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Digital service for measuring children’s patient experience of preoperative medical clowning

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Healthcare organizations have recently recognized patient experience as an important part of their quality care. By measuring and improving the patient experience, healthcare organizations can affect multiple parts of the care. However, children’s patient experience has yet been understudied although it has been recognized that adults cannot provide as accurate views of children’s experiences as children.

This thesis focused on studying how digital services can be used to measure patient experiences. A digital service was designed and developed for measuring children’s patient experience. Then, the digital service was used and evaluated in a case study, where the effects of preoperative medical clowning to patient experience were studied. The patient experience was studied from three different point of views; the child patients, their parents and the nurses. The case study was conducted at HUS Children’s Hospital in Helsinki. This thesis was part of the LAPSUS research project.

Based on the results of this study, a digital service can be used to measure patient experience. Children as young as 4 can report their experiences with child-friendly digital services. Findings of the case study indicate that preoperative medical clowning affects the patient experience of child patients and their parents in a really positive way. The study did not find differences in the cannula insertion procedure regarding the presence of the preoperative medical clown from the nurses’ point of view.

This study provides insights on patient experience and ways to measure it with a digital service. Also, this thesis was the first study about the effects of the preoperative medical clowns to patient experience in Finland. The recommendations of the study are to support both patient experience measurement with a digital service and preoperative medical clowns more in children’s hospitals.

Keywords: digital service, patient experience, child patient, preoperative medical clowns, children’s hospital

Language: English
Potilaskokemus on viime aikoina todettu tärkeäksi osaksi terveydenhuoltoalan palveluiden laatua. Mittaamalla ja parantamalla potilaskokemusta terveydenhuollon organisaatio voivat vaikuttaa moniin hoidon alueisiin. Lasten potilaskokemusta on kuitenkin vielä tutkittu vähän, vaikka on todettu etteivät aikuiset pysty kertomaan lasten kokemuksista yhtä tarkasti ja kattavasti kuin lapset itse.


Tutkimus tarjoaa tietoa potilaskokemukseen digitaalisesta mitattavuudesta, sekä lasten potilaskokemuksesta. Tutkimus oli ensimmäinen toimenpidelkovnerian vaikuttavuutta potilaskokemukseen tutkiva tutkimus Suomessa. Tutkimuksen suosituksena on tukea enemmän sekä potilaskokemukseen mitattavista digitaalisten palveluiden avulla, sekä toimenpidelkovneriaa lastensairaaloissa.

Asiakirjat: digitaalinen palvelu, potilaskokemus, lapsipotilas, toimenpidelkovneria, lastensairaala

Kieli: Englanti
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Abbreviations and Acronyms

API  Application programming interface
CX   Customer experience
EACH Eauropen Association for Children in Hospitals
HCAHPS Hospital Consumer Assessment of Healthcare Providers and Systems
HUS  The Hospital District of Helsinki and Uusimaa
JSON JavaScript Object Notation
mYPAS Modified Yale Preoperative Anxiety Scale
PX   Patient experience
UNCRC United Nations Convention on the Rights of the Child
UX   User experience
VAS  Visual analogical scale
Chapter 1

Introduction

Healthcare organizations have just recently acknowledged that patient experience is an important factor of quality care, and thus it is an important factor to be measured (Ahmed et al., 2014; Beattie et al., 2015; LaVela and Gallan, 2014; Stiefel and Nolan, 2012). Measuring patient experience can affect multiple different parts of the healthcare service, like practical, managerial and clinical areas of care, improvements of care, strategic decision making and performance benchmarking (Beattie et al., 2015; LaVela and Gallan, 2014). However, measuring patient experience is hard because firstly, it lacks a common and accurate definition, and secondly, because there are multiple methods for measurement (Ahmed et al., 2014; Beattie et al., 2015; Wolf, 2017b; LaVela and Gallan, 2014). Nevertheless, children’s patient experience has yet been understudied, and the research on patient experience has focused mostly on adults’ perspectives. Moreover, studying children differs from studying adults, and a special care for the methods and tools need to be addressed (Punch, 2002).

This study aims to examine how digital services can be used to measure patient experiences. Because children’s patient experience is yet understudied, and the same methods cannot be used as with adults, a digital service for measuring children’s patient experience is designed and developed in this study. Then, the digital service is used in a case study, in which the effects of preoperative medical clowning to patient experience are studied. The case study is conducted in the Hospital District of Helsinki and Uusimaa (HUS) Children’s Hospital. This thesis is part of the LAPSUS research project, which aims to examining the dimensions of patient experience from the perspectives of pediatric patients and their families.
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1.1 Background and motivation

Digitalisation and technical advancement in the 21st century has lead to disruptive and challenging market changes in many businesses (Bolton, 2016). Customer behaviour and preferences are quickly changing, and to retain their competitiveness in the new markets, companies must continue to create excellent customer experiences through services (Bolton, 2016; Stickdorn and Schneider, 2011). To answer to the new and evolving customer expectations, companies must gather customer feedback and act upon it. The new technologies enable gathering customer feedback instantly, here and now, compared to sending paper questionnaires home few weeks after the service encounter (Thomas and Applegate, 2010). Also customers, who are nowadays more used to the disruptive nature of technology, want to give the feedback instantly and not weeks later (Bolton, 2016).

Just like any other businesses, also healthcare organization and hospitals need to adapt to these new changes in the markets. Healthcare organizations have recently acknowledged the importance of patient experience as a factor of their quality care, and thus it is an important factor to be measured (Ahmed et al., 2014; Beattie et al., 2015; LaVela and Gallan, 2014; Stiefel and Nolan, 2012). Although the importance of good patient experience is acknowledged, it still lacks a common and accurate definition (LaVela and Gallan, 2014; Wolf, 2017b). Regardless, measuring patient experience is important, because it can affect practical, managerial and clinical areas of care, and the results can be applied to concepts like improvements of care, strategic decision making and benchmark performance (Beattie et al., 2015; LaVela and Gallan, 2014).

The patient experience research conducted to this date concerns mostly the views of adults. Generally the views of the children have been studied through proxies; someone other than the children themselves (Kortesluoma and Nikkonen, 2004; Stälberg et al., 2017; Söderbäck et al., 2011). However, others cannot provide as detailed and accurate views of children’s experiences as children themselves (Chesney et al., 2005; Kortesluoma and Nikkonen, 2004). Moreover, United Nations Convention on the Rights of the Child (UNCRC) and the European Association for Children in the hospital (EACH) state that children should be heard in matters related to them and that sick children have rights in healthcare (United Nations, 1989; EACH, 2013). Thus, it is important to give children the possibility to express their experiences in a way that is natural to them.
In addition, more hospitals have started to use innovative digital services to support their operations and customers. For example, the New Children’s Hospital in Helsinki implements a real-time location technology to enable better parental information about their child’s care, staff resource management and device availability (New Children’s Hospital Press release, 2018). Moreover, the New Children’s Hospital provides multi-purpose service system on a tablet device for ward patient to for example, enable better communication between home and the hospital (New Children’s Hospital Press release, 2018). Thus, the use of digital services in the hospital context could be natural for both the healthcare organizations and patient families.

The Finnish medical clowns have worked in the University hospital across Finland already from year 2002 (Lindberg et al., 2017). However, the preoperative medical clowns have started working in the HUS Children’s Hospital during 2016. This form of medical clowning is more goal-oriented, as the preoperative medical clowns accompany child patients to their treatments or operations and aim in relieving the difficult and scary situations (Lindberg et al., 2017). However, preoperative medical clowning and its effects to patient experience have not been systematically studied in Finland before.

As stated earlier in this section, patient experience is an important factor of quality care. However, it is still understudied, let alone children’s patient experience. Also, the use of digital services in measuring patient experiences has not yet been widely studied. In addition, the effect of preoperative medical clowning has not yet been studied in relation to patient experience. Thus, this study meets the demand for studying how patient experience could be studied with digital services, how children’s patient experience could be studied and the effects of preoperative medical clowning to patient experience. Actually, this is the first study about the effects of preoperative medical clowning on patient experience in Finland.
1.2 Objectives and research questions

The objectives of this study are twofold. The first objective is to study how digital services can be used to measure patient experiences. Because adults are able to answer more traditional patient experience questionnaires, even in a digital format, we wanted to address the use of a digital service in studying children's patient experience. However, when children and their patient experience is studied, special considerations and design decisions need to be addressed. Thus, this study uses the service design approach to first design and then develop a special digital service for measuring children's patient experience. The research problem of this thesis is as follows:

RP: How can digital services be used to measure patient experiences?

The second objective of this study is to evaluate the applicability of the designed and developed digital service. In order to evaluate the applicability of the digital service, it is used in a case study to research the effects of preoperative medical clowning to patient experience. The applicability of the digital service is evaluated from two point of views. The first point of view evaluates the usability of the digital service. The second point of view is that could patient experiences be revealed by using the digital service. If results for the case study can be found, it indicates that the digital service is applicable for measuring patient experience. Thus, to study the applicability of the digital service in measuring patient experience, the following research questions are answered:

RQ1: How does the preoperative medical clown affect the patient experience of the child patients?

RQ2: How does the preoperative medical clown affect the patient experience of the child patients' parents?

RQ3: How does the presence of the preoperative medical clown affect the cannula insertion procedure from the nurse’s point of view?

As the research problem combines multiple different fields of research together, the findings of this study contribute to many fields too. These fields are such as service design, patient experience, measuring patient experience, child patients and preoperative medical clowning. The findings of this study can be applied in children’s hospitals, which want to provide digital services to the child patients to measure and improve children’s patient experience.
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1.3 Context and scope

This thesis is written as a part of the LAPSUS research project. The LAPSUS research project (Renewing Hospital for Families with Children, in Finnish Lapsiperheiden Uudistuva Sairaala) was funded by Business Finland and is a joint research project of Aalto University, Tampere University of Technology, Hospital District of Helsinki and Uusimaa (HUS), Oulu University Hospital and Turku University Hospital. The project is closely related to the design of the New Children’s Hospital building in Helsinki. The objectives of the research project were describing the dimensions of patient experience from the perspectives of pediatric patients and their families, developing methodology and instrumentation for monitoring patient experience and value creation, and linking patient experience data to continuous improvement of care.

The design and development of the digital service focuses on the design process and final service, rather than to the technical details. The design of the digital service uses the service design and double diamond approach. The digital service was implemented as a website on a tablet device, which child patients could then use independently for reporting their experiences.

The case study was conducted in the HUS Children’s Hospital in Meilahti, Helsinki. The patients of the hospital will move to the New Children’s Hospital, which is located next to the old Children’s Hospital in Meilahti, during the fall 2018. More specifically, the study will be conducted in the Day Surgery Unit of the HUS Children’s Hospital. The Day Surgery Unit operates on small surgical operations, where child patients can come from home and leave home on the same day.

In addition, only child patients who have a cannula insertion relating to their operation at the Day Surgery Unit are included in the study. This is because the cannula insertion procedures are quite common in the Day Surgery Unit, and that way the sample size to the research could be high but still the patient group would be as similar as possible.

The viewpoint on the medical clowning is the preoperative medical clowning, and the effect of the more traditional medical clowning in Finland, where two clowns visit the pediatric wards is not studied in this thesis. This is because these two forms differ from each other and in the preoperative medical clowning the medical clown stays with the child patient throughout the hospital day.
1.4 Structure of the thesis

This thesis starts from a background study of the related topics in chapter 2. Then, the service design principles, methods and tools in addition to the Double diamond model approach are examined in chapter 3. Also, the evaluation criteria for the digital service are presented in that chapter.

The chapter 4 describes how the research was conducted, starting from the design process to presenting the digital service. Then the case study conducted in the hospital is introduced. Finally, the data analysis is described.

Then, the results and findings of the study are reported in chapter 5. First, the designed and implemented digital service is evaluated against the selected criteria and then the case study results are presented. The results of the case study are discussed from three points of view, the children’s experiences, child patients’ parents experiences and from the nurses’ point of view for the cannula insertion procedure.

Next, in chapter 6 the study results and used research methods are discussed in more detail. The findings are also reflected to earlier studies related the themes of the study. Also, the validity of the study is examined, with the recommendations and future work ideas.

The final chapter 7 concludes the thesis with the conclusions derived from the results and findings.
Chapter 2

Background

This chapter introduces background information on the subjects of the study. The information was collected by a literature review, and this chapter presents the key findings of that literature review. The literature review includes theoretical background for emotions and experiences, patient experience, researching children and medical clowns’ work.

The background study was conducted by searching academic databases, such as Google scholar and Aalto Finna, and literature for relevant topics. Topics and keywords applied to the search were terms like patient experience, children, hospital, research, study, medical clowns, anxiety, pain and measurement. These keywords were applied both separately and together with operators AND or OR. In addition, searches for medical clowns contained different synonyms for medical clowns, such as dream doctor or therapeutic clown.

First this chapter provides background for experiences and emotions, following with discussion on patient experience in more detail. Then, the special issues and considerations that need to be addressed while researching children are examined. The last section introduces the history and work of medical clowns.
2.1 Experiences and emotions

The word "experience" is nowadays used in many acronyms to define exact, context specific experiences, such as user experience (UX), customer experience (CX) and patient experience (PX). Yet, all of these different experiences rely on the meaning of an experience. The English Oxford Dictionary defines experience as follows:

"An event or occurrence which leaves an impression on someone."


Therefore, experience is something that affects us and leaves a feeling, an emotion to someone. Emotion on the other hand is defined as follow in the English Oxford Dictionary:

"A strong feeling deriving from one’s circumstances, mood, or relationships with others."


Actually, both experiences and emotions are incidents, which leaves an effect on someone. Experiences can be seen as private to oneself, or shared if they are socially mediated (Greene and Hogan, 2005). In either way, experiences and emotions require interpretation both to oneself and to others, and this interpretation is usually linguistic or symbolic (Greene and Hogan, 2005). Also, this interpretation can happen only after the person is aware and conscious about the experience and emotion (Greene and Hogan, 2005). Compared to adults, children can consciously process and understand only a small part of their experiences and emotions (Greene and Hogan, 2005).

As a result of both the private and shared nature of experiences and emotions, researchers can try to understand children’s emotions both by observing them and by allowing children to report them (Greene and Hogan, 2005). However, researchers can never completely access and understand those experiences, because they see and interpret them from their own point of view, which is usually from the adult’s point of view (Greene and Hogan, 2005; Punch, 2002). Also, if both children and adult’s perceptions of the same experiences or emotions are researched, they should be seen as complementary perspectives and not try to find the one single truth (Greene and Hogan, 2005).
2.1.1 Emotion categorization

Emotions can be classified and categorized in many ways. Here, we will examine two of those categorization in more detail: The circumplex of emotions by Russell (1980) and the wheel of emotions by Plutchik (2001). These models are also used in this study for emotion categorization. Both of these models begin from two actions: grouping similar emotions together and opposite emotions away from each other (Plutchik, 2001; Russell, 1980).

![Figure 2.1: A modified representation of the circumplex of emotions based on Russell (1980).](image)

The circumplex of emotions by Russell (1980) divides emotions into two dimensional bipolar space with arousal and valence as its dimensions. The horizontal axis of the model represents the degree of arousal of an emotion, and the vertical axis represents the degree of valence (Russell, 1980). For example, excitement is placed on the top right of the circumplex, as it is high arousal but pleasant emotion. On the contrary, fatigued would be placed on the bottom left, as it is low arousal and more unpleasant emotion. Sad and happy would be placed on the far left and right of the horizontal axis. The figure 2.1 presents the basic representation of the circumplex of emotion.
The wheel of emotions on the other hand divides emotions into a star like shaped wheel with concentric circles representing different emotions. Plutchik (2001) divides emotions to eight primary emotions, which are joy, acceptance, fear, surprise, sorrow, disgust, anger and expectancy (Plutchik, 2001). These emotions are arranged so that similar emotions are close and opposing emotions are far from each other. The more inner in the wheel an emotion is, the more basic the emotion is, and the more outer the emotion is, the more complex the emotion is (Plutchik, 2001). The figure 2.2 shows the wheel of emotions and how it categorizes the emotions in more detail.
2.2 Patient experience

This section examines patient experience in more detail. First, we will introduce one commonly used definition of patient experience in more detail. Secondly, techniques for studying and measuring patient experience are reviewed. Finally, we will explore how children have been studied in hospital context.

2.2.1 Definition

Although patient experience as a theme has obtained more recognition in the recent years, it still lacks a common and accurate definition (LaVela and Gallan, 2014; Wolf et al., 2014; Wolf, 2017b). In a report of the Beryl Institute’s benchmarking study, Wolf (2017b) stated that in 2015 only 47% of US hospitals and 53% of non-US hospitals had a formal definition of patient experience, whereas in 2017 the same numbers were 65% and 64%. Out of these definitions, the most commonly cited definition for patient experience was the Beryl Institute’s definition (Wolf, 2017b). That definition is the following:

"The sum of all interactions, shaped by an organization’s culture, that influence patient perceptions across the continuum of care"


Next, this definition will be examined in more detail. The sum of all interactions involves all the patient’s touch-points and connections with different people, processes, policies, communications, actions and environments (Wolf et al., 2014). These interactions or events cannot be recognized in isolation, but rather they influence each other and are interconnected (Mannonen et al., 2017). Organization’s culture includes the whole organization’s vision, values and all the people and community connected to it (Wolf et al., 2014). Recently it was recognized how big of an impact people engagement, all patient, family and employee engagement, has on patient experience (Wolf, 2017a). The patient perceptions are the views of the patient, what the patient recognizes, understands and remembers (LaVela and Gallan, 2014; Wolf et al., 2014). The patient perceptions affect how the patient evaluates the experience, and thus it has the most power over the patient’s patient experience.
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(LaVela and Gallan, 2014). The continuum of care means the whole patient journey, from all encounters of all sides of the system and services (Wolf et al., 2014). In addition to these aspects, patient experience comprises quality, safety, service, cost and outcomes (Wolf, 2017a). In the middle of these aspects are the patient engagement and employee engagement (Wolf, 2017a). Figure 2.4 summarizes the expanded perspective on patient experience.

Figure 2.3: An expanded perspective on patient experience by Wolf (2017b).

One element of a good patient experience is patient-centered care (Greenfield et al., 2014). In their study, Greenfield et al. (2014) defined patient-centered care as a care that "emphasizes a holistic, humanistic approach that puts patients first, at the center of medical care". They also identified six themes of patient-centered care, which are holism, naming, heed, caring, agency and
empowerment, and continuity of care (Greenfield et al., 2014). These six themes interweave each other, but they also have one common and combining theme, which merges them together as a whole. This seventh theme is space, which covers both physical and psychological space, and it means that patients expect to have their own space, both physically and emotionally, where they can be heard and where the six themes of patient-centered care can occur (Greenfield et al., 2014). If patients would not have their own spaces, they might feel translucent and invisible, and thus the six other themes are not met and patient experience would not be as good as it could. Greenfield et al. (2014) suggest that when these themes are realized, the patient experience is better. Figure 2.4 presents the themes together, and gives examples of how the patient might feel when the themes are present.

Figure 2.4: Six themes of patient-centeredness by Greenfield et al. (2014).
The term patient experience is regularly mixed with other alike, yet different, terms, such as patient satisfaction, patient perceptions and patient engagement (Ahmed et al., 2014; Needham, 2012; LaVela and Gallan, 2014; Beattie et al., 2015). Patient satisfaction is the gap between what the patient expected from the care, and what actually happened and how it made the patient feel (Beattie et al., 2015; LaVela and Gallan, 2014). Patient satisfaction can be measured with questions that include emotional words such as “happy”, “satisfied” and “pleased” (LaVela and Gallan, 2014). Patient perceptions are the views that the patient has of the care (LaVela and Gallan, 2014). Patient’s perceptions affect how the care and experience is evaluated by the patient (LaVela and Gallan, 2014). In fact, it is the only input to patient experience from the patient’s point of view, as can be seen also from the Beryl Institute’s definition of patient experience, at the page 11 (Beryl Institute, 2014; LaVela and Gallan, 2014). Patient engagement means the state where the patient is committed and involved in the care, and to their own health and well-being (LaVela and Gallan, 2014). Patients who are engaged in their care tend to positively affect their care and thus advance their recovery (LaVela and Gallan, 2014). It could be said, that these other terms and definitions focus on some aspect of patient experience, but they cannot thoroughly describe the nature of patient experience. Patient experience is the overarching theme that combines these other terms together.

Further, patient experience differs from customer experience. Customers are typically people who feel well and who want to use a product or service, whereas patients are people who have an injury or illness, and who might feel pain, vulnerable, exhausted or confused (Torpie, 2014). These patients wish to become healthy and to return to normal state by the use of a healthcare service, whereas normal customers of any service wish to advance their status further from the already healthy state (Torpie, 2014). Patients need to have great trust to their service provider, and they might not have the time or an alternative to choose and compare options ahead (Torpie, 2014). On the other hand, normal customers might have the time and resources to compare options and take the best alternative they find, if any at all (Torpie, 2014). Healthcare customers are advised to be called patients, and not customers, users or consumers (Torpie, 2014; Wolf et al., 2014).

Kaipio et al. (2017) identified in their research five different phases of a child family’s patient journey. These phases are symptoms phase before diagnosis or operation, hospitalization phase after diagnosis or operation, recovering at home, control visits to the doctor’s practice and returning to everyday life (Kaipio et al., 2017). This study focuses on the patient journey phases
that happen in hospitals. Those phases are the diagnosis or operation before hospitalization, the hospitalization phase and control visits to the doctor’s practice.

Coyne (2006) states that managing and reducing children’s stress during hospitalization does not only affect the current emotions, but also affect how children assess and manage the future experiences and emotions. Thus, although this thesis study focuses on the phases that happen in hospital, those phases affect the emotions and perceptions that patients might have during other phases. For example, if the patient had a positive stay at the hospital during the first diagnosis phase, he or she might be more happy to return to the hospital. Also, after a positive hospital and patient experience, it might be easier to return to everyday life. Likewise, if the patient had a negative experience, he or she might be more anxious about returning there and it might be harder to recover from the experience and return to everyday life.

2.2.2 Measuring patient experience

Healthcare organizations have just recently acknowledged that patient experience is an important factor of quality care, and thus it is an important factor to be measured (Ahmed et al., 2014; Beattie et al., 2015; LaVela and Gallan, 2014; Stiefel and Nolan, 2012). Measuring patient experience affects practical, managerial and clinical areas of care, and the results can be applied to concepts like improvements of care, strategic decision making and benchmark performance (Beattie et al., 2015; LaVela and Gallan, 2014). In addition, the results of patient experience measurements can indicate if interventions and differences in care influence patient experience. In conclusion, patient experience data can be used for improvements, performance monitoring and research in hospital context.

Measuring patient experience is hard, not only because the definition of patient experience is ambiguous and complex, and there are many alike yet different terms as explained before, but also because there are multiple methods to measurements (Ahmed et al., 2014; Beattie et al., 2015; LaVela and Gallan, 2014). Both quantitative and qualitative methods can be used to study patient experience (Ahmed et al., 2014; Beattie et al., 2015; Foot and Fitzsimons, 2011; LaVela and Gallan, 2014). Also, different methods can reveal different findings and thus the results diverse (Ahmed et al., 2014).
Qualitative methods include for example in depth interviews, focus groups, letters, cards, observation and diaries (Foot and Fitzsimons, 2011; LaVela and Gallan, 2014). These methods give the patient or object of the study the freedom to describe the experience in their own words (LaVela and Gallan, 2014). Qualitative methods may lead to obtaining a deeper and more detailed understanding of the phenomena (Foot and Fitzsimons, 2011; LaVela and Gallan, 2014; Tsianakas et al., 2012). On the other hand, comparison and generalization is hard with qualitative data, because the sample sizes are smaller and the answers are not predetermined (LaVela and Gallan, 2014).

Quantitative methods include for example surveys and questionnaires (Foot and Fitzsimons, 2011; LaVela and Gallan, 2014). These methods can be performed on paper or nowadays digitally by computer, tablet or smartphones (Ahmed et al., 2014; Foot and Fitzsimons, 2011; LaVela and Gallan, 2014). Quantitative methods can produce data that can be statistically analyzed to find patterns, trends, comparison between objects and to monitor change (Foot and Fitzsimons, 2011; LaVela and Gallan, 2014; Tsianakas et al., 2012). These methods can be applied to great sample sizes (LaVela and Gallan, 2014). However, these methods do not usually reveal deep and detailed answers, because the questions and answer options are generally predetermined by the researcher (LaVela and Gallan, 2014).

The best outcomes are acquired when both quantitative and qualitative methods are used (Foot and Fitzsimons, 2011; LaVela and Gallan, 2014). Based on Wilson (2006), this use of multiple methods is called research method triangulation, and the use of quantitative and qualitative methods is called qualitative-quantitative triangulation. Triangulation may help to find the more informative and broader issues, and also reduce the limitations of any one method (LaVela and Gallan, 2014; Wilson, 2006).

In addition to the method selection, one aspect that affects the outcomes of patient experience measurements is the timing of the measurement (LaVela and Gallan, 2014). The measurements can take place either during the health care encounter, or afterwards at home. In their study, Bjertnaes et al. (2012) discovered that the more time there is between the clinical encounter and the patient experience measurements, the worse experiences are reported. Thus, it would be good to measure the experience as close to the encounter as possible.
Until the year 2008 there has not been a common, standardized and publicly reported survey for patient experience (HCAHPS, 2017). This is partly because hospitals measured patient experience generally to their own, internal use (HCAHPS, 2017). Also, because different methods are better fit for different purposes, it might be hard to create a survey, which would be fit for every occasion. Next, the first standardized survey, the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS), will be examined.

The Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) was the first standardized, publicly reported patient experience survey. The survey is for adult patients who can answer it between 48 hours to six weeks after a clinical encounter by mail or telephone. HCAHPS includes 32 questions, that measure eleven different aspects. These aspects are how well nurses and doctors communicate with patients, how responsive hospital staff are to patients’ needs, how well hospital staff help patients manage pain, how well the staff communicates with patients about new medicines, whether key information is provided at discharge, and how well patients understand the type of care they need after leaving the hospital, the cleanliness and quietness of patients’ rooms, patient’s overall rating of the hospital and whether they would recommend it to family and friends. Rather than asking how satisfied patient are with the care, HCAHPS asks how often if at all patients experience different aspects of the care. Since HCAHPS is standardized, it allows objective comparison between hospitals. This was actually one of HCAHPS objectives when it was implemented. Another objective was the public reporting to improve quality care and accountability of the hospitals. (HCAHPS, 2017)

Later, it was acknowledged that pediatrics and children need their own patient experience measurement survey, as HCAHPS is targeted for adults only. Thus, Toomey et al. (2015) created the Child HCAHPS in 2015. They developed the survey based on applicable parts of the adult HCAHPS and literature review, and then had experts and focus groups to define aspects to include in the survey. Later, they had multiple testing rounds, and finished with a survey that included 62 questions about the clinical encounter. These questions measure aspects such as communication, safety and comfort, hospital environment and global rating. Questions from the survey are for example "During this hospital stay, how often did your child’s nurses listen carefully to you?", "During this hospital stay, how often did providers involve your child in discussions about his or her health care?" and "Would you recommend this hospital to your family and friends?". However, as can
be seen from the formulation of the questions, the HCAHPS is answered by the parent and not the child itself. Thus, the Child HCAHPS uses a proxy for children to discover the patient experience. Actually, it seems that the Child HCAHPS measures more the patient experience of the child patient’s parent in the pediatric context rather than that of the child patient.

Although research on patient experience is quite new, children have already been studied in the hospital context with multiple different methods. These studies have addressed children’s views on e.g. hospitalization, health services, illness, pain or anxiety. Recently, also children’s patient experience has been studied. The methods that can be used in researching children and their patient experience will be introduced in section 2.3.3 in more detail.

2.3 Research with children

This section covers the special aspects of what to consider when researching children. The first section covers the special considerations and ethical aspects, which need to be addressed when researching children. Second, methods used for researching children in the hospital context are discovered.

2.3.1 Special considerations

According to the United Nations Convention on the Rights of the Child (UNCRC) article 12, children, who are able to form their own views and express them, have the right to express those views and they should be heard in matters affecting the child in an age appropriate manner (United Nations, 1989). Other important articles to consider while researching children in the hospital context are the articles 3 and 24. The article 3 states, that any institution, which acts in a way that concerns children, must have the best interest of the child as a primary consideration. The article 24 on the other hand states, that ”- - Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health.” (United Nations, 1989).

The European Association for Children in hospital (EACH), is an international organization, which provide rights of sick children and their families in healthcare (EACH, 2013). The EACH recognizes and endorses rights by
the United Nation, and the aforementioned articles work as the basis of their own rights. The EACH rights work as a guidance to hospital regulations and guidelines in many European countries (EACH, 2013). All of these aforementioned rights influence researching in general and especially with children, because they regulate that children must be included in decisions affecting them in an age appropriate manner, the healthcare institutions must consider the children’s best interest and in a way that children have the right to the enjoyment of the highest attainable standard of health (EACH, 2013; United Nations, 1989).

Generally, when children have been studied, they have been studied through proxies; someone other than themselves, like their parents. (Kortesluoma and Nikkonen, 2004; Stålberg et al., 2017; Söderbäck et al., 2011). However, it has been recognized that the views of the proxies are not the same as the views of the children (Chesney et al., 2005; Kortesluoma and Nikkonen, 2004). Adult’s views may be different from children’s views, or they can even be incorrect in the worst case (Söderbäck et al., 2011). Punch (2002) argues that adults can interpret children’s world only partly, and they can never fully understand it, because they are always viewing the children and their world from the adult’s point of view. To conclude, children should be included in research concerning them for two reasons: first, the regulations and children’s rights require it and secondly, the results are not the same when proxies are used.

As stated above, children view the world differently compared to adults. Thus, when children are included in the research, some special aspects need to be addressed. One of these aspects is the cognitive development stage of the child. There exists many different theories about children’s cognitive development, but the one created by Piaget and Inhelder (1969) is followed in this study. Piaget and Inhelder (1969) have categorized children’s cognitive development into four different phases. These phases and their key characteristics are displayed in table 2.1. At the preoperational stage when children learn languages they still might use words with different meaning than adults use them (Kortesluoma et al., 2003). Children at this stage usually answer questions quite accurately, but pretty unilaterally (Kortesluoma et al., 2003). Also, children at age 3 and older can form understandable wholes of of their experiences and from the age 4 onward they can connect single incidents with other memories (Kortesluoma et al., 2003). Yet, researchers must recognize that although these theories give a foundation to children’s cognitive development, not all children are the same and the transitions between the stages are quite seamless (Piaget and Inhelder, 1969; Punch, 2002).
Table 2.1: The children’s cognitive development stages based on Piaget and Inhelder (1969).

<table>
<thead>
<tr>
<th>Age (years)</th>
<th>Name</th>
<th>Characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-2</td>
<td>Sensorimotor stage</td>
<td>Concrete thinking through senses and movement. Children are extremely egocentric.</td>
</tr>
<tr>
<td>2-7</td>
<td>Preoperational stage</td>
<td>Language, symbolic thinking and intuitive thought emerges. Still egocentric.</td>
</tr>
<tr>
<td>7-11</td>
<td>Concrete operational stage</td>
<td>Logical thinking and classification emerges. Not egocentric any more.</td>
</tr>
<tr>
<td>11-</td>
<td>Formal operational stage</td>
<td>Abstract thinking and problem solving emerges.</td>
</tr>
</tbody>
</table>

2.3.2 Ethics

Ethics are an important aspect that researchers need to address when researching children. When children are participating to any research in Finland, both their own and their guardian’s consent are required. The research contents need to be described to children in an age-appropriate manner, with picture cards if necessary (FinPedMed, 2009). Then, it must be ensured that children have understood the research implications to their age-appropriate level (FinPedMed, 2009).

Additional ethical aspects appear during the research with children. For example, researchers need to be aware of uneven power structures, special vulnerability and competences of children. The uneven power structures may arise when the researcher introduces oneself to the child, or in the research environment (Phelan and Kinsella, 2013; Punch, 2002). For example, it depends what kind of language the researcher uses when talking to the child, what the researcher is wearing and where the research takes place (Phelan and Kinsella, 2013; Punch, 2002). It is much harder for the child if the researcher uses really complex and scientific words, dresses really formally in a space designed for adults to feel comfortable than if all of these are done in a more relaxed and child-friendly way. These conditions also affect how
CHAPTER 2. BACKGROUND

rapport is built between the child and the researcher. Rapport needs to be built with both the child and their parents or guardians (Punch, 2002). Vulnerability of the child may lead for the child to exaggerate and try to please the researcher with what the child thinks are the right answers (Punch, 2002). Children’s answers can also be sensitive to suggestibility (Kortesluoma et al., 2003). To conclude, while conducting research with children, the researcher must be aware of all these ethical aspects and considerations that might affect the research and the results.

Fortunately, the selected research method can help to overcome some of these ethical aspects. Research methods have traditionally been divided into adult and child friendly methods, but Punch (2002) argues that all of the research methods should be person-centered and adapted for the purpose. In other words, the selected research method needs to be adapted to the research context and research subject, and not to children or adults only (Punch, 2002). Selecting and combining different methods can lead to solve the different ethical problems, like to decrease the uneven power-structures and to support children’s skills and capabilities (Carter and Ford, 2012; Punch, 2002).

Another way to divide research methods is to divide them into traditional and innovative methods. Traditional methods include methods that have traditionally been used with adults, and then they are modified a little to adapt to research with children too. Traditional methods include methods like interviews, focus groups, observation and questionnaires (Carter and Ford, 2012; Groundwater-Smith et al., 2015; Punch, 2002). Innovative methods on the other hand include methods like art-based methods, drawing and storytelling. Innovative methods can support children’s capabilities, skills and interests and in that way encourage them to share their experiences in a natural and fun way (Carter and Ford, 2012). Even young children can answer health questionnaires, which are made in an age-appropriate manner and with visual analogical choices (Chesney et al., 2005). Yet, researchers must acknowledge that different methods generate data differently and consider if methods are used because they are fun or because they generate data effectively (Punch, 2002). For example, in their study Punch (2002) stated that information obtained from photos had interesting findings, but they were more limited than the information generated from written worksheets. Also, questionnaires can generate simultaneous data, because participants can answer it simultaneously, but the data may be too apparent, if used as the only research method (Groundwater-Smith et al., 2015; Punch, 2002). Thus, combining visual, written and traditional methods cab lead to broader data compared to using only one research method (Punch, 2002).
2.3.3 Methods for studying children

Majority of the studies performed in hospitals use interviews as a research method. For example, Coyne (2006); Curtis et al. (2004); Forsner et al. (2005); Kortesluoma and Nikkonen (2004); Sartain et al. (2001) and Schalkers et al. (2015) all used interviews as a part of their study. Most of these interviews were semi-structured interviews, and the child patients interviewed were between ages 4 to 19. The interviews lasted from 10 minutes to up to an hour. Also, many of the interviews took more of the form of a conversation, rather than a formal interview, e.g. Forsner et al. (2005). The interview could also take the form of a group discussion, like the study by Curtis et al. (2004). In addition, many of the interviews with children, especially with younger children, used some type of a conversation incentive or a prompt, like a photo, a drawing or a toy (Curtis et al., 2004; Kortesluoma and Nikkonen, 2004; Schalkers et al., 2015).

Other frequently used method in the hospital context is questionnaires. Questionnaires require little experience and equipment, and they are also quick to complete (Boynton and Greenhalgh, 2004). In their study, Carney et al. (2003) used four different versions of a questionnaire and compared the effectiveness of the different versions. They used structured and unstructured, and also verbal and visual questionnaires. These questionnaires included writing poems, filling out speech bubbles and drawing. Pelander and Leino-Kilpi (2010) used sentence completion in their research, where they studied the best and worst experiences children had in the hospital. Curtis et al. (2004) used an online questionnaire in their research, because their time with the participants were limited and often interrupted. Thus, they decided to use a short and quick questionnaire focusing on already known issues.

As stated in section 2.3, studying children differs from studying adults (Punch, 2002). Thus, also the questionnaires and their format needs to be adapted to child-friendly format. This can be achieved by incorporating more symbols and visuals in the questionnaire. Also, the clarity of the language and response type can affect how well children can answer the questionnaire (Punch, 2002). Children aged 6-13 respond little better to verbal Lickert scales which use familiar words for frequency or thoughts, e.g. never-always and strongly agree-strongly disagree, than compared to visual analogical scales (VAS) or numeric Lickert scales (Laerhoven et al., 2004; Mellor and Moore, 2014). Similar to the interviews, questionnaires can also use prompts, visuals or other special aspects to be more suitable for children. Visuals, such as different
symbols or faces are frequently used in questionnaires for children (Boynton and Greenhalgh, 2004; Buchanan and Niven, 2002). For example, many hospitals use a face scale for measuring children’s anxiety and pain. These faces work as a self-report measure, where children are asked to point to the face that best describes their feeling at the given moments (Hicks et al., 2001; Kuttner and LePage, 1989; Wright et al., 2010). These self-reports have been found correlating to observer reported measures in the context of day surgery (Wright et al., 2010). Also, self-report measures with pictures are easily applicable for young children and also in a busy environment, because they do not require training or reading skills (Wright et al., 2010). Children as young as 4 or 5 years have been found to be able to answer to these kinds of scales (Hicks et al., 2001; Wright et al., 2010). Figure 2.5 present the faces scales for pain by Hicks et al. (2001) and figure 2.6 the anxiety and pain faces scale by Wright et al. (2010).

Figure 2.5: Faces pain scale by Hicks et al. (2001).

Figure 2.6: CAPS faces pain scale above and anxiety scale below by Kuttner and LePage (1989).
In addition to just complement questionnaires, images can be used more independently as a method to study children in hospital. They can be used for example in picture cards, which can be analog or digital to show specific events to children. Then, the children can narrate their views and experiences based on the images. FinPedMed has their own set of picture cards to help children and adults understand the patient information, when there is difficulty to understand written instructions (FinPedMed, 2009). Also, emotion cards can be used in the hospital context. Bone et al. (2014) used emoticons as a part of their study of children and adult’s experiences on mental health services. Emotion cards can help children at any age to express and process their emotions (Tukiliitto, 2017). Emotion cards can be applied in many different contexts with children and young people, such as individual or group discussions, in healthcare, in crisis situations or in youth work (Puurunen and Vaitiniemi, 2015; Salama, 2014; Tukiliitto, 2017).

Moreover, photographs, photo-voice and photo-elicitation have been used to study children in hospitals (Curtis et al., 2004; Schalkers et al., 2015; Stenhammar, 2017). Ready made photos can be used in group interviews to raise topics (Curtis et al., 2004). Additionally, children can take their own photos from subjects in the hospital, and later discuss about the photos and their experiences with researchers (Schalkers et al., 2015; Stenhammar, 2017). Children as young as 6 have been able to use the photo-elicitation method.

Recently, when digital products have become part of children’s everyday lives, also digital research methods have emerged. For example, video diary as a method has been used to study patients aged 10 to 16 patient experience (Karisalmi, 2016). Also, different interactive applications have emerged. For example, in their research, Stålberg et al. (2017) used an Inter-Active Communication Tool Activities (IACTA) to tell a story of the hospital day to introduce the upcoming situations to the children and also to communicate with them. Likewise, O’Neill et al. (2018) used an interactive application to study children’s perspectives on healthcare. They used an evaluated survey, the Children’s perceptions of healthcare survey, through the application. Children aged 3 to 17 were able to participate. In both studies, children and their parents identified the use of the interactive tool as fun and easy.
2.4 Medical clown work in hospitals

This section presents the work of medical clowns in hospitals. First, the history of the work and art of medical clowns are introduced. Secondly, the special form of preoperative medical clowning is examined. Finally, some earlier studies about the medical clowns are presented.

2.4.1 History

Professional medical clowning was developed back in 1986, when a professional circus clown Michael Christensen co-founded the Big Apple Circus Clown Care Unit in New York City (Mortamet et al., 2017; Oppenheim et al., 1997). The idea generated after one of their clown friends from circus was admitted to the hospital and his friends visited him later dressed as clowns (Dionigi, 2012). Afterwards the hospital professionals witnessed how big of a positive impact the clowns’ visitation had had (Dionigi, 2012).

In the same year, a child-life specialist Karen Ridd created the Therapeutic Clown Program at Hospital for Sick Children in Toronto (Mortamet et al., 2017). These two models create the basis for medical clowning, which has now spread to dozens of countries (Mortamet et al., 2017; Oppenheim et al., 1997). However, majority of the medical clown organizations emerged only during the 21st century (Vagnoli et al., 2016). The term medical clown has many synonyms, such as dream doctor, hospital clown, clown doctor or therapeutic clown. In this study, the term medical clown will be used.

Medical clowns are professional performers, who are trained for working in the highly sensitive hospital context (Dionigi, 2012). They use the art of clowning and different clowning techniques derived from the circus environment to help child patients in hospitals to cope with difficult emotions such as stress, fear, helplessness and sadness (Barkmann et al., 2013; Dionigi, 2012). These clowning techniques include methods like forms of play, music, magic tricks, games, pantomime, stories, puppetry and soap bubbles (Barkmann et al., 2013; Dionigi, 2012; Costa Fernandes and Arriaga, 2010; Mortamet et al., 2017). Medical clowns adapt their performances to every individual child and their circumstances respectively (Battrick et al., 2007; Dionigi, 2012). Thus, they need good observation and listening skills, in addition to improvisation and creativity, so that they can adapt to quickly changing situations and make every encounter unique (Dionigi, 2012).
Although medical clowns use the same clowning techniques and methods regardless of countries, their goals and approaches vary between different countries. Also, the number of medical clowns at the time and the outfits they have may differ between countries and hospitals. Some medical clowns work as pairs, some alone, and some wear more hospital related clothes like a decorated doctor’s coat and some wear just normal clown clothes. The different approaches can be divided into three different categories. The first approach is to provide distraction and joy through play, independent from the hospital and medical treatments. In this approach, clowns visit the hospital and the goal is to create a fun and positive atmosphere wherever they are, and possibly to reduce stress. They may visit pediatric wards and children’s rooms, but these visits and performances take usually only up to 10 minutes. The second approach takes a step away from only performing to the child to engage more in empowering the child before treatments. This approach is often called therapeutic clowning, as they connect the clowning to clear therapeutic goals to prepare the child emotionally for the upcoming treatments and procedures, but still they are not present during the those treatments. The third approach to medical clowning is to use the clowning methods also during treatments and medical procedures. For the clown to be able to use clowning and distraction methods during the treatments, the clown needs to have a good connection to the child, and this is achieved with deep and lasting encounters before the treatment. Thus, this approach takes a lot more time than the other approaches. Also, this approach requires close collaboration between the medical clowns and nurses, doctors and other medical professionals at the hospital. In addition, medical clowns learn the history of the child, both the medical but also for example how the child has acted during previous treatments, if had any. This last approach is closest to the preoperative medical clowning, which this study focuses on. The next section describes in more detail how preoperative medical clowning started in Finland, and also how it is currently applied in the HUS Children’s Hospital. (Langemeijer, 2012).
2.4.2 Preoperative medial clowning in Finland

Medical clowns and the HUS Children’s Hospital have collaborated from 2002. The most common form of medical clowning at the hospital has been two medical clowns visiting and performing regularly at the children’s wards. During 2016 the other form, the preoperational medical clowning, was first introduced to the surgery unit of the hospital. The preoperational medical clowning collaboration started with the medical clowns exploring the surgery unit’s operations and procedures. Later in 2017, the preoperational medical clowning had become a regular, practical part of the surgery unit and the preoperational medical clowns visited the unit weekly. (Leppänen, 2018)

Because the preoperational medical clowning is such a novel form of medical clowning in the HUS Children’s Hospital, there is not much literature about it. There has been medical clown studies and graduation theses on the topic of medical clowns, but these have focused on the form of medical clowns visiting wards, and not the preoperational medical clowning, see e.g. Harberg et al. (2014); Korhonen and Varis (2012). Actually, this study is the first ever scientific study executed on the topic in Finland. Thus, this section’s information comes from the two available sources about preoperational medical clowning in Finland, reports by Leppänen (2018) and Lindberg et al. (2017).

The preoperative medical clowns are seen to be part of a child-centered healthcare and part of the healthcare team to some extent (Leppänen, 2018). They have longer encounters with the child patients and their family, compared to the patient encounters at the wards (Leppänen, 2018). At first, there were two preoperative medical clowns working at the unit at the same time, but it was later recognized that one clown at a time works better (Lindberg et al., 2017). This was because one clown at a time can better listen and adapt to the quickly changing situations, give more space for the patients to create new situations and to include more people to the situations (Lindberg et al., 2017). Also, it is easier for the child to have a good connection to one medical clown at a time than two (Lindberg et al., 2017).

The preoperational medical clowns work at close collaboration with other medical professionals at the HUS Children’s Hospital, such as nurses and anesthesia doctors. However, they are not yet seen as a part of the medical care but rather enablers and supporters of the care. For example, the medical clown can focus on keeping the child patient calm during the treatment as the nurses can then focus on performing the medical treatment rather than comforting the child. (Lindberg et al., 2017)
Compared to the medical clown pairs visiting the wards, preoperative medical clowns have a clear goal and agenda. The most important goal of the preoperative medical clowns is to support the child at the most critical times of the care, such as transition to the operation or cannula insertion. Their agenda is not only to entertain but also they try to discuss and manage the critical and complex situations, emotions and treatments that might arise during the day. Also, the medical clown can try to change the atmosphere of the situation to a more suitable one, for example by comforting and calming during a procedure or inspire at another moment to create dreams or imaginary worlds. Even only the presence of the medical clown may help the child at the moment, and also later to process the situations afterwards. (Lindberg et al., 2017)

Methods that the preoperative medical clowns use at the HUS Children’s Hospital are for example, to create dreams that the child can dream during anesthesia, discuss what parents have to do during the anesthesia dictated by the child, what concrete things the clown must do if the child has a moment of pain or anxiety or create songs together to change the mood. All of these methods aim for the empowerment of the child, as the clown always asks and lets the child to decide on all matters. (Lindberg et al., 2017)

In the Day Surgery Unit, where this study was conducted, the preoperative medical clowns usually meet the child patients at the waiting room. The patient and their families might already be waiting for the clown in the waiting room after registration, or the clown might be there already. The waiting room has usually many patient families at the same time. They might all be at different points of the hospital day, some just arriving and some just leaving. In addition, the medical clown needs to decide to whom to offer the preoperative medical clowning services and who would benefit from it the most. These are usually the patients who have a lot of anxiety and fear, and the nurses may help with these decisions. (Lindberg et al., 2017)

At first, the preoperative medical clown feels the atmosphere of the room and the family, and then adjusts the encounter and methods to their feelings. Because the waiting room has many people in it, the clown must decide whom to target the encounters to, it can be just one family or patient or the clown can try to include everyone in the room in the play. The patient and the family must give a verbal or non-verbal consent to the clown to continue with the encounter, and it always continues on the child’s terms. After the medical clown has encountered the patient family, the topics may shift to include the upcoming treatments and procedures with the help of the clown-
ing techniques. Then, when the treatment is about to start, the medical clown always asks if the child and the family wants the clown accompanying and present at the treatment. If they give their consent, the medical clown accompanies the treatment and executes some distraction techniques, magic tricks or other clowning techniques during the treatment and before anesthesia. After the operation and after the child has woken up from the anesthesia, the medical clown can yet encounter the child. At this point, the majority of the medical clowns work is already done, but they can still help the children to wake up and feel better after the operation. Also, it is important to give conclusion to the whole day of encounters and the connection between the preoperative medical clowns and the patient and their family. (Lindberg et al., 2017)

2.4.3 Earlier studies of medical clowns

As stated earlier, this is the first scientific study about preoperational medical clowning in Finland. The earlier studies have concentrated on medical clowns visiting children’s wards, see e.g. Harberg et al. (2014); Korhonen and Varis (2012). One reason could be that these studies have been conducted before the preoperational medical clowning started in Finland. However, one of the findings of Harberg et al. (2014) is that in addition to just visiting the children’s wards, medical clowns could be used more with painful operations. This refers to preoperational medical clowning, which has started operation alongside and complementing the more traditional medical clowning.

Worldwide, medical clowning has been studied more. In recent years, the number of scientific studies about medical clowns has increased (Langemeijer, 2012). Research about medical clowns have been conducted in Israel, Netherlands, Portugal, Austria, Sweden, Germany and Brazil to name a few (Langemeijer, 2012). Langemeijer (2012) divides these studies by their methodologies in four different categories; the first is about the feelings and experiences children, nurses, parents and doctors have about medical clowns, the second about evidence based research by contrasting a control group and a group who met the medical clown, the third one is also an evidence based research but without the control group and the fourth one is all theory-based research.
This study of the preoperational medical clowning in the HUS Children’s hospital is the combination of the first two categories, as it studies the effects on children’s, parent’s and nurses experiences with preoperational medical clown, but the study has also a control group and a group that meets the medical clown. Some studies on these two categories will be presented next.

Dionigi and Gremigni (2016), Meiri et al. (2016), Vagnoli et al. (2010) and Wolyniez et al. (2013) all have studied how the presence of a medical clown in a procedure affects the child patient’s or parent’s anxiety and pain compared to a control group. All of them but Wolyniez et al. (2013) used observer based ratings, where someone else than the patient themselves rated their anxiety or pain level. For example, both Dionigi and Gremigni (2016) and Vagnoli et al. (2010) used the Modified Yale Preoperative Anxiety Scale (mYPAS). Meiri et al. (2016) on the other hand asked parents to assess their children’s pain and anxiety level. They also timed the duration of the whole procedure and the duration of crying (Meiri et al., 2016). Wolyniez et al. (2013) assessed the children’s pain by using Faces pain scale to 4-7 year old children and a visual analogical scale (VAS) to children older than 8. They also assessed parent’s anxiety by an observer rated scale (Wolyniez et al., 2013).

The findings of the above mentioned studies state that those patients and their parents who had a medical clown in their procedures, were less anxious (Dionigi and Gremigni, 2016; Meiri et al., 2016; Vagnoli et al., 2010). Also, pain was reduced for children under 7 years for those who had a clown, although a local anesthesia was found better pain reducer than a medical clown (Meiri et al., 2016; Wolyniez et al., 2013).

In their study, Tener et al. (2016) studied nine child patients and their accompanying parents to reveal their subjective experiences with a medical clown. They used semi-structured interviews as a research method (Tener et al., 2016). The intervention of the medical clown was found to positively change children’s perceptions of three aspects of the stay; hospital, the experiences of the examination and their life narrative (Tener et al., 2016). Tener et al. (2016) state that medical clowns have a meaningful and therapeutic meaning for children in hospitals.

Ofir et al. (2016) also researched the therapeutic affect of medical clowns for children and their parents. The findings were that medical clowns have therapeutic affect through empowerment, re-framing and therapeutic alliances with the child (Ofir et al., 2016). Medical clowns helped both the child and their parents (Ofir et al., 2016).
One important aspect to address when researching medical clowns is the fear towards clowns. This irrational fear of clowns is called coulrophobia and it is experienced more by girls than boys (Meiri et al., 2017). In their study, Meiri et al. (2017) researched the fear of clowns in hospitalized children. Their findings were that only 1.2% of the general pediatric hospitalized children had a fear of clown (Meiri et al., 2017). In the Children’s Hospital in Finland, medical clowns always require and ask for a verbal or non-verbal permission from the children and their parents for their presence (Lindberg et al., 2017). Therefore, they will not contact children who express their fears towards clowns.
Chapter 3

Design process and methods

This chapter presents some background for the process and methods used in this study to design and develop the digital service. The selected approach of the study was the service design approach, and in more detail the service design’s double diamond model. The first section 3.1 introduces the key principles of service design. Then, the selected process, the double diamond model is described in more detail in section 3.2, and some service design methods and tools are discussed in section 3.3. To conclude, the evaluation criteria for the developed digital service are described in section 3.4.

3.1 Service design principles

Service design is still an evolving field, which has mainly emerged and established in the past few decades (Curedale, 2013). Just like patient experience it still lacks a common and accurate definition (Curedale, 2013; Stickdorn, 2011b). However, there are a set of attributes that often arise when the definition of service design is discussed. These attributes are that it is an interdisciplinary approach, it combines the tools and methods of the different disciplines, it takes various stakeholders into account and it aims to create services that are useful, usable, desirable, effective, efficient and distinctive (Mager, 2009; Stickdorn, 2011b). Also, service design is often characterized to be more of a way of thinking, which includes five core principles (Stickdorn, 2011a). These five principles of service design are user-centered, co-creative, sequencing, evidencing and holistic (Stickdorn, 2011a).
The service design’s user-centered approach means that the service is created and experiences from the customer’s or user’s perspective. Co-creative principle means that all stakeholders should be included in the design process. Sequencing suggests that the service process is a sequence of interrelated actions, and should be visualized as such. Evidencing means that although services are usually intangible, they should be visualized as tangible objects during the service design process. The last principle, holistic, means that the entire context of the service should be studied and acknowledged. (Stickdorn, 2011a)

These principles are applied in this research by designing the digital service for the child patients in a child-friendly manner (user-centered), including stakeholders like nurses, medical clowns, child patients and their parents in the design process (co-creative), understanding the whole patient journey of the child patients and creating a visualization of this journey (sequencing), creating a tangible prototype of the digital service during design (evidencing) and understanding the whole hospital context, the different view points of different stakeholders and the whole patient experience (holistic).

Service design is actually a nonlinear creative process, and thus it is not possible to define a process with sequential and strictly defined steps to execute it (Stickdorn, 2011c). However, it is possible to define an outline process for it (Stickdorn, 2011c). The process can be defined with iterative phases, but the number of phases can alter from three to even seven (Mager, 2009; Miettinen and Koivisto, 2009; Stickdorn, 2011c). All of the different phases still outline the creative process of iterative diverging and converging. The diverging phase aims to find more options and alternatives, to eventually find maybe a creatively disruptive idea (Brown, 2009). The convergent phase then is about limiting these options, to find and decide on the best actionable idea (Brown, 2009). This study applied a four phase design process, the Design Council’s double diamond process, which is introduced next.

### 3.2 Double diamond process

The service design double diamond model was created by the Design Council back in 2005. It consists of four distinct phases that outline many design processes. These phases diverge and converge alternately for exploring new options and then focusing on the selected solution. The four different phases are discover, define, develop and deliver. The figure 3.1 shows these phases
and how the design process diverges and converges to give the process the shape of a double diamond. (Design Council, 2007)

Figure 3.1: An overview of the double diamond model Design Council (2015).

The first phase, the discover phase, is about discovering the problem space (Design Council, 2015). It is a divergent phase, where the designers should have an open mind to as many ideas and influences as possible (Design Council, 2007). This phase should gather inspiration, ideas, perspectives, insights, experiences and user needs to identify the problem (Design Council, 2015; Van Dijk et al., 2011). After this phase the designers should have a rich knowledge base and as many ideas as possible from the problem space (Design Council, 2015). The methods and tools used in this phase should generate engaging results, which build a solid foundation for the rest of the project (Van Dijk et al., 2011). Example methods that could be used in this phase are market and user research, user journey mapping, user diaries, service safari, stakeholder maps, customer journey maps, contextual interviews personas and user shadowing (Design Council, 2007, 2015; Van Dijk et al., 2011). However, it should be remembered that not all these methods and tools need to be applied, but the designers can decide which ones they decide to suit best for the purpose (Van Dijk et al., 2011).

The second phase, the define phase, is about defining the problem based on the findings from the discover phase (Design Council, 2015). In this phase the designers search for interpretation and alignment from all the options discovered earlier (Design Council, 2007). They try to prioritize the findings
to find the most important aspects and points to where to act first (Design Council, 2015). Designers visualize the insight gathered in the first phase to new concepts for testing (Van Dijk et al., 2011). Thus, this phase is a convergent phase where the design process converges to a single problem statement. Methods used in this phase include methods such as user personas, brainstorming, design scenarios and the design brief (Design Council, 2015; Van Dijk et al., 2011).

The third phase of the double diamond model is the develop phase. This phase is about developing the solutions, which have first been discovered and defined earlier (Design Council, 2007). In the development phase, the solutions are created, prototyped, tested and iterated (Design Council, 2007, 2015). With an iterative process, the final solutions and concepts can be refined and tested with the end users (Design Council, 2015). This phase is again a divergent phase, where different versions of the solutions are developed, tested and refined and developed again. Thus, the output of this phase is multiple different versions of the same solution. Methods generally used in this phase are the service blueprint, experience prototyping, business model canvas and testing (Design Council, 2007, 2015).

The fourth and the last phase is the deliver phase. This phase includes the delivery and launch of the final solution (Design Council, 2007). It includes final testing of the service or concept, ensuring that feedback systems are in place and also evaluating the just finished process and giving feedback (Design Council, 2015). Methods applied in this phase are final testing, scenarios, approval and evaluation (Design Council, 2007, 2015).

### 3.3 Service design methods and tools

As the previous section presented, there are many methods and tools that can be applied during the double diamond and service design process. Although tools are usually presented with a certain phase of the process, they can still be applied in other phases too (Van Dijk et al., 2011). Also, designers can decide the best tools and method for each project respectively, as there is no right or wrong way to apply the tools or the process (Van Dijk et al., 2011). Actually, experimenting with different tools and methods is highly recommended for the service design process (Curedale, 2013; Van Dijk et al., 2011). This section describes in more detail the selected methods for this study.
Stakeholder maps are usually created at the first phases of the design project for a visual representation of the service’s key stakeholders and their relationships (Curedale, 2013; Van Dijk et al., 2011). Stakeholder map starts with identifying all the stakeholders, and then connecting them together and representing their relationships in a visual way (Curedale, 2013; Van Dijk et al., 2011). Stakeholder maps can highlight the different stakeholder groups and their concerns, interests and views, to visualize the complex connections around a service (Van Dijk et al., 2011).

Customer journey maps are visual representations of the customer’s interactions with the service (Van Dijk et al., 2011). It visualizes the different touchpoints, experiences and emotions the customer might have when using a product or service (Curedale, 2013; Van Dijk et al., 2011). The map is usually created with enough insights to the customers journey, which can be gathered by interviews, blogs or video diaries (Van Dijk et al., 2011). The customer journey is constructed from the customer’s point of view, and it presents an overview of the service experience with positive and negative experiences (Curedale, 2013; Van Dijk et al., 2011). The visual representation enables comparison of different experiences of the same service and helps in creating a consistent experience for different customers (Curedale, 2013; Van Dijk et al., 2011).

Observation or shadowing means that the designers and researchers observe the different stakeholders of the service at the context of the service (Brown, 2009; Curedale, 2013; Van Dijk et al., 2011). By observation, the designers and researchers can report behaviours and experiences, which the stakeholders are not aware of and thus they cannot report them (DiCicco-Bloom and Crabtree, 2006; Van Dijk et al., 2011). By spending time with the stakeholders at the service environment, the researchers can truly generate a holistic view of the service from the points of view of the different stakeholders (Brown, 2009; Curedale, 2013; Van Dijk et al., 2011).

During the observations, researchers can also conduct unstructured interviews to elicit more detailed views and a more holistic understanding of the service (DiCicco-Bloom and Crabtree, 2006). These interviews can also be called contextual interviews, as they happen at the service’s context or environment (Curedale, 2013; Van Dijk et al., 2011). By conducting the interviews at the service location, more detailed views can be uncovered compared to what people can describe (DiCicco-Bloom and Crabtree, 2006; Curedale, 2013; Van Dijk et al., 2011). Spending time at the service location provides a holistic understanding about service environment (Van Dijk et al., 2011).
3.4 Criteria for evaluation

To assess the outcome of the service design process, the designed and developed digital service needs to be evaluated. To enable the evaluation, a set of evaluation criteria needs to be determined. The criteria are selected from the point of view of how applicable the digital service is for measuring children’s patient experience. The applicability is assessed from two different point of views; how usable the digital service is in the pediatric context and the ability to reveal results in the case study about patient experience.

Nielsen (1994) argues that usability is not a one-dimensional property, but rather it is associated with the five following attributes: learnability, efficiency, memorability, errors and satisfaction. In brief, these different attributes highlight that the system should be easy to learn at first, then efficient to use, easy to remember and come back to after a brake, there should be a minimum number of errors and the system should be pleasant to use to some extent (Nielsen, 1994). On the other hand, ISO 9241-210 (2010) defines usability as “the extent to which a system, product or service can be used by specified users to achieve specified goals with effectiveness, efficiency and satisfaction in a specified context of use”. Combining and constraining these two definitions, the digital service of this study should be easy to learn and efficient to use in the Day Surgery Unit by the child patients. To assess the usability of the digital service, usability testing should be conducted. There exists many ways to conduct usability testing, most common ones are user testing with the real users and summative evaluations of the user interface (Nielsen, 1994, 2018).

User testing means testing the system with the real users of the system by giving them a task to complete and then the testers give insights and feedback on the usage (Nielsen, 2018). In this study, user testing should be conducted in the hospital with the real users, the child patients, by giving them the task to answer to the questions of the digital service.

Another way to evaluate usability is summative evaluation. Summative evaluation is evaluation of the final user interface and it can take the form of a expert evaluation (Leventhal and Barnes, 2008). Expert evaluation is an usability evaluation conducted by usability experts, by evaluating the conformance of the user interface to common standards or guidelines (Leventhal and Barnes, 2008). For the expert evaluation of the digital service in this thesis, Nielsen’s heuristics are used and thus the conducted expert evaluation is
a heuristic evaluation (Leventhal and Barnes, 2008; Nielsen, 1994). Heuristic evaluation compares the user interface to ten usability heuristics to find what is good and bad about it, and results in a list of usability problems, which can later be improved (Nielsen and Mack, 1994; Nielsen, 1994). Heuristic evaluation can be conducted individually or in groups, and the more people and time is used for the evaluation, the better results are usually achieved (Nielsen and Mack, 1994; Nielsen, 1994). Thus, also the research nurse should be asked to evaluate the digital service from the heuristics point of view. The research nurse conducts the case study in the hospital and witnesses the child patients usage of the digital service, and thus she is an expert on the case study to evaluate the service.

Another point of view to the usability that should be evaluated is the efficiency of the digital service. Efficiency of the system could be evaluated from different point of views. However, as the users of the system were children aged from 4 to 17, who are in different stages of the cognitive development (see table 2.1), the time it takes to answer and use the digital service could not be used as an efficiency measure. Instead, the user success rate was used as a metric for the efficiency of the system. The user success rate measures the percentage of tasks that users complete correctly (Nielsen, 2001). Measuring the success rate is an easy way to evaluate the system’s usability and user success is actually the essence of usability (Nielsen, 2001). For this case, a correctly completed task should be the task of responding and saving the answers of the digital service for the two time points that were requested. The ratio between all study participants and those were able to use the digital service successfully for the two measurement points should be calculated.

The other evaluation criteria in addition to the different aspects of usability is the ability of the digital service to reveal the patient experiences of the two patient groups in the case study. This criteria should be studied by comparing the patient experiences of the two different patient groups. In other words, the system should be able to find the effect of preoperative medical clowns to patient experience, if they have an effect.

To conclude, the applicability of the digital service for measuring patient experience should be evaluated. The used evaluation criteria should be usability and the ability to reveal patient experiences of the two patient groups of the case study. The usability of the system should by evaluated by conducting user testing, heuristic evaluation and calculating the success rate for the digital service.
Chapter 4

Implementation of the study

This chapter presents how the study was implemented as a whole. First, the section 4.1 describes how the digital service was designed and implemented with the double diamond model. Then, the specific hospital context, the Day Surgery Unit is introduces in section 4.2. Thirdly, the implemented digital service is described in more detail in section 4.3. To conclude, the two last sections of this chapter present how the case study was conducted at the hospital and how the measurement data was analyzed.

4.1 Design process

4.1.1 Discovery

The whole study and its discovery phase started with a literature review to the themes of the study. Themes that were discovered and familiarized with were experiences, emotions, patient experience, children as research subjects, children in hospital, the hospital context and medical clowns. The findings of literature review can be found in the background chapter of this thesis, in chapter 2. This literature review and research can be considered as both market and user research for the discovery phase.

After the literature review, unstructured interviews were conducted with the case study’s different stakeholders, such as representatives of the hospital, the nurses, the nurse managers, the medical clowns and their representatives.
The use and purpose of unstructured interviews is further described in section 3.3. The findings from these interviews related to deeper understanding of the hospital’s processes, the unit’s daily operating models, the patient journeys and the working principles of the medical clowns.

Following the interviews, observations about the preoperative medical clowns and the child patients were conducted in the hospital, both in the Day Surgery and Day Hospital units. The use and purpose of observation during the design process is further described in section 3.3. In total, three observation days were conducted, on in the Day Surgery Unit and two in the Day Hospital Unit. After each observation, findings and perceptions were shared and documented between the observers. These findings and perceptions included insights on aspects such as how patients arrive and sign up to the units, how they spend the time before the operation, how patients transition to the operation, the start of the operation and possible anesthesia, the awakening from anesthesia, time after the operation and how the patients are sent home.

Next, a stakeholder map and two patient journey maps of the two different units were created based on the findings from the interviews and observations. The patient journey maps worked as customer journey maps, as the patients are the customers of the hospital. The use and purpose of these methods are further described in section 3.3. Both of the methods are advised to be used at the beginning of a design project (Curedale, 2013; Van Dijk et al., 2011). These patient journey maps were iterated and evaluated by the nurses and nurse managers working in the different units respectively. The finalized patient journey for the Day Surgery Unit can be found in Figure 4.1. The patient journey map presents the different actions the patient experiences during the day, and also some of the other actors the patient meets during the day. The presence of the medical clown is highlighted in the journey, because the medical clown is one of the key actors in this study.

During the discovery phase, daily workday reports of the preoperational clown’s work days were received. The medical clowns write these reports on other days too, for learning and reflection purposes. These reports provided deep insights on the medical clown’s work, as their viewpoints on the happenings and encounters of the observation days could then be discovered. In addition to the medical clown’s daily reports, children’s perceptions on patient experience and hospitalization were discovered. These perceptions were discovered through video diary data created for the research of the master’s thesis of Nina Karisalmi (2016). The master’s thesis was carried out in the
same LAPSUS-project and in the same research group as this master’s thesis. The video diary data was about children’s patient experiences expressed by themselves (Karisalmi, 2016). The data included insights on children’s viewpoints of being a patient and living with illness.

Figure 4.1: Patient journey map in the Day Surgery Unit
CHAPTER 4. IMPLEMENTATION OF THE STUDY

4.1.2 Define

In the define phase of the double diamond process, the problem statement of the case study was defined to the final form, the research technique and questions were formulated and a research plan was written.

The problem statement of the case study was redefined to "How preoperational medical clowns affect the patient experience of children undergoing a cannula insertion?" The research was decided to be conducted only in the Day Surgery Unit in the Children’s Hospital in Helsinki. The Day Hospital Unit was excluded from the study, because the patient groups and their journeys were found to be too complex and varying after the observation days and the creation of the patient journey map. Aspects that affected the different patient journeys were such as the patients are divided into several different rooms in the unit, the cannula could be inserted in different locations of the hospital and the preoperational medical clown may not reach to every cannula insertion because of concurrent schedules. Thus, the patient could have had very different experiences and it might have been too difficult to compare them.

However, in the Day Surgery Unit the patients have the same kind of patient journey during the day, the schedule and operations are sequential, and thus the preoperational medical clown can reach to every cannula insertion and operation and the patients are all waiting in the same room, which can help with the encounters with the medical clown. The patient groups and their patient journeys were found more consistent in the Day Surgery Unit compared to the Day Hospital Unit, and thus the research was decided to be conducted there. Furthermore, the insertion of the cannula was decided instead of a single operation, because the Day Surgery Unit operates on multiple different operations, such as various endoscopic operations, but many of them include the insertion of a cannula. If only one operation would have been focused on, the research patient group could have been left to too scarce. Also, the preoperational medical clown can attend the beginning of the operation regardless of the specific operation.

After the problem statement was settled, the research technique and questions were decided. As it was witnessed during the observation days and as the nurses of the unit emphasized, the schedules of the Day Surgery Unit are usually very busy. In addition, the preoperative medical clown requires time for the encounters with the patient and the family before the operation. This is because the better the preoperational medical clown and the patient
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know each other, the better their connection is. For these reasons, the research technique was required to be quick and not to take time away from these other actions and encounters during the day. Thus, a website with a digital questionnaire on a tablet device was decided as a research technique. This research technique would enable quick answering to the patients and a digital, synchronous way to gather the answers. Also, the use of a website on a tablet would be a scalable option, because many patients could then answer the questionnaires at the same time on their own tablets. Furthermore, the questionnaires were designed to be easy and fun to use, and thus visuals and images were used as much as possible. The use of the specific visuals, such as facial expressions, were derived from the earlier studies discussed already in section 2.3.3. Also, the questionnaire was designed in an age-appropriate manner. Children aged 4 to 10 were designed their own questionnaire, and children 11 years and older received a modified version of the same questionnaire.

Then, after the research technique had been decided, the patient experience aspects and the questions to be researched were formulated. These aspects and questions were based on the earlier studies on both medical clowns and children’s patient experience and also to the current problem statement. The details of the digital service are discussed more in section 4.3 and screenshots from the website can be found in the Appendix B.

To finalize the define phase, a research plan was written for the hospital. This plan included detailed plans on the research, for example what would be measured, when, what would be asked, from who and by whom. The research plan worked as a design brief before the start of the study.

4.1.3 Development

The development phase of the double diamond model started with paper sketching. Sketches are often used at the early stages of design and implementation, as they are quick, timely, inexpensive, disposable and plentiful (Buxton, 2007). Sketches can be created in many numbers and versions, and still be thrown away (Buxton, 2007). Many different, easy and fast sketches were created and iterated. Then they were converted to digital form and a prototype was created with the Sketch program. Compared to sketches, prototypes are used in the later stages of design and implementation, as they require more investments of resources, such as time and money (Buxton,
Prototypes can still be iterated and changed, but they are not as plentiful as sketches (Buxton, 2007). The prototype included detailed views of the website and it was interactive. Later, the prototype was showed to the study nurse, who would contact the patient families and conduct the research in the hospital. The study nurse, who was seen as the expert on the hospital unit’s operation, evaluated many different aspects of the prototype. The first aspect was if the website and questionnaire would be quick enough to be answered in the busy Day Surgery Unit context. The study nurse evaluated that this aspect would be covered as long as the questions and the answer options would be clear enough for all the child patients. The second aspect was the clarity and descriptiveness of the images and emotions. The evaluation of this aspect resulted in changing the emotion card images to more clear ones, as the first ones included wolves experiencing different emotions and they were found to be too confusing even to adults. Thus, these emotion card images were replaced with simple emoji faces to describe the emotions more clearly. The third evaluation aspect was the coverage of the emotion spectrum and the actions for the best and worst things during the day. The coverage of the emotions meant that do the emotions cover all the emotions the child patients may experience during the day, in both positive and in negative. Also the actions were evaluated from the point of view that do they represent the most often occurring actions that the children do during their hospital day. The evaluation resulted in adding annoyance to the emotion spectrum. At first both questions about the best and worst things had the same answer options, but after the evaluation the action of the worst things were modified. The actions were changes from gaming, videos, music, reading, playing and food to examination, pain, nausea, anesthesia, waiting and boredom. These new actions were thought to better represent the negative aspects of the day rather than just being the same as with the best aspects. The actors in both of the questions remained the same, and they were nurses, doctors and medical clowns. One answer option was also added to both of the best and worst questions, and this was the "Other" option. The images and emoji of all of these answer options were evaluated to be clear and representative, and they were not changed.

4.1.4 Deliver

The last phase of the double diamond model, the deliver phase, initiated with a decision about the technical stack and setting up the coding environment. Backend was decided to be done with Django rest framework and frontend
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with React. An application programming interface (API) was created to connect the backend and frontend. The coding started from the database structures. Then, different views and question sets were created to the different user groups. These user groups were the children, the youth and the nurse. Later, the coding continued from the broader lines to the details. When the website was finished, it was deployed to Heroku, where anybody with the correct link could use it.

After the digital service created for the children and nurses were ready, the questions for the child patient’s parents were finalized. These forms were created with Google Forms survey tool, and like the children’s surveys, they were also answered on the tablet devices.

After the digital service and the parent’s questionnaires were ready, they were once again evaluated and tested by the research group. This evaluation and testing was conducted before the pilot days started at the hospital. All the questions were read and their comprehensiveness was evaluated. Also the color theme for the parent’s questionnaire was decided upon.

When the case study started in the hospital in May 2018, two pilot days were conducted at the Day Surgery Unit. The first pilot day was without the preoperational medical clown and the second one was with the medical clown. During these pilot days, the usability and operation of the website and questionnaires were confirmed. In total 9 child patients and their parents participated to these pilot days. These participants were asked opinions about the digital service such as was it easy and clear to use, where there any questions and did the service work as expected. The parents’ questionnaire was also evaluated by asking if the questions were clear and were there any difficulties. Also observations about the use and efficiency of the digital service were made throughout the day.

One aspect that was further evaluated during the pilot days was that how young children could answer the questionnaire. Based on the literature, children as young as 3 were found to able to answer questions about their emotions. However, because this research used a custom made digital service, the correct minimum age for the digital questionnaire needed to be confirmed. The services was tested with children aged 3 and older, but it was found that children aged 3 years were not as consistent in their answers as older children. Thus, the minimum age for the research participants was decided to be 4.
After the pilot days a few changes were made to the digital service. The biggest change was to merge two question sets together. Before the pilot days, it was designed so that the child participants would answer twice to different questions after their operation. The first question set would be right after they had woken up and the other just before they would leave the unit. However, it was discovered that conducting these two questionnaires was too time consuming and the question sets were too repetitive, as some of the questions were the same. Thus, they were merged into one question set to be conducted after the operation.

4.2 Hospital context

This study was conducted in the Day Surgery Unit in the HUS Children’s Hospital in Meilahti, Helsinki for six weeks during May and June 2018. The Day Surgery Unit generally operates on small surgeries, where the patient can come to the hospital and leave home the same day. The most common procedures the unit operates on are inguinal and umbilical hernias, gastrointestinal endoscopy, bronchoscopy, cystoscopy, removal of skin changes, removal of metal rods, screws and plates placed to support the bones and rheumatoid punctures. Most of these operations require a cannula to be inserted before the actual operation, and many of them are operated under anesthesia. Typically the unit has 6 to 8 patients a day, depending on the schedules. The patients can be minors of any age.

The Day Surgery Unit comprises of five rooms, which are the office, the reception/examination room, the waiting room, the operation room and the recovery room. The office is where the unit’s nurses and secretaries keep records, have small meetings and meet the medical clown at the beginning of the day. The reception/examination room is the first place where the patient and their family arrives when they enter the unit. Here they meet the nurses and possibly doctors of the day, receive information, change clothes to hospital clothes and receive the possible premedications. Then they move to the waiting room, which is the adjacent room. Here they wait for the operation together with other Day Surgery Unit’s patients. The waiting room can have up to six patients at a time, all in different phases of the hospital day. When the operation time arrives, the nurses come and ask the patient for the operation, which happens in the operation room on the other side of the corridor. The patients go to the operations one by one, and
parents or guardians can accompany the child until the anesthesia begins. After the operation, the patients are moved to the recovery room adjacent to the operation room to wait for awakening. Here, the patients are continuously monitored by a nurse. After the child has woken up in the recovery room and feels okay, they are moved back to the waiting room to rest in a bed and to be with their parents. Here, patients rest as long as they feel fine and can eat and drink normally after the anesthesia. The nurses monitor and examine the patients yet again before they are given the permission to leave home.

The Day Surgery Unit was applicable as the research unit because its patients have a very similarly structured day in the hospital, and most of the patients receive cannula for their operation and anesthesia. Also, the medical clowns have worked in the Day Surgery Unit before, so the unit is familiar to them in addition to them being familiar to the unit’s nurses and doctors. Furthermore, as the operations are sequential, the medical clown has the opportunity to accompany and attend all of the operations of the day. The medical clown has also time to meet the patients in the waiting room, and it might actually help their encounters that the patients are all in the same waiting room, although it may also be very challenging.

4.3 Digital service

This section presents the designed and implemented digital service for measuring children’s patient experience of preoperative medical clowning. The digital service comprises of two different sets of questions; questions before the operation and questions after the operation. The digital service also includes the questions asked from the operational nurse after each study participant’s operation. The parent’s questions were created in isolation of the digital service, more specifically with Google Forms survey tool.

The digital service was implemented with Django REST framework and React, and it was hosted as a website on Heroku during the research. This way, multiple participants could participate and use the service at the same time through tablet devices. The tablet devices were provided to the participants by the study, so they were not required to use their own devices in the hospital. The research nurse provided the tablet devices to the participants at the time of answering, and then collected them away when they were ready.
The digital service did not collect any personal data of the participants. All participants were anonymised and a special research number was assigned to each participant after they decided to participate to the study. This number was then used to connect the different answers with the specified patient. In addition to this research number, the digital service only used the age range of the participant. The age was required because the service had two different versions, one for children aged 4 to 10 and another for 11 to 17.

The digital service used mainly pictures and emoji with text to present the answer options. The emoji were provided by the EmojiOne’s free license, which required an attribution on the service (EmojiOne, 2018). This attribution was visible on the footer of each page presenting emoji. Thus, even young children could answer to the questions independently. For the youngest participants, who could not read yet, their parents or the study nurse read the questions and answer option out loud, and then let the child answer by themselves to the question. The adults were advised to not interfere with the child’s answers, but only to help to read the options. If the child could read, they could use the digital service all by themselves.

The questions in the digital service were derived from the background research done for this study. Some of the questions and the overall design of the research are based on earlier studies on children. For example, the overall study design was partly based on the earlier medical clown studies conducted by Vagnoli et al. (2010) and Wolyniez et al. (2013). Also, the studies by Vagnoli et al. (2010) and Wolyniez et al. (2013) contributed to the questions and measures about the children’s anxiety and pain, in addition to the studies by Hicks et al. (2001) and Kuttner and LePage (1989), as their faces of pain and anxiety scales are used as a basis for the faces scales in this study too.

In addition, the use of emotions was derived from the idea of using digital emotional cards, as analog emotional cards are already used for children in different contexts (Bone et al., 2014; Salama, 2014; Tukiliitto, 2017). Furthermore, the selected emotions were based on the circumplex of emotions by Russell et al. (1989) and the Wheel of emotions by Plutchik (2001). The use of facial expressions and children as experts on their own experiences were also supported by the literature. Naturally, some modifications to these questions and emotions were made to fit for this specific research better. For example, different images for the anxiety and pain face measures were used, so that they were more consistent with the other emoticons of the digital service.
The digital service also considered the different cognitive development stages of children. The youngest children who could participate to this study were still on the preoperational stage categorized by Piaget and Inhelder (1969). In this stage the language, symbolic thinking and intuitive thought emerges as shown earlier in this thesis in table 2.1. These limitations were considered when designing the digital service. For example, the language of the questions and the captions to the images were designed to be as short, informative and general as possible, to enable even young children to understand them. Also, descriptive visuals were used throughout the website for the same reason. For the older children, option about free feedback was given, as they could elaborate more on the topic as their abstract thinking is more developed based on the cognitive stages by Piaget and Inhelder (1969). Thus, two versions of the same digital service was created; one for children aged 4 to 10 and the other for children aged 11 and over. This categorization was based on both the different cognitive development stages and the categorization by FinPedMed (2009) and the consent forms. The more detailed descriptions of the digital service’s questions can be found in chapter 5 and screenshots in the Appendix B.

4.4 Case study

The research for the case study was conducted in the HUS Children’s Hospital during May and June 2018 for a period of six weeks. During the study period, participation was requested from every patient and their parents coming to the Day Surgery Unit, provided that they matched the study conditions. These study conditions were the child patient’s age and the ability to speak and understand Finnish. After the first pilot days, children aged four and above were decided to be included to the study. Both the child and the accompanying guardian had to consent to the study, or the participation was rejected. Any certain operations were not specified for the patients, but every patient who might have a cannula insertion was included in the study. Then during the operation, the operational nurse recorded if the cannula was not used. This could happen for example if mask anesthesia was used instead of a cannula for some reason.

LAPSUS research project has been granted an ethical approval from the Ethics Committee for Gynecology and Obstetrics, Pediatrics and Psychiatry at HUS. The approval was valid from August 2015 until the end of June
2018. As this study is part of LAPSUS research project the ethical approval covers this study. Also, the empirical part of the study was conducted in the hospital before the end of June 2018.

As already mentioned in this thesis, both the children’s and their accompanying parent’s consent was required for research participation. The research and its contents were presented to the family and for the child in an age-appropriate manner. The family received a research release, which can be found in Appendix A in Figure A.1. The accompanying parent or guardian received and signed the guardian’s consent form. For children, different age-appropriate consent forms were created, and they were presented to the children according to their age. All of the different consent forms can be found in figures in Appendix A.

This study had a dedicated study nurse in the hospital to conduct the research. The study nurse had plenty of experience from working with children in the Children’s Hospital in Helsinki, and she had worked in the Day Surgery Unit before. Thus, she knew well the procedures and practices of the unit in addition to working well with child patients and their families. The same study nurse conducted the research for the whole study period, excluding one day when the writer of this thesis was substituting her. On some days, the study nurse worked also as the unit’s nurse in addition to conducting the research.

The families were approached by the study nurse after the family had moved to the waiting room, after the first meeting with a nurse in the registration/examination room. This process was set, because the families usually receive a lot of important information from the nurses at the first meeting. Also, the families have more time to ask questions and focus on the study in the waiting room rather than in the examination room, to where others may be waiting for their turn. The families were approached quite quickly after the first meeting, so that they would not have encountered with the preoperative medical clown yet. This way, even the patients who entered the unit on the days when the preoperative medical clown was at the unit, the first questions would not yet present the effects of the preoperative medical clown. If the family decided to participate to the research, the study nurse provided them with the research release, and asked them to sign the consent forms. After this, the study nurse provided the family with the first round of research questions on a tablet device. Both the child patient and their parents got their own tablet devices and a set of questions to answer to. The family was given as much time as they needed to answer the questions. Then
the family proceeded with the hospital day as they normally would. Later, just before the family would be sent home, the study nurse approached them with the second round of research questions on the tablet device. After the child and the parents were finished, the study nurse would thank them for participation and give them a paper with a link to a questionnaire, which the family could answer from home a few days after the hospital day.

The research process was same regardless of the day and presence of the preoperative medical clown. The research was conducted in the Day Surgery Unit in the Children’s Hospital in Helsinki for four days a week for six weeks beginning from the middle of May 2018. From the total of four research days a week, two days were with the preoperational medical clown present at the unit and two were without the preoperative medical clown at the unit. The days when there was no preoperative medical clown present at the unit were control days, and the patients in those days were the control group. The preoperational medical clown professionals changed between the research days, and there were six of them in total for 12 research days. The patients came randomly to the hospital on different days, and the research did not affect the admission to the operations or the treatments.

4.5 Data analysis

The data of the study was analyzed after the six weeks of research in the hospital. The different data sets for the children, parents and nurses were kept and analyzed separate from each other. First the data of the child patients were analyzed, then the answers of the nurses and lastly the parents. As the data had both quantitative and qualitative questions, the quantitative answers were first analyzes and before the qualitative ones.

The child patients and nurses data was initially in the same format, different from the parents data. The child patients and nurses data was generated through the digital service in a json format, which was then converted to an Excel format before the final analysis. On the other hand, the parent’s data was generated through Google Forms and could be already downloaded in an Excel form. Also, the Google Forms could generate automatic charts of the data, which could display the responses in real time.

The child patient’s data was analyzed first. After the data was converted into Excel form, the patients were categorized into a clown group and reference
group. The clown group had been in the hospital during a day when there was a preoperative medical clown in the hospital, and the reference group on the other hand during a day when there was not a preoperative medical clown in the hospital. After this categorization, all child patients who had not had the cannula insertion, and had for example a mask anesthesia instead, were excluded from the data. Also child patients who lacked the response from either one of the response times for some reason were excluded from the analysis. Then each question from the survey was analyzed one by one. For the quantitative data, descriptive statistics such as means and variance were calculated and appropriate histograms, charts or tables were created to represent the data in a visual form. For the qualitative data, common themes were identified from the individual answers. During the analysis and for all of the questions the two patient groups, clown group and reference group, were compared with each other.

All of the nurses’ data generated in this study was quantitative. Thus, only descriptive statistics and mathematical models were used in the analysis. The verbal feedback that nurses gave during the study was not analyzed systematically. The analysis from the nurses’ point of view was also conducted only to child patients who had a cannula insertion, and others were excluded from the analysis. The child patients who visited the hospital during a clown day were categorized further into two groups; a clown induction group and a non-clown induction group. The children in the clown induction group had a preoperative medical clown accompanying them during the start of the anesthesia and cannula insertion, whereas the non-clown induction group had a cannula insertion without the clown. Both of these group still met and encountered the preoperative medical clown during their day at the hospital. This further categorization was required for example for comparing the induction timings of the patients groups. The analysis for the nurses’ data was conducted question by question, contrasting the different patient groups to each other.

Most of the quantitative data generated from the parents’ questions was already analyzed by the Google Forms. For example, the survey tool generated pie charts and histograms from the close ended questions of the questionnaire. The open ended questions and the qualitative data generated by them was analyzed further in Excel, by identifying and categorizing commonly occurring themes from the answers. The themes were found by searching for specific words and their synonyms and then color coding these answers. The identified themes were for example emotion categories, person groups and positive or negative answers, depending on the question.
Chapter 5

Results

This chapter presents the results to the evaluation of the digital service and the study results obtained in the case study. The evaluation of the digital service was conducted against the evaluation criteria defined in section 3.4. The two main evaluation criteria were the usability of the system and the ability to find differences for the two different patient groups in the case study. The results for the usability evaluation are described in section 5.1, and the results for the case study in sections 5.2, 5.3 and 5.4 from the point of view of child patients, their parents and the nurses respectively.

5.1 Evaluation of the digital service

The usability of the digital service was assessed against the evaluation criteria specified in section 3.4. The usability evaluation aspects were the results for the user testing, heuristic evaluation and the success rate of the system.

The first evaluation, the user testing, was conducted at the beginning of the case study at the HUS Children’s Hospital in May 2018. As described already in section 4.1, the digital service was tested with 9 child patients during the first two days of the case study. These child patients first used the digital service, and then they were asked if it was easy to use or did they have any questions or problems during the use. Based on this testing, the digital service was changed to include two different questionnaire times instead of three. Otherwise the responses of the child patients and their parents to the
digital service were positive. Both commented that the emoji used in the
digital service were familiar, as both children and their parents use them on
a regular basis, and it was fun to use them in the questionnaire. Also, they
appreciated that the use of the digital service was quick and easy. Moreover,
the pilot testing confirmed that children as young as 4 were able to answer
to the questionnaire quite independently. However, the youngest children
who could not read yet required some assistance in reading the questions
and detailed answer options such as the specific emotions. Otherwise the
youngest children could also answer by themselves to the questions. The
results of the user testing indicate that the digital service was easy to use
from the test users point of view.

The second evaluation round was conducted after the case study, as a sum-
mative, heuristic evaluation. The system was inspected from the point of
view of the ten usability heuristics by Nielsen and Mack (1994). The author
of this thesis conducted this heuristic evaluation. The results for the heuristic
evaluation are presented next.

Visibility of the system status. This usability heuristic means that the system
should always show the state of the action, and give reasonable feedback in
a reasonable time. This heuristic was applied in the digital service in a way
that after the user has selected an answer option for a questions, the services
gives feedback by changing the selected answer’s background changes color
and the button for submission from white to green as can be seen from Figure
B.4. However, the overall system status cannot be seen, as the digital service
does not show how many questions are left and how many have already been
answered.

Match between system and real world. Rather than using system specific
language, the system should use language and concepts that the users are
familiar with. In the digital service, this was really important as the users
were children, which might not understand any technical or system specific
words. Thus, the digital service used as short and descriptive words for
different emotions and aspects of the hospital day. Also, the selected visuals
used were commonly used emoji, so that children would understand them
to some extent without the need to be able to read and understand written
text.

User control and freedom. This heuristic concerns the exits for mistake steps
for selecting functions and the possibility for undo and redo. The digital
service did not have undo or redo functions, but the possibility to go forward
without answering a question was permitted. The permission was implemented in a way that the Submit-button was disabled before an answer was provided. Also, the questionnaire was quite straightforward and the only function the users could perform was to answer to the questions. Thus, no extensive use of incorrect functionality could be performed.

**Consistency and standards.** The users should not need to think if same names, functions or images mean the same thing across the service. Thus, same kind of visuals and words were used throughout the digital service. For example, both the anxiety and pain measures had the same visuals and verbal scales. Also, the used emoji were chosen from the commonly used emoji library and the emotions they presented were primary emotions. If more complex emoji were used, the interpretation of the emotions could have been different between the respondents.

**Error prevention.** The system should be designed in a way that prevents users from having errors. The major error that the digital system could have had was if the user did not answer to all of the questions and the answers would not be registered to the system. Thus, the digital system was designed in a way that users need to select an answer before the submit-button was enabled and then continuing to the next question.

**Recognition rather than recall.** The options, actions, information and objects of different states should be available when needed, and user should not need to remember it from one part to other. The digital system did not have any extensive dialogues or required information, and the users could answer to the questions based on their current information. Also, all of the answer options were always visible when needed.

**Flexibility and efficiency of use.** Experienced users should have accelerators or shortcuts to enable more efficient use of the system. The users of the digital system were quite a similar group of users, and there were no clear cut to experienced or inexperienced users. Also, the functions were quite simple and the service were used on a tablet device, and thus there were no shortcuts offered. However, when the research nurse was entering the research id for the participant (seen in Figure B.3), the tablet opened a number keyboard for faster input.

**Aesthetic and minimalist design.** The system should not provide any unnecessary information, which clutters the view and diminishes the important information. For each view of the digital service, there were only the current
question and the possible answer options visible. No other information was provided as it was not required for answering to the questions.

*Help users recognize, diagnose and recover from errors.* If errors occur, the error messages should be presented in the user’s language rather than system specific codes. For the research nurse’s part of the digital service, the inputs were evaluated before continuing and the error reasons were shown to some extent. For example, for the research id of the child, the input was required to be a positive number between 0 and 500 and a error message was shown if it was not. For the children’s part of the digital service, no error messages were implemented, because the answer options were predetermined and no other functionality than selecting an answer was possible.

*Help and documentation.* Help and documentation needs to be offered even though the system could be used independently. The help should be clear and easy to search and provide concrete actions for recovering. The digital service did not offer any written documentation, but verbal help was provided throughout the study. The designer of the service provided help for the research nurse when needed and the research nurse again provided help for the child patients and their parents when needed.

After the heuristic evaluation by the author, the research nurse was asked to evaluate the digital service related to the usability heuristics. She evaluated the digital service both from her own and the children’s point of view. This was decided because the research nurse was the one conducting the research for the case study in the hospital and witnessed the children's use of the digital service the most. The questions presented to the research nurse can be found from the Appendix C. The questions related to the usability heuristics, and concerned themes such as the learnability, ease of use, errors, need for assistance and consistency of the views.

For the evaluation from her own point of view, the research nurse stated that the digital service was easy to learn and really easy to use. Also, no additional help documentation was needed at all, as some guidance was received at the beginning, which was enough. Moreover, the digital service used clear and consistent language, visuals and logic throughout the system. No unnecessary information or recollection of information was required, as the questions were detached from each other. However, it was not possible to go back to previous questions and there were few errors at the start of the case study, as some responses were not saved, but these errors were quickly recovered and fixed.
For the child patients’ point of view, the research nurse reported that the digital service was easy to use, and even the youngest children could answer the questions with just a little guidance. Apart from this guidance for the youngest, the child patients did not require any other help. The language was also clear and consistent for the children, and the visuals and images were a major help. The information provided for each view was sufficient and answer options were plentiful. For the future, the research nurse stated that the digital service could definitely be used to collect and analyze the child patients’ experiences.

To conclude the results of heuristic evaluation, the results indicate that the digital service was quite compliant with the usability heuristics. Both the research nurse and the child patients could use the system without major assistance, only the youngest ones required help in answering the questions. The digital service was consistent, had sufficient amount of information and the use if visuals enhanced the usability for the children. However, some errors occurred at the beginning of the case study, and it was not possible to move between the questions.

In addition to testing and heuristic evaluation, the efficiency of the digital service was evaluated. Although some child patients did not have the opportunity to answer to one of the question times, due to transition to other unit after the operation, the success ratio gives a good enough estimate for the efficiency of the digital service. For the 98 patients who participated to the research, 84 provided complete answers to both questionnaire times, and thus the success ration of the digital service is 86%. The results is good, as most of the websites have a success ratio of 50% (Nielsen, 2001). Thus, the digital service was efficient in collecting experience data from the child patients.

For conclusion, the results of the evaluation of the digital service indicate that it was easy and efficient to use the digital service by the child patients and the research nurse at the case study context. The second evaluation criteria, the results for the case study are discussed next.
5.2 Children’s experiences

5.2.1 Demographics

In total 96 child patients participated in the study, from which 70 patients were included in the analysis. Excluded cases were such as where the child was received a mask induction or local anesthesia instead of a cannula, or the patient was transferred into another unit after the operation, or answers to one of the question sets were missing for some reason, like network connection problems. All the 70 child patients who were included in the analysis received a cannula during their operation, and spent the whole hospital day in the Day Surgery Unit. The number of refusals to the study was really low; only 5 patient refused to participate when asked during the 6 weeks of research. In most of the refusals the child refused to participate for some reason, for example they were Finland-Swedish speaking and were not content with their Finnish skills. Only one parent refused to give consent and participate to the research, and also only one child said be afraid of clowns.

Firstly, the participated children were divided into two groups based on the day they visited the Day Surgery Unit; the medical clown day and the reference day. The patients visiting the hospital during a medical clown day encountered and met with the preoperative medical clown, and they composed the medical clown patient group. On the other hand, patients visiting the hospital during the reference day did not encounter and meet the preoperative medical clown during their hospital day, and thus they composed the reference patient group.

Furthermore, the child patients visiting the hospital during the medical clown day were divided into two different groups, based on the fact if the preoperative medical clown was accompanying them to their operation, cannula insertion and induction of anesthesia. Thus, patients in the medical clown group were further divided into a medical clown induction and a non-medical clown induction. The medical clown induction patient group had a preoperative medical clown accompany them during the cannula insertion and the non-medical clown patient group did not have a preoperative medical clown in their cannula insertion. Nevertheless, both of these patient groups encountered the preoperative medical clown during their hospital day, and thus the preoperative medical clown could have an influence to their emotions and experiences. For example, the preoperative medical clown could have such
a good encounter with the patient that the patients anxiety and fears for the operation decrease so much, that the patient feels no need for the preoperative medical clown to accompany the operation. Still, the preoperative medical clown leaves an influence and affects the child patient’s experiences, even without accompanying the operation. On the other hand, the presence of the preoperative medical clown at the beginning of the operation can affect some aspects, such as timing of the start of anesthesia. Thus, it was important to keep a record on the presence of the preoperative medical clown so that right patient groups could be compared during the research.

Overall, the child patients can then be divided into three groups; first, the reference day group and the medical clown day group, which can be further divided into two distinct groups; the clown induction and non-clown induction. The reference day group cannot be divided like this, because all of them received the cannula without the preoperative medical clown. These different groups and the number of patients in each group can be seen below in 5.1. In total 38 patients were accepted to the medical clown day group and 32 to the reference day group. As stated earlier in this thesis, the patients came randomly to the hospital on different days, and thus the different patient groups have different number of participants.

<table>
<thead>
<tr>
<th>Cannula insertion with a medical clown</th>
<th>Medical clown induction</th>
<th>Reference day</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clown induction</td>
<td>29</td>
<td>Non-medical clown induction 9</td>
</tr>
<tr>
<td>Non-clown induction</td>
<td>32</td>
<td>32</td>
</tr>
</tbody>
</table>

The age distribution of the two different patient group days can be found in Figure 5.1. The mean age of the medical clown day patient group was 8,5 years, the youngest patient during that day was 4 years and 8 months, and the oldest was 15 years. The mean age of the reference day was 10,3 years, and the youngest patient during that day was 4 years and 6 months, and the oldest was 17 years.
Also the age distributions of the medical clown induction group and non-medical clown induction group were calculated. These distributions can be seen from Figure 5.2. These distributions were calculated to reveal differences in ages of the two patient groups, because child patients can also refuse when the preoperative medical clown asks if they would accompany the patient to the operation and cannula insertion. The preoperative medical clown could also miss the operation time for schedule problems, and thus the age is not the only reason why the preoperative medical clown did not accompany some patients to the operation. Still the child patient and the preoperative medical clown encountered during the day. As the figure also shows, the patients who had the preoperative medical clown present during their cannula insertion appears to be younger than those who did not have the preoperative medical clown. The mean age for the medical clown induction was 8 years and for the other group it was 10.3 years. Thus, it could be assumed that younger children are generally accompanied more to the operation, at least during this study. However, the non-medical clown induction group of the medical clown day had only 9 patients and they were all different age, which could affect the results. Also, for the 11 year-old’s and older, the patients are divided evenly to each of the patient groups and also one 14 year old was accompanied by the preoperative medical clown to the cannula insertion.
Figure 5.2: Age distributions of the medical clown induction group and the non-medical clown induction group during the medical clown day.

5.2.2 Emotions

Child patients were asked about their current emotion on both questionnaire times, before and after the cannula insertion. The question was presented in Finnish but translates to “What do you feel right now?” The answer options were displayed as emoji faces presenting different emotions, and the view of the question can be seen from Appendix B in Figure B.4. The possible emotion options are joy, enthusiasm, fun, content, boring, confusion, annoyance, surprise, sadness, fear and anger. Children could only select one emotion, which would represent the ultimate feeling at the given time.

During the analysis of the answer to this question, the medical clown day patient group was compared with the reference day patient group. This comparison was decided because all the child patients in the medical clown day group encountered the medical clown, and thus the medical clown could affect the emotions and experiences of the child patient and their parents, even though the medical clown would not accompany the cannula insertion. However, the patients and parents in the reference day did not meet the medical clown at any time during their hospital day.
Table 5.2 presents the emotions of the medical clown day patient group and Table 5.3 present the emotions of the reference day patient group. The rows presents the different emotions experienced before the cannula insertion, and the columns represent the experienced emotions after the cannula insertion. The row and columns present only the experienced emotions, and thus same emotions do no occur on the rows and columns, or the different tables. Also, the values are shown as percentages to enable comparison, because the two groups had different number of participants. The deeper cell colors present higher occurrence values and the lighter cell colors smaller occurrence values.

As Table 5.2 shows, patients in the medical clown day group experienced mostly joy, confusion and annoyance before the operation. Each of these emotions were experiences by 16% of the patients. The second most experiences feelings were boring and fear, as 13% of the patients experienced each of these emotions before the operation. After the operation, the most experienced emotions by 32% of the patients was joy. The second most experienced emotion was fun by 21% and then content by 13% of the patients. The most frequent emotion combinations of the medical clown group before and after the operation were joy to joy and annoyance to joy. Before the operation none of the child patients experienced enthusiasm or sadness. After the operation, none experiences sadness, fear or anger.

For the patients in the reference group, the most experienced emotion before the operation was joy by 22%, then fear by 19% and then confusion by 16%. After the operation the most frequently experienced emotions were joy by 25%, confusion by 22% and content by 19%. The most experienced emotion combination before and after the operation were joy to joy, which was experiences by 9% of the patients. None of the reference day group patients experienced surprise or sadness before the operation, and after the operation none experienced annoyance, sadness or anger.

By comparing the tables can be discovered that more patients in the medical clown group feel joy and fun after the operation than in the reference group. In the medical clown group 32% experience joy and 21% fun after the operation, whereas in the reference group the numbers are 25% and 6%. In addition, confusion is experienced more in the reference groups, by 22%, whereas in the medical clown group the number is only 5%.
Table 5.2: Experienced emotions of the medical clown day patient group.

<table>
<thead>
<tr>
<th>Emotions</th>
<th>Before</th>
<th>Joy</th>
<th>Enthusiasm</th>
<th>Fun</th>
<th>Content</th>
<th>Emotions after</th>
<th>Boring</th>
<th>Confusion</th>
<th>Annoyance</th>
<th>Surprise</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Joy</td>
<td>8%</td>
<td>3%</td>
<td>5%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>16%</td>
</tr>
<tr>
<td>Fun</td>
<td>3%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>8%</td>
</tr>
<tr>
<td>Content</td>
<td>3%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>8%</td>
</tr>
<tr>
<td>Boring</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>5%</td>
<td>3%</td>
<td>5%</td>
<td>3%</td>
<td>13%</td>
</tr>
<tr>
<td>Confusion</td>
<td>5%</td>
<td>3%</td>
<td>5%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>16%</td>
</tr>
<tr>
<td>Annoyance</td>
<td>8%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>3%</td>
<td>3%</td>
<td>3%</td>
<td>3%</td>
<td>16%</td>
</tr>
<tr>
<td>Surprise</td>
<td>3%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>3%</td>
<td>5%</td>
<td>3%</td>
<td></td>
<td>8%</td>
</tr>
<tr>
<td>Fear</td>
<td>5%</td>
<td>3%</td>
<td>3%</td>
<td></td>
<td></td>
<td></td>
<td>3%</td>
<td>3%</td>
<td>3%</td>
<td></td>
<td>13%</td>
</tr>
<tr>
<td>Anger</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>3%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>32%</td>
<td>11%</td>
<td>21%</td>
<td>13%</td>
<td>11%</td>
<td>5%</td>
<td>5%</td>
<td>3%</td>
<td>100%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 5.3: Experienced emotions of the reference day patient group.

<table>
<thead>
<tr>
<th>Emotions</th>
<th>Before</th>
<th>Joy</th>
<th>Enthusiasm</th>
<th>Fun</th>
<th>Content</th>
<th>Emotions after</th>
<th>Boring</th>
<th>Confusion</th>
<th>Annoyance</th>
<th>Surprise</th>
<th>Fear</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Joy</td>
<td>9%</td>
<td></td>
<td>3%</td>
<td>3%</td>
<td>6%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>22%</td>
</tr>
<tr>
<td>Enthusiasm</td>
<td></td>
<td></td>
<td>3%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>3%</td>
</tr>
<tr>
<td>Fun</td>
<td>3%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>6%</td>
</tr>
<tr>
<td>Content</td>
<td>3%</td>
<td>3%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>13%</td>
</tr>
<tr>
<td>Boring</td>
<td>3%</td>
<td></td>
<td>6%</td>
<td></td>
<td></td>
<td></td>
<td>3%</td>
<td>3%</td>
<td>3%</td>
<td></td>
<td></td>
<td>13%</td>
</tr>
<tr>
<td>Confusion</td>
<td>3%</td>
<td></td>
<td>3%</td>
<td></td>
<td></td>
<td></td>
<td>3%</td>
<td>3%</td>
<td>16%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Annoyance</td>
<td>3%</td>
<td></td>
<td>3%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>6%</td>
</tr>
<tr>
<td>Fear</td>
<td>3%</td>
<td>3%</td>
<td>6%</td>
<td></td>
<td></td>
<td></td>
<td>3%</td>
<td>3%</td>
<td>19%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anger</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>3%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>25%</td>
<td>13%</td>
<td>6%</td>
<td>19%</td>
<td>9%</td>
<td>22%</td>
<td>3%</td>
<td>3%</td>
<td>100%</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
CHAPTER 5. RESULTS

Table 5.4: Emotion categorization.

<table>
<thead>
<tr>
<th>Positive</th>
<th>Neutral</th>
<th>Negative</th>
</tr>
</thead>
<tbody>
<tr>
<td>Joy</td>
<td>Boring</td>
<td>Annoyance</td>
</tr>
<tr>
<td>Enthusiasm</td>
<td>Surprise</td>
<td>Sadness</td>
</tr>
<tr>
<td>Fun</td>
<td>Confusion</td>
<td>Fear</td>
</tr>
<tr>
<td>Content</td>
<td></td>
<td>Anger</td>
</tr>
</tbody>
</table>

After the emotions were analyzed individually, the emotions were categorized and divided into three groups; positive, neutral and negative. The emotion division can be found in Table 5.4. Then, the same analysis were performed to the emotion categories as for the individual emotions above. Tables 5.5 and 5.6 present these analysis results. These tables show that the medical clown group experienced all emotions categories quite equally before the operation, which was before the medical clown’s encounter and effect on the child patients’ experiences. Then, after the operation, 76% of the child patients in that group experienced positive emotions, 18% neutral emotions and 5% negative emotions. On the reference group, before the operation 47% experienced positive emotions, and the rest quite equally neutral and negative emotions. After the operation, the numbers for the group were 63% for positive emotions, 34% neutral emotions and 3% negative emotions. Thus, the percentage point change of positive emotions during the medical clown day was 44%, as before the operation only 32% felt positive emotions and 76% afterwards. The same percentage point change of reference day was only 16%. Also, the change of neutral emotions increased 9% points during the reference day whereas during the medical clown day it decreased 19% points. To conclude, the children in the medical clown group appear to experience more positive emotions and less neutral emotions after the operation compared to the reference group. This was the case even though before the operation the reference group experienced more positive emotions than the medical clown group in this study. Based on this study, it appears that the medical clown group’s emotions change more towards positive ones compared to the reference group.
To conclude, the children in the medical clown group appear to experience more positive emotions and less neutral emotions after the operation compared to the reference group. The amount of negative emotions appears to be same between the two groups by 5% and 3%. The change in the amount of positive emotions is greater during the medical clown day as it changes 44% points, compared to the reference day where it increased only 16% points. Also, the amount of neutral emotions increases during the reference day, whereas it decreases during the medical clown day. Based on this study, it appears that the medical clown group’s emotions change more towards positive ones compared to the reference group.
5.2.3 Anxiety

The anxiety level of the child patients was evaluated both before and after the operation as a self-reported measure. Children were asked to rate their anxiety level with a five point Lickert type of scale and question "How much anxiety do you feel?" The answer options were presented as emoji faces varying from a happy "Not at all" to a "Very much" with a sad face emoji. A screenshot from the question can be found in Appendix B in Figure B.5.

The analysis and comparison was made both between the different day groups and between the different induction groups. Comparison between the days was conducted to reveal the overall effect of the presence of the preoperative medical clown during the day. The comparison between the two different inductions, the one where the preoperative medical clown was present during the cannula insertion and the one where not on the reference day, was conducted to find if the preoperative medical clowns presence during the induction had a different effect on the anxiety than just the presence during the day. The different patient groups' anxiety levels before the operation can be found in Figure 5.3 and the anxiety levels after the operation can be found in Figure 5.4. These figures show that most of both the medical clown group patients felt moderate anxiety before the operation, and no anxiety after the operation. The reference day’s patients on the other hand felt little anxiety before the operation and no anxiety after.

Means were calculated for each of the patient groups. Before the operation, when the preoperational medical clown had not yet affected the anxiety levels of the patients, the means of the anxiety levels were 2.53 for the medical clown day group, 2.59 for the medical clown induction group and 2.25 for the reference group. After the operation the means were 1.37 for the medical clown day group, 1.41 for the medical clown induction group and 1.41 for the reference group. Overall, the the anxiety levels were between the values "Little" and "Moderate" before the operation and close to value "Little" after the operation for all the patient groups. However, the two medical clown groups felt more anxious before the operation, when the preoperative medical clown had not affected their emotions, and also their anxiety levels decreased more compared to the reference group. The changes in the anxiety levels are presented in Figure 5.5.
Figure 5.3: Anxiety distributions of the different patient groups before the operation.

Figure 5.4: Anxiety distributions of the different patient groups after the operation.
CHAPTER 5. RESULTS

5.2.4 Pain

The pain level that the cannula insertion cause was asked from the child patients after the operation. The same 5 point Likert type of scale was used for this question as was used with the anxiety evaluation. The scale started from point 1 "Not at all" to 5 "Very Much". The view for this question in the digital service can be found in Appendix B in Figure B.6. The comparison was made between the medical clown day and the reference day.

Figure 5.6 presents how the main scores were divided between the different patient groups to the different scores. As the figure shows, most of the patients in both groups felt no pain during the cannula insertion. However, the medical clown group’s answers are divided more to other answers as well. The mean value for the pain for the medical clown group was 2.05 and for the reference group it was 1.84. It appears that the medical clown group experiences little more pain, but most of their answers are moderate or little pain. These differences were not statistically different when calculated. Also, pain is really subjective experience, and as stated in the demographics, the children in the medical clown group were significantly younger than those in the reference group. This might have affected the results.

Figure 5.5: Changes in the anxiety level of different patient groups.
CHAPTER 5. RESULTS

5.2.5 Best and worst aspects in the hospital

The best and worst aspects of the hospital day were asked from the child patients after the operation. The question presented the answer options as emoji combinations and text, and the detailed view can be found in the Appendix B. The figure B.7 shows the best aspect options and the figure B.8 shows the worst aspects in the hospital. The translated questions were ”What was the best thing in the hospital?” and ”What was the worst thing in the hospital?”. The questions and answer options were the same for all the patient groups and patients were able to select only one option. The two questions had little bit different answer options because of the different nature of the questions.

The comparison and analysis of this question was made between the medical clown day and the reference day, because as stated earlier, the presence of the preoperative medical clown could affect the experiences of the patients in the medical clown day group. Figure 5.7 shows the answers to the best and figure 5.8 the worst aspect of the hospital day for both the patient groups.
CHAPTER 5. RESULTS

Figure 5.7: The best aspects of the hospital stay.

Figure 5.8: The worst aspects of the hospital stay.
The figures show that for over 50% of the patients in the medical clown day group the best aspect of the hospital day was the preoperative medical clown. For the reference group, the best aspect was the nurses by 25%, which was the second best aspect for the medical clown day group too by 13%. The third best aspect for both days was food, by 8% in the medical clown group and 19% by the reference group. However, 19% of the reference day group’s patients answered “Don’t know”, contrasting to only 3% of the other group. To conclude, the best aspects in the hospital from the point of view of the child patients were the preoperative medical clowns, nurses and food. The reference group had a much higher answer percentage to the ”I don’t know” option compared to the medial clown group.

The worst aspects of the hospital day from the child patients’ point of view were quite the same between the two patient groups. For both groups, over 30% answered that waiting was the worst aspect of the hospital day. Second worst aspect was pain for both groups, with over 20% answering percentage for both groups. Both groups had also a great percentage of ”Don’t know” answers, but the medical clown group had almost double the amount by over 20%, as for the reference group the number was 13%. In addition, anesthesia option was answered over 10% of the patients in both groups. Also, only one child answered that the medical clown was the worst aspect of the hospital day. However, the same child also answered that the medical clown was the best aspect of the hospital day. To conclude, the worst aspects of the hospital day were almost the same between the two groups. The worst aspects based on this study were waiting, pain and anesthesia. However, many child patients also answered ”Don’t know”, and patient in the medical clown group answered it double the amount compared to the reference day group.

5.2.6 Open answers

The older children aged 11 to 17 years were able to give open feedback on both answering times. The view of the feedback question can be found in Appendix B in Figure B.9. However, only 5 children gave this feedback, as it was not compulsory. Half of the answers were positive and half negative. In the positive answers, children complimented the medical clowns and the nurses. The negative answers were about long waiting times, hunger or boredom.
5.3 Parents’ experiences

The child patients’ parents answered to questionnaires at three time-points. They answered twice at the hospital, before and after the child’s operation, and then once at home a few days after the hospital day. Parents’ were asked questions about their background information and questions related to emotions, expectations and fluency of the operation and hospital day.

The Figure 5.3 below presents background information obtained from the parents in the questionnaires. Most of the respondents were mothers, and most of the families had visited the Children’s Hospital before.

Figure 5.9: Background information from the parents questionnaire.
Before the operation, half of the parents were generally restful and calm, although many admitted feeling anxious about the upcoming operation. Over 70% of the parents answered that their child appears anxious before the operation, and 20% answered that the child is calm or happy. 50% of the parents hoped that the operation or treatment would offer a clear diagnosis for the child, relief for the sickness and symptoms.

After the operation, 65% of the parents said to feel relief and 7% were pleased. Only 6% answered with what was categorized as a negative feeling, such as sad, tired or frustrated. Over 90% of the parents reported that the operation went well or really well and the operation met the expectations well or really well. In addition, many of the parents thanked the competent healthcare professionals, both nurses and doctors and also the preoperative medical clown. Moreover, many thanked the preoperative clown for decreasing both the parent and child’s anxiety before the operation. Many reported that the preoperative clown had given the family something else to think about before the operation, thus helping with the long waiting times. Below are some translated, but otherwise direct quotes from the parents’ answers.

"The medical clown was wonderful and relieved child and parent’s anxiety."

"The medical clown amused the child and relieved anxiety while waiting for the operation. I think that we will remember the medical clown for a long time. The hospital day went well and the care was really good."

"The medical clown was a lovely surprise and it was wonderful, reassuring and liberating to laugh in a situation like this."

The home questionnaire was finally answered by only 15 parents. The answers supported the earlier answers, as many reported that the hospital day and operation went well, and it met the expectations. Also, many thanked the preoperative medical clown for relieving anxiety and taking the mind off the operation. The nurses and doctors were also thanked for a good care and services. Many parents felt that their opinions were heard during the hospital day and they were well informed for the schedules and events of the day.

To conclude, from the child patients’ parents point of view the hospital day went generally well, and the preoperative medical clown relieved the anxiety of both the parent and the child.
5.4 Nurses’ point of view

The effect of the preoperational medical clown on the cannula insertion was evaluated by an operational nurse. The operational nurse was present in the operation room during the cannula insertion and operation, but did not operate in it. The viewpoints of the nurse were collected after each operation by a paper version of the questionnaire created in the digital service, if the child patient attended the study. The operational nurse would give the paper version to the study nurse, who would then transfer the nurse’s answers to the digital service. The research process shaped to be like this, because the paper version was easier to administer and answer in the operation room than a tablet device. The nurses’ questionnaire included questions about the fluency of the cannula insertion, the anxiety of the child from the operational nurse’s point of view and some background information. The nurse’s questionnaire can be found from Appendix B in Figure B.11. The cannula insertions procedures were compared between the clown day patient group and the reference day’s patient group.

The fluency of the cannula insertion was evaluated with a five-point Lickert type of scale, where value 1 meant that the procedure went well and 5 that it went bad. The average fluency of the cannula insertion of the medical clown induction group was 1,11 and the average of the reference day was 1,13. Both averages are close to 1, which means that on average, the cannula insertions went well. The Figure 5.10 shows the distributions of the cannula insertion fluency from the operational nurse’s point of view. Thus, it could be stated that the fluency of the cannula insertion was not different between the days from the operational nurse’s point of view.

The operational nurse also evaluated the observed anxiety of the child patient. Like the fluency of the cannula insertion, the anxiety was evaluated with a five point Lickert type scale. The average anxiety of the medical clown day’s patient group was 2.13 and that of the reference day was 2. Both of these values are close to value 2, which means “quite little”. The Figure 5.11 presents the anxiety distributions of the two patient group with a 5 point scale, where 1 is Little anxiety and 5 is Much anxiety.
Figure 5.10: The fluency distribution of the two patient groups from the nurse’s point of view.

Figure 5.11: The child patients’ anxiety distribution of the two patient groups from the nurse’s point of view.
In addition to these aspects studied with the questionnaire through the digital service, the timing of the cannula insertion was studied. The timing was collected from the hospital’s computer system, as they already mark specific timings for the procedures and the study nurse had access to these timings. For example, the time when the patient enters the operation room and the start of the anesthesia are already timed by the computer systems. The anesthesia is usually started quickly after the cannula has been inserted, and thus that timing could be used to calculate the time it took to insert the cannula. In some cases though, blood examples were taken from the cannula before the anesthesia was started. These cases were reported by the operational nurse and were excluded from the analysis. Nevertheless, this timing process by the computer systems was described easier by the nurses compared to having a dedicated timer and timekeeper in the small operation room during the procedure. Also, no other information was collected from the hospital’s computer systems and only the study nurse calculated the timings.

The timings of the cannula insertion were compared between the medical clown day’s patient group (Medical clown induction) who had the medical clown with them during the cannula insertion and the reference day’s patient group (Reference induction). The medical clown day’s patients who did not have the medical clown with them during the cannula insertion were excluded, because the medical clown could have had an affect to their mood or anxiety, and thus affect the timing even though they were not present.

The inductions times for the two patient groups are presented in a table format in Table 5.7 and in a chart format in Figure 5.12. As the table and chart present, the medical clown inductions have taken between 3 and 11 minutes, whereas the reference inductions have taken from 1 to 10 minutes. Almost half of the medical clown inductions have taken 4 or 5 minutes, and the average of that group is 5.3 minutes and the variance is 3.7. Most of the reference day inductions have taken also 4 or 5 minutes, and the average of the group is 5.4 minutes and the variance is 4.7. These values are very similar, although the variance of the reference group is greater. However, these differences are not statistically different, and thus there are no differences between the timings of the cannula insertion between the two patient groups. Further, based on this study it appears that the presence of the medical clown did not have prolonging or shortening affect to the timing of the cannula insertion. All in all, the cannula insertions were similar between the two different patient groups from the point of view of the operational nurse.
Table 5.7: Induction time distribution in minutes of the two patient groups.

<table>
<thead>
<tr>
<th>Time (min)</th>
<th>Medical clown induction</th>
<th>Reference induction</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>0%</td>
<td>2%</td>
</tr>
<tr>
<td>2</td>
<td>0%</td>
<td>5%</td>
</tr>
<tr>
<td>3</td>
<td>14%</td>
<td>5%</td>
</tr>
<tr>
<td>4</td>
<td>24%</td>
<td>15%</td>
</tr>
<tr>
<td>5</td>
<td>24%</td>
<td>17%</td>
</tr>
<tr>
<td>6</td>
<td>3%</td>
<td>12%</td>
</tr>
<tr>
<td>7</td>
<td>17%</td>
<td>10%</td>
</tr>
<tr>
<td>8</td>
<td>7%</td>
<td>5%</td>
</tr>
<tr>
<td>9</td>
<td>0%</td>
<td>2%</td>
</tr>
<tr>
<td>10</td>
<td>0%</td>
<td>2%</td>
</tr>
<tr>
<td>11</td>
<td>3%</td>
<td>0%</td>
</tr>
</tbody>
</table>

Figure 5.12: Induction time distribution in minutes of the two patient groups.

To conclude, it appears that the medical clown did not have any affect to the cannula insertion procedure from the operational nurse’s points of view. All aspects that were research in this study appeared same between the two different patient groups, the medical clown day group and the reference day group. There were no differences between the fluency of the cannula insertion, the child patient’s anxiety from the operational nurse’s point of view or the timings of the cannula insertion procedures were not different.
Chapter 6

Discussion

This chapter discusses the connections between the results of this study and the existing literature. The first section 6.1 compares the results to the research questions to the existing literature of relevant topics. The second section 6.2 discusses advantages and limitations of the used research instrument. Then validity of the research is discussed in section 6.3 and to conclude, recommendations and future work is discussed in section 6.4.

6.1 Answers to the research questions

The research problem of this study was ”How can digital services be used to measure patient experiences?” This problem was first addressed by designing and developing a special digital service for measuring children’s patient experience with the service design approach. The digital service was created for child patients, rather than adults, because when children’s patient experience is studied, special considerations and design decisions regarding the study instrument are required. More traditional digital questionnaires were used when studying the child patient’s parent’s patient experience. Then, the applicability of the digital service for measuring patient experience was evaluated in a case study, where the effects of preoperative medical clowning to patient experience were studied. The evaluation of the digital service was conducted from two point of views; usability and the ability to reveal patient experiences for the case study.
The feedback from the child patients and parents on the digital service was positive. The child patients and parents commented on the emoji to look fun and familiar as they use and see them on a regular basis. Both also reported that it took only little time to answer to the digital questionnaires, which was seen as a good thing. Moreover, many child patients were able to answer to the questionnaire by themselves, and did not require any instructions. Only youngest children, aged 4 or 5 who could not read yet required a little help from their parents or the research nurse to read the questions, but otherwise the response to the digital service was good.

The child patients’ parents questionnaire was created with Google Forms and the parents gave good feedback on the questionnaire. Most of them answered to the questionnaire at the same time as their child answered to their own questionnaire. The questionnaire was said to be clear, fast easy to answer, and the parents did not have trouble with it during the study. Some questions were marked as compulsory and some were options. For example, the questionnaire before leaving home from the hospital had an optional open field to give feedback, and over 70% of the parents answered to it. Moreover, most of this feedback was positive.

The results of the usability evaluation of the digital service also indicate that the digital service was easy to use by both the research nurse and the child patients. The section 5.1 discusses the results in more detail, but overall the digital service was evaluated to be compliant with the Nielsen’s heuristics and its success ratio was as high as 86%, although not all child patients even had the chance to use the digital service for both of the questioning times.

Secondly, the ability reveal patient experiences for the case study was evaluated. If results to the case study were found with the digital service, it indicates that the digital service was able to measure patient experience in the case study context. The patient experience of the case study was researched from three different point of views, which were divided into three research questions. The results to these research questions are next discussed one by one.

The first research question was RQ1: How does the preoperative medical clown affect the patient experience of the child patients? The section 5.2 of this thesis present the results of the children’s questionnaires, which were obtained from children using the digital service on a tablet device. The results show that child patients, who visited the hospital on a day when a preoperative medical clown was present, experienced more positive emotions
after the operation compared to the child patients who visited the hospital on a reference day. Also, the increase in the amount of positive emotions was greater when the preoperational medical clown was present in the hospital. Moreover, child patients’ anxiety decreased more during the preoperational medical clown day than during the reference day, whereas pain during the cannula insertion was experienced quite the same. The best aspects of the hospital day were the medical clown, nurses, and food for the medical clown patient group, and for the reference group the best aspects were nurses, food, and games. Reference group had also a great amount of “Don’t know”-answers.

Since children’s patient experience has yet been researched quite little, there is not much literature about the emotional aspects of children’s patient experience. From the literature review, the only mention of children’s emotions during the hospital day that I found was when Karisalmi (2016) mentioned that children felt anxious, sad, and annoyed to go to the hospital, but felt happy and relieved afterwards. The results of this study are in accordance of these findings. However, studying the emotional aspects of patient experience in relation to medical clowns seems to be a new research subject. Thus, the finding that the children feel more positive emotions with the medical clown is a new finding.

The study results on the child patients’ anxiety with medical clowns are mostly in accordance with the previous studies conducted about anxiety and medical clowns. The findings of the studies by Dionigi and Gremigni (2016), Meiri et al. (2016), Vagnoli et al. (2010) and Wolyniez et al. (2013) all state that the presence of the medical clown during the hospital day decreased the child patient’s anxiety. This study found greater decrease in the children’s anxiety during the medical clown day compared to the reference day. On average, child patients on the medical clown day experienced more anxiety before the operation when they had not yet encountered the preoperative medical clown, but after the operation all groups experienced anxiety quite similarly, the medical clown induction group the least. Although the anxiety levels were quite the same for both patient groups, it still seems that the preoperative medical clown decreased the children’s anxiety and so had an effect to it. This effect is consistent with the earlier studies, although the two patient groups did not have great differences in the amount of their anxiety levels. In addition, many of the child patients’ parents stated that the preoperative medical clown decreased both their and their child’s anxiety before the operation. Contrasting to the earlier studies, this study found no difference on the observer rated anxiety measures by the operational nurse.
Conversely, this study found no difference in the child patients’ pain experienced during the cannula insertion between the medical clown group and the reference group. The pain was rated by the child patients themselves with the same five point emoji scale that anxiety was rated. The pain level was rated only after the whole operation just before leaving home. This could have affected the ratings, as children had to remember the cannula insertion from all other happenings from the day, such as the induction of anesthesia. Many also received Emla cream as local anesthesia to their hand before the cannula insertion, which could affect the pain experience. Earlier studies on the effect of the presence of a medical clown to the pain experience of children state that pain is better managed with a local anesthesia than with medical clown, but the medical clown might affect the pain scores of younger children (Meiri et al., 2017; Wolyniez et al., 2013). However, both studies stated that even though the medical clown affected the pain levels only little, the medical clown affected the anxiety levels of both children and parents, and thus the presence of the medical clown during procedures should be supported. The results of this study are support these findings.

The measure timings could have affected the results of this study, for example the anxiety levels. The anxiety was rated by the child patient only upon arrival to the hospital and just before leaving. Thus, the most critical timing, the time of the operation was not measured at all by the child, but by the operational nurse. The child patient’s anxiety could have been better monitored and analyzed if the child had rated their anxiety just before the operation. The pain was rated only once, just before leaving the hospital, and thus children had to remember the cannula insertion and the pain it caused from all other event of the day. It could be hard to rate the pain level if it was not memorized. In addition, the experience of pain and anxiety are highly subjective experiences and hard to evaluate objectively. Thus, comparing the ratings of different people can be seen problematic.

The findings of the best and worst aspects of the hospital day are quite similar than what has been revealed on earlier studies. For example, the studies by Karisalmi (2016), Pelander and Leino-Kilpi (2010) and Stenhammar (2017) found that people and especially nurses are one of the best things in hospital from the children’s point of view. In the study by Stenhammar (2017), medical clowns were also mentioned as a positive aspect of the hospital day. Similar to this study, food was also mentioned as one of the best aspects of the hospital stay in the studies by Coyne (2006), Curtis et al. (2004) and Stenhammar (2017). However, it was found to be one of the worst aspects too, when it related to eating restrictions before the operation or diets in
CHAPTER 6. DISCUSSION

a long run (Karisalmi, 2016; Pelander and Leino-Kilpi, 2010; Stenhammar, 2017). During this study, many children were restricted from eating before the operation, but were given ice cream and juice after the operation. Some children expressed feeling hungry before the operation and some parents gave feedback about the long waiting times and how it increased hunger. In comparison, in the earlier studies the food usually refers to proper meals offered by the hospital. The worst aspects of the hospital stay are also consistent to the earlier study findings, as waiting and pain are also mentioned in the findings of Pelander and Leino-Kilpi (2010) and Stenhammar (2017). All in all, the best and worst aspects seem to be pretty similar compared to the earlier studies.

The amount of medical clown as the best aspect of the hospital day stands out from the results of this study, as over 50% of the medial clown day’s children selected it to be the best aspect of the hospital day. Other best aspects are quite equal between the two study groups and earlier studies. The worst aspects are also quite similar between the two groups and the earlier studies. However, the reference day had almost 20% of "Don’t know" answers on both aspects, which could suggest that they are quite indifferent about the events of the day.

The age difference between the two study groups could affect the results of this study. The mean age of the medical clown group was two years younger compared to the reference group. Thus, the two groups could experience anxiety and pain differently, and also interpret emotions differently. However, the patients were randomly assigned to the study groups based on the day they arrived to the hospital. All children aged 4 to 17 who gave consent to participate in the study were included. Only five children refused to participate to the study. Thus, the samples of the study represent the HUS Day Surgery Unit’s patients well. Also, the medical clowns can have a good contact with children regardless of their age, and thus the age is not a restrictive attribute.

Child patients and their families willingly participated to this study for various reasons. Firstly, this could be due to positive expectations towards medical clowning, possibly resulting from favourable media coverage in Finland (see, e.g. Laakso (2017)). Secondly, many parents considered the research subject important. Some even expressed the importance in their answers, stating that "it is good that this subject is studied and children’s stay in the hospital is enhanced". Thirdly, the participation did not require any significant effort, as the questionnaires were easy and fast to respond during the
hospital stay. This was also emphasized when the study was introduced to
the families. Finally, many families participated to the study, even if they
had not met with a medical clown before or it was the reference day. All in
all, 98 families participated to the study and only 5 refused.

During this study, six different medical clown professionals worked during
the study in the Day Surgery Unit. The medical clown professionals rotated
between the days, but for each day only one medical clown was present. The
changes between the days could affect the outcomes but probably not very
much. This is because the personality of the clowns are anyways different,
but still they encounter the child and families in a really sensitive and ex-
clusive way. Each encounter is individual and exclusive, even if the child
and medical clown are the same. The medical clowns adapt their energy
levels and methods to each child respectively, and thus the encounter is more
child centered than clown centered. Of course the personalities affect the
encounter in some ways, but the core, the regard of the child patient’s needs
and wishes, remain the same regardless of the medical clown.

The second research question was RQ2: How does the preoperative med-
ical clown affect the patient experience of the child patients’ parents? The
section 5.3 covers the results in more detail. Most of the parents stated that
the medical clown decreased both the child patient and the parent’s anxiety.
Over 70% of the parents described that their child to seemed anxious before
the operation. They also reported that the medical clown distracted them
from thinking about the operation, and gave something else to think about
before the operation. The long waiting times were criticized, as they could
be as long as three hours. Overall the parents were really pleased and thank-
ful for the treatment they get from the HUS Children’s hospital. Moreover,
many thanked the highly skilled healthcare professionals at the hospital, the
nurses, the doctors and also the medical clowns. Thus, it can be stated that
the medical clown had a positive effect on the parent’s patient experience.

The parents viewpoint on the medical clowns presence have not yet been
widely researched, but some studies have been conducted. For example,
Wolyniez et al. (2013) found out that the presence of the medical clown in
a procedure helped with parental anxiety for children younger than 7 years.
Contrasting, Vagnoli et al. (2010) found no differences for the parents’ anxi-
ety when they compared the operations with parents, parents and medication
and parents and a medical clown. Tener et al. (2016) interviewed child pa-
tients and parents to study the interactions and effects that a medical clown
has with the family. They found out that the presence of a medical clown has
a central, meaningful and a therapeutic effect to the child parents’ narratives. Also, the children viewed the hospital to be a more positive place once they met the medical clown, a place where the clown exists, and in many cases the families brought the clown character home and to other difficult situations for support (Tener et al., 2016).

The findings of this study from the parents’ point of view are quite in accordance with these earlier studies, as many parents in this study reported that the medical clown decreases both their and their child’s anxiety. Also, some parents in this study predicted that the family will remember the medical clown for a long time after the hospital visit and I heard a couple of times when the child patients said "I want to come here again tomorrow to see the medical clown!" Parents in this study also described feeling reassuring and liberating to laugh with the medical clown in a context like the hospital. Moreover, some parents in the reference group wished to have met the medical clown as they thought that that way the long waiting times would have gone faster. All in all, it could be stated the findings support the presence of the medical clown, and a positive effect to the patient experience also from the parent’s point of view.

The little criticism that patient families gave through the questionnaire’s open feedback option was mostly about the long waiting times or requirement to leave some personal items to the lockers in the hall. Only few gave feedback that parents were not informed well about schedule changes, but on the other hand most stated that they were well informed. Only one parent gave negative feedback on the operating doctors, as the parent felt that the child’s fear was not taken into account during the anesthesia induction. The same parent stated that all went well with the medical clown. Otherwise, parents gave mostly positive feedback on themes like the healthcare professionals, communication, operation, the study and the overall on the hospital day.

Although most of the research findings of this study are consistent with earlier studies, this study is the first study in Finland about how preoperative medical clowns affect patient experience. The patient experience is defined in this study to include all interaction that influence the patient perceptions, and thus many different aspects like emotion, anxiety and best and worst aspects were studied. All these aspects give insight on the interactions and perceptions that the child patients and their parents had during the hospital day, and thus reinforces their patient experience.
The third research question of this study was RQ3: How does the presence of the preoperative medical clown affect the cannula insertion procedure from the nurse’s point of view? The results are presented in more detail in section 5.4. The studied aspects were the fluency and timing of the cannula insertion procedure and the anxiety of the child patient. The results had no differences between the two patient groups, and thus the preoperational medical clown had no effect on the cannula insertion from the nurse’s point of view.

This point of view actually studied how the presence of the medical clown affect the cannula insertion procedure, and not how nurses experience the medical clown’s presence and how it affects their experiences. The viewpoint on the procedure is actually more of an objective one, although the reporter is an operational nurse from the procedure, than the point of view of the nurse’s experiences. Although these findings are neutral about the presence of the medical clown to the procedure, it could still affect the experiences of the nurses and through them also the patient experience. Moreover, the neutral result implies that the presence on the medical clown during the cannula insertion does not prolong the procedure and thus use extra resources.

As discussed earlier in this section, earlier studies about the effect of the preoperational medical clown to the child patient’s anxiety has been studied before, and these earlier studies have found the preoperative medical clown decreasing the anxiety for both children and parents (Dionigi and Gremigni, 2016; Meiri et al., 2016; Vagnoli et al., 2010; Wolyniez et al., 2013). Contrasting to these earlier studies, this study found no differences in the child patient’s anxiety during the operation, from the nurse’s point of view. However, the operational nurse rated the anxiety only just after the operation, and not at the present time of the anxiety. Also, the operational nurse had not met with the child patient before the operation, and thus the evaluation could be different from the child patient’s own evaluation.

The fluency of the cannula insertion as a measure is quite hard to evaluate. The operational nurse did not operate in the procedure, but registered information to computer systems and viewed the procedure from aside. Thus, the operational nurse was a good assessor but the fluency as a measure could be hard to evaluate. For example, the one case discussed earlier where the parent felt that the operating doctors did not take the child patient’s fear into account during the anesthesia induction, was rated "pretty good" by the operational nurse. Also, there are many cases when the operating nurses and doctors ask for the preoperative medical clown to participate to a can-
nula insertion, because they know that the patient fears it or the situation might be difficult for some other reason. These situations, and the efficiency of the cannula insertion, might still be difficult with the medical clown, but anyways it would be better than without. The only way to measure the real difference in these kind of situations would be when the same patient would go through the same operation with and without the medical clown and then compare the experiences. However, the earlier experiences would then affect the later experiences and even this comparison would be difficult. Thus, the evaluation of the efficiency of the cannula insertion from the nurse’s point of view was difficult for many reasons, and thus the results might not reveal any differences between the two groups. All in all, it is really complex to measure and compare the efficiency of the cannula insertion procedure.

Although the nurse’ evaluated mostly the cannula insertion procedure in this study, some of them also gave me verbal feedback on the medical clowns. They expressed how the medical clowns bring joy to their work, and also help with the communications with the patient families. The nurse might join the play and jokes that the medical clown and the families have. Also, as the nurses have more administrative work at the hospital compared to the medical clowns, and thus they have less time to be with the patients. The medical clown on the other hand can spend as much time with the patients as they see helpful. Then, the medical clown can inform the nurses about different aspects they have found out during their time together with the patient, and the nurses can then use this information in their work. For example, I witnessed a case when the medical clown informed the nurses that the patient had had a bad previous experience about the cannula insertion, which the nurses did not know about, but that the patient and the medical clown had a good play about dinosaurs, and they could use this theme during the cannula insertion and for example the child patient wanted to order a dinosaur dream for the anesthesia. All this information, communication and common ideas for relieving the upcoming procedure would not had happened without the preoperative medical clown.

Most of the earlier medical clown studies are from the child patients or parents’ point of view, and the nurses’ experiences have not been studied as widely. In the study by Tener et al. (2016), 95% of the nurses evaluated the intervention of a medical clown to be moderately to extremely useful. Contrasting, in the study by Vagnoli et al. (2005), nurses reported the medical clown to be disruptive to the preoperative procedure. The verbal feedback of this study supports the findings by Tener et al. (2016), and the results and verbal feedback are opposite to the results of Vagnoli et al. (2005). How-
ever, the study of Vagnoli et al. (2005) was conducted over 10 years ago, and the familiarity, use and performance of the medical clowns might have changed during these years. The feedback the nurses gave during this study support the positive effects the medical clown have for the other healthcare professionals, but it should be further studied.

6.2 Remarks on the study

The selected research instrument of this study was digital questionnaires for all participants, child patients, parents and nurses. This selection was not obvious, and different options were considered at the beginning, during the discover and define phase of the double diamond model. However, after the literature review, familiarization of the hospital context and the research problem, the use of a questionnaire was evaluated to be the best suited for this study. Reasoning behind this selection was for example the busy research context at the HUS Day Surgery Unit, the multiple research subject at the same room at the same time, the requirement for the research method to be similar between two groups who have different experiences and the possibility to create different versions for differently aged children.

Other research instruments could have been used, especially with children, but by selecting a questionnaire the author of this thesis wanted to make sure that the child patients have enough time with the preoperative medical clowns and not spend most of the time with the research instrument. This way the preoperative medical clown could have a proper encounter with the families, and affect the patient experience to the maximum. Still, even with this quick questionnaire method, the preoperative medical clowns were sometimes required to step aside during the research introduction and response times. They commented that it felt little confusing to step aside and almost stop the encounter, but understood that it was a requirement for the study, which they still supported. Also, the research nurse and the preoperative medical clowns communicated very well together and arranged the research times and encounters better as the study went on. There were no such research time arrangement difficulties during the reference day.

Questionnaires have been used before in studying children in the hospital context, and the related matters are discussed already in the section 2.3.3. As in this study, researchers must be careful when designing questionnaires. This study emphasized the use of visuals in the child patients’ questionnaire.
Text was also used to complement the visuals, and the words were carefully selected to be as short, descriptive and clear as possible. This way, even the youngest children who just learned to read could respond to the questions by themselves. Also some questions used a verbal Lickert type of scales, which have been found to be most suitable response type for children aged 6-13 (Laerhoven et al., 2004; Mellor and Moore, 2014). Other questions used predefined answer options, which were carefully selected and iterated before the final selection. For the best and worst aspect questions, answers like "I don’t know" and "Something else" were also offered, so that it was possible to state that the predetermined answers did not offer the correct answer.

The representation of the emotions and in addition to the interpretation of emotions could affect the results of this study. Although the images were big and empathized it could be argued if they could be interpreted similarly by every child patient. This is why also text was included alongside, to define the emotion more accurately. Also, the emotions categorizations by Plutchik (2001) and Russell (1980) combined with the study nurse’s expertise were used in the emotion selection. Emotions from all over the emotion spectrum, which were close to primary emotions and those that the children might experience in the hospital, were selected. Yet, all emotions were required to be distinct from each other and the number of options was limited. Still, children’s interpretation of the emotions and images might affect their selections, especially with younger children who could not read yet. However, the categorization of the emotions to positive, neutral and negative decreased the need to understand the emotions precisely. The findings of this study on the emotional aspects support that children as young as 4 can answer emotional aspects related to their experiences, as long as supportive emoji are used.

For the anxiety and pain questions, instead of the original faces pain or anxiety scales by Hicks et al. (2001) or Kuttner and LePage (1989) a modified faces pain scale was used. This new version of the faces included emoji faces from happy to sad, as the emoji was seen as an updated version of the faces to this date, when emoji are used on a regular basis. Figure of the scale can be found from Appendix B in Figure B.5. The anxiety and pain rating scale used was also a representation of the existing anxiety and pain measures, but they were not identical. For example, the scale had two positives, two negatives and a neutral option, whereas the faces pain and anxiety scales had scale from neutral to four or five negative options. The amount of more negative options gives more room for measuring the extent of anxiety than just two options. Also, other anxiety rating scales could have been used, like mYPAS, which was used in the study by Dionigi and Gremigni (2016), but it was evaluated
to take too much time in this study’s context. In addition to mYPAS, there are already reviewed anxiety measures for measuring children’s anxiety in the hospital context, but these measures are usually rating that have more than 10 questions or aspects, and thus they take time to answer. This study did not have such resources that those aspects could have been evaluated, and thus a simpler measure was required.

Also, there is a difference if the anxiety and pain is rated by the research subject or some observer, like a nurse. For example, the earlier studies by Dionigi and Gremigni (2016), Meiri et al. (2016) and Vagnoli et al. (2010) used observer based ratings, where someone else than the child rates the child patient’s anxiety. These studies used mYPAS or asked the parents to rate the anxiety, and mYPAS was evaluated to be too time consuming to be used in this study. All of these studies found that the presence of the medical clown during the hospital day decreased the child patient’s anxiety. On the other hand, Wołyniez et al. (2013) used Faces pain scale with 4-7 year old’s and a visual analogical scale with older children. They also found the presence of a medical clown decreasing the child patients anxiety. This study was a mixture of these methods, as both self-reported anxiety measures and observer based ratings were used. All children rated their anxiety with a modified faces anxiety scale but also the operational nurse rated the child patient’s anxiety during the operation. This study found greater decrease in the children’s anxiety during the medical clown day compared to the reference day.

Surprisingly to the easy and fast answering and good feedback in the hospital, only 15 of the parents answered to the questionnaire at home a few days after the hospital stay. The parents were given a paper with instructions and a link to the questionnaire on a paper when they left the hospital, but no reminders were send to them. The link was also made a really short and descriptive, so that the parents would not have trouble entering it to the browser. The low number of respondents could be due to forgetting about the hospital day and research when starting the busy everyday lives of child families, or that the paper went missing or was forgotten in a bag or pocket. Also, the parents might have forgotten about the study for few days and then thought that it was too late to answer to the questionnaire a week later, and then did not respond to it at all. The great participant percentage of those who were asked to participate to the study and the low response rate on the home questionnaire support the local and timely measurement of patient experience.
Contrasting to the child patients and parents results, the nurses’ data did not reveal any differences between the two patient groups. This could be because of couple of reasons. Firstly, the results could be so that the two groups had no differences at the operation time, when the nurse evaluated it. At this point, the child patients and the parents were to asked to rate their anxiety or emotions, and they answered only when arriving to the hospital and when leaving home. Secondly, the nurse’s point of view might be different from those of the parents and child patients. The nurses might look at the cannula insertions and children’s anxiety from a professional view point, whereas the child patient and the parents’ look from their own subjective point of view. Thus, for example the anxiety measures might be different, as parents and the child might say that their anxiety is the greatest they have experienced, but the nurse might have seen even more anxious persons during their career, and thus evaluate the anxiety lesser. Thirdly, the nurses’ research questions and measures might not have been suitable for the occasion. For example, the questions might have been too wide, or the measures too narrow. However, the operational nurse did not give feedback on this and still the answers focused on only few of the answer options.

To conclude, the research method, the digital service and digital questionnaires, were seen as a suitable research method from the participants and the nurses point of view. The data obtained from the method was also easily analyzable, as it was already in a digital format and could be converted to excel format, where analysis was made. Also, the research method found differences from the experiences of the two patient groups. Thus, it could be stated that a well designed and visual digital questionnaire could be used to study children’s patient experience.

6.3 Validity of the study

This study used a specific research approach, a double diamond model, throughout the research. This approach was used systematically, with many iteration round for each phase of the model. Also, experts of different fields, such as nurses and medical clowns, were consulted and included in the study design throughout the study. The iteration rounds were done to for things like the selected emotions, the study process at the hospital and parents questions. After each iteration, feedback was gathered from the experts of the field.
The research was designed mostly by the author of this thesis based on the service design double diamond model, but others were included in different parts of the research. For example, during the discovery, define and designing of the digital service, the advisers of this thesis and other researcher of the LAPSUS research project provided support for the theoretical background as they have researched patient experience before. One of them also participated to the observations and interviews conducted in the hospital. Also, the research nurse conducted the research in the hospital for most of the days as she could work as a nurse alongside to the research. I participated to the research for the pilot days and two other days. Moreover, the medical clowns helped me to understand their work and principles, and provided me with really good and deep insight to medical clowning.

The patient experience, hospital context and medical clowning were all new topics to me when I started this research, but with the help of these experts I became fully involved and fascinated about these topics. This newness of the topics could be seen as both good and bad thing regarding the research. For example, I did not have any assumptions about the medical clown work or the hospital in general. I started the research with the literature review and observations, and thus I could question everything and report anything I saw. Afterwards I interviewed the professionals, but only after I had had my first impressions of the topics. On the other hand, having no prior knowledge on these topics could affect my interpretation and assumptions I made along the way.

However, I was not heavily involved during the research was conducted in the hospital, as the research nurse was the one asking families to participate and managing the tablets to the respondents. I on the other hand received the results and once the research was finished at the hospital, conducted the analysis. This separation of the research and analysis can help with me not having presumptions about the specific responses and conducting the analysis just based on the data.

The research nurse was also working as a nurse during the research, so the participated families connected the research nurse and the study easily to the hospital. When I was conducting the research for the few days in the hospital or observing the medical clowns, I was wearing my own casual clothes with a name tag stating that I was a researcher. The families did not question my presence or wonder what I was doing, but it was still different for me to approach the families as I had not done it before, compared to the research nurse who had made it as her work for years. The research nurse worked
fluently in the hospital context and could help the patient families with other matters too besides the research.

Before the research was launched in the hospital, two pilot days were conducted in the hospital to ensure a clear and functioning research process at the hospital. One of the pilot days was with a preoperative medical clown and the other one was without one. Also the usability and applicability of the digital service and other questionnaires were evaluated during these pilot days. The digital service was further evaluated by the research nurse before the pilot days and she also gave feedback during the digital service design and implementation. This way, it was made sure that the research instrument would be appropriate for the research.

As discussed earlier in this thesis, studying children differs from studying adults. Thus, special aspects are required to be taken into account when researching children. The extent to which these aspects are considered could affect the validity of this study. As stated above, the research nurse was the one who mostly met with the child patients and their parents during the research. She has worked with children in the hospital context for many years, and thus she was excellent with them and their parents. One of the reasons for such a high participant percentage could be how the research nurse introduced the research to the families. Also, she was advised to give children room for the responding to the questions, which she did. Anyway she was close enough to give advise and instruction if anyone needed them. This helped to balance the power differences that children and adults have during the research. Children’s special competences were also taken into account during the design of the research and the digital service. This could be seen from the use of visuals in the questionnaires and the different versions that were designed for the different ages. Children’s vulnerability was also considered as the research and the data was anonymous. The child patient’s age and sex was collected, but these were kept separate from the result data, which was analyzed completely anonymous. Thus, some aspects regarding the research of children were considered in this research, but the sufficiency could be further argued.

The research context was quite specific in this research, as it was only one unit at the HUS Children’s Hospital. However, I argue that the results concerning the context could be generalized also elsewhere, for places where children undergo medical examinations or treatments with a cannula insertion and where a preoperative medical clown would have sufficient encounter times with the patients. As stated in this thesis, the research was almost
conducted in two different units, but the other one was excluded because its patients had such different patient journeys and diverse patient groups. Nonetheless, the research and results could be applicable in that unit too, for each of the patient groups respectively. In addition, this study had quite good sample size, over 30 patients in both the preoperational medical clown and the reference groups. Both groups were randomly constructed, and the few restrictions were their age, the ability speak Finnish and the insertion of the cannula. Thus, I argue that this study could be applicable to other situations too, where medical clown could attend the insertion of a cannula for child patients aged 4 to 17.

The digital service on the other hand was created specifically for this research context. The questions and answer options were carefully selected for the occasion, and they were only in Finnish. Thus, the digital service could not be generalized as such. However, the study results suggest that the digital service, a kind of a visual questionnaire on a tablet device, can uncover the patient experiences of child patients aged 4 to 17. Thus, if the questions and answer options would be modified, the research method could be generalized to suit other situations too.

In addition, as both the child patients questionnaire and the parents’ questionnaire were regarded as an easy and reliable way to get feedback and viewpoints of the persons from the hospital stay, a questionnaire on a tablet device could further be used as a research method to study patient experience in other hospital units too.

6.4 Recommendations and future work

The objectives of this study were to design and develop a digital service for measuring children’s patient experience, and then to study the applicability of that service in a case study. Service design approach, tools and methods were used during the design and development of the digital service. The case study researched the effects of preoperative medical clowns to patient experience. These objectives relate to many fields, such as service design, measuring patient experience, children’s patient and preoperative medical clowning. Also, this study was the first ever study in Finland to study the effects of preoperative medical clowning to patient experience. Thus, this thesis provides a good basis for multiple recommendations and future work ideas for the future.
The first recommendation would be to use digital services in measuring patient experiences more extensively than what is done currently. This study indicates that children as young as four are able to respond to digital questionnaires concerning their experiences at the hospital, when the questionnaire is created in a child-friendly way. Moreover, children are the experts of their own experiences, and they should be included in matters related to them. Also, based on this study, child patients were familiar with using the tablet device and emoji representing different aspects of the hospital day and results were obtained from the use of the digital service.

Second recommendation would be to support the patients’ feedback process of the hospital day already in the hospital in a timely manner. This way the patients, let it be the children or adults, can tell about their prevailing experiences at the time, rather than remembering it later. The low participant percentage for the home questionnaire of this study implies that even if the questionnaire and feedback process would be easy at home, people do not remember or bother to answer it. Also, people’s descriptions of their experiences differ regarding if they are asked in a timely manner or days after the experience. Moreover, this study supports the feedback collection even before the treatment or operation at the hospital. In this study both child patients and their parents responded to questionnaires before the child patient’s treatment, and these responses revealed expectations and current emotions towards the procedure. By these timed interventions, the current emotions and experiences could be studied in more detail. This way, the more detailed experience of the hospital day could be monitored, and then improved based on the findings. It might be easier to improve the experience based on more detailed descriptions rather than an overall score of the hospital day. In addition, collecting the feedback in a digital format would enable simultaneous analysis, or analysis after each day, rather than getting feedback with days, weeks or even months delay.

Third recommendation would be to support the preoperative medical clowns work at children’s hospitals more extensively. Currently, the preoperative medical clowns work in one or two units at the HUS Children’s hospital for few days a week. For this study, the medical clowns received a grant from the Finnish Ministry of Education and Culture, which enabled such an extensive research and activity of the preoperational medical clowns for the study period. Otherwise, the Finnish medical clowns work is enabled by different subsidies, donations and membership fees (Sairaalaklovnit, 2018). I recommend that the medical clowns work should be supported more, so that more child patients and their families can have a preoperative medical
clown present during their hospital day. As was discovered in this thesis, the presence of a preoperative medical clown would improve their patient experience. This recommendation applies to HUS Children’s Hospital but also to other pediatric hospitals in Finland, and also globally.

Another recommendation, related to the third recommendation, is to help new units in introducing and applying preoperative medical clowning. During the study period, the medical clowns and other healthcare professionals worked really well together. This was probably because they had already worked together in the unit, and everybody was familiar with the routines. However, some medical clowns and nurses revealed that the start of the collaboration had some difficulties for different reasons. For example, the roles and responsibilities were unclear between the professionals. Also, some nurses admitted on having some bias for the medical clowns before they witnessed them working and proved them wrong. To help solve these difficulties, I recommend that the unit which would like to start applying preoperative medical clowning could observe and familiarize themselves with the work of the preoperative medical clowns in some a unit, where the preoperative medical clowning is already applied. Then, the whole unit and the preoperative medical clowns could agree upon their plans and routines for the new unit. Open communication and feedback for every direction would be really important in these situations. Of course, this clarification of roles and responsibilities would be good to review for the units where preoperative medical clowning is already applied too.

As this is the first study about preoperative medical clowning in relation to patient experience, both of the subjects have been understudied so far. Thus, I recommend more research about both themes, and also about their relations.

One future work subject would be to further study the use of digital services for children in hospitals. As the findings of this study reveal, children as young as 4 were able to answer digital questionnaires on a tablet device, once child-friendly and clear visuals and emoji are used. The digital service and questionnaire could be studied and improved further, based on the usability evaluation results obtained in section 5.1. Once the digital service would be further improved, it could be used more extensively in pediatric hospitals to enable children to express their experiences in a systematic way. Moreover, more study about other research methods about measuring children’s patient experience should be conducted.
Moreover, children’s patient experience should be further studied. Traditionally, children’s patient experience has been studied through their parents. However, children and their parents’ experiences differ from each other and thus the real experts of children’s experiences should be heard; the children themselves. This study and other research conducted in the LAPSUS research project indicate that children are able to express their own experiences once a child-friendly methods are used. This study also indicates that children are able to use digital service with a digital questionnaire independently to answer to questions related to their experiences. The research conducted in the LAPSUS research project about children’s patient experience and different measurement tools provide a good basis for the such future research.

Additionally, preoperative medical clowning could be further studied in many ways. For example, as this study applied a quantitative method, a more qualitative study should be conducted to obtain the more deeper and detailed understanding of the phenomena. In-depth interview with child patients, their parents and nurses could be conducted now that this study revealed some insight on their experiences of the preoperative medical clowning that could be used in designing the interview. Child patients who have been in the hospital and gone to a treatment or operation both with and without a medical clown, could be interview about the differences of these experiences.

This study concentrated only to the patient experience of one hospital day and treatment, but some families told that they still regularly remember the earlier encounters and experiences with a medical clown. Thus, this longer lasting effect of the medical clowns should be further studied. In this regard, also expectations of the future hospital stays could be studied, comparing the expectations of patients who have experiences with a preoperative medical clown and patients who do not. Also, the information about the presence of the medical clown during the upcoming hospital day might affect these expectations and experiences. During this study, I heard one parents to state that they decided to come to the hospital on the specific day because they knew that the medical clown would then be present.

This study regarded the nurses’ experiences of the preoperative medical clown only from the cannula insertion procedures point of view. Their own experiences were only little discussed verbally, but this part was not included in the study as is. Thus, the nurses’ own experiences of the preoperative medical clowning should be further studied. These experiences are important for both the nurses but also to medical clowns, as these two groups work in close
collaboration and coworkers in the hospital. The nurses’ experiences could reveal insight to their employee engagement, which in turn affect the patient experience, as pointed out by Wolf (2017a). In addition to the nurses’ experiences, doctors’ and other healthcare professionals’ experiences could be studied.
Chapter 7

Conclusions

This thesis was part of the LAPSUS research project, which was funded by Business Finland and was closely related to the design of the New Children’s Hospital. The objectives of the research project were describing the dimensions of patient experience from the perspectives of pediatric patients and their families, developing methodology and instrumentation for monitoring patient experience and value creation, and linking patient experience data to continuous improvement.

This thesis studied how digital services could measure patient experiences. Because children require special considerations when their patient experience is explored, a special digital service was designed and developed for the purpose. For examining the child patient’s parents patient experience, a more traditional digital questionnaires were used. Also nurses answered to a digital questionnaire. To evaluate the applicability of the digital service for measuring patient experience, it was evaluated from two point of views; usability and the ability to reveal patient experiences for the case study. The case study was conducted in the Day Surgery Unit in HUS Children’s Hospital for six weeks period during May and June 2018. The case study examined the effects of preoperative medical clowns to patient experience.

The usability of the designed and developed digital service was evaluated with user testing, heuristic evaluation and a success ratio calculation. The results for the evaluation indicate that the digital service was easy to use in the study context, and it could be used more in the future to examine children’s patient experiences. The second evaluation aspect of the digital service is answered through the following research questions:
CHAPTER 7. CONCLUSIONS

The first research question was RQ1: How does the preoperative medical clown affect the patient experience of the child patients? The results for this research question reveal that the preoperative medical clowns positively affects children’s patient experience during a hospital stay, when the child patients undergo an operation or treatment which includes a cannula insertion. The results show that child patients, who visited the hospital on a day when a preoperative medical clown was present, experienced more positive emotions after the operation and a greater decrease in anxiety compared to the child patients who visited the hospital on a reference day. In addition, majority of the child patients of the medical clown patient group stated that the medical clown was the best aspect of the hospital day.

The second research question was RQ2: How does the preoperative medical clown affect the patient experience of the child patients’ parents? The findings of this research state that the preoperative medical clowns have a positive effect on the child patient’s parents’ patient experience. The child patient’s parents reported that the medical clown decreased both their own and their child’s anxiety, in addition to distracting them from thinking about the operation, and giving something else to think about before the operation. Moreover, many thanked the highly skilled healthcare professionals at the hospital, the nurses, the doctors and also the medical clowns.

The third research question of this study was RQ3: How does the presence of the preoperative medical clown affect the cannula insertion procedure from the nurse’s point of view? This study did not find differences between the two patient groups, and the fluency, timing or the anxiety of the child patients during a cannula insertion from the nurses’ point of view. Thus, based on this study, the presence of the preoperative medical clown had no effect to the cannula insertion procedure.

Based on the findings of this study, digital services can be used to measure patient experiences in hospital in many ways. Children as young as 4 are able to provide insights on their patient experience, if child-friendly instruments are used. The designed and developed digital service with emoji was evaluated to be easy and fun to use. Also, it was evaluated to be applicable to study the patient experience in the case study, where the effects of preoperative medical clowns to patient experience were studied. The results of the case study revealed that preoperative medical clowns affect the patient experience of child patients and their parents in a positive way. This study did not show differences in the cannula insertion procedure from the nurses point, when the preoperative medical clown was present or not.
To conclude, digital services should be supported more in measuring patient experiences in hospital. By using digital services created for children, even children as young as 4 can provide insight on their patient experience. Also as the case study revealed, preoperative medical clowns have a rally positive effect to child patients and their parents’ patient experience. Thus the work of preoperative medical clowns, and the use of digital services for measuring patient experiences should be supported more in children’s hospitals.
References


REFERENCES


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Appendix A

Research documents

This Appendix A presents the research documents that were given to the research participants. Every participant received the research release presented in figure A.1. Each of the participant’s guardian was asked to read and sign the guardian’s consent form presented in figure A.2. For each child, their age-appropriate consent form was given and signed. The consent forms are presented respectively; consent form for children aged 4 to 10 in figure A.3, for children aged 11 to 14 in figure A.4 and for children aged 15 to 17 in figure A.5.
Tutkimustiedote

Toimenpideklovnerian vaikuttavuus potilaskokemukseen ja henkilökunnan työhön lastensairaalassa

Aalto-yliopisto, HYKS Lastenklinikka, Tampereen Teknillinen Yliopisto sekä Turun ja Oulun yliopistolliset sairaalat ovat käynnistäneet tutkimuksen, jonka tavoitteena on ottaa mahdollisimman hyvin huomioon potilaiden kokemukset uusien lastensairaalojen ja -osastojen toimintaa suunniteltaessa ja kehitettäessä. Tutkimuksen nimi on LAPSUS: Lapsiperheiden uudistuva sairaala – potilaskokemus palvelupolkujen arvon kehittäjänä. LAPSUS-tutkimukseen liittyen pyydämme sinua ja perhettäsi osallistumaan tähän tutkimukseen, jossa tarkoituksena on tutkia sairaalaklovnien läsnäolon merkitystä ja vaikutusta potilaskokemukseen lastensairaaloihin ja laiton yhteydessä.

Mistä tutkimuksessa on kysymys

Potilaat tutkitaan kahdesta ryhmästä. Toinen ryhmä tapaa sairaalaklovnin sairaalapäivän aikana ja toinen ryhmä ei. Tutkimuksessa verrataan näiden kahden ryhmän potilaskokemuksia.

Tutkimus tehdään

1. Pyytämällä vanhempia/huoltajia vastaamaan kyselyihin ennen ja jälkeen toimenpiteen
2. Pyytämällä lapsipotilaita käyttämään kokemusmittaria ennen ja jälkeen toimenpiteen
3. Keräämällä tietoa lapsiperheiden näkökulmasta sairaalapalveluiden käytön sujuvudesta
4. Keräämällä tietoa hoitohenkilökunnan näkökulmasta laskimokanyylin laiton sujuvudesta

Tutkimuksen kohteena ovat lapset, jotka tulevat suunniteltusti HYKS Lastenklinikalle toimenpiteeseen tai tutkimukseen, johon liittyy laskimokanyylin laitto. Tutkimus keskittyy lapsipotilaisten sekä vanhempien kokemuksiin. Tutkimukseen pyritään saamaan mukaan 100 perheettä.

Tutkimuksen toteutus

Tutkimus toteutetaan tutkijoiden ohjauksessa yhteistyössä hoitohenkilökunnan ja lasten vanhempien/huoltajien kanssa.

Lapsipotilaan vanhemmille/huoltajielle suunnattuun kyselyyn pyritään keräämään esitetöijä mm. lapsen aikaisempiin sairaalakokemukseihin liittyen sekä tietoa vanhempien odotuksista ja tunteista toimenpiteeseen liittyen. Kyselyt toteutetaan sähköisenä kyselynä ja niitä tehdään sairaalakäynnin aikana ja kotona. Kyselyt voidaan tehdä vanhemmalle/huoltajalle sopivassa paikassa ja sopivana aikana, kuitenkin ennen toimenpiteeseen tuloa ja pari päivää toimenpiteen jälkeen.

Lapsipotilaalle suunnattu kokemusmittariin pyritään keräämään tietoa lapsen odotuksista ja kokemukseista toimenpiteeseen liittyen. Mittauksia tehdään ennen laskimokanyylin asettamista ja sen jälkeen. Mittaukset toteutetaan digitaalisen mittarin avulla, jota voidaan käyttää puhelimella, tabletillalla tai tietokoneella.
Tutkimukseen osallistuminen
Osallistuminen on vapaaehtoinen ja perustuu potilaiden ja heidän vanhempiensa halukkuuteen kertoa omista kokemuksistaan. Lasten osallistuminen perustuu aina heidän ja vanhempien kirjalliseen suostumukseen.

Tutkimus toteutetaan aikavälillä 1.5.-30.6.2018

Tutkimuksen luottamuksellisuus
Tutkimuksessa koottu aineisto tallennetaan tulosten analysointia varten tutkimustietokantaan, joka on vain tutkimukseen osallistuvien tutkijoiden käytössä. Aineistoa käsitellään luottamuksellisesti. Tutkimustuloksia ei voida yhdistää osallistujien eli ne eivät sisällä mitään henkilö- tai tunnistetietoja.

Lisätietoja tutkimuksesta
Lapsus-tutkimushankkeen vastuuohja ovat HYKS Lastenklinikka ja Aalto-yliopisto

Lista yhteystiedoista

Figure A.1: The research release
Alaikäisten (alle 18-v.) lasten huoltajien suostumusasiakirja potilaskokemustutkimukseen

Olen saanut tätä tutkimusta koskevan tiedotteen ja suullista tietoa tästä tutkimuksesta ja ymmärtänyt tutkimusta koskevan tiedon. Minulla on ollut riittävästi aikaa harkita lasteni osallistumista tutkimukseen.

Tiedot antoi ___________________________. Olen saanut myös esittää hänen kysymyksiä tutkimuksesta. Myös lapselleni on kerrottu tästä tutkimuksesta, ja hänen myönteinen mielipiteensä on selvitetty siten, kuin se hänen kehitystasonsa huomioiden on ollut mahdollista.


Ymmärrän, että lapseni osallistumisen tähän tutkimukseen on vapaaehtoista ja voin perua tämän suostumuksen, ja keskeyttää hänen osallistumisensa milloin tahansa ennen tutkimuksen päättymistä. Olen tietoinen myös siitä, että keskeyttämiseen mennessä kerättyjä tietoja käytetään osana tutkimusaineistoa. Tutkimuksen keskeyttäminen ei kuitenkaan vaikuta millään tavoin lapseni mahdollisesti tarvitsemaan hoitoon. Olen keskustellut tutkimuksesta lapseni kanssa ja kuullut heidän myönteisen mielipiteensä osallistumisesta.

Annan suostumukseni siihen, että lapseni osallistuvat tähän tutkimukseen;

Lapsen nimi, syntymäaika, osoite:
___________________________________________________________________________________________________
___________________________________________________________________________________________________
___________________________________________________________________________________________________

_________________________________________________
Huoltajan allekirjoitus

Nimen selvennys   Päiväys

Olen kertonut tästä tutkimuksesta tutkimustiedotteent mukaisesti sekä lapselle että hänen huoltajilleen (huoltajalle) ja otan vastaan tämän suostumuksen;

Tutkijan allekirjoitus   Paikka ja päiväys

Nimen selvennys

Tätä suostumusasiakirjaa on tehty kaksi kappaleetta, joista toinen annetaan huoltajille (huoltajalle) ja toinen arkistoidaan Lapsus-tutkimushankkeen toimesta.

Figure A.2: Consent form for guardians
Alaikäisen (4-10v.) lapsen suostumusasiakirja potilaskokemustutkimukseen

Tutkimuksen nimi: Toimenpidelovnerian vaikuttavuus potilaskokemukseen ja henkilökunnan työhön lastensairaalassa

Hoitajan tai tutkijan nimi: ________________________________________________________________________________

Hoitaja tai tutkija on pyytänyt minua mukaan tähän tutkimukseen. Minua on hoidettu sairaalassa.

Tutkimuksessa selvitetään, kuinka lapsia voitaisiin hoitaa paremmin sairaalassa. Tutkimuksessa kerron mitä
minusta hoito ja sairaalassa käynnit tuntauvat. Joskus kerron tunteistani puhelimen, tabletin tai tietokoneen kautta, joskus
juttelemme tai tutkijat seuraavat tapahtumia sairaalassa.

Hoitaja tai tutkija on kertonut minulle tästä tutkimuksesta. Hän on kertonut, mitä tutkimuksessa tehdään. Olen
saanut kysyä mieleen tuleita kysymyksiä.

Hoitaja tai tutkija on puhunut vanhempieni kanssa tutkimuksesta. Myös he ovat suostuneet siihen, että osallistun

Hoitaja tai tutkija on puhunut vanhempieni kanssa tutkimuksesta. Myös he ovat suostuneet siihen, että osallistun
tutkimukseen.

Olen saanut kertoa, haluan osallistua tähän tutkimukseen. Tiedän, ettei minun tarvitse osallistua, jos en halua.

Jos haluan myöhemmin lopettaa tutkimukseen osallistumisen, ei kukaan ole sitä minulle vihainen. Silloin minun
pitää kertoa vanhemmileni tai jollekin tutkimusta tekevälle aikuiseelle, että en tahdo enää olla mukana. Lääkäri ja
hoitajat hoitavat minua silti parhaalla mahdollisella tavalla.

Minun tutkimusasiotani pääsevät näkemään vain minä, vanhemmat ja tästä tutkimusta tekevät aikuiset.

Jos haluan osallistua tähän tutkimukseen, kirjoitan nimeni tähän suostumukseen.

Nimeni: ________________________________________________________________________________

Päivämäärä: ________________________________________________________________________________

Hoitajan tai tutkijan nimi: ________________________________________________________________________________

ja allekirjoitus: ________________________________________________________________________________

Päivämäärä ja paikka: ________________________________________________________________________________

Figure A.3: Consent form for children aged 4-10 years.
Pyynnöt ja toimenpiteet

1. Tiedä, että yleisesti lapsen tutkimus vaatii suostumustävitteen lapsen äidiltä ja vanhemmiltä.

2. Tutkimus on suunniteltu hoitoon ja sairaaloon liittyvien kokemuksien käsittelemiseen lapsen perspektiivin pohjalta.

3. Tutkimuksessa käytetään puhelimen, tablelin ja tietokoneen avulla kerrottavien kokemuksien analysointiä.

4. Tutkimusajankohtaiset tapahtumat sairaalassa seurataan ja toimittavia kokemuksia kuvattuna.

5. Tutkimukseen voi osallistua lapsen äiti tai vanhempi.

6. Suostumuslomakkeen allekirjoitus tapahtuu lapsen vanhemmilla, jotta he saavat hyväksyntää lapsen osallistuminen.

7. Tutkimukseen voi osallistua lapsen iloitsemuksen ja keskinäisyyden kannalta.

8. Suostumuslomakkeen täytyy allekirjoittaa lapsen vanhemmin, jotta lapsen osallistuminen on julkinen ja lainmukainen.

9. Suostumuslomakkeen täytyy allekirjoittaa lapsen vanhemmin, sillä lapsen suostumus on oikeusruxia.

10. Suostumuslomakkeen allekirjoitus tapahtuu lapsen vanhemmin, sillä lapsen suostumus on oikeusruxia.

11. Suostumuslomakkeen allekirjoitus tapahtuu lapsen vanhemmin, sillä lapsen suostumus on oikeusruxia.

12. Suostumuslomakkeen allekirjoitus tapahtuu lapsen vanhemmin, sillä lapsen suostumus on oikeusruxia.

Tutkimuksen nimi: Toimenpidelovnerian vaikuttevuus potilaskokemukseen ja henkilökunnan työhön lastensaarialassa

Hoitajan tai tutkijan nimi: __________________________________________________________

## Alaikäisen (15-17v.) lapsen suostumusasiakirja potilaskokemustutkimukseen

Olen saanut tätä tutkimusta koskevan tiedotteen ja suullista tietoa tästä tutkimuksesta ja ymmärtänyt tutkimusta koskevan tiedon. Minulla on ollut riittävästi aikaa harkita osallistumistani tutkimukseen.

Tiedot antoi ____________________________. Olen saanut myös esittää hänelle kysymyksiä tutkimuksesta.


Ymmärrän, että osallistumiseni tähän tutkimukseen on vapaaehtoista ja voin perua tämän suostumuksen, ja keskeyttää osallistumisen milloin tahansa ennen tutkimuksen päättymistä. Olen tietoinen myös silloin, että keskeyttämiseen mennessä kerättyjä tietoja käytetään osana tutkimusaineistoa. Tutkimuksen keskeyttäminen ei kuitenkaan vaikuta millään tavoin mahdollisesti tarvitsemaani tai perheenjäseneni tarvitsemaan hoitoon.

_Annansuostumuksen siihen, että osallistun tähän tutkimukseen;

<table>
<thead>
<tr>
<th>Allekirjoitus</th>
<th>Syntymäaika</th>
<th>Päiväys</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nimen selvennys</td>
<td>Osoite</td>
<td></td>
</tr>
</tbody>
</table>

Olen kertonut tätä tutkimuksesta tutkimustiedotteen mukaisesti osallistujalle ja otan vastaan tämän suostumuksen.

<table>
<thead>
<tr>
<th>Tutkijan allekirjoitus</th>
<th>Paikka ja päiväys</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nimen selvennys</td>
<td></td>
</tr>
</tbody>
</table>

Tätä suostumusasiakirjaa on tehty kaksi kappaletta, joista toinen annetaan osallistujalle ja toinen arkistoidaan Lapsus-tutkimushankkeen toimesta.

Figure A.5: Consent form for children aged 15-17 years.
Appendix B

Digital service screenshots

This Appendix A presents the views from the digital service implemented to this study. The order of the views is chronological, the first figure of this appendix represents the first view in the digital service. The first three views and inputs are operated by the study nurse, and then from the fourth view onward the digital service is used by the child patient. The image B.11 presents the operational nurse’s questionnaire.

![Kokemusmittari](image)

Figure B.1: Selection of the respondent.

![Kyselyn aika](image)

Figure B.2: Selection of the timing and questionnaire set.
Figure B.3: Submission of the respondent’s research number. Above is before entering the number and below after.
Figure B.4: Selection of the current emotion. Above the view before the selection and below after the selection has been made.
Figure B.5: Selection of the anxiety level.

Figure B.6: Selection of the pain level. Above before selection and below after selection.
Figure B.7: Selection of the best aspect in hospital. Above before selection and below after selection.
Figure B.8: Selection of the worst aspect in hospital. Above before selection and below after selection.
Figure B.9: Free feedback view for the older children aged 11-17 years.

Figure B.10: The last thank you view from the children’s questionnaire.
Figure B.11: The operational nurse’s questionnaire in the digital service.
Appendix C

Heuristic evaluation questions

This Appendix presents the questions asked from the research nurse about the heuristic evaluation of the digital service. The first questions from 1 to 11 present the viewpoints of the research nurse, and the following questions present the viewpoint of the children.

The viewpoint of the research nurse:

1. Was it easy to use the digital service in the case study?
2. Did you learn to use the system quickly?
3. Did you need written help documentation for the use of the digital service?
4. Did you run into errors while using the digital service?
5. Did the digital service provide enough information on the state of the system, such as how much is done and how much is left?
6. Did the digital service provide undo and redo options? Did the service provide possibility to cancel options?
7. Was the used language clear and understandable?
8. Did the use of the digital service require recollection of information? For example, recollection of information between two different questions?
9. Did the digital service provide extra or unnecessary information?

10. Was the digital service consistent between the different views of the system?

11. Do you think that the digital service could be used in future for collecting children’s patient experience data?

The viewpoint of the child patients:

1. Was it easy for the children to use the digital service?

2. Did children need assistance in using the digital service?

3. Was the language used in the digital system clear and understandable for the children?

4. Did the child patient need help remembering different parts of the digital service?

5. Was the structure of the digital service logical and clear?

6. Was enough information provided for the child patients in every view and question of the digital service?

7. Do you think that children could use the digital service more in the future?

Open comments and feedback: