.2 Process

In this section, possible weaknesses and limitations of the project's process will be discussed.

8.2.1 Limitations due to the covid-19 pandemic

As mentioned in the introduction chapter of this report, many limitations appeared and delimitations had to be made due to the covid-19 pandemic. Thanks to the prototype being digital, no changes to the original plan of creating the prototype needed to be made. The first part of the project, thereby the initial interviews and requirement elicitation, also took part before the covid-19 situation became critical. These could therefore be performed as planned by meeting patients at the Children's Department of Neurology.

The major changes that had to be made were regarding the evaluation of the medium- and high fidelity prototype of Hälsokollen. Due to the visiting-restrictions at hospitals that was introduced at that stage of the process, as well as recommendations to work from home as much as possible, it was no longer possible to visit the CN to perform evaluations with patients. The evaluations therefore had to be made online, through video calls and screen sharing on a computer. This was considered a good solution to the problem and the results from the evaluation of the medium fidelity prototype was considered to be almost the same as if the evaluation would have been performed in the same room. The evaluation of the high fidelity prototype on the other hand could have shown different results if the evaluation would have been performed on a smart phone, with the facilitators and the participants being in the same room. This due to the fact that the participants could have had experienced Hälsokollen more realistically on the device it was designed for, i.e. smart phone. Feedback about the touch interaction with Hälsokollen then had to be skipped, when mouse interaction was used instead. The reason that the authors of this report chose to have the participants evaluate the interactive prototype on their computer instead of on their phone was because the authors could not see the participants interaction path when they were sharing the prototype from their phone-screen. This was possible to see when they shared their computer screen, where the pointer is visible. Moreover, since the participants had to evaluate the prototype on their own computers and share their own computer screens, this might have been experienced as an uncomfortable thing to do with two strangers. There was also one participant who had some troubles sharing her screen, which seemed to bothered her judging from her comments “I’m not so good with computers” and “I need to get help from my husband”. This might have affected her self esteem and performance during the evaluation, which could have been prevented if the evaluation was held in person.

Moreover, due to the fact that the evaluations had to be made through video calls, the consent form and the participant’s consent had to be made verbally as well. Leaving consent information verbally might not have been optimal, considering that the information provided might have been less clear for the participants. Furthermore, it is possible that they might have felt more pressure agreeing with the conditions when prompted face to face and verbally, even though the facilitators did not perceive that any of the participants showed or said something that indicated this. In future work, an improvement could perhaps bee to send information about the consent in text form for the users to be able to read it in their own pace. Although, the questions asked were not of personal character, and any personal thoughts and feelings that were expressed were initiated by the participants themselves. Furthermore, the recordings made during the evaluations were only to be used to fill out gaps and clear out ambiguities in the evaluation notes, and are to be deleted after the project is finalized.

Further on, due to the fact that it was no longer possible to visit the CN to perform evaluations with patients, participants had to be contacted through post mail. An information letter was written by the authors of this report that was posted to the patients by the project initiators together with the patients reminders for their appointments. This, along with the applying-for-participation process being more complicated, could potentially have led to less participants signing up to the evaluations than if the participants could be recruited in person when visiting the CN. Therefore, 5 to 18 year old children that did not have a long-term illness was decided to be contacted to participate in the evaluations as well. Even though involving these participants might not be as optimal as having the intended target users, it was still considered valuable since the main focus of the medium- and high fidelity prototype evaluations was not on the content of Hälsokollen, but rather on the design.

8.2.2 Creation of prototypes

One of the things that were considered throughout the project, and especially during the creation of prototypes, was the fact that young children could have a hard time understanding more abstract or hypothetical concepts [49], such as that prototypes are only representations of “the real thing”. Therefore, the medium- and high fidelity prototype was made with as much real-life examples and details as possible, considering the authors limited knowledge within the medical field and the time limitation aspect. This decision showed to work well in general, even though some participants mentioned for example that they thought Hälsokollen could include more colors when evaluating the black-and-white medium fidelity prototype, not realizing it was black-and-white on purpose.

Moreover, something that might have affected the results from the high fidelity prototype evaluation with potential users was the fact that the prototype was not made fully interactive. The reason for not making all the required screens and interactions was the time constraints. Neither was there enough time to make all possible screens that would be included in the “real” version of Hälsokollen, or to have the participants evaluate all the screens that actually was created in this project. One example of this, from the page “My questions”, is that one could only click on the answered question to see a close-up and not the question without an answer. Another example are the editing buttons on the editing page on “My page”, which did not work more than being able to be opened up and closed. This seemed to confuse several participants who for example tried to pick a color and start making a drawing without success. This might have confused the participants, lowered their user experience of using Hälsokollen and possibly made them misunderstand which elements were actually supposed to be interactive in the tool. Although, this was attempted to be counteracted as much as possible by explaining to each participant, who tried interacting with a non-interactive element, how the tool was supposed to react if it was complete.

The reason for choosing a web page design adjusted for a smart phone view instead of a tablet was to make it accessible to more children. Throughout the project, a majority of the children participating in the project stated that they were using a smart phone more than a computer or tablet. Joyce and Nielsen [44] also stated that all of the teenagers participating in their most recent studies had a smart phone, but not all had tablets or computers. Additionally, Bekker and Antle [23] showed that young children are practicing on their fine manipulation, which could be a reason why the young children in Sherwin and Nielsen's [60] study had trouble using a mouse pointer accurately. Moreover, Internetstiftelsen [43] reported that most Swedish children's experience of using computers increase first when they receive their own computers around the years of 11-13. Therefore, it seemed rational to create these early design prototypes of Hälsokollen, that were to be evaluated in this project by a large age span of children, in the form of a touch interface. Due to the decision of what form Hälsokollen should take (web version or mobile application) not being final before the creation of the low fidelity prototype of it, it was decided to design a web page design adjusted for a smart phone view instead of a mobile application. This to enable the project initiators, or other people who potentially would continue to develop this project, to make the decision later. In other words, it will probably be easier to expand the design, of web page adjusted for a smart phone view, into either a tablet- or computer web-version or a mobile phone application in future work, than if the design would have been made into a mobile application from the start. Another positive aspect of designing for a web page design adjusted for a smart phone view is that it might more easily be integrated into the 1177 healthcare guide. Although, this type of design might also increase the risk of data breach than if the data would be stored locally on an phone application, which might also make users feel less safe using it. This could instead be a positive aspect of designing for a mobile application. Some other positive aspects of designing for a mobile phone application are firstly that it might be easier for younger children to find/access the tool themselves than if it would be on a webpage. Secondly it might not need to require an authorized login, due to the fact that the data is stored locally. Although, if the user would change his/her phone or if the user's phone was to be lost, all the user's private data would be lost with it, which could be a significant negative aspect.

Moreover, it was part of the initial requirements to create a web-based tool to be used on smart phones, tablets or computers, and therefore, other types of solutions such as tangible interfaces were not considered in the project. Since the child end users of Hälsokollen can have varying cognitive and/or motoric difficulties, it would therefore be value for continuous work to investigate other types of solutions and technologies that potentially could better meet those needs.

8.2.3 Interviews and evaluations of prototypes

During the projects feedback sessions with experts, potential users and other participants, a few things can be mentioned that could possibly have affected the end result.

During the requirement elicitation phase when participants were interviewed at the Children's Department of Neurology, participants were asked to participate in the interviews either before or after their doctor's appointments. This led to some interviews being interrupted before all questions were asked, by a doctor coming to fetch the patients for their appointments. Due to the fact that the interviews had to be performed in an examination room, used for taking blood samples etc., an interview could also be interrupted by a nurse needing to use the room shortly. The fact that all questions were not always answered was a shame but not considered to be a major problem since the answers that was collected still was valuable. Another reason for not receiving answers to all interview questions from all participants, as well as why some participants received different follow up questions, is due to the informal structure of the interviews. This was not considered an issue since it enabled the facilitators to discover additional relevant topics, depending on the conversation's natural path.

There are also some insights about the performance of the medium fidelity prototype evaluation. For example, the decision to perform a pilot test with the first participant applying for participation in the evaluation was indeed an important decision, since it revealed a few issues in the evaluation procedure and script that was critical to solve before the next evaluation session could be performed. However, there were still things in the procedure that might have affected the results. For example, participants were to answer questions about what they disliked in the interface and if they had any suggestions of improvements. These questions might have been more difficult to provide a straight and honest answer to, due to a potential fear of hurting the facilitators' feelings. This could potentially also be more prominent due to the fact that the evaluations were carried out face to face (although on distance), and the fact that none of the participants knew any of the facilitators personally.

As discussed previously in this chapter, not all parts of the high fidelity prototype had been made interactive for the high fidelity prototype evaluation. Even though the usability issues that were directly related to this factor were taken into account and considered a "non-issue" for the interface design when analysing participants' task performances, it could still have affected participants' perception and experience of using the prototype, which furthermore might have affected their interview responses. Another aspect that might have affected the analysis of the results of the high fidelity prototype evaluation is that some participants shared a video of their face when at the same time sharing their computer screen, while some participants did not. It might then have been more difficult to fully interpret the actions and experiences of the participants that did not share a video of their face. Therefore it could be considered to include a video for all participants in future work, in case the evaluations still have to be made online.

One thing that might have affected the recruitment of participants was that due to the fact that we could not directly contact patients, we could not ensure that the information about the study was forwarded in the best possible way. For example, the study by Mack, Giarelli and Bernhardt [49] that was discussed in more detail in the theory chapter, showed that recruitment of adolescents to research projects is difficult, and especially when the research is about long-term or chronic illnesses where the aim is to get adolescents', that have those illnesses, input. They explained that this was due to the fact that adolescents do not want to be reminded of the things that make them different from other adolescents. Therefore, they argued that it could be of importance to present the information about the study in such way that does not scare away adolescents from participation. Since the aim of the medium- and high fidelity prototype evaluations was to get participants' input on the prototypes and their design, which was the information that was forwarded to the potential participants, rather than investigating participants' thoughts and feelings about their diagnosis and/or treatment, this could potentially have scared away less people from participation. However, the fact that Hälsokollen is still targeted towards children with long-term illnesses, with the aim of making them more aware of and involved in their diagnosis and/or treatment, there might still be adolescents (or other potential participants) that did not want to participate due to this factor.

Due to the fact that one of the main stakeholders of this project are children, it was important to get children's own input. This was a bit tricky when evaluating with the youngest children (5-8), especially during the interviews with patients and caregivers in the requirement elicitation phase, where many children mostly sat quiet while their caregivers were speaking. It is not clear whether this meant that they agreed with their caregivers and did not feel the need of repeating the information, or if they simply were too shy to say something, which was another thing that was noted during these interviews as well as during the following evaluations of the medium- and high fidelity prototypes. The fact that the interviews were performed in a non-comfortable environment, instead of an environment of participants own choosing, as well as having to speak to two older people which they had never met before, potentially added to children's shyness as well. By conducting the interview in an environment of their choosing and possibly having an initial informal meeting with the child in beforehand, they might have participated more actively in the the interviews. Furthermore, three types of physical artifacts were brought to the interviews (three "books of participation", a picture of an iPad frame and sticky notes representing the different ideas of features that could be included in a tool like Hälsokollen) to make the interviews more relaxed and to add concreteness to the discussions. Even though the initial purpose, of having participants pasting the features (i.e. sticky notes) they would like to include in Hälsokollen onto the iPad frame, was not used by the majority of participants, the artifacts were still used for example by children that were too shy to speak but instead could point on the features/sticky notes they liked. This experience taught the authors the value of using and keep using children-friendly methods throughout the project, even though more could have been done if the circumstances would have allowed it. Moreover, the fact that some children participated in the different evaluations together with their caregivers, and some without (which was mostly the case for the 9-12 group), could potentially also have affected children's responses.

8.2.4 Creation of guidelines

What could be important to mention about the creation of the guidelines is that the design guidelines presented are the most important ones among the ones found, according to the authors of this report. Even though all the guidelines presented have been backed up by empirical research, and some of literature research as well, biases could still have played a role when creating the guidelines. For example, during the creation of the guidelines, different findings have been combined to create specific guidelines according to how the authors interpreted the findings and their relationship to each other. Not to state that they would be more or less relevant than the ones created in this project, but other authors might have done other interpretations, which possibly might have created other combinations of findings. Additionally, since bullet points of interesting findings were noted down throughout the project, it is possible that the authors over-interpreted results that was found later in the project to belong to the bullet points that has already been noted, which might have affected which guidelines were created. Although, the aim of the design guidelines of this project was not to be the “only truth” and perfect, but to function as an inspiration and a possible guidelines for future work within similar projects.

8.3 Future Work

Throughout the whole project, many ideas have been noted down as possible future work. To begin with, it is proposed that prototypes of Hälsokollen could be evaluated with more users within the main target group, thereby children with long term illnesses, to validate the findings of this study and possibly find more or other relevant design guidelines. Further on, it would be interesting to make a study focusing more on the children who have cognitive and/or motoric difficulties as a result of their long-term illness, to see how the design guidelines might differ. It would then be possible to perhaps create more specialized and personalized designs for certain illnesses and difficulties, that incorporates more of the accessibility recommendations for the web. Furthermore, it could be interesting to investigate what other types of mediums or technical solutions might be suitable. Moreover, it would be interesting to create more than 3 versions/levels of Hälsokollen, were the user can customize the tool based on more parameters than now, to fit it even better to their specific needs.

A few suggestions for future work regarding new features were also taken notes of during the project. These were considered promising, but were not able to be implemented due to lack of time. Some of the ideas were to include educational games, quizzes or videos in Hälsokollen and another was to include some fun background themes to select between. Although, what is relevant to note about the background themes is that it would be important to make sure they do not confuse the user of what is interactive and not in the digital tool.

Moreover, one could investigate if it would be appreciated and beneficial to include a reminder-function in Hälsokollen, to remind users to take their medicines or to write about themselves, for example. This could then possibly give some extra help for children to become more involved in their own health care. The persuasive system model by Oinas-Kukkonen and Harjumaa [54] states that reminders could be a persuasive feature that will help the user to more likely achieve their goal. It might also be interesting to see if it would be appreciated to include a page in Hälsokollen were a user could write down everything about their next appointment at the hospital, such as the date, department, which nursing staff they will meet and what the appointment will be about etc. This might possibly enable the user to prepare/feel more prepared for specific appointments.

A suggestion that came up, but might be more difficult to implement due to patient data security regulations, was to include a social feature in Hälsokollen. The feature would enable users to connect and share their experiences with other children having the same condition as them. Oinas-Kukkonen and Harjumaa [54] describes in their article about the persuasive system model that users are more likely to perform a target behaviour if they can observe through the system that others are performing the behaviour along with them. The social contact feature could then possibly both entertain the users and motivate them to become more involved in their own health. Another feature that is difficult to implement today, is to be able to send messages to nursing staff outside of appointments. This is something that was mentioned as a desired feature by many participants who participated in the project. Although, the project initiators stated that the nursing staff would not be able to use this feature today, due to their working schedule being too full. Because the hospitals methods might change in the future, this feature suggestion might be possible further ahead. Something that might be able to be included today, which might satisfy some of the needs that the previous feature would, is a frequently asked question section or some sort of chatbot that could answer simple questions. Finally it might be interesting to investigate if some sort of gamification, in the form of praises or rewards, could be included in Hälsokollen. According to Oinas-Kukkonen and Harjumaa [54], a digital tool that reward or praise target behaviors could have great persuasive powers.

9

Conclusion

In conclusion, the research question *What design guidelines should be taken into consideration when designing an adaptable eHealth technology for 5 to 18 year old children?*, as well as the sub-question *What is a plausible design suggestion of such an eHealth technology, to be used by 5 to 18 year old children with long-term illnesses within Swedish health care?*, have been answered by proposing a design prototype and a collection of 12 design guidelines to take into consideration when designing such technologies. Through an iterative and user-centered design process, this was created as a result of a collaboration with the Children's Department of Neurology, the Play Therapy and the Centre of Digital Health at Sahlgrenska University Hospital.

The overall result of evaluating the design prototype showed that the general idea of the digital eHealth tool called Hälsokollen, as well as its design, was widely appreciated and accepted by the majority of people who evaluated it, including the different stakeholders. There are however still room for improvement and many suggestions of alternative solutions, which fosters potential future development of Hälsokollen. The 12 guidelines created concludes a set of interesting findings made in this project, related to themes such as content, design, interaction and experience of using an adaptable eHealth technology like the one designed in this project. For example, it was found that it could be of importance to allow users to tell about their thoughts, feelings and experiences that are not obviously tied to predefined categories or topics, or to the illness itself. Because of the unpredictable circumstances that occurred due to the ongoing covid-19 pandemic, as well as the explorative nature of the project, the guidelines should be considered as inspiration and suggestions for the future development of similar eHealth technologies.

Further on, a collection of suggestions for future work have been elicited throughout the project. They include ideas such as implementation of more features in Hälsokollen, like social contacts and activities, different types of reminders, as well as educational games and quizzes. Furthermore, additional ways for users to customize the Hälsokollen, to fit their individual needs, could be investigated as well as the type of medium or technology used for the tool. Additionally, putting more focus on how Hälsokollen could use accessibility standards, to better meet the needs of children with cognitive and/or motoric difficulties, could be of value. Finally, it is proposed to evaluate Hälsokollen with more children within the target group, thereby children with long-term illnesses, to validate the findings from this study and possibly find additional design guidelines.

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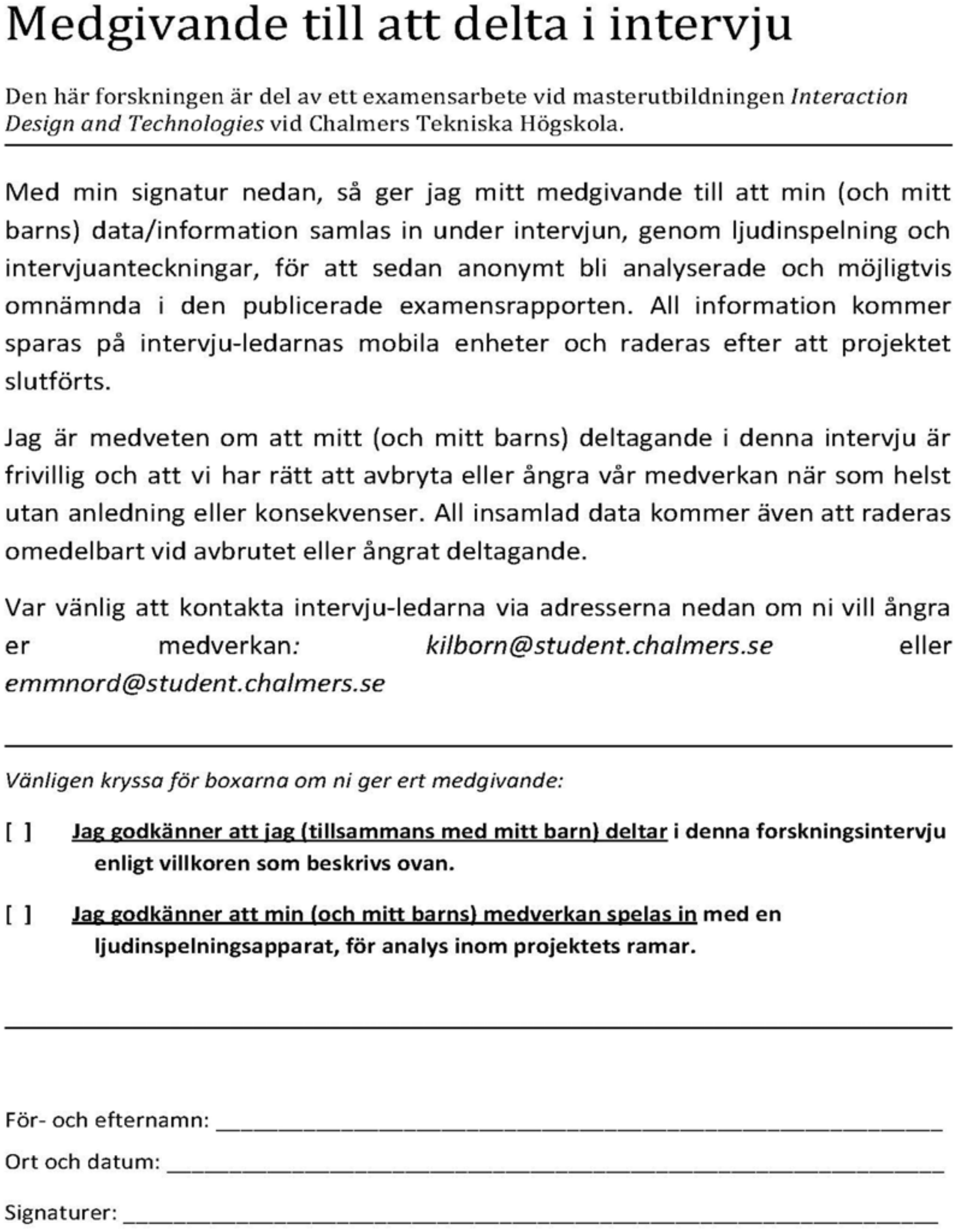
A

Consent form interviews



Medgivande till att delta i intervju

Den här forskningen är del av ett examensarbete vid masterutbildningen *Interaction Design and Technologies* vid Chalmers Tekniska Högskola.

Med min signatur nedan, så ger jag mitt medgivande till att min (och mitt barns) data/information samlas in under intervjun, genom ljudinspelning och intervjuanteckningar, för att sedan anonymt bli analyserade och möjligtvis omnämnda i den publicerade examensrapporten. All information kommer sparas på intervju-ledarnas mobila enheter och raderas efter att projektet slutförts.

Jag är medveten om att mitt (och mitt barns) deltagande i denna intervju är frivillig och att vi har rätt att avbryta eller ångra vår medverkan när som helst utan anledning eller konsekvenser. All insamlad data kommer även att raderas omedelbart vid avbrutet eller ångrat deltagande.

Var vänlig att kontakta intervju-ledarna via adresserna nedan om ni vill ångra er medverkan*:* *kilborn@student.chalmers.se* eller *emmnord@student.chalmers.se*

Vänligen kryssa för boxarna om ni ger ert medgivande:

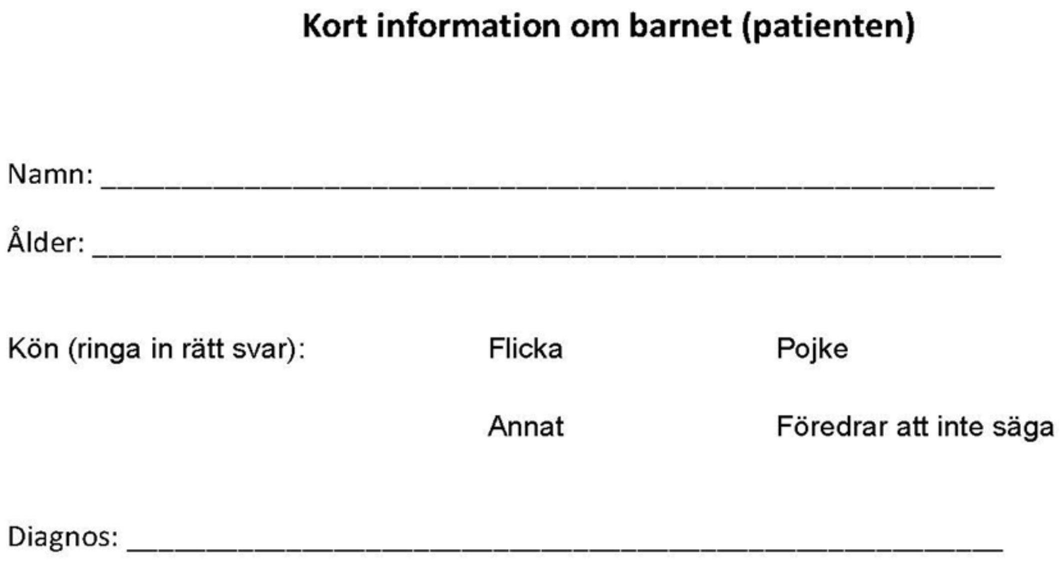
[ ] **Jag godkänner att jag (tillsammans med mitt barn) deltar i denna forskningsintervju enligt villkoren som beskrivs ovan.**

[ ] **Jag godkänner att min (och mitt barns) medverkan spelas in med en ljudinspelningsapparat, för analys inom projektets ramar.**

För- och efternamn: ____

Ort och datum: ____

Signaturer: ____



Kort information om barnet (patienten)

Namn: ____

Ålder: ____

Kön (ringa in rätt svar): Flicka Pojke

Annat Föredrar att inte säga

Diagnos: ____

B

Interview questions

The questions in italics are the more easier alternatives of the questions, for younger children and children with possible cognitive impairments. The questions in bold are for adolescents and the questions in normal text are meant for all children.

Hej vad heter du? Hur gammal är du?
Vad har du för favoritfärg?
Vad gör du på fritiden?

Hur ofta kommer du hit på besök?

Vi har hört att vissa barn som kommer på besök på den här avdelningen ibland använder en liten bok där de kan berätta om sig själva och visa för doktorn, t.ex. sina tankar, åsikter och frågor som man undrar över *visa boken*. Är detta något som du använder eller har hört något om?
Nej:
När du är på ett besök här för att träffa en sköterska eller läkare, hur brukar ni prata med varandra? Brukar ni bara prata eller brukar du använda något mer som stöd (t.ex. foton, teckningar eller en text du förberett)? Tycker du det är lätt att berätta för läkaren vad du tycker, tänker och känner? Varför/varför inte? Om du hade haft den här boken, tror du att du hade velat använda den? Vad skulle du vilja berätta i den och hur (rita/skriva)?
Ja:
Vad brukar du berätta om i boken? Hur (rita/skriva)?

Doktorn har berättat för oss att det finns en bok som barn kan skriva eller rita i för att berätta för doktorn vem de är, vad de tycker om, om de undrar över eller tänker på något som har med deras sjukdom att göra. Har du gjort detta någon gång?
Nej:
När du är här på besök och pratar med doktorn, hur brukar ni prata med varandra? Brukar du till exempel. Prata? Rita? Skriva? Vad brukar du rita/skriva om då? Tycker du det är lätt att berätta för läkaren vad du tycker, tänker och känner? Varför/varför inte? Hade du velat ha en sådan bok? Hade du velat berätta om dig själv där?
Ja:
Tycker du om att använda den? Vad brukar du berätta om i boken? Hur brukar du berätta detta? Rita/skriva? Båda?

Vet du vad en hemsida/läsplatta/app på en telefon är? Har du använt en dator, läsplatta/padda eller app någon gång?
Om du tänker dig att den där boken vi pratade om tidigare istället skulle finnas på en hemsida eller i en app istället, som barn som kommer på besök här på avdelningen kan använda för att lättare kunna prata om din sjukdom med doktorn. Då skulle barn t.ex. kunna få information om
Hur dina mediciner funkar
Information om [diagnosen]
Att du kan rita och skriva saker om dig själv Att du kan se i appen vad du har skrivit och målat för längesedan
Tror du det skulle vara lättare eller svårare för dig att berätta för din doktor om dig själv ifall du hade haft en sån här hemsida/app?
Tror du det skulle vara lättare eller svårare för dig att förstå din diagnos bättre ifall du hade haft en sån här hemsida/app?

Som vi visade finns det massor av olika saker man skulle kunna se/göra i appen. Vilka av de här 4 sakerna hade du helst velat kunna se/göra? Varför just a och b? Varför valde du inte x och y? Om du fick välja helt själv vad mer du skulle vilja se/göra i appen, vad skulle du välja då?

C

Interview results

How often do the patients at the Children's Department of Neurology have doctor's appointments?
All age groups
About half the groups of participants received this question. All groups of participants that got the question about how often they had doctor's appointments reported that they met their doctor a few times per year.

How do the patients communicate with their nursing staff today?
Age 5-8
2/3 groups of participants in this age group reported that they usually just talk with their nursing staff, without the support of any tools such as pictures, prepared questions etc. However, 1/3 of the groups did use pictures and drawings as a tool to support their communication with their nursing staff. 2/3 groups also said that they had not seen, nor used, delaktighetsboken (the book of participation), whereas 1/3 groups reported having seen the books but not used them themselves.
Age 9-12
The 1 group of participants in this age group said that they usually prepared the questions they wanted to ask on their next doctor's appointment before seeing their doctor. They also said that they had never seen delaktighetsboken (the book of participation) before.
Age 13-18
All the groups of participants in this age group said that they just talked with their nursing staff, without the support of tools. None of the groups had heard about delaktighetsboken.
Parents input (children did not answer due to young age or cognitive impairments)
All the groups of participants that had children under 5 years old or with a cognitive level of a 0-5 year old said that they just talked with their nursing staff, without the support of tools. None of the groups had heard about delaktighetsboken.

What do patients think works well with their way of communicating with their nursing staff today?
Age 5-8
Among the participants in this age group, one group said that their way of communicating with their nursing staff was perceived as simple, amusing and efficient, whereas one group mentioned it being simple and one efficient. Most groups reported being positive towards the nursing staff's ability to communicate with and listen to the patient.

Age 9-12
The 1 group of participants in this age group said that they thought it was easy to talk to and answer questions from their doctor. *Age 13-18*
In this age group, 2/3 groups of participants did not receive the question. The last group of participants (a 16 year old girl) said that she thought it was easy to tell her doctors about her thoughts and feelings, and that she was comfortable sharing this verbally.
Parents input (children did not answer due to young age or cognitive impairments)
Among participants that had children under 5 years old or that had children with a cognitive level of a 0-5 year old, 2/4 groups said that they thought it was easy to communicate with the doctors and that they were good listeners. The other two groups did not receive the question.

What might patients think works less well with their way of communicating with their nursing staff today?
Age 5-8
In the age group 5-8, one group of participants said that they thought there was a risk of forgetting or misinterpret information, because it is communicated verbally. One group also thought that some doctor's way of communicating was a bit old fashioned. They mentioned that they would have appreciated the use of tablets or digital games in these doctors' communication style rather than physical toys such as building blocks. One group did not receive the question.
Age 9-12
Did not receive the question.
Age 13-18
Did not receive the question. *Parents input (children did not answer due to young age or cognitive impairments)* Did not receive the question.

What are the patients' thoughts about "delaktighetsboken" and the use of such communication supporting tools?
Age 5-8
In this age group, 2/3 groups of participants thought delaktighetsboken generally could be useful for patients and caregivers at the children's department of neurology. 2/3 groups pinpointed certain characteristics of the book to be more useful, such as the ability to include pictures and that it allowed patients to prepare themselves for doctor's appointments in the calmness of a home setting. One group also mentioned that they would have appreciated to have a mobile application, in which they could save pictures they wanted to discuss around during doctor's appointments, before hearing about the tool to-be-designed in this project.
Age 9-12
This 1 group of participants thought that the book might not be necessary for them personally, but that they could see a need among patients and caregivers at the children's department of neurology generally. They also mentioned that it could be useful if the patient is not very talkative, or when patients want their nursing staff to be aware of their fears related to the illness and/or treatment.
Age 13-18

In this age group, all groups of participants were positive towards delaktighetsboken. 1 group said that it would be useful both for the patient and for nursing staff, while another group said that it would be great for patients that have a hard time expressing themselves verbally, that are shy or tired of needing to repeat information when meeting new nursing staff. This was the opinion of a mother - her daughter did not prefer using the book over not using it, or vice versa. One group of participants (a 16 year old girl) especially mentioned that it would be good to have somewhere to write down questions you want to ask, in beforehand.

Parents input (children did not answer due to young age or cognitive impairments)

In this group, caregivers were generally positive towards delaktighetsboken, but mostly under certain circumstances. For example, one caregiver mentioned that it could be useful for patients with specific needs, while a parent to a child with specific needs said that it would not be useful for them. One caregiver said that it would be useful to have everything documented when they meet new nursing staff, but the same caregiver also said that she was unsure whether doctors would have time to read patients' books all the time. She also said that she would appreciate if her daughter could prepare herself for the doctor's appointment by watching video clips of how different medical procedures, such as blood sampling, is carried out.

What are the general perception and opinion of the tool to-be-designed in this project

Age 5-8

All groups of participants generally thought the tool to-be-designed in this project was a good idea. One group said it would be fun to have a tool like this, while another group said that it could support your memory and that it would be good during certain circumstances, such as when the patient is not very talkative. They also said that it could empower the patient to ask their own questions without relying on his/her caregivers. *Age 9-12*

The 1 group of participants in this age group thought the tool to-be-designed was a great idea and that it seemed simple to use. They also saw a value of having a digital tool rather than a physical book, since the tool can be adjusted as the child ages.

Age 13-18

In this age group, all groups of participants had a positive attitude towards the tool to-be-designed. One group said that they generally liked the idea and that it was good that is was personal. One group said that it seemed simple and fun, and that it could be useful for patients with different impairments. The 15 year old boy in this group however thought that it was a bit unclear what the drawing- and games feature was. The last participant (16 year old girl) preferred and thought it was easier expressing past events through text. She also thought this would be more efficient in situations where she would meet new nursing staff, both in terms of not needing to repeat information but also for herself to be better prepared for these occasions.

Parents input (children did not answer due to young age or cognitive impairments)

All groups of participants in this age group were generally positive towards the tool to-be-designed. One group said that it could be calming for parents to be able to read information in the app during critical events, and also to write down the events and show the information for different nursing staff. One group thought it would be good for older children, and one that it would be useful as long as it is usable and safe to use.

Is there a need for a tool like the one to-be-designed in this project?
Age 5-8
The groups of participants in this age group mentioned a couple of different advantages of having a digital tool. All groups said that they thought it would help them better communicate with their nursing staff, because it could be used to prepare the patient for the doctor's appointment (by saving questions or pictures they want to talk about), or in situations where children are being shy. One group also said that the app could help them get a better understanding of the diagnosis, and to get valid information. The mother in one group also said that they would prefer a mobile application before a physical book because their daughter was more used to this.
Age 9-12
The 1 group of participants in this age group thought this app could help them better communicate with their nursing staff. They also thought it could help patients get a better understanding of the diagnosis, if the child could sit together with his/her caregivers when the child is young and by themselves when they are older.
Age 13-18 2 out of 3 groups of participants answered this question. One participant mentioned that she definitely thought she would use this app, especially if she would have been younger. She also mentioned that the app could help the user understand more about their diagnosis. Both groups of participants said that the application could help improve the communication with nursing staff.
Parents input (children did not answer due to young age or cognitive impairments)
4 out of 5 groups were positive to this application. One group stated that they would not use it today, due to the child's cognitive disabilities, but possibly in the future. Two groups stated that the application could help improve the communication with nursing staff. Two groups stated that the application might help children understand their diagnosis better, even though they were quite hesitant. Lastly two groups mentioned that if they would have this communication tool, they would prefer to use a digital application before a physical book.

Which of the features presented are wanted or considered most important to include in the tool?
Age 5-8
When asked the question regarding which components they liked the most among the suggestions presented, all components except for "My doctors and nurses" were mentioned by at least one participant. Although, one participant did answer that she liked all functions. "My history" was mentioned by one participant, "Question to the doctors" were mentioned by three participants and the rest were mentioned by two participants each. Both writing, talking and drawing were mentioned as preferred way of communication by at least one participant per way of communication.
Age 9-12

The child and her parents mentioned that the components they liked the most, among the suggestions, were "Questions to the doctor" and "Games". They did also say that they liked all components. The child's preferred way of communication in the application was writing, but the parents said that it would be smart to be able to choose between different options.
Age 13-18
When asked the question regarding which components they liked the most among the suggestions presented, all components except for "My History" were mentioned by at least one participant. Although, one participant did answer that she liked all functions. Both writing, talking and drawing were mentioned as preferred way of communication by at least one participant per way of communication.
Parents input (children did not answer due to young age or cognitive impairments)
When asked the question regarding which components they liked the most among the suggestions presented, all components except for "My History" and "My page" were mentioned by at least one participant. 3 groups out of 5 said that all functions were great.

Which of the features presented are unwanted or considered less important to include in the tool?
Age 5-8
One group out of 3 mentioned that it might be difficult to include information about the child's diagnosis at such a young age. The mom mentioned that it might be better when the child is older.
Age 9-12
The mother of the child mentioned that the function to be able to see all their doctors might not be as important to them, since they only meet a few.
Age 13-18
None of the groups mentioned that they disliked any of the functions.
Parents input (children did not answer due to young age or cognitive impairments)
2 out of 5 groups mentioned that including "Games" in the application might be less important or more difficult than the other functions, even though it might be good as well.

What new ideas of possible features are mentioned?
Age 5-8
2 out of 3 groups had their own suggestions of components. Suggestions regarded adding a page for social activities, having slide-shows and to de-dramatize the child's diagnosis in the app. Other suggestions that came up were to be able to write about your progresses, to estimate their feelings through smileys and to have some sort of talking-bot in the app who can answer simple questions.
Age 9-12
The parent to the child had a few suggestions of possible components in the application. He said that the app could contain social contacts, to be able to contact children with the same diagnosis. Further on, the app could include the function to be able to send messages to the doctor outside appointments. Lastly, he mentions the importance of security. One could for example unlock the phone with bankID

or a password.

Age 13-18

2 out of 3 groups had suggestions of new possible components in the application. One of the children mentioned that information about departments could be added in the section called "My doctors". The other child mentioned that one could add a function to be able to write down your fears. The mother of one of the children also mentioned that slide-shows could be a good thing for children. For example to learn how one takes a blood sample.

Parents input (children did not answer due to young age or cognitive impairments)

All groups had at least one suggestion of additional components in the application. A few suggestions related to security and reliability, were a participant wanted the app to be connected to 1177 and to be very secure. Two participants wanted the information in the app to be written by professionals, to ensure its quality and correctness. One participant also wanted to be able to communicate with the nursing staff outside appointments. Other suggestions that came up were about including a page to write a diary in, to be able to change languages and to re-name the page "Mina sidor" to "Det här är jag".

Other findings from the interview

Age 5-8

More general topics that came up during the interview with one child and his parent, were about the fact that this child visits many different doctors and departments. Further on the parent mentioned that it is easy to put children with a diagnosis in a box, which one should be careful to promote. Lastly, the mother mentioned that the child was very shy today and was therefore having trouble participating. Another parent mentions that the app could be useful for explaining his daughter's unusual diagnosis to other people, apart from nursing staff. The mother of the same child also mentions that a mobile application is much easier to access than a web page.

Age 9-12

No general comments were found.

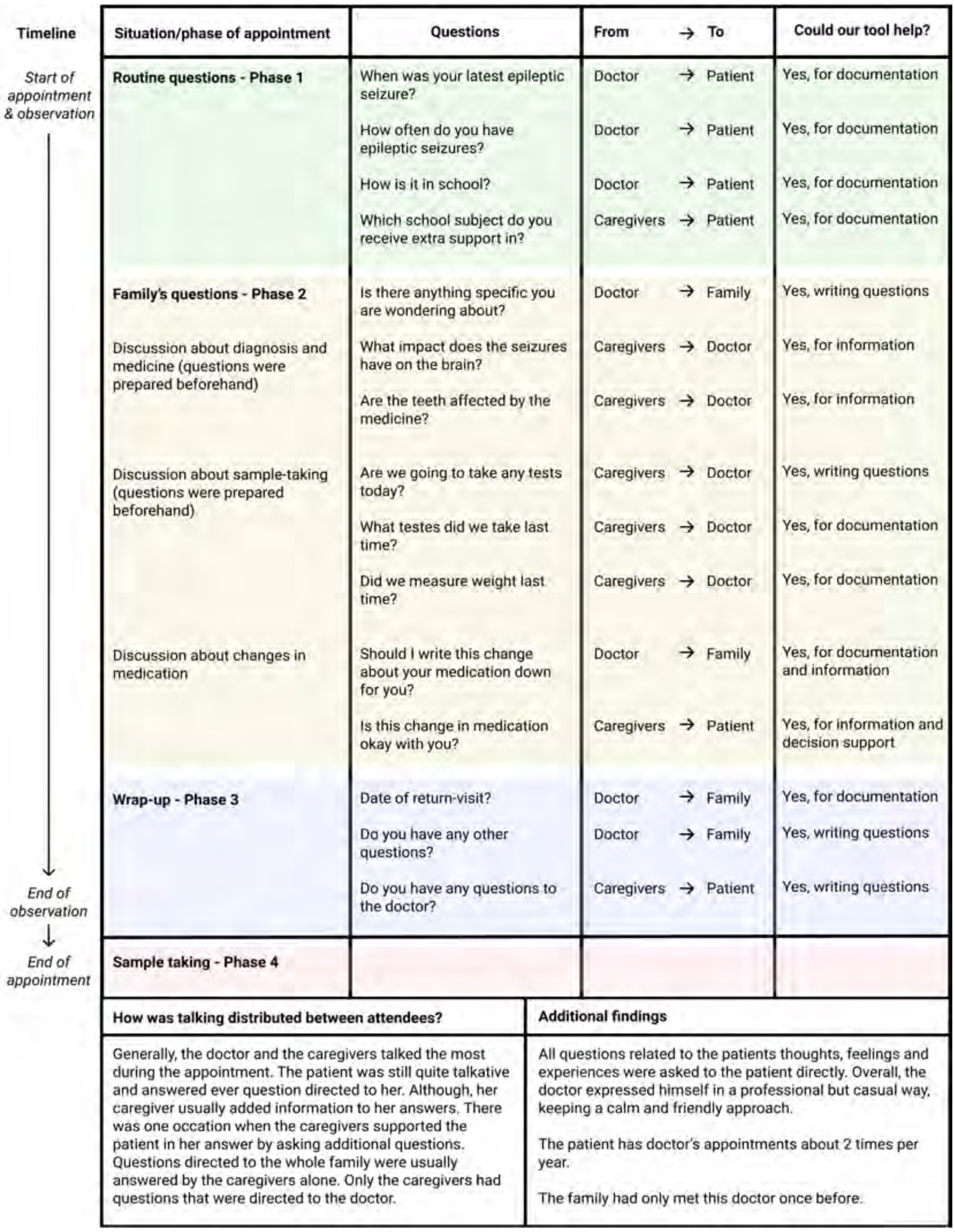
Age 13-18

A more general opinion that came up during the interview, while talking about the game-function, was a child's favorite games. The games she mentioned were Minecraft, The Sims, Assassins Creed and games about home decoration.

Parents input (children did not answer due to young age or cognitive impairments)

A more general thought that one parent mentioned, was that it is difficult to know the best way for a child to learn about their diagnosis. The parent also mentioned that her daughter, although only 4 years old, likes to ask a lot of questions about her diagnosis already. Another parent, mentioned that there is a similar application to the one that this project is developing, called “Rättvisat". This application is mainly aimed towards people with communication difficulties.

D
Observation results

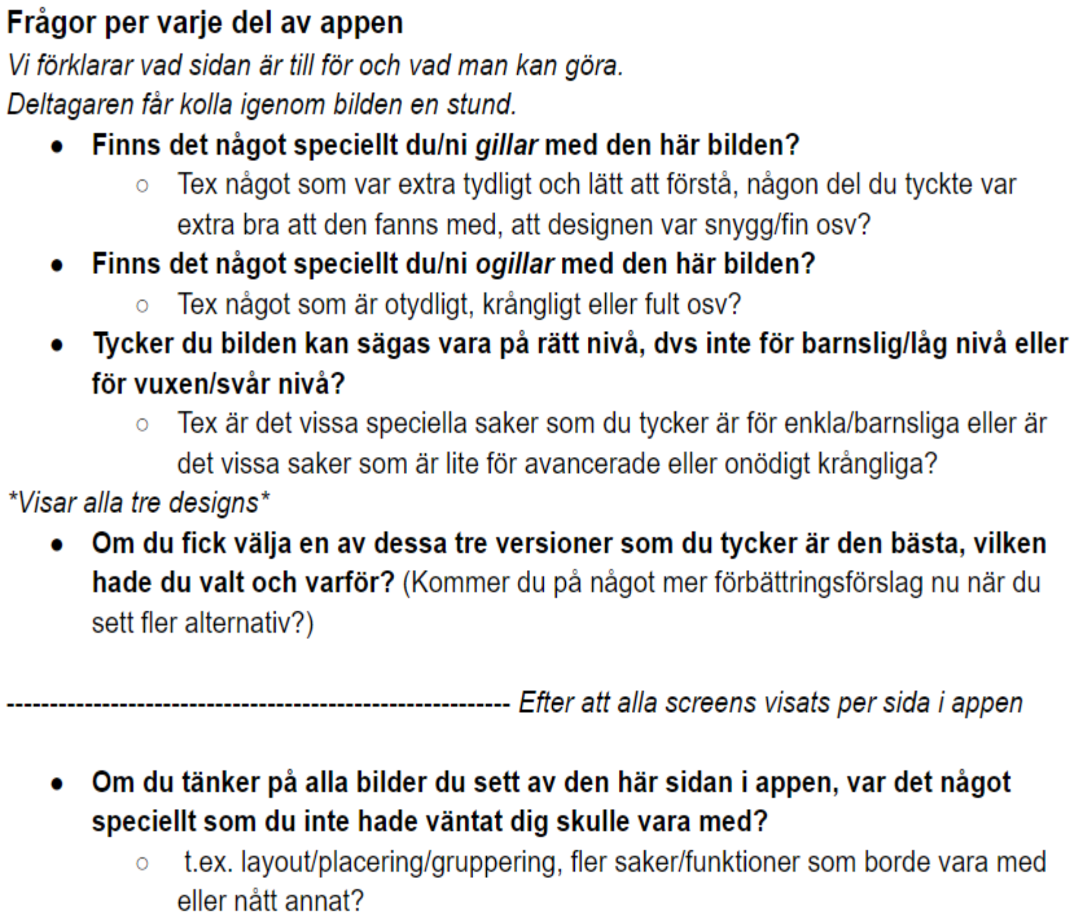


Timeline	Situation/phase of appointment	Questions	From → To	Could our tool help?
Start of appointment & observation	**Routine questions - Phase 1**	When was your latest epileptic seizure?	Doctor → Patient	Yes, for documentation
		How often do you have epileptic seizures?	Doctor → Patient	Yes, for documentation
		How is it in school?	Doctor → Patient	Yes, for documentation
		Which school subject do you receive extra support in?	Caregivers → Patient	Yes, for documentation
	Family's questions - Phase 2	Is there anything specific you are wondering about?	Doctor → Family	Yes, writing questions
	Discussion about diagnosis and medicine (questions were prepared beforehand)	What impact does the seizures have on the brain?	Caregivers → Doctor	Yes, for information
		Are the teeth affected by the medicine?	Caregivers → Doctor	Yes, for information
	Discussion about sample-taking (questions were prepared beforehand)	Are we going to take any tests today?	Caregivers → Doctor	Yes, writing questions
		What testes did we take last time?	Caregivers → Doctor	Yes, for documentation
		Did we measure weight last time?	Caregivers → Doctor	Yes, for documentation
	Discussion about changes in medication	Should I write this change about your medication down for you?	Doctor → Family	Yes, for documentation and information
		Is this change in medication okay with you?	Caregivers → Patient	Yes, for information and decision support
	Wrap-up - Phase 3	Date of return-visit?	Doctor → Family	Yes, for documentation
		Do you have any other questions?	Doctor → Family	Yes, writing questions
End of observation		Do you have any questions to the doctor?	Caregivers → Patient	Yes, writing questions
End of appointment	**Sample taking - Phase 4**			

How was talking distributed between attendees?	Additional findings
Generally, the doctor and the caregivers talked the most during the appointment. The patient was still quite talkative and answered ever question directed to her. Although, her caregiver usually added information to her answers. There was one occation when the caregivers supported the patient in her answer by asking additional questions. Questions directed to the whole family were usually answered by the caregivers alone. Only the caregivers had questions that were directed to the doctor.	All questions related to the patients thoughts, feelings and experiences were asked to the patient directly. Overall, the doctor expressed himself in a professional but casual way, keeping a calm and friendly approach. The patient has doctor's appointments about 2 times per year. The family had only met this doctor once before.

E

Medium fidelity evaluation questions



Frågor per varje del av appen

Vi förklarar vad sidan är till för och vad man kan göra.
Deltagaren får kolla igenom bilden en stund.

- **Finns det något speciellt du/ni *gillar* med den här bilden?**
    - Tex något som var extra tydligt och lätt att förstå, någon del du tyckte var extra bra att den fanns med, att designen var snygg/fin osv?
- **Finns det något speciellt du/ni *ogillar* med den här bilden?**
    - Tex något som är otydligt, krångligt eller fult osv?
- **Tycker du bilden kan sägas vara på rätt nivå, dvs inte för barnslig/låg nivå eller för vuxen/svår nivå?**
    - Tex är det vissa speciella saker som du tycker är för enkla/barnsliga eller är det vissa saker som är lite för avancerade eller onödigt krångliga?

Visar alla tre designs

- **Om du fick välja en av dessa tre versioner som du tycker är den bästa, vilken hade du valt och varför?** (Kommer du på något mer förbättringsförslag nu när du sett fler alternativ?)

--- *Efter att alla screens visats per sida i appen*

- **Om du tänker på alla bilder du sett av den här sidan i appen, var det något speciellt som du inte hade väntat dig skulle vara med?**
    - t.ex. layout/placering/gruppering, fler saker/funktioner som borde vara med eller nått annat?

F

Results medium fidelity evaluation

F.0.1 Start page

Version 1

Ages 5-7

Båda var positiva och tyckte sidan var tydlig (barnet och den andra föräldern). Föräldern nämnde att "Mina sidor" var en specifik funktion som var extra bra. Det som ogillades var uteslutande att bakgrundsteman låg på startsidan och inte under inställningar. Dessa kommentarer kom dock endast från föräldrar och nämndes inte av några barn. En förälder nämnde även här att bakgrundstemat borde flyttas till inställningar (samma som tidigare). En förälder nämnde även saker som kan göras tydligare, därmed att lägga till bilder på startsidan. Ett barn hade inga förbättringsförslag. Alla tyckte nivån var lagom. En nämnde att bilder är bra för att få appen personlig/rolig. Gällande version så hade endast en deltagare en stark preferens för en design, husen (ett barn). Två föräldrar tyckte knapp-designen och rondellen var lika bra. Husen var den enda design som fick någon negativ kommentar (av en förälder). Symbol-kvarteret nämndes inte av någon deltagare som varken bra eller dålig. En tyckte att inget var förvånande, och en att det förvånande var positivt. Det positivt överraskande handlade främst om innehållet/funktioner, där mina frågor, min sida och bilder på personal och avdelningar.

Pediatric nurses and parents to children that were formerly patients at CDN

De tyckte sidan hade rätt sammanfattande information och tydliga bilder. Det var inget speciellt de ogillade. Förbättringsförslag är att göra knappar tydliga att man kan klicka på dom och byta ikonen för "min sida" på startsidan till att ha en bild på barnet. Tyckte nivån var lagom, lade en betoning på att det var bra med bilder som komplettering till text. Föredragen version av startsidan var Knapp-designen. Det var inget speciellt som var förvånande.

Pilot test (Mom and 6 year old child)

Pojken tyckte att "Min sida och "Bakgrundstema" var bra. Pojken gillade inte "Mina frågor" och "vi på sjukhuset" men han visste inte varför. Mamman tyckte att bakgrundsteman passar bättre under inställningar. Även om hon hade lite kluvna tankar om det kanske passade att ha funktionen där för små barn. Förkorta texter så mycket som möjligt samt ha bakgrundsteman under inställningar. Lagom men text ska vara så kort som möjligt samt kompletteras med bilder. Föredragen version var husen-designen. Det som var förvånande var att ha bakgrundsteman direkt på startsidan och inte i inställningar.

Version 3

Ages 8-18

Alla var positiva, där teman som nämndes var om tydlighet, estetik och innehåll/funktioner. Av innehållet så nämndes Mina frågor och Min sida av en person. Inga specifika saker utpekades som negativt med startsidan av denna åldersgrupp. Majoriteten hade inga förbättringsförslag och två av dessa fick inte frågan. En person nämnde att namnet "Vi på sjukhuset" var lite otydlig (Vi håller med och har funderat över den här kommentaren men ännu inte hittat en bättre beskrivning för nivå 1. Men nivå 2 kan hete Mina vårdkontakter). Alla deltagare i denna åldergrupp tyckte den "svåra" nivån var lagom. En person nämnde också att hon trodde även barn i den lägre åldersgruppen skulle kunna använda sidan, eftersom man kan förstå innehållet både genom text och bild. Det var en jämn fördelning mellan hur många som gillade Knapp-designen och Rondellen (1 Flicka/Pojke och 1 Nivå2/Nivå3 per alternativ). Däremot så var åsikten starkare för Rondellen än den var för Knapp-designen, där de två deltagarna även nämnde att alla designs var bra/lika. Husen gillades av en person (14 år), men ogillades av två (16 och 9 år). Alla nämnde vars en sak som var förvånande/oväntat. Majoriteten (3/5) var positivt överraskade över innehållet/funktioner, som bakgrundsteman, min sida och tips inför besök, medan 2/5 var negativt överraskade över att saker var otydliga, t.ex. ikoner och formuleringar.

F.0.2 My page - Startpage

Version 1

Ages 5-7

De teman som dök upp var innehåll/funktioner och empowerment. En person hade inget speciellt att tillägga. Det innehåll som nämndes var att det är bra att ha en egen profilbild samt att man kan lägga in saker om sig själv (förälder). Samma förälder sa att sidan var bra för empowerment, eftersom den kan hjälpa barn att prata lättare om sig själva. En deltagare nämnde att namnet "Annat" var lite otydligt. En deltagare fick inte frågan. Det förbättringsförslag som nämndes var gällande tydlighet, att namnet på "Annat"-sidan kunde göras lite tydligare för att förstå vad man ska göra där. En deltagare fick inte frågan. Alla deltagare ansåg att nivån var lagom. Nivå 1 föredrogs av en förälder. Ett barn sade att hon var neutral i frågan. En deltagare fick inte frågan. Majoriteten av feedbacken var positiv, däribland "Att skolan var med" och "Att kunna lägga in film". Ett barn sa att inget var förvånande och en deltagare fick inte frågan.

Pediatric nurses and parents to children that were formerly patients at CDN

Bra att den skapar empowerment genom att barnen kan bli mer självständiga, samt estetiskt tilltalande och tydlig genom att vara bra illustrativ och ha lätt text. Inget speciellt ogillades. Förbättringsförslag: En förälder (arbetar med sällsynta sjukdomar vgr) nämnde även att hon tyckte att mer information och egna upplevelser om sin diagnos bör ligga under "Min sida". Men då intervjuer under förstudien gett motsägande resultat så bortser vi från detta. Nvån var lagom. Nivå 1 föredras eftersom den kan användas av alla åldrar oavsett svårigheter. Frågan om något var förvånande ställdes inte.

Pilot test (Mom and 6 year old child)
Barnet tyckte det var bra innehåll/funktioner (jag gillar att samt i skolan) och estetiskt tilltalande (ikonerna). "Bra att veta om mig" och "Annat-knappen" kanske ansågs lite tråkiga (sa barnet) samt att man kanske inte behöver ha Annat-knappen alls (sa föräldern). Gällande tydlighet, så nämnde föräldern att namnet "Annat" var lite otydligt. Förbättringsförslag: Gällande innehåll så nämnde en förälder att det kan vara bra med hjälp-fråge-fält där frågan är halvt ifylld, för att underlätta för små barn att svara på frågor. Nivån var lagom, men föräldern nämnde att det kan vara bra att lägga till hjälp-fråge-fält för små barn så det blir lättare att svara på frågor/skriva ner saker. Barnet gillade båda nivåerna. En negativ kommentar dök upp gällde både innehåll/funktioner samt tydlighet, dvs att namnet på sidan "Annat" var lite otydligt vad det innebar samt att man kanske kan skippa att ha den sidan överhuvudtaget.

Version 3
Ages 8-18
Alla utom en gillade saker relaterat till innehållet/funktioner. Av dem nämnde många att intressen, skolan osv var bra och relevanta områden att ha med, och att det var bra att de var uppdelade på olika sidor. Den sista personen gillade inget speciellt mer än något annat. 2/5 nämnde att de ogillade saker relaterat till estetik och tydlighet, däribland textstorlek och ikoner. Resterande deltagare hade inget speciellt som de ogillade. De flesta hade ändringsförslag relaterat till estetik och tydlighet, och nämnde att de ville ha anpassningsbar textstorlek samt andra textformuleringar, ikoner och knappstorlekar. En deltagare hade inga specifika förbättringsförslag. Alla deltagare ansåg att nivån var lagom. 3/5 föredrog nivå 2 före nivå 1, där alla barnen var 14 år eller äldre. De två som föredrog nivå 1 nämnde tydlighet och estetik som anledningar, och var mellan 9-11 år gamla. Bland de saker som nämndes som förvånande med denna sida, var det övervägande positiva överraskningar gällande innehållet/funktioner. En deltagare ansåg att det inte fanns något som var förvånande.

F.0.3 My page - Editing page

Version 1
Ages 5-7
Två deltagare-sällskap nämnde att sidan generellt sett var bra! En av dessa nämnde också innehåll/funktioner som positivt, i det här fallet att det var kul att man kunde lägga in film. Inga deltagare fick denna fråga konkret, men inget speciellt nämndes som ogillat heller. Deltagarna hade inga speciella förbättringsförslag. Alla deltagare tyckte att nivån kändes lagom. Kommentarer om vad som var förvånande med denna sida var positiva och hörde till innehåll/funktion, där spela in video och att kunna berätta om skolan pekades ut. En deltagare nämnde också att inget speciellt var förvånande med sidan.

Pediatric nurses and parents to children that were formerly patients at CDN.
Nämnde inget specifikt som bättre än nåt annat, utan tyckte hela sidan kunde vara empowering genom att motivera barnen att använda den. Frågan ställdes ej, men inget speciellt nämndes som ogillat varken innan eller efter heller. Förbättringsförslag hörde till innehåll i appen, att barnet själv skulle kunna beskriva sin sjukdomshistoria och upplevelse av den. Lagom nivå pga tydliga knappar. Frågan ställdes ej gällande om något var förvånande.

Pilot test (Mom and 6 year old child)
Barnet tyckte smileygubbarna var bra. Barnet sade att inspelning och video ska bort. Men då det upplevdes som att den unga deltagaren mest pekade på lite saker utan någon direkt tanke så bortses den här punkten. Förbättringsförslag hörde till tydlighet och estetik. Barnet nämnde att han ville ha roligare smileys som hade färg och kunde röra sig. Hans mamma nämnde även att ljud- och video-inspelningen borde göras enklare att förstå och använda. Lagom nivå. Inget var förvånande.

Version 3
Ages 8-18
Alla deltagare utom en gillade saker relaterat till sidans innehåll/funktion, där exempelfrågorna och de olika sätten att berätta om sig själv (skriva, rita, lägga in bilder, video osv) pekades ut. En deltagare gillade inget speciellt mer än något annat. Hälften av deltagarna, som fick frågan om vad de ogillade, nämnde saker relaterat till tydlighet, främst gällande knapparna. Den andra hälften hade inget speciellt som de ogillade. Hälften av deltagarna, som fick frågan om de hade några förbättringsförslag, hade förslag relaterade till innehåll/funktion, där de tyckte exempelfrågorna kunde ändras/förbättras. Den andra hälften hade inga förbättringsförslag. Alla deltagare tyckte nivån kändes lagom svår. En deltagare tyckte dock att exempelfrågorna kunde göras lite "svårare" (gå mer på djupet?). Kommentarer om vad som var förvånande med denna sida var positiva och hörde till innehåll/funktion, där ljudinspelning pekades ut. En deltagare nämnde också att inget speciellt var förvånande med sidan.

F.0.4 My questions

Version 1
Ages 5-7
En deltagare gillade saker relaterat till innehåll/funktion, nämligen att kunna skriva ner sina frågor, att både vårdpersonal och föräldrar kan svara på frågor, och att barn kan lägga in bilder osv till frågan. En deltagare sa att hon gillade sidan generellt men pekade inte ut något specifikt. En förälder tyckte inte att historiksidan var så estetiskt tilltalande, då varje fråga tog upp mycket skärmplats. En förälder tyckte det var överdrivet att kunna lägga in bilder osv när föräldrar skriver in frågor, men sa samtidigt att det är bra att barn kan göra det. Eftersom detta gränssnitt designas utifrån barnens perspektiv kommer vi därför behålla funktionen. Förbättringsförslag som dök upp hörde till innehåll/funktion, där en förälder önskade mindre cards/fråga för att få plats med fler frågor, samt en sorteringsfunktion för

att enkelt bläddra fram obesvarade frågor. En förälder nämnde också att vi kunde inspireras av appen Trello. Alla deltagare tyckte nivån var lagom. Alla deltagare föredrog nivå 1 och sa att den var bra anpassad för barn, medan nivå 2 ansågs vara mer för vuxna. En förälder tyckte inte att det fanns nått specifikt oväntat, mer än möjligtvis att man tydligt kunde se när sjukhuset har svarat (innehåll/funktion). En deltagare fick inte frågan.

Pediatric nurses and parents to children that were formerly patients at CDN
Gillade hela funktionen att kunna skriva ner frågor och att de sparas (innehåll/funktion) och tyckte den förstorade bilden av en fråga såg estetiskt tilltalande ut.Frågan ställdes ej. Förbättringsförslag som nämndes relaterade till innehåll/funktion, med förslaget att läkaren inte bara ska kunna svara på frågor utan även lägga in råd som barnet ska tänka på, t.ex. inför nästa besök. Lagom nivå eftersom barnen själva kan välja uttryckssätt. Fick ej se den andra versionen. Frågan ställdes ej gällande om något var förvånande.

Pilot test (Mom and 6 year old child)
Mamman gillade historikfunktionen och tyckte den var tydlig. Mamman ogillade en sak relaterat till tydlighet, nämligen att det inte var så tydligt att man själv ska skriva ner frågor som man sen kan ta med till läkaren för att få svar. Mamman hade förbättringsförslag relaterat till innehåll/funktion, där en funktion att både kunna lägga in egna frågor och ha en FAQ-avdelning önskades. Hon ville också kunna se datum när en fråga lades till/ändrades. Vidare önskade hon ökad tydlighet på FAQ-frågor i form av att ha illustrativa bilder tillhörande varje fråga, så att barn enkelt kan förstå vad frågan handlar om (t.ex. ett gosedjur på en fråga om ifall det är okej att ta med gosedjur till besöket). Mamman ansåg att nivån var lagom, men ansåg att kalender-funktionaliteten kanske var lite överflödig på denna nivå. Föredrog nivå 1, men hade velat ha datum på sina egna frågor och att det stod "FAQ" på FAQ-frågor. Mamman tyckte det var förvånande att man inte förstod att man själv skulle skriva ner frågor.

Version 3
Ages 8-18
Det som gillades med denna sida hörde till tydlighet (t.ex. textformuleringar), estetik (t.ex. layout) och innehåll/funktion (t.ex. möjlighet att uttrycka sig på olika sätt). En deltagare sa också att allt med denna sida var bra. Alla utom en sa att det inte fanns något speciellt som de ogillade. Det som ogillades var en textformulering som skulle kunna förkortas. Ett förbättringsförslag som kom fram var att visa vilken tid/datum som ett svar på en fråga lagts in. Resterande deltagare hade antingen inga förbättringsförslag eller besvarade ej frågan. Nivån verkade lagom för alla deltagare i denna åldersgrupp. 2/5 föredrog nivå 1 och 1/5 nivå 2. De resterande två deltagarna hittade för- och nackdelar med båda nivåerna och verkade tycka att en kombination av de två hade varit optimalt. Det två kommentarer som nämndes som förvånande med denna sida var relaterat till innehåll/funktion, där en deltagare tyckte att det fanns information som saknades och en att man fick mer information än förväntat, vilket var positivt. Resterande tre deltagare sa att det inte fanns något

speciellt oväntat/förvånande.

F.0.5 My treatment

Version 1
Ages 5-7
Den ena deltagargruppen (en förälder och ett barn) tyckte att sidan var bra och tydlig. Den andra deltagaren (förälder) tyckte innehållet på sidan var väldigt bra speciellt för att kunna prata om mediciner på ett anpassat sätt med sitt yngre barn. Hon tyckte även den var tydlig och estetiskt tilltalande. I den ena deltagargruppen, med ett barn, så ogillade pappan "ändra knappen" och menade att den var onödigt tydlig på sidan för barn att se, då det är främst vårdepersonal som ska ändra här. Han tyckte om vårt förslag om att lägga knappen under informationsknappen. I övrigt hade denna grupp inga andra förbättringsförslag. Den andra deltagaren, förälder, fick inte frågan tydligt, men tog heller inte upp något negativt eller hade något förbättringsförslag. 2/2 deltagargrupper tyckte att nivån kändes bra/lagom. 1/2 deltagargrupper fick se båda versionerna. Den gruppen som fick se båda versionerna, ett barn och en pappa, föredrog nivå 1. 1/2 deltagargrupper fick frågan om det fanns något förvånande med sidan. Pappan i ena gruppen, med ett barn, sade att "ändra knappen" var lite onödigt tydlig på sidan för barn att se, då det är främst vårdepersonal som ska ändra här. Han tyckte om vårt förslag om att lägga knappen under informationsknappen.

Pediatric nurses and parents to children that were formerly patients at CDN
Det framgick i efterhand inte riktigt vad dom gillade och inte. Svarade inte på frågan när den ställdes, ställde motfrågor istället. Så antar att de inte tyckte något var dåligt. En av kollegorna sade att det hade varit bra att ha en funktion där läkaren kan skriva ner råd som barnet ska ta med sig. De tyckte att det skulle ligga under "Min behandling". Ena kollegan tyckte även att information om dos, hur ofta man tar medicinen, utseende etc skulle vara med (innan hon fick se nivå 2). Däremot sade hon att de yngsta barnen kanske inte behöver det. De pratade även om att man kan göra appen till ett verktyg för barn att kunna tracka och hantera sin diagnos lite mer detaljerat, tex vikt etc. Exempel som togs upp var en epilepsi-dagbok, huvudvärksdagbok och hantering av diabetes. De fick ej frågan om huruvida de tyckte nivån på sidan var lagom. Den ena kollegan sade att hon tyckte att nivå 1 passade för yngre barn och nivå 2 för äldre barn. Frågan om det fanns något förvånande med sidan ställdes ej.

Pilot test (Mom and 6 year old child)
Mamman tyckte att sidan var tydlig med bilderna och estetiskt tilltalande. Det var inget speciellt som ogillades med den här sidan. Mamman tyckte att några möjliga förbättringsförslag hade varit att med en bild visa om medicinen är flytande/tablett/spruta. Det hade också varit intressant att se när medicinen gavs ut och ens dosering (på nivå 1, hon sa detta innan hon fick se nivå 2). Mamman tyckte att nivån var lagom. Mamman tyckte att nivå 1 var lättare för både yngre och äldre att förstå. Frågan om det fanns något förvånande med sidan ställdes ej.

Version 3
Ages 8-18
Alla deltagare nämnde minst en sak som de gillade med denna sida. Majoriteten handlade om innehåll/funktion, där bl.a. bilder på medicinen och hur medicinen påverkar kroppen nämndes som bra information. Tre deltagare sa också att de tyckte sidan var estetiskt tilltalande. Alla utom en deltagare hade inget speciellt som de ogillade med sidan. Det som ogillades var fonten på medicinernas namn. Det förbättringsförslag som kom fram var att ha medicinernas namn i fetstil. Resterande deltagare hade inga förbättringsförslag eller fick ej frågan konkret, men nämnde inte heller några förbättringsförslag någon annan gång under testet. Nivån verkade lagom för alla deltagare. Alla utom en deltagare föredrog nivå 2. Den som föredrog nivå 1 gjorde det för att hen tyckte innehållet där var enklare beskrivet. Majoriteten av deltagarna som fick frågan tyckte inte något var speciellt förvånande. En person sade att han inte förväntade sig bilder på medicinerna men att det var bra att det var med.

F.0.6 My nursing staff

Version 1
Ages 5-7
En deltagargrupp (en förälder och ett barn) tyckte båda att sidan var bra generellt sett. Den andra deltagaren (förälder) hann inte se den här sidan men hade tidigare pratat om att det hade varit bra med bilder på läkarna och mottagningen, vilket vi har. Så man kan kanske anta att hon också hade tyckt om den designen. 2/2 deltagargrupper hade inget speciellt negativt att säga om sidan. Inga deltagargrupper fick frågan om förbättringsförslag ställd eller den här sidan visad pga tidsbrist. 1/2 deltagargrupper fick se sidan och höra frågan. En deltagare (förälder) sade att han tyckte att det var en lagom nivå. 1/2 deltagargrupper fick se sidan och höra frågan. En deltagargrupp (både flickan och pappan) tyckte att nivå 1 var bäst. 1/2 deltagargrupper fick frågan om de ansåg att något var förvånande med sidan, men ingen av dem nämnde något.

Pediatric nurses and parents to children that were formerly patients at CDN
Tyckte att sidan var estetiskt tilltalande samt att den verkar bra att ha för att kunna ha koll på sina vårdkontakter. Tyckte inget var speciellt dåligt. En av kollegorna pratade om att det hade varit bra att ha med kontaktuppgifter etc på sidan. Hon sa även att det hade varit bra att en lista med mottagningar att välja mellan dök upp i appen. Förutom det så hade det varit bra att ha bilder på läkarna som är tagna i förväg. Hon tyckte även att det var ett bra alternativ att man tar kortet själv på plats. Fick ej frågan om nivån var lagom. Visades ej den andra versionen pga tidsbrist. Frågan ställdes aldrig gällande om något var förvånande.

Pilot test (Mom and 6 year old child)
Mamman tyckte det var bra att ha riktiga bilder på läkaren. Mamman nämner att hon inte gillade att neurologavdelnings-texten var understruken då det såg ut

som en klickbar länk. Detta borde ändras. Mamman har som förbättringsförslag att ha med kontaktuppgifter, adress och telefontider till mottagningarna på sidan. Mamman tyckte att den här sidan hade en lagom nivå. Det ansågs inte relevant att visa den alternativa sidan. Mamman tyckte inte något var förvånande.

Version 3
Ages 8-18
Positivt feedback gavs som hörde till teman om Tydlighet, Estetik och Innehåll/funktioner. Några specifika saker som nämndes var att det var bra att ha med bilder/figurer på de läkare man ska till, att bilderna/gubbarna var söta och roliga, samt att det står vilken roll som vårdpersonalen har. En person sade att hon gillade idén generellt sett. 3/5 tyckte inget var speciellt dåligt med sidan. En person nämnde att innehållet hade lite för lite information/kontaktinformation om vårdpersonalen. En annan nämnde att han tyckte bilden på en av gubbarna såg lustig ut. En kommentar som dök upp var att det kunde va bra att ha kontaktuppgifter på sidan också. Annars var det inga förbättringsförslag som togs upp. Två stycken fick inte frågan. Alla som fick frågan sade att nivån var lagom. Två stycken blev antingen inte visad frågan eller visade sidan. De kan möjligtvis sägas tycka att nivån var okej iaf. Den ena gjorde klarat att han förstod allt på sidan och hur den fungerade. Den andra deltagaren hade tidigare pratat om komponeneter hon gillade och ville ha med, vilka fanns på den här sidan. Resultaten var rätt spridda. Alla tre som röstade på den enkla nivån sade att det var pga att en bild på mottagningen var en bra idé. Slutsatsen blir därför att lägga till alternativet att ha med en bild eller ej till både nivå 2 och 3. Alla saker som ansågs förvånande på sidan sades fortfarande vara positiva. Saker som nämndes vara att gubbarna bredvid vårdpersonalens namn var gulliga/roliga samt att hela sidan i sig var oväntad men positiv. Två deltagare tyckte inget var speciellt förvånande.

F.0.7 My Page (History)

Version 1
Pilot test (Mom and 6 year old child)
Generellt sett så gillar mamman sidan. Pojken säger däremot att han tycker den ser gammal ut (kanske för att allt är i grå färg). Mamman säger att sidan hade varit en lagom nivå om den var mer likt en almenacka. Med detta menar hon att man bör lägga till datum när sidorna är skrivna eller några slags rubriker. Det verkar därför som att hon lutar mer åt att gilla nivå 2. Det var inget på sidan som hon tyckte var förvånande.

F.0.8 My Page (Example page)

Version 1
Pilot test (Mom and 6 year old child)
(Exempelsida "i skolan") - Pojken gillade att man kan lägga in bilder/smileygubbar, men inte videoklipp och ljud. Mamman tyckte det saknades en funktion för att läsa upp exempelfrågorna/texten man lagt in. Pojken tyckte ljud och film var oväntat.

Mamman tyckte nivån var lagom, om man la in en uppläsningsfunktion.

F.0.9 My questions (Pop-up)

Version 1
Pilot test (Mom and 6 year old child)
Pilottest: Mamman gillade sidan man ser när man klickar in på en specifik fråga (förstorad bild). På denna sida föredrog hon nivå 1, men hade önskat att den även innehöll datum för besöket frågan hör till.

F.0.10 My Diagnosis (My Treatment)

Version 1
Pilot test (Mom and 6 year old child)
Mamman tyckte sidan var estetiskt tilltalande i att den var snygg, och tydlig med bra bilder. Hon tyckte även att texten var lagom kort samt att det var bra att man kunde ha alternativet att lyssna på texten. Det var inget speciellt hon ogillade, ville förbättra eller var förvånad över att det var med. Hon tyckte även att nivån var lagom samt att hon föredrog nivå ett.

F.0.11 Preparation before an appointment

Version 1
Pilot test (Mom and 6 year old child)
Positiv feedback som mamman tog upp var att det var tydligt att man lämnade appen när man klickade på knappen på sidan. Hon tyckte däremot att texten kan behöva kortas ner en del och göras enklare. Detta hade även gjort nivån på sidan ännu mer passande för små barn. Ett annat förbättringsförslag hon tar upp är att Dunder-fågeln hade kunnat läsa upp texten på sidan ifall man trycker på lyssna-knappen. Slutligen så föredrog hon version 1.

F.0.12 Background color

Version 1
Pilot test (Mom and 6 year old child)
Mamman tyckte inte något var speciellt bra eller dåligt med sidan. Hon tyckte heller inget var förvånande. Nivån sade hon kändes enkel och lagom. Ett möjlig förbättringsförslag hon tog upp är däremot att ha med samma ikon på denna sida som på startsidan för att göra det mer tydligt var man hamnat.

F.0.13 Miscellaneous

Pediatric nurses and parents to children that were formerly patients at CDN
Tyckte att det var en bra idé att ha olika nivåer/versioner av appen för olika åldrar INNAN vi sa någonting om det. Detta visar på att det är en bra idé.

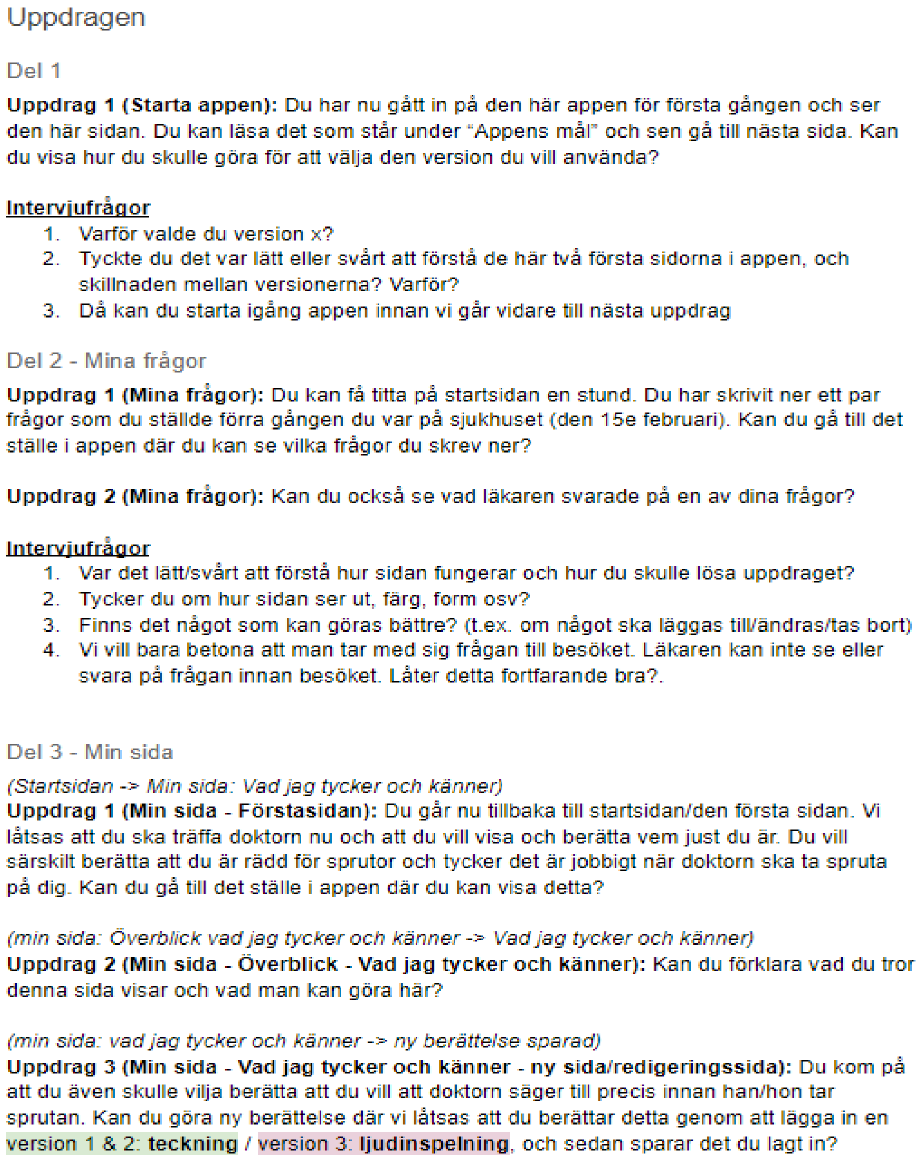
G

All final screens

All the different screens in the three versions of the final high fidelity prototype can be found in this Figma-document: `https://www.figma.com/file/6ECGGFsiyXyULjErkBHyz2/Master-thesis-report-prototype?node-id=0%3A1`

H

High fidelity evaluation questions and tasks



Uppdragen

Del 1

Uppdrag 1 (Starta appen): Du har nu gått in på den här appen för första gången och ser den här sidan. Du kan läsa det som står under “Appens mål” och sen gå till nästa sida. Kan du visa hur du skulle göra för att välja den version du vill använda?

Intervjufrågor

1. Varför valde du version x?
2. Tyckte du det var lätt eller svårt att förstå de här två första sidorna i appen, och skillnaden mellan versionerna? Varför?
3. Då kan du starta igång appen innan vi går vidare till nästa uppdrag

Del 2 - Mina frågor

Uppdrag 1 (Mina frågor): Du kan få titta på startsidan en stund. Du har skrivit ner ett par frågor som du ställde förra gången du var på sjukhuset (den 15e februari). Kan du gå till det ställe i appen där du kan se vilka frågor du skrev ner?

Uppdrag 2 (Mina frågor): Kan du också se vad läkaren svarade på en av dina frågor?

Intervjufrågor

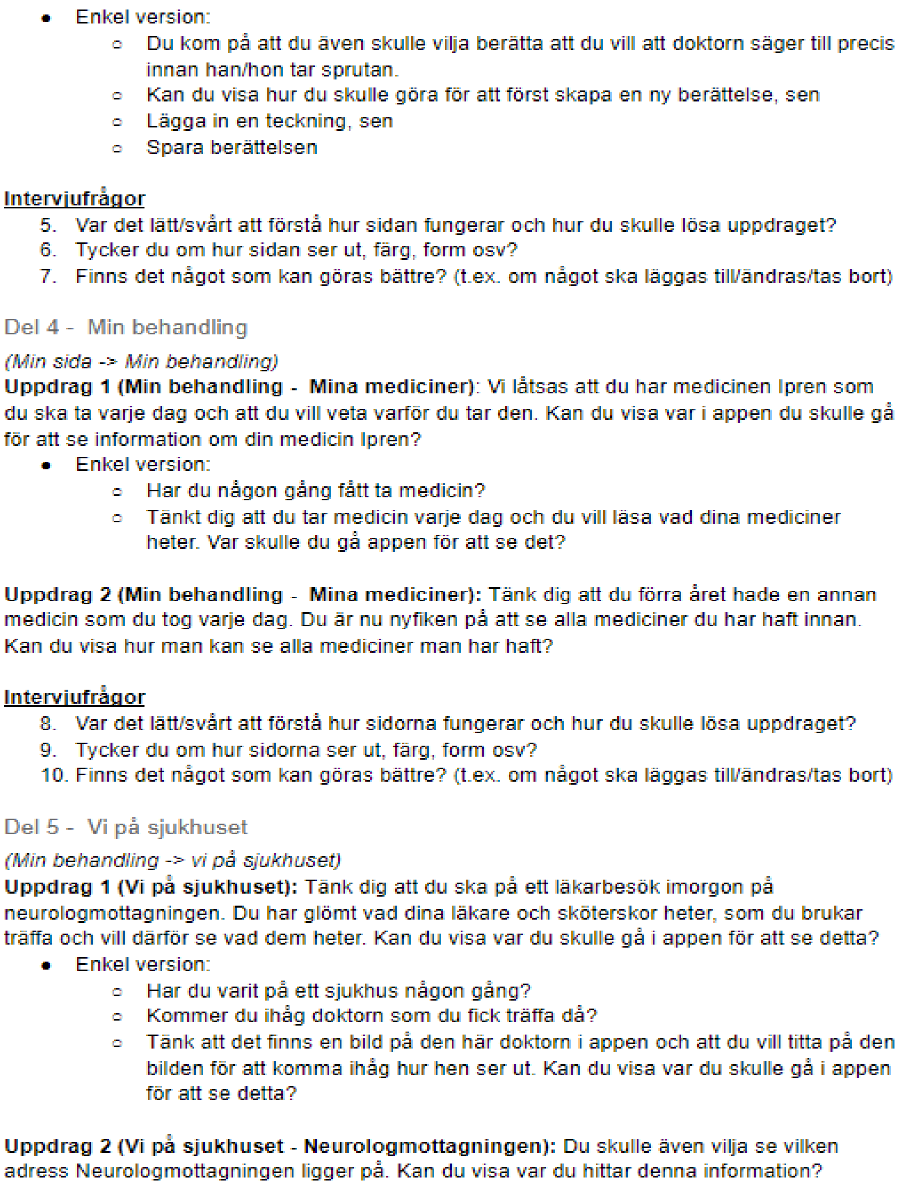
1. Var det lätt/svårt att förstå hur sidan fungerar och hur du skulle lösa uppdraget?
2. Tycker du om hur sidan ser ut, färg, form osv?
3. Finns det något som kan göras bättre? (t.ex. om något ska läggas till/ändras/tas bort)
4. Vi vill bara betona att man tar med sig frågan till besöket. Läkaren kan inte se eller svara på frågan innan besöket. Låter detta fortfarande bra?.

Del 3 - Min sida

(Startsidan -> Min sida: Vad jag tycker och känner)
Uppdrag 1 (Min sida - Förstasidan): Du går nu tillbaka till startsidan/den första sidan. Vi låtsas att du ska träffa doktorn nu och att du vill visa och berätta vem just du är. Du vill särskilt berätta att du är rädd för sprutor och tycker det är jobbigt när doktorn ska ta spruta på dig. Kan du gå till det ställe i appen där du kan visa detta?

(min sida: Överblick vad jag tycker och känner -> Vad jag tycker och känner)
Uppdrag 2 (Min sida - Överblick - Vad jag tycker och känner): Kan du förklara vad du tror denna sida visar och vad man kan göra här?

(min sida: vad jag tycker och känner -> ny berättelse sparad)
Uppdrag 3 (Min sida - Vad jag tycker och känner - ny sida/redigeringssida): Du kom på att du även skulle vilja berätta att du vill att doktorn säger till precis innan han/hon tar sprutan. Kan du göra ny berättelse där vi låtsas att du berättar detta genom att lägga in en version 1 & 2: **teckning** / version 3: **ljudinspelning**, och sedan sparar det du lagt in?



- Enkel version:
    - Du kom på att du även skulle vilja berätta att du vill att doktorn säger till precis innan han/hon tar sprutan.
    - Kan du visa hur du skulle göra för att först skapa en ny berättelse, sen
    - Lägga in en teckning, sen
    - Spara berättelsen

Intervjufrågor

5. Var det lätt/svårt att förstå hur sidan fungerar och hur du skulle lösa uppdraget?
6. Tycker du om hur sidan ser ut, färg, form osv?
7. Finns det något som kan göras bättre? (t.ex. om något ska läggas till/ändras/tas bort)

Del 4 - Min behandling

(Min sida -> Min behandling)

Uppdrag 1 (Min behandling - Mina mediciner): Vi låtsas att du har medicinen Ipren som du ska ta varje dag och att du vill veta varför du tar den. Kan du visa var i appen du skulle gå för att se information om din medicin Ipren?

- Enkel version:
    - Har du någon gång fått ta medicin?
    - Tänkt dig att du tar medicin varje dag och du vill läsa vad dina mediciner heter. Var skulle du gå appen för att se det?

Uppdrag 2 (Min behandling - Mina mediciner): Tänk dig att du förra året hade en annan medicin som du tog varje dag. Du är nu nyfiken på att se alla mediciner du har haft innan. Kan du visa hur man kan se alla mediciner man har haft?

Intervjufrågor

8. Var det lätt/svårt att förstå hur sidorna fungerar och hur du skulle lösa uppdraget?
9. Tycker du om hur sidorna ser ut, färg, form osv?
10. Finns det något som kan göras bättre? (t.ex. om något ska läggas till/ändras/tas bort)

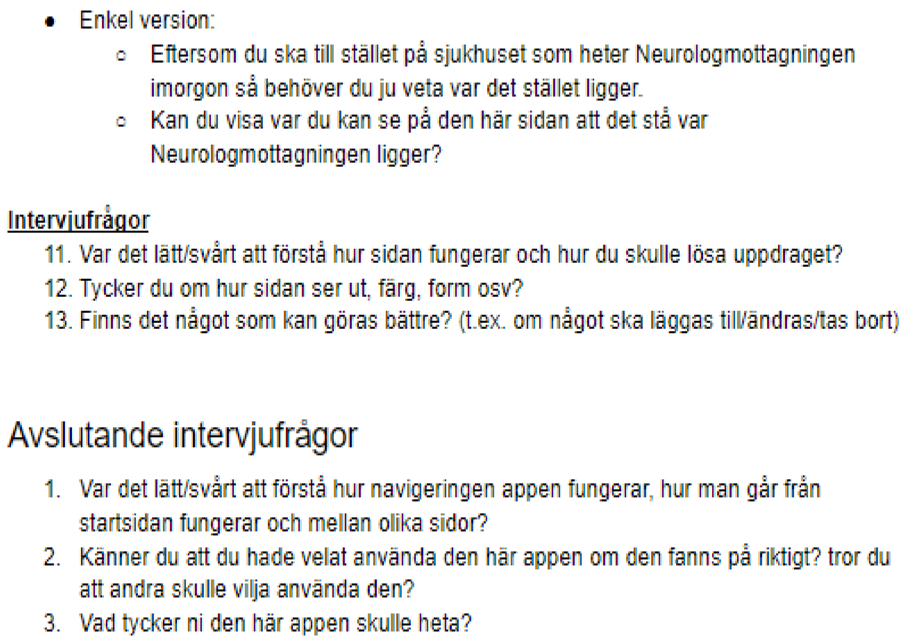
Del 5 - Vi på sjukhuset

(Min behandling -> vi på sjukhuset)

Uppdrag 1 (Vi på sjukhuset): Tänk dig att du ska på ett läkarbesök imorgon på neurologmottagningen. Du har glömt vad dina läkare och sköterskor heter, som du brukar träffa och vill därför se vad dem heter. Kan du visa var du skulle gå i appen för att se detta?

- Enkel version:
    - Har du varit på ett sjukhus någon gång?
    - Kommer du ihåg doktorn som du fick träffa då?
    - Tänk att det finns en bild på den här doktorn i appen och att du vill titta på den bilden för att komma ihåg hur hen ser ut. Kan du visa var du skulle gå i appen för att se detta?

Uppdrag 2 (Vi på sjukhuset - Neurologmottagningen): Du skulle även vilja se vilken adress Neurologmottagningen ligger på. Kan du visa var du hittar denna information?



- Enkel version:
    - Eftersom du ska till stället på sjukhuset som heter Neurologmottagningen imorgon så behöver du ju veta var det stället ligger.
    - Kan du visa var du kan se på den här sidan att det stå var Neurologmottagningen ligger?

Intervjufrågor

11. Var det lätt/svårt att förstå hur sidan fungerar och hur du skulle lösa uppdraget?
12. Tycker du om hur sidan ser ut, färg, form osv?
13. Finns det något som kan göras bättre? (t.ex. om något ska läggas till/ändras/tas bort)

Avslutande intervjufrågor

1. Var det lätt/svårt att förstå hur navigeringen appen fungerar, hur man går från startsidan fungerar och mellan olika sidor?
2. Känner du att du hade velat använda den här appen om den fanns på riktigt? tror du att andra skulle vilja använda den?
3. Vad tycker ni den här appen skulle heta?

I

Summary of results, high-fidelity prototype

I.0.1 Introduction page

Mission 1
Version 1 (age group 5-8)
The child participant in this age group did not seemed to have any issues understanding the content or how to perform the task.

Version 2 (age group 9-12)
Most participants in this age group did not seem to have any issues understanding the content or how to perform the task. Only one boy asked the facilitators whether the arrow he was pointing at was going to take him to the next page, which he clicked before the facilitators got the chance to respond.

Version 3 (age group 13-18)
Participants in this age group did not seem to have any issues understanding the content or how to perform the task.

Interview questions
Version 1 (age group 5-8)
The child participant in this age group chose the version that was designed "for her" , where her decision was based on the description of the different versions. Both participants also reported that it was easy to understand the content and the difference between the versions.

Version 2 (age group 9-12)
All participants except for one in this age group chose the versions that were designed "for them", where their decision was based on the description of the different versions. The one participant that chose version 3 instead of 2 was a 12 year old boy, i.e. a participant that are in the upper edge of this age span and soon will go over to the older age span. All participants said that they thought it was easy to understand the content and the difference between the versions.

Version 3 (age group 13-18)
From the two participants in this age group, both participants based their decision on which version to use on the description of the versions. One of them chose the

version that was designed "for them", while one chose version 2 instead of 3. The explanation was that this participant did not want to read or do a lot (which was how she interpreted version 3), while version 1 seemed too simple. She also said that she thought it was unclear whether "läskunskaper" (reading skills) referred to "how much one can read" or "how well one can read". Besides this, both participants thought it was easy to understand how to perform the task and what the difference between the versions was.

I.0.2 My questions

Mission 1

Version 1 (age group 5-8)

The child participants in this group managed to perform the task after some time and with support. The other participant said that her child would probably need a parent's support to perform the task. Other comments that came up were that the start page was aesthetically pleasing and that it was easy to distinguish the different buttons/the different pages and their content, from each other.

Version 2 (age group 9-12)

All participants except one in this age group managed to perform the task without issues. The one that managed after some time and with support said that he did not see the "my questions"-button at first. Other comments that came up was that the start page was aesthetically pleasing and that the icons were good looking, especially that you could add your own picture as icon for my page.

Version 3 (age group 13-18)

Both participants in this age group did perform the task without any issues.

Mission 2

Version 1 (age group 5-8)

The child participants in this group did perform the task without any issues. She did however not see the "agneta har svarat"-icon, but managed anyway. Other comments that came up was that it was appreciated to have the feature my questions and that you can write down the responses you get.

Version 2 (age group 9-12)

All participants except one managed to perform the task without any issues. The participant that took a bit longer to complete the task managed without problem once her mother explained the task in other words.

Version 3 (age group 13-18)

The participants in this age group did perform the task without any issues.

Interview questions

Version 1 (age group 5-8)

In this age group, participants said that it was or probably would be easy to understand what you are expected to do on this page, if the user have the cognitive ability of a normally developed 5 year old (or older). However, the question mark in the icon used on the "my questions"-button on the start page could be made more prominent to make this even easier. The participants reported liking the look of the page, including images/icons. It was also appreciated that one could add more fun to the page trough background colors and themes. Furthermore, there were no suggestions of improvements in this age group. The question on whether participants liked the idea that all questions are brought to and answered during rather than in between appointments was not asked to this age group.

Version 2 (age group 9-12)
All participants in this age group said that it was easy to understand the first part of the task (understand how to enter the feature "my questions"), but that the second task was a bit harder to complete. This seemed to have mostly to do with the way of presenting that a questions was answered/not answered, which was also the thing that was said could be improved. Generally, participants seemed to like the appearance of the two pages, and the icon on the start page. All of the participants (1 BN), except one that did not receive the question (not PU), were still positive towards feature after having explained that questions are brought to and answered during rather than in between appointments, even though one group (not PU) said that they would have wanted to be able to ask questions and receive responses in between appointments as well..

Version 3 (age group 13-18)
In this age group, both participants said that they thought it was easy to understand how the feature works and how to perform the task. They generally liked the appearance of the page and the amount of coloring etc, even though one participant said that one could tell it was a medical tool. She said that this could be both positive and negative depending on age and personal preferences. She thought younger children probably would prefer more colors etc, but that she personally thought it gave a professional impression. After having explained that questions are brought to and answered during rather than in between appointments, one participant said that she thought it would claim unnecessary time from appointments, which could be saved if one could ask and get responses on questions in between appointments. The other participant still thought it was a good feature, and liked the general idea of having everything related to her disease at one place.

I.0.3 My page

Mission 1
Version 1 (age group 5-8)
The child participant in this age group had no issues completing the task. The other participant said that it would probably be somewhat understandable for a normally developed 5 year old, especially with the support of an adult.

Version 2 (age group 9-12)
None of the participants in this age group, except for one, had any issues completing the task. One completed the task after some time with the support from the facilitators. The issues related to how one is expected to go back to the start page (through the back-button) and to the feature "my page" in itself, which the participant needed support with.

Version 3 (age group 13-18)
One of the participants in this age group did not have any issues related to performing the task, while the other completed the task after some time and support from the facilitators. The issue related to the back-button, which was mixed up with the "previous month"-button in the calendar-view. Furthermore, it did not seem obvious that "my page" was the feature to be used when wanting to tell about fears related to the disease/treatment/appointment, even though it is something you are afraid of.

Mission 2
Version 1 (age group 5-8)
The child participants seemed to grasp the overall purpose, functionality and content of the overview-page. The other participant also said that this would probably be somewhat understandable for a normally developed 5 year old, especially with the support of an adult.

Version 2 (age group 9-12)
All participants in this age group seemed to grasp the overall purpose, functionality and content of the overview-page.

Version 3 (age group 13-18)
All participants in this age group seemed to grasp the overall purpose, functionality and content of the overview-page.

Mission 3
Version 1 (age group 5-8)
The child participant in this age group did not have any issues related to completing the task. The other participant did not think it would be an issue for a normally developed 5 year old.

Version 2 (age group 9-12)
All participants except one completed the task with a small delay. One participant completed it with a small delay and support.

Version 3 (age group 13-18)
None of the participants had issues related to completing the task (except from how to close the drawing-tab).

Interview questions

Version 1 (age group 5-8) Both participants in this age group said that they thought it was or would be easy to complete the task, also for a normally developed 5 year old with some support of an adult. Both of them also liked the appearance of the page, including icons, images and the amount of text. None of them had any suggestions of improvements.

Version 2 (age group 9-12)
All participants in this age group said that it was easy or quite easy completing the task and understanding the pages in general. The one thing that was reported as confusing by one participant was the overview-page. All participants said that they liked the appearance of the pages, that it was clean and simple with its colors and icons. 2/4 participants had suggestions of improvements, where one suggestion was about being able to sort out notes you are looking for based on keywords/themes instead of the date it was saved. Furthermore, one suggestion was to make the "edit"-button on a note more distinguishable, e.g. use a stronger color.

Version 3 (age group 13-18)
Both participants in this group said that it was not super-clear what this page had to offer. One said that she probably would need to get familiar with the tool before being able to complete tasks without trouble. One said that it was easy to understand that you could write about your fears etc when you entered my page, but when standing on the start page, one could easily think this belonged to "my treatment" or "preparation before the appointment". Both participants liked the appearance of the pages, that it was clean and gave a serious impression at the same time as it offered some fun and guidance with the icons. None of the participant had any suggestions of improvements.

I.0.4 My treatment - My medicines

Mission 1
Version 1 (age group 5-8)
The child participant managed to complete the task with some delay, after having excluded "my nursing staff" as the correct answer. The other participant said that a normally developed 5 year old would probably understand this.

Version 2 (age group 9-12)
All participants in this age group completed the task without any issues.

Version 3 (age group 13-18)
All participants in this age group completed the task without any issues.

Mission 2
Version 1 (age group 5-8)
The child participant in this age group completed this task without issues. One participant said that it was good that the button to "previous medicines" were placed

at the bottom of the page - this seemed most logic to her.

Version 2 (age group 9-12)
2/4 participants completed the task without any issues. One participant managed after having realized that all medicines on the first page are current and having seen the "previous medicines"-button at the bottom of the page. The other participant managed after some time spent on mixing up "my medicines" with "my diagnosis".

Version 3 (age group 13-18)
Both participants in this age group completed the task without any issues.

Interview questions
Version 1 (age group 5-8)
A participant stated that adding a picture of a medication tablet on the start page would help make it easier to find information about your medication. The other participant stated that she thought this page would be simple to understand for a 5-year-old. Both groups liked how the page looked like. No group of participants had any further suggestions of improvements.

Version 2 (age group 9-12)
All participants thought the page was simple to understand. One participant did mention that she did not notice the "previous medicines" button at first because it was very small. Further on, 3/4 participants stated that they liked the overall look and design of the page. One participant mentioned that one should increase the size of the text on the "history-page" for younger children. Further suggestions of improvements were to make it more clear that one can upload your own images of the medicines, make the icon on the start page more clearly related to the content of the page and to change the headache-icon due to it looking strange. One participant also stated that the "previous medicines" button could be made easier to notice.

Version 3 (age group 13-18)
Both participants in this age group said that it was easy to understand the purpose of the page and how to complete the task. Both participants liked the appearance of the pages. One participant also said that she liked the way information about medicines was presented in an informal and easily-accessible way, and being able to see pictures of medicines with names that might be difficult to remember. None of the participants had any suggestions of improvements, however, one participant said (again) that she thought it could be both positive and negative that the tool give such a "medical" impression.

I.0.5 My nursing staff

Mission 1
Version 1 (age group 5-8)
The child participant did not think it was a hundred percent clear how she should

complete this task. She did need some simple guidance from her mother to find it. The other participant said that children might mix the pages "Vi på sjukhuset" and "Tips inför besöket together.

Version 2 (age group 9-12)
None of the four participants in this age group had any problems completing the task.

Version 3 (age group 13-18)
None of the two participants in this age group had any problems completing the task.

Mission 2
Version 1 (age group 5-8)
The child participant did not have any problem completing the task. The other participant, with a younger child, said that she thought five-year-olds would be able to complete this task as well.

Version 2 (age group 9-12)
3/4 participants did not have any problems completing the task. One participant, completed the task after going back to the start page once.

Version 3 (age group 13-18)
One of the participants had trouble completing the task without requesting aid form the facilitators. Although, it turned out to be because of a misunderstanding of the task rather than the task being difficult. The other participant had trouble completing the task as well but later managed on her own. At first she thought that the information of the task might be at the page "Tips inför besöket".

Interview questions
Version 1 (age group 5-8)
All groups of participants thought the page was easy to understand and looked good in terms of colors, pictures etc. One participant mentioned that she thought young children would understand the logic on the page very well. Both groups suggested that one might add a map-function on the page as well, to easier find the location of a certain department.

Version 2 (age group 9-12)
All participants thought the page was easy to understand. Although, two participants did mention that it could have been made clearer that one could click on the card to receive more information. Three out of four groups of participants thought the design and appearance of the page was simple and aesthetically pleasing, mentioning for example the nursing-staff icons as being pretty. One participant said that the page could have had more color. Further suggestions of improvements made were to add an explanation of what a department does, add information of what hospital the department belong to on the first screen of the page, and to add a feature of being able to view a history of your previous nursing staff. Two groups of participants did not have any suggestions of improvements.

Version 3 (age group 13-18)
One of the participants said that apart from the misunderstanding with the task, she thought it was simple. The other participant said that it was unclear that you could click on the department to get more information. She suggested to add an arrow and clarifying text to solve this problem. Further on, she said that one could add the function to be able to add nurses phone numbers. Regarding the appearance of the digital tool, one of the participants said that she did not like the people-icon because it didn't look serious. The other participant said that she liked the feature to be able to add real pictures of the nursing staff.

I.0.6 Final interview questions

Version 1 (age group 5-8)
Both groups found the digital tool's navigation clear and easy to understand. One group only mentioned positive things, such as the application being cohesive and fun with pictures etc. The other group of participants had a suggestion to change or remove house-icons on the start page that did not fit properly with the page it represented. Both groups said that they though the digital tool would be very useful and that they definitely would use it if it would be released. One of the groups did also say that it was important that the tool would have a high security regarding data storing, if they were to use it. One group received the question regarding name suggestions of the app and suggested something regarding "Rättighet" and "Delaktighet".

Version 2 (age group 9-12)
All groups of participants thought the navigation in the digital tool was easy to understand, and one mentioned that the amount of hierachies used was appropriate. All groups of participants said that they thought that people with this type of condition definitely would use this digital tool. The one group of participants were the child has a long term illness also said that they would use it themselves. Name suggestions of the digital tool that were suggested by the participants were: "hälsoappen", "hälsokollen", "e-hälsoappen", "min vård", "läkarappen", "barnappen".

Version 3 (age group 13-18)
Both participants thought the navigation in the digital tool was very easy to understand. One of the participants did mention that they thought that the roundabout-lines, connecting the buttons on the start page, could be skipped. The participant said that she would prefer to only have buttons instead. Both participants said that they thought that other people, with a long term illness, would like to use this digital tool. One of the participants, that has a long term illness herself, also said that she thought the tool would be really helpful and that she would like to use it herself. The other participant said that she knows a friend diagnosed with a long term illness, that she on the contrary does not want anything to do with her illness. Moreover, name suggestions of the application that came up were "Min sjukdom",

"Min diagnos" Mitt sjukhusbesök" or something fun or cool. Another general opinion stated by one of the participants was that the blue theme of the application gave too much of a "hospital feeling" , that some people might want and some might not want. When presented with the feature to be able to change background color, she thought this was a great and important feature.