Towards fear-free hospital visits •

An application empowering children with Congenital Heart Defects and their parents

Master Thesis • Brittany Joyce Müller



TU DELFT | Faculty of Industrial Design Engineering

Delft, March 2023

Master Thesis - MSc Design for Interaction | Medisign Specialisation
Faculty of Industrial Design Engineering
Delft University of Technology

Towards fear-free hospital visits - An application empowering children with Congenital Heart Defects and their parents

by Brittany Joyce Müller

TU Delft supervision
Prof. dr. ir. Kleinsmann, M.S. (Maaike) | chair
Prof. dr. ir. Goossens, R.H.M. (Richard) | mentor

In collaboration with
the Hospital Hero foundation

Company supervision
Msc. Poot, C.C. (Charlotte)

TU Delft Delft University of Technology

HospitalHero

ACKNOWLEDGMENTS

This project has been a wonderful journey and an amazing conclusion of my masters at TU Delft University. My time at the Hospital Hero foundation and the Willem-Alexander Children's Hospital have taught me valuable lessons I will take with me for the rest of my life. I was very lucky to work with and be supported by so many amazing people, without whom this project would not have been possible.

I would like to start off by thanking the wonderful people of the Hospital Hero team. You guys are a talented group of people that feels like family. Charlotte, I am extremely grateful for your support and guidance. I learned a lot from you on a professional level and you helped me grow on a personal level. Nicole, your enthusiasm and drive to help patients are admirable. Thank you for answering my many questions and showing me around the hospital. Dayella, I want to thank you for your creative ideas, enthusiasm, and support with the design of my prototype. I enjoyed working together very much.

Maaike & Richard, I want to thank you for your support through the whole process. Your expertise was invaluable. Your trust in me pushed me to deliver my best possible work.

Mom, your weekly 'Hi honey, how are you?' texts often directly followed by a phone call mean more to me than you realise. Thank you for always being there for me.

Dad, thank you for your analytical questions. You helped me make sense of my thoughts. Without you, this report would not have been up to the quality it is now.

Grandpa & grandma, you are wonderful people. Your relentless interest and enthusiasm for my project, even when life was really difficult for you, means more to me than you know. Thank you for the weekly phone calls, life lessons and hugs.

Rosanne! My one and only hippo. Your friendship made me who I am today. Thank you for the late-night audio recordings. Who knows, maybe life has a career switch for you in store.

Ekin, I cannot thank you enough for your support and friendship. You made the last two years of our education feel like a breeze. Our many (and I mean many) phone calls, your reassurance, and guidance (I can still hear you say "don't make the same mistakes I did") have kept me sane during this project.

Sylvia, my creative buddy and sparring partner. Your cheerfulness (really, how do you manage this?), friendship, and your 'you-are-close-to-your-deadline' lasagna helped me in more ways than you know.

Tiemen, thank you for your constant reassurance, even when I drove you crazy with my self-doubt. Thank you for the late-night conversations, many forehead kisses, and your relentless support. I love you. Words cannot describe how much you have helped me grow as a person.

I want to thank all the healthcare workers of the Willem-Alexander children's hospital, parents, and children who made the time to share their expertise and experiences with me. It has been a wonderful experience working with you. Your contribution to this project has been invaluable.

EXECUTIVE SUMMARY

Children with a Congenital Heart Defect (CHD) need to visit the outpatient clinic regularly their whole lives, often starting from birth. These hospital visits are frequently accompanied by feelings of anxiety and fear, which can have a detrimental impact on a child's life. In collaboration with the Hospital Hero Foundation and the Willem-Alexander Children's Hospital, the aim of this project was to **design an intervention that reduces children's feelings (aged four to ten) of fear and anxiety during outpatient visits to the paediatric cardiology department.**

Employed Methodologies

Throughout the project, the following methods were employed:

1. Literature research exploring the background of paediatric hospital-related anxiety and fear, and existing anxiety-and-fear-reducing strategies.
2. Interviews with children (with and without CHD), parents, and paediatric healthcare workers to map the current situation.
3. In-depth observations of the current context of an outpatient visit to the cardiology department. 4. The facilitation of creative sessions to generate ideas and concepts, ultimately resulting in the final design.

Home-Based Preparation

Home-based preparation was chosen as the leading fear-and-anxiety-reducing strategy. This strategy focuses on providing paediatric patients with information prior to their hospital visit. Due to the developmental and cognitive levels of the defined age group, the responsibility of home-based preparation lies with the caregivers/ guardians of the patients.

The following main research question was defined: **How can design support children (between the ages of four and seven) and their parents in the home-based preparation process of an outpatient visit to the paediatric cardiology department?**

Research Outcomes

Exploring the current preparation touchpoints, practised preparation methods, and the hospital experience from the child's perspective resulted in the following summarised research outcomes:

- Every paediatric patient and their situation is unique. As a result, every child experiences an outpatient visit differently. Therefore, customised preparation is required.
- Parents encounter barriers during the home-based preparation of their children. Existing preparation touchpoints, including the Hospital Hero application, do not accommodate these barriers.
- Preparation of children should contain context-specific details and focus on sensory stimuli.

Intervention

Based on the research outcomes, a home-based preparation approach was defined. Context-specific triggers of fear and comforting elements were mapped and selected as preparation content. This resulted in the design of an online module that can empower children with CHD and their parents with home-based preparation. The online module was evaluated with parents and healthcare workers and shows promising results. Recommendations regarding improvements and implementation are provided.



▲ **Figure 1.** Overview of the designed intervention.

TABLE OF CONTENTS

GLOSSARY 08

Chapter 1. General Introduction 09
1.1 Introduction to the Project 10
1.2 The Client: The Hospital Hero Foundation 10
1.3 Project Assignment 13
1.4 Project Approach 14

Chapter 2. Exploring Paediatric Hospital-Related Fear and Anxiety 17
2.1 Study Purpose 17
2.2 Method 18
2.3 Fear and Anxiety 18
2.4 Developmental and Cognitive Levels 19
2.5 Existing Strategies that Reduce Fear and Anxiety 22
2.6 Design Opportunity 24

Chapter 3. Defining a Home-Based Preparation Approach 27
3.1 Study Purpose 27
3.2 Recommended Preparation Aspects and Preparation Materials 28
3.3 Barriers Faced in Home-Based Preparation 33
3.4 A Home-Based Preparation Approach 37
3.5 Limitations 38

Chapter 4. Mapping the Hospital Experience 39
4.1 Study Purpose 39
4.2 Methods 40
4.3 Outpatient Visit to the Paediatric Cardiology Department of the WACH 42
4.4 Conclusion 52
• Requirements 53
4.5 Limitations 54

Chapter 5. Concept Generation 55
5.1 Approach 55
5.2 Methods 56
5.3 Diverging 57
5.4 Converging 59
5.5 Final Concept 63
5.6 Limitations 65

Chapter 6. Final Design 67
6.1 Approach 67
6.2 Design Choices 68
6.3 Intermediate Evaluation of the Design Choices 75
6.4 Final Design 77

Chapter 7. Evaluation 83
7.1 Study Purpose 83
7.2 Method 84
7.3 Results 86
7.4 Conclusion 91
7.5 Limitations 92
7.6 Recommendations 93
7.7 Concluding Remarks 96

BIBLIOGRAPHY 97
APPENDIX 99

GLOSSARY

Congenital Heart Defects (CHD)
A collective term used to indicate abnormalities in the heart structure that occur during the development of the fetus.

Conditional Stimuli (CS)
In this project: A neutral stimulus that is repeatedly associated with pain, fear and/or anxiety, until it acquires the ability to trigger negative emotions.

Echocardiogram | Short: echo
In this project: One of the check-up procedures performed during a regular outpatient visit to the cardiology department. Ultrasound waves are used to produce a visual display of the (actions of the) heart, for the diagnosis or monitoring of heart defects.

Electrocardiogram (ECG). Dutch: Hartfilmpje, ECG
In this project: One of the check-up procedures performed during a regular outpatient visit to the cardiology department. Sensors attached to the skin are used to detect the electrical signals produced by the heartbeat of a patient.

Healthcare Worker (HCW)
A healthcare worker is anyone who works in a healthcare or social care setting. In this project, the use of 'healthcare worker' refers to people affiliated with paediatric healthcare provided in the outpatient clinic of a (Dutch) children's hospital.

Juliana Children's Hospital (JCH). Dutch: Juliana Kinderziekenhuis (JKZ)
A Dutch children's hospital that is part of the HagaHospital, situated in Den Haag.

Outpatient visit. Dutch: Polikliniekbezoek
A visit to the outpatient clinic of a hospital, consisting of several medical check-up procedures followed by a consultation with the treating physician. An outpatient visit does not require admission or the occupation of a hospital bed.

Parents
In this project: guardians or caretakers of a child.

Remedial Educationalist. Dutch: Orthopedagoog
Expert in the field of the upbringing and education of children.

Sophia Children's Hospital (SCH). Dutch: Sophia Kinderziekenhuis (SKZ)
A Dutch children's hospital that is part of the Erasmus Medical Centre, situated in Rotterdam.

Willem-Alexander Children's Hospital (WACH). Dutch: Willem-Alexander Kinderziekenhuis (WAKZ)
The context of this project. A Dutch children's hospital that is part of the Leiden University Medical Centre, situated in Leiden.

Chapter 1. General Introduction



1.1 Introduction to the Project

Every day, four children are born with a Congenital Heart Defect (CHD) in the Netherlands (Stichting Hartekind, n.d.). CHD is a collective term used to indicate abnormalities in the heart structure that occur during the development of the fetus (Sun et al., 2015). CHD is the most common type of birth defect, affecting 1 in 100 children in the Netherlands. Approximately two-third of these children undergo one or more life-saving medical procedures shortly after birth. But their medical journey does not end there; "For many of these patients, congenital heart disease is accompanied by substantial stressors and challenges throughout their lifespan" (Luyckx et al., 2014, p.145). A heart defect is a lifelong burden.

CHD patients have to attend regular check-ups to monitor their health, often starting from birth. Some patients have to visit the hospital once every three months. These hospital visits can have a big impact on a child's life. Children often experience fear and anxiety in anticipation of and when engaging in healthcare settings with medical professionals (Lerwick, 2016). These recurring feelings of anxiety and fear can result in nightmares, behavioural abnormalities, developmental issues and even post-traumatic stress disorder (Vleugel-Ruissen & Keijzer, 2019). Left untreated, healthcare-induced childhood trauma can cause significant mental health issues in a child's life (Lerwick, 2016). On top of that, unpleasant healthcare experiences can create long-term negative associations with healthcare in general, resulting in children being less likely to seek medical help when needed, with all its social and economic consequences. Besides long-term consequences, fear and anxiety can also have an immediate effect on paediatric patients. Children experiencing feelings of anxiety and fear often demonstrate physiological and behavioural distress, including aggression, withdrawal, lack of cooperation, and difficulty coping with and recovering from procedures (Smith, 2014). This distress can interfere with the effectiveness and efficiency of the delivery of needed medical attention (Rodriguez et al., 2012). An anxious child can negatively affect the stress levels of medical professionals, which can lead to inaccuracies and reduced effectiveness of the treatment (Vleugel-Ruissen & Keijzer, 2019).

Thus, mitigating fear and anxiety is essential in promoting an overall positive experience for patients. When fear and anxiety are decreased, "children are able to approach medical situations with a sense of comfort, achievement, and control" (Smith, 2014, p.10). Hence, reducing healthcare-related fear and anxiety will not only positively affect the present experiences of children and their parents, but can also significantly improve paediatric patients' development and well-being later in life. This is where Hospital Hero steps in.

1.2 The Client: The Hospital Hero Foundation

Hospital Hero is a non-profit foundation that aims to decrease anxiety and fear among all paediatric patients before, during, and after medical procedures. To reach this goal, the foundation has developed the Hospital Hero application in collaboration with the Biodiversity Centre Naturalis in Leiden. The application was developed by two paediatric nurses of the Willem-Alexander Children's Hospital (WACH), who observed a lot of anxiety and fear in children during medical procedures. They envisioned a future where children would be able to approach medical situations with a sense of comfort and control.

1.2.1 The Hospital Hero Application

The Hospital Hero application is designed for paediatric patients between the ages of four and ten. At the time of writing, the application features aspects of a procedural outpatient visit to either the paediatric cardiology department of the WACH or the Juliana Children's Hospital (JCH). The outpatient visit is divided into seven steps, see Figure 2. The application intends to guide the users during their outpatient clinic journey from beginning to end. The first step, 'Preparation', is intended to be explored before the hospital visit. Steps two to seven are intended to be inspected during the hospital visit and provide active distraction.

Preparation

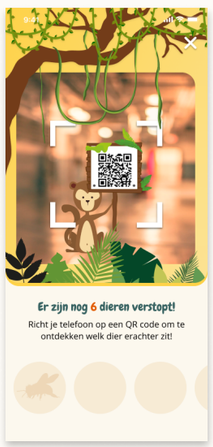
At the time of writing, the application does not cover the entire outpatient visit. The application only prepares users for three check-up procedures CHD patients regularly undergo. The preparation includes a picture and a short textual description of the procedure, see Figures 13 and 14. For one of these procedures, the application also features an interactive game, see Figures 10 to 12. The application nudges users to play the interactive game before the hospital visit as part of the preparation step (i.e. step one).

Distraction

The application offers age-appropriate distraction during the hospital visit in the form of searching and collecting animals through QR code scanning. Once the animals are found, the user can access educational information about this animal. To make this feature engaging for children that have to visit the hospital multiple times a year, the hidden animals change regularly.



Figure 2. The home screen shows the personalised hospital journey of the paediatric patient. ▶

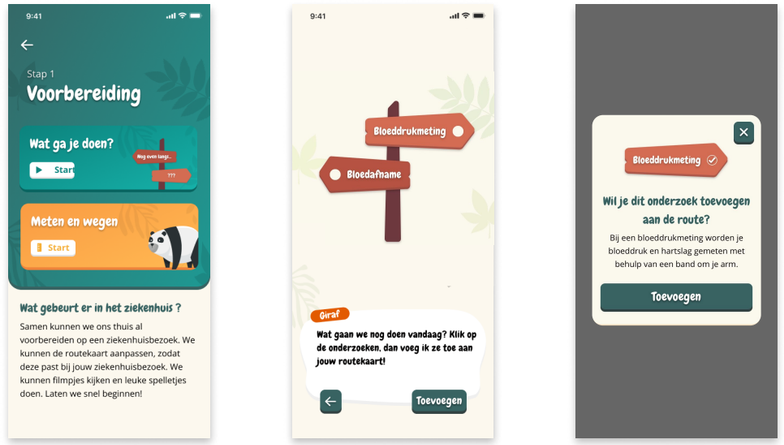




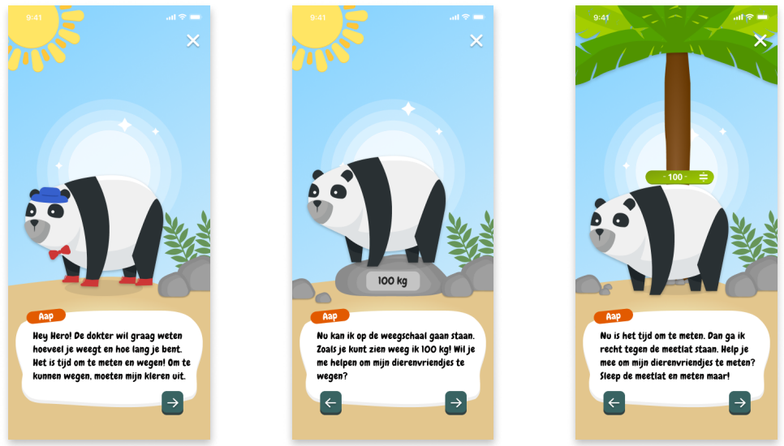




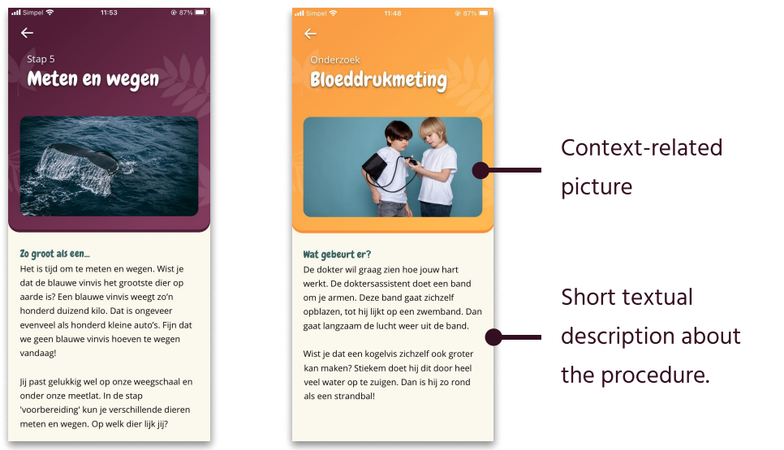
▲ **Figures 3-6**. Users can search and collect animals that are hidden in the hospital through QR code scanning.



▲ **Figures 7-9**. During the preparation step, users can personalise their journey by adding medical procedures that are scheduled during their hospital appointment.



▲ **Figures 10-12**. An interactive game that visualises the steps paediatric patients need to undergo when their weight and length measurements are being taken.



▲ **Figures 13-14**. Each step contains information about the procedure.

1.3 Project Assignment

The initial project assignment provided by the Hospital Hero foundation was to **design an intervention that reduces children's feelings (aged four to ten) of fear and anxiety during outpatient visits to the paediatric cardiology department**. This project will look at the entirety of a regular outpatient visit, not limited to the three featured procedures in the application. No requirements regarding the type of intervention (i.e. product or product-service combination) were provided.

In order to explore the numerous aspects of fear and anxiety related to hospitals and to identify design opportunities suitable for the Hospital Hero foundation, the assignment given was intentionally broad. During the course of this project, the provided assignment was transformed into a more focused research question.

1.3.1 Project Scope

To scope the initial project assignment, the following restrictions and decisions regarding the target group and context have been made:

Target Group

The initial target group of this project included all CHD patients with a cognitive developmental age of approximately four to ten years old, similar to the target group specifications of the current Hospital Hero application. A possible symptom of a congenital heart defect is stunted cognitive development (Mayo Clinic, n.d.). Paediatric patients with extreme cognitive delays and children outside the defined cognitive-developmental age range of four to ten were not the focus of this project.

Type of Fear and Anxiety

The initial focus of this project was on hospital-related fear and anxiety in mild to medium stages. Extreme phobias and traumas were not part of the scope of this project.

Context of the project: Willem-Alexander Children's Hospital

The aim of the Hospital Hero foundation is to reach as many paediatric patients as possible, meaning that the intervention should be preferably applicable to the majority of (Dutch) children's hospitals. The context of this project will be limited to the outpatient clinic of the Willem-Alexander Children's Hospital. The WACH is part of the Leiden University Medical Centre (LUMC), a university-affiliated teaching hospital providing medical care for residents of Leiden, the Netherlands, and its surrounding area. The WACH is a paediatric hospital for patients up to the age of 18. Figures 15 and 16 show parts of the outpatient clinic of the WACH.





▲ **Figures 15-16**. Pictures featured on the WACH website that provide an impression of their outpatient clinic [1].

1.4 Project Approach

The design process of this project was divided into four phases, inspired by the double-diamond approach (Design Council, 2019). The four phases include: (1) Discover, (2) Define, (3) Develop, and (4) Deliver, see Figure 17. Each phase was concluded with a deliverable, visualised at the bottom of the figure. The following paragraphs explain the purpose of each phase and summarise the results.

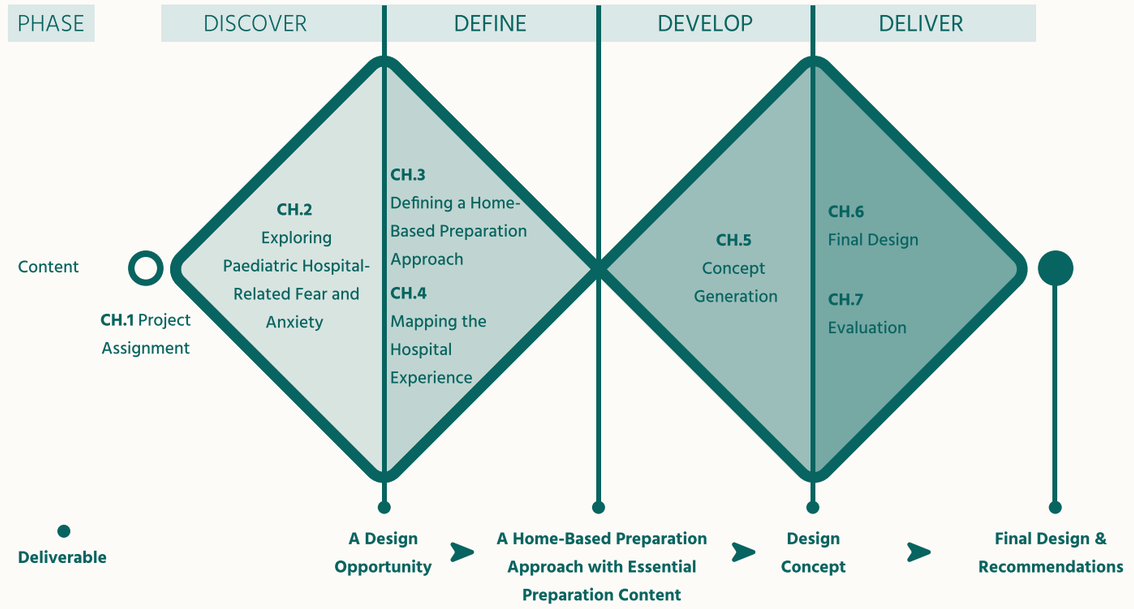
1. Discover

The aim of the first phase was to gain a broader understanding of hospital-induced fear and anxiety in paediatric patients and to explore current strategies that aim to reduce these negative emotions during outpatient visits. Chapter 2 discovered these topics by means of literature research. At the end of this chapter, home-based preparation was chosen as the leading fear-and-anxiety-reducing strategy. Based on this decision, the initial project assignment was transformed into a research question.

2. Define

The aim of the second phase was to define a home-based preparation approach and map the essential preparation aspects. Chapter 3 explored the barriers parents encounter during home-based preparation, existing preparation materials, and the recommended preparation approach by paediatric experts. These insights resulted in the generation of a home-based preparation approach. The essential content of the preparation approach is explored and mapped in Chapter 4.

▼ **Figure 17**. Project structure, based on the Double Diamond Approach (Design Council, 2019).



3. Develop

The first half of the second diamond is dedicated to the development of concepts. Chapter 5 details the ideation and conceptualisation process. Several idea-generating techniques have been employed to create four preliminary ideas. These ideas were altered and improved based on insights gathered during paired comparison sessions with CHD patients and brainwriting sessions with designers. The Develop Phase was concluded with one final concept.

4. Deliver

The goal of the Deliver Phase was to evaluate the final design. Based on the final concept, high-fidelity prototypes were made. The design choices of the prototype were evaluated by paediatric experts. Improvements were made based on the gathered insights. This second iteration was evaluated with paediatric healthcare workers and parents. Insights yielded from these qualitative evaluation sessions were added to the list of recommendations for the client.

Takeaways from this chapter

• The majority of children with a congenital heart defect need to regularly visit outpatient clinics throughout their lives to monitor their health. Literature shows that these hospital visits can result in recurring feelings of fear and anxiety.

• Hospital-related fear and anxiety can interfere with the effectiveness and efficiency of the delivery of needed medical attention and can result in nightmares, behavioural abnormalities, developmental issues and even post-traumatic stress syndrome.

• The project assignment provided by the client (i.e. the Hospital Hero foundation) was to **design an intervention that reduces children's feelings of fear and anxiety during outpatient visits to the paediatric cardiology department.**

• The initial target group consisted of children with Congenital Heart Disease with a cognitive developmental age of approximately four to ten years old.

• The context of this project was the outpatient clinic of the Willem-Alexander Children's Hospital.

Chapter 2. Exploring Paediatric Hospital-Related Fear and Anxiety

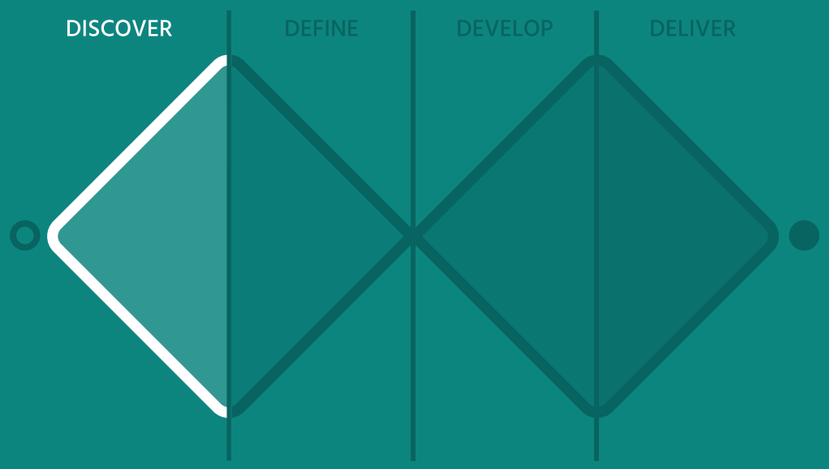
2.1 Study Purpose

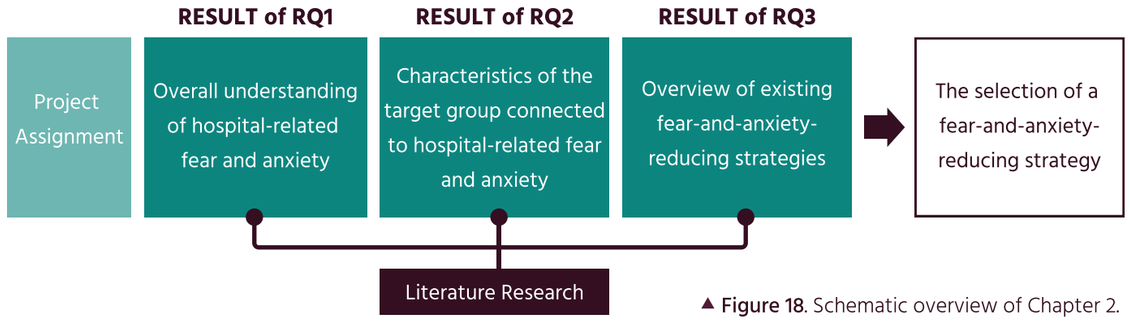
The Hospital Hero application currently employs preparation and distraction strategies to decrease paediatric anxiety and fear. This chapter explores the difference between anxiety and fear and how these emotions are manifested in the paediatric healthcare context. Additionally, this chapter explores design opportunities by looking into existing strategies that reduce anxiety and fear. Based on these explorations, one fear-and-anxiety-reducing strategy was chosen as a baseline for the development of the intervention, see Figure 18. This chapter answered the following research questions:

RQ1 – What is the difference between fear and anxiety and how are these emotions manifested in the hospital context?

RQ2 – How do cognitive levels and developmental stages of children (aged four to ten) affect their hospital-related experiences?

RQ3 – Which strategies currently exist that aim to avoid or reduce hospital-induced paediatric fear and anxiety?





▲ **Figure 18**. Schematic overview of Chapter 2.

2.2 Method

A literature search was performed with the following electronic databases: PubMed, Google Scholar and the official websites of (Dutch) children's hospitals. The literature search was split into three search categories: (1) Anxiety and fear in general, (2) paediatric hospital-induced anxiety and fear, and (3) existing strategies to reduce hospital-induced anxiety and fear. The book 'Voorbij de angst: Distress bij kinderen in de (para)medische setting' (Vleugel-Ruissen and Keijzer, 2019) functioned as a starting point for each category, whereafter the snowball method was conducted to find more literature about the subject. The search terms used that initiated the snowball method included: Paediatric, Children, Patient, Fear, Anxiety, Distress, Hospital, Intervention, and Strategy. The book was selected as a starting point due to its relatively recent date of publication, the great similarities between its content and the aim of this project, and the strong connection the writers make between literature and practice in Dutch hospitals.

2.3 Fear and Anxiety

RQ1 – What is the difference between fear and anxiety and how are these emotions manifested in the hospital context?

Fear and anxiety are two separate emotional phenomena. A distinction can be made based on (1) antecedent conditions (i.e. the event that triggers the emotional response) and (2) the manifestation of behaviour (Perusini & Fanselow, 2015). Table 1 highlights the differences between fear and anxiety based on this distinction.

	Anxiety	**Fear**
	Pre-stimulus (future-oriented)	**Post-stimulus** (present-oriented)
Antecedent Condition	Anticipation of a possible threat on a cognitive level	Identifiable and specific threats in the immediate sensory environment
Manifestation of Behaviour	Physical tension and chronic over-arousal (reflecting readiness for dealing with future danger), long-acting	Fight-or-flight response, short-lived

▲ **Table 1**. The difference between fear and anxiety. The content is based on Perusini & Fanselow (2015) and Heeren (2020).

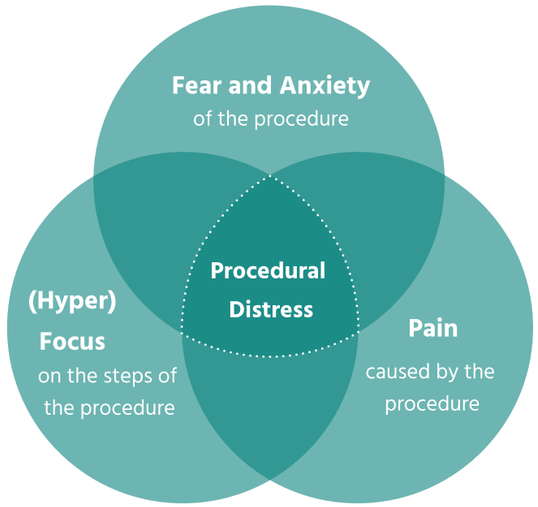
2.3.1 Three-pathways-to-fear

According to the three-pathways-to-fear model, fear and anxiety can be acquired through three different pathways: (1) Conditioning, (2) information transmission, and (3) modelling (Rachman, 1977). Conditioning is a direct pathway in which people start to associate neutral stimuli with pain or fear due to former experiences. These neutral stimuli become conditional stimuli (CS). The strength of the fear is determined by the frequency and intensity in which the pain or fear is associated with the presence of CS. Meaning that chronically ill children who regularly need to visit the hospital, are more likely to acquire stronger hospital-related fears compared to children with limited hospital experiences. Stimuli that closely resemble the fear-evoking ones can become secondary CS. A common example of a conditional stimulus is a needle. When a child starts to associate the white jacket healthcare workers are wearing with painful invasive procedures, white jackets might become secondary CS.

The remaining two pathways of the model assume that fear and anxiety can be acquired by indirect processes, i.e. in the absence of direct contact with fear stimuli. People can acquire fear responses through information transmission; receiving (subjective or objective) information about frightening events or situations. For example, a television show with realistic injuries or parents claiming that having your blood samples taken is painful and scary. Fears acquired through information transmission are more likely to be mild than severe. The last pathway assumes that fear can be acquired through observational learning (i.e. modelling). People, especially in early childhood, learn a lot from the behaviour of people around them (Nickerson, 2022). Primary attachment figures, often parents, are the most important source for children to model their behaviour. When parents (subconsciously) show physical signs of fear and anxiety, e.g. for a needle, children might start to fear needles themselves even though they have never been in immediate contact with them.

2.3.2 Procedural Distress

Patients of all ages experience fear, pain, and (involuntary) resistance during medical procedures. This phenomenon is called procedural distress (Mendels et al., 2022). Figure 19 shows that procedural distress arises from the combined effects of fear and anxiety, pain, and (hyper)focus.



▲ **Figure 19**. Procedural distress arises from the combined effects of fear and anxiety, pain, and (hyper)focus on medical procedures. Modified from Mendels et al. (2022).

2.4 Developmental and Cognitive Levels

RQ2 – How do cognitive levels and developmental stages of children (aged four to ten) affect their hospital-related experiences?

The younger the child, the harder it is for them to understand what is happening and what to expect.

As children grow up, they start to develop a better understanding of why they need to visit the hospital and what kind of examinations and check-ups will take place. Every age group experiences a visit to the hospital in a different way, due to developmental and cognitive levels and corresponding developmental fears (Knipping, n.d.; Vleugel-Ruissen & Keijzer, 2019).

As children start to experience and learn how the world works, they go through so-called developmental fears (Knipping, n.d.). This is an umbrella term for the most common fears children experience when going through each stage of development. These fears differ in severity and intrusiveness specific to the person. Developmental fears often occur in chronological order, but the age a specific fear or anxiety response occurs the first time, varies greatly per individual. Table 2 highlights the developmental fears per age category. More details about developmental fears and cognitive development are discussed for children between the ages of four and ten.

		TARGET GROUP (4-10 years old)		
Age	**0-2 years old**	**2-7 years old**	**7-11 years old**	**11+ years old**
Developmental Fears and Anxiety	Fear of strangers (Dutch: Eenkennigheid)		Fear of physical harm, illness, and death	Fear of disfigurement
	Seperation anxiety (Dutch: Verlatingsangst)		Fear of the dark and being alone	Anxiety about social rejection, loss of social status, and humiliation
		Fear of unfamiliar and excessive stimuli	Fear of social rejection	Anxiety about intercourse and intimicy
		Fear of fantasy characters, events and objects linked to magical thinking		Anxiety about the future
			Fear of family discruption	
			Fear of failing school	

▲ **Table 2**. Overview of developmental fears. The content is based on Knipping (n.d.) and Vleugel-Ruissen & Keijzer (2019).

Children aged 2-7

During this stage of life, thinking and language skills are developing significantly, but logical thinking strategies are still lacking (Vleugel-Ruissen & Keijzer, 2019). Explanations about what will happen and when are usually not well understood. Children between the ages of two and seven have a rich imagination, making it hard for them to make distinctions between fantasy and reality. Unfamiliar medical equipment and unexpected noises, which adolescents can rationalise, might trigger fear responses in children (Knipping, n.d.).

Another important fear is caused by the feeling of not being in control. Children between two and seven are very focused on doing things themselves and being in control of their own bodies and actions (Vleugel-Ruissen & Keijzer, 2019). Healthcare environments and being in need of medical care can make children feel out of control.

At this age, children's cognitive development is characterised by egocentrism, i.e. the child's inability to differentiate between their perspective and their (social) environment (Babakr et al., 2019). Consequently, procedural pain is not perceived as something that is necessary in order to get better but as undeserved punishment (Vleugel-Ruissen & Keijzer, 2019). This is amplified by the fact that children up to the age of five think in extremes, e.g. all right or wrong, calm or blind panic, safe or mortal danger. There is usually no in-between, so it is very hard to imagine that something will pass quickly or that something was not so bad (Vleugel-Ruissen & Keijzer, 2019).

According to Piaget's theory of cognitive development, the anxiety of children between the ages of two and six is concerned with immediate, concrete threats (Muris et al., 2000). Hence, following the theorised distinction between anxiety and fear (see section 2.3, Table 1), children in this age category are more prone to experiencing fear rather than anxiety. They are more concerned with the immediate sensory environment (fear) and are by nature less future-oriented (anxiety).

Children aged 7-11

Children between the age of seven and eleven start to consider the perspectives of the people around them and the egocentrism of the earlier years starts to disappear (Babakr et al., 2019). Pain is no longer seen as a punishment, but as something unpleasant, that is necessary in order to get better. The child gets increasingly better at logical thinking but is limited to what they can experience or have experienced in the past (Vleugel-Ruissen & Keijzer, 2019). Children in this age category start to be able to discover contradictions and inaccuracies. Well-intentioned advice or predictions about the amount of pain of medical procedures that turn out to be false can make the child feel betrayed.

Piaget's theory of cognitive development states that children between the age of seven and eleven are "increasingly able to infer cause-effect relationships and to anticipate potential negative outcomes, thereby broadening the range of fear-provoking stimuli" (Muris et al., 2000, p.46). Meaning that children start to think more future-oriented, allowing them to not only experience fear but also anxiety.

2.4.1 Paediatric Coping Mechanisms

People can either have an active or avoidant coping approach when dealing with fear or anxiety (Lerwick, 2016). Examples of an active coping approach include acknowledging emotions, being aware of stressful stimuli, and actively searching for information. Paediatric patients who actively cope with (future) medical procedures, can create an internal locus of control (Lerwick, 2016). This internal locus of control refers to the belief that events and/or outcomes are a result of one's own choices and actions. In other words, active coping strategies can help children feel in control during medical procedures.

Around the developmental age of seven, children start to realise that they can play an active role during medical procedures, consequently experiencing more control over the situation and their bodies (Vleugel-Ruissen & Keijzer, 2019). Around this age, children also start searching for and understanding explanations about what will happen. Younger children (i.e. below the age of seven) rely on their parents to create an internal locus of control. They do not possess the cognitive and physical ability to actively carry out an active coping mechanism and thus strongly rely on the support of their parents to feel in control during medical procedures (Lerwick, 2016).

An avoidant coping approach correlates with an external locus of control, meaning that children believe that the outcomes are less influenced by their own choices and actions and are more predisposed by outside influences (Lerwick, 2016). Examples of an avoidant coping approach include avoiding information about the event, denying worries or distancing one's self from stressful stimuli.

2.5 Existing Strategies that Reduce Fear and Anxiety

A multitude of strategies and interventions to avoid and reduce (paediatric) fear and anxiety exist. This sub-chapter will explore and summarise which strategies exist and by doing so answers the third research question:

RQ3 – Which strategies currently exist that aim to avoid or reduce hospital-induced paediatric fear and anxiety?

Procedural distress, discussed in section 2.3.2, explains that fear and anxiety are not isolated phenomena. In order to reduce hospital-related fear and anxiety, a multimodel approach that tackles each component of procedural distress is required (Mendels et al., 2022). Figure 20 (on the next page) visualises existing strategies for each component of procedural distress. It is important to keep in mind that each child experiences a hospital visit in a different way. The visualised strategies might not work for each paediatric patient.

2.5.1 Intervention Strategies for (Hyper)Focus

To avoid (hyper)focus on medical procedures, intervention strategies focus on involving, connecting and engaging with the paediatric patient (Mendels et al., 2022). Interventions such as (educational) toys, interactive reading books, smart devices, and Virtual Reality are currently used to distract and engage children during medical procedures. Some examples of distraction methods can be seen in Figures 21 and 22. These intervention strategies shift the focus from something painful or scary to a more positive and fun interaction with the intervention, parents, and/or healthcare workers.



▲ **Figure 20**. A multimodal approach to reduce procedural distress (Leroy, 2021).

▼ **Figures 21-22**. Reading books and VR headsets can distract paediatric patients during medical procedures [3] [4].





▼ **Figure 23**. The Buzzy saturates the nerves responsible for the transmission of pain stimuli to the brain, thereby limiting pain experience [4].



2.5.2 Intervention Strategies for Pain

To avoid or limit the experience of pain, several effective pain reduction methods exist. For example, the WACH offers paediatric patients the possibility to use bandaids containing narcotics or a cream for local analgesia that prevent pain associated with needle insertion. Besides analgesic drugs, drug-free pain-relieving methods exist. An example is the Buzzy, see Figure 23. This small device in the shape of a bee vibrates against the skin of the patient. In combination with the cold 'wings' pressed against the skin, the Buzzy saturates the nerves responsible for the transmission of pain stimuli to the brain, thereby limiting the pain experienced by the (paediatric) patient (Vleugel-Ruissen & Keijzer, 2019).

In addition, creating a bond of trust between the child-parent pairs and healthcare workers is crucial to limit pain experiences. Patients who trust the involved healthcare worker(s) and their medical actions, experience less pain, fear and anxiety, show better compliance, heal faster, and have fewer traumatic memories. Overall, (paediatric) patients that have developed a bond of trust retain more confidence in healthcare (Mendels et al., 2022). To develop a bond of trust, information transmission and preparation are very important. This leads to the last component of procedural distress: Fear and Anxiety.

2.5.3 Intervention Strategies for Fear and Anxiety

Hospital-related fear and anxiety can be reduced by informing and preparing the patient about the planned medical procedures. Explanations before and during the outpatient visit help children understand what is happening and can help them create an internal locus of control (Lerwick, 2016). Children have a rich imagination, as described in section 2.4. Without accurate information, children of all ages often develop distorted ideas (Gillis, 1990). Explanations beforehand can set straight any fantasies that have led to misconceptions and fears about the hospital visit. Additionally, research has shown that unexpected stress is more upsetting than expected stress (Lazarus & Folkman; 1984, Petrillo & Sanger, 1980; Vernon, 1973).

Another effective intervention strategy to reduce anxiety and fear is Comfort Talk (Comfort Talk®, n.d.). This strategy avoids the use of alarming words but instead uses words that are simple and calming. According to the three-pathways-to-fear model, fear can be acquired through information transmission. Words like needle and pain put emphasis on these sensations and can trigger fear and anxiety responses. By making use of calming and neutral words, this can be avoided. During information transmission, the language must be coordinated with the content and what the paediatric patients are actually going to experience. Efficient preparation should manage expectations, organise predictability and avoid unexpected events (Mendels et al., 2022).

2.6 Design Opportunity

Paediatric patients with CHD need to visit the outpatient clinic on a regular basis their whole lives, often starting from early childhood. The three-pathways-to-fear model indicates that people can acquire anxiety and fear by means of conditioning. The literature shows that there is a correlation between the strength of the fear and the frequency with which the triggers of fear are encountered. Thus, in order to avoid the accumulation of (strong) hospital-related fears, it is important to employ fear-and-anxiety-reducing strategies as early as possible in the patient

journey. Therefore, the choice has been made to limit the age range of the initial target group to four to seven years old.

Children below the age of seven strongly rely on their parents to create an internal locus of control. In addition, this age group is especially focused on the behaviour of their parents (i.e. modelling). Thus, the behaviour of parents before and during the outpatient visit greatly influences how children experience their visit. These factors combined, make parents a crucial factor in fear-and-anxiety-reducing strategies for young children.

(Hyper)focus and pain are components of procedural distress that manifest themselves during medical procedures. Fear and anxiety are emotions that can be experienced before, during and after the hospital visit and without the presence or supervision of paediatric (healthcare) workers (HCWs). As a result, the responsibility of some fear-and-anxiety-reducing strategies shifts from the HCWs to the parents in the home situation. In contrast to paediatric HCWs, parents are generally not educated or trained to perform these fear-and-anxiety-reducing strategies.

The Hospital Hero application already supports parents with one previously discussed fear-and-anxiety-reducing strategy: preparation. At the time of writing, the majority of the offered preparation consists of a picture and short textual information about the procedure targeted at children. Children below the age of seven lack the cognitive skills to comprehend textual information. In addition, children below the age of seven are mainly concerned with their immediate sensory environment. The current Hospital Hero application provides limited information about this. Hence, insights obtained from the literature show that the offered preparation tools by the current Hospital Hero application can be improved.

All these insights combined resulted in the following design opportunity: Decrease hospital-related paediatric fear and anxiety by supporting parents in the home-based preparation of their children. The initial design assignment provided by the Hospital Hero foundation was transformed into the following research question:

How can design support children (between the ages of four and seven) and their parents in the home-based preparation process of an outpatient visit to the paediatric cardiology department?

By focussing on home-based preparation, the intervention has the potential to tackle all components of procedural distress. Preparation can contribute to a stronger bond of trust between children and HCWs (see 'Intervention strategies for pain'), as well as avoid (hyper)focus on the activities during the medical procedures.

Takeaways from this chapter

• Children aged four to seven are more concerned with the immediate sensory environment (fear) and are by nature less future-oriented (anxiety).

• Fear-and-anxiety-reducing strategies should be employed as early as possible to avoid a build-up of negative experiences (conditioning).

• Parents are a crucial factor in fear-and-anxiety-reducing strategies for children below the age of seven. This age group strongly relies on parents to create an internal locus of control. The behaviour of parents also greatly influences how children experience their outpatient visit (modelling).

• Fear and anxiety are emotions that can be experienced before, during and after the hospital visit and without the presence or supervision of paediatric HCWs. As a result, the responsibility of some fear-and-anxiety-reducing strategies shifts from the HCWs to the parents in the home situation.

• The design opportunity to support parents in the home-based preparation of their children (for an outpatient visit to the cardiology department) was identified in the literature. The following research question was defined: **How can design support children (between the ages of four and seven) and their parents in the home-based preparation process of an outpatient visit to the paediatric cardiology department?**

Chapter 3. Defining a Home-Based Preparation Approach

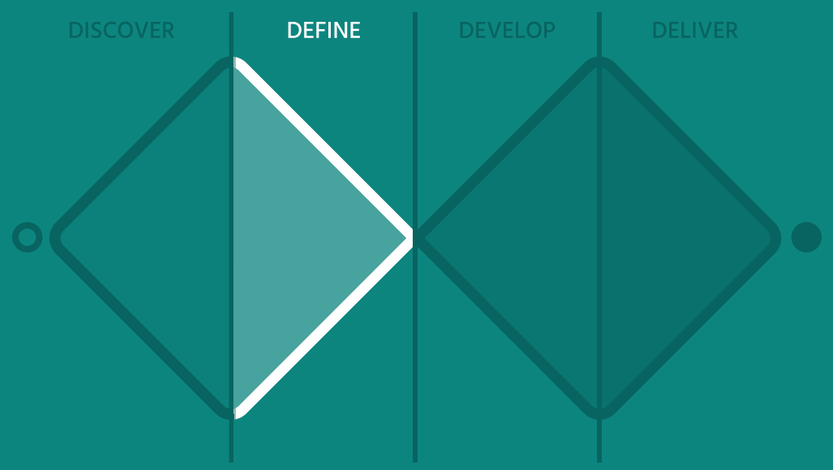
3.1 Study Purpose

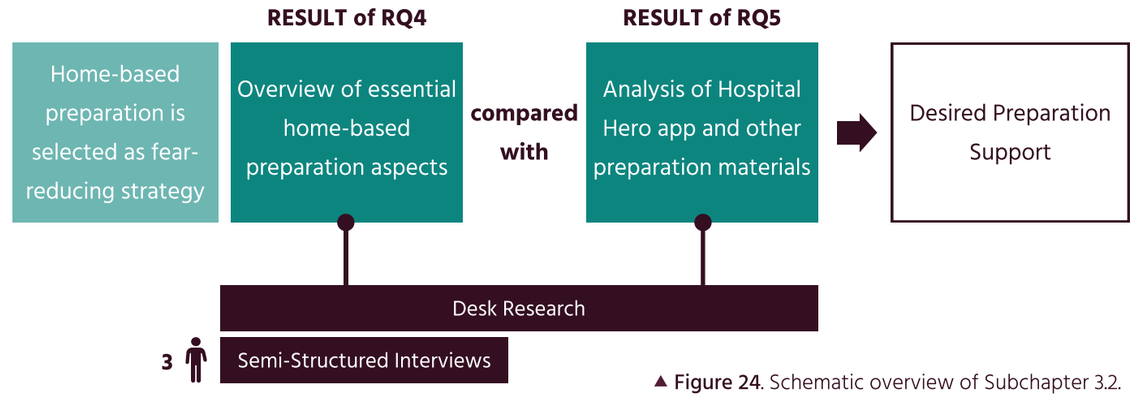
In the previous chapter, home-based preparation was chosen as the strategy to reduce fear. The aim of this chapter is to define a home-based preparation approach. First, the essential aspects of a home-based preparation approach recommended by paediatric experts are mapped. These essential aspects are compared with the current Hospital Hero application and other existing preparation materials. In addition, this chapter explores the barriers parents encounter during home-based preparation. This chapter answers the following research questions:

RQ4 – What are the essential aspects recommended by paediatric departments and professionals regarding the home-based preparation of paediatric patients?

RQ5 – How do existing preparation materials, including the Hospital Hero application, support parents during the home-based preparation of their child?

RQ6 – Which barriers do parents encounter when preparing their children for an outpatient visit?





▲ **Figure 24**. Schematic overview of Subchapter 3.2.

3.2 Recommended Preparation Aspects and Preparation Materials

This section maps out the essential preparation aspects that are advised by paediatric experts. The recommendations are analysed from the perspective of parents and compared to existing preparation materials. A schematic overview of this subchapter is visualised in Figure 24.

3.2.1 Methods

Desk Research

The aim of the desk research was to (1) find out how paediatric departments envision preparation at home and which aspects they deem essential during the preparation, and (2) map the existing preparation materials.

The official website of the Child & Hospital foundation was consulted (Kind & Ziekenhuis, n.d.). The recommendations about preparation featured on their website were established by certified paediatric experts. The website directly refers to three Dutch children's hospitals: (1) Wilhelmina Children's Hospital, (2) Emma Children's Hospital, and (3) Jeroen Bosch Hospital. All four websites featured a page with recommendations for parents regarding the preparation of paediatric patients for a hospital visit. The websites did not mention the type of hospital visit (e.g. admission or outpatient visit) or claimed that the recommendations were not affected by it. The provided information and recommendations about preparing children were gathered from the four web pages, colour-coded based on the origin of the source, and collected in one overview. The gathered information was clustered to filter out the essential aspects of home-based preparation, see Appendix B.

All websites suggested the use of preparation materials. These recommendations were the starting point for mapping existing preparation materials. Explorative and randomised reviews of online sources were conducted to find additional materials. The desk research was not limited to only cardiology-related preparation materials.

Semi-Structured Interviews with Paediatric Experts

Paediatric experts employ preparation methods as a fear-and-anxiety-reducing strategy for children who need to undergo surgery. The aim of the semi-structured interviews was to explore the preparation strategies these experts employ to extract knowledge from and draw connections to preparation in the home situation.

The semi-structured interviews were conducted with one paediatric clinical psychologist and two medical pedagogical care workers. The interview protocol can be found in Appendix C. Each interview took between 30-60 minutes and was conducted face-to-face. Audio recordings were made and/or notes were taken during the interviews.

3.2.2 Recommended Home-Based Preparation Aspects

RQ4 - What are the essential aspects recommended by paediatric departments and professionals regarding the home-based preparation of paediatric patients?

The essential aspects of home-based preparation are clustered into four categories. Each category is described below.

Method of Preparation

Before parents start to prepare their children, paediatric experts and departments recommend that parents educate themselves: "First, make sure you know exactly what will happen during the appointment or admission of your child" (UMC Utrecht, n.d.). Paediatric departments mainly provide recommendations about (non-)verbal communication approaches between parent and child. The use of supporting preparation materials is recommended for younger children if they do not understand verbal explanations. More information about these supporting materials can be found in section 3.2.3.

In Chapter 2, it was discovered that the behaviour and body language of parents can influence the hospital experience of their children. Paediatric experts recommend paying attention to the following things during the preparation process: staying calm, exuding confidence, and avoiding a negative tone of voice and extreme facial expressions. Guidelines on how to achieve these things are not mentioned.

Paediatric departments and experts of the WACH advised using Comfort Talk (see section 2.5.3) when preparing children for a hospital visit. All websites refer to additional materials that explain Comfort Talk and how parents can utilise this.

Details of Explanation

From primary school onwards (i.e. four years and older), paediatric departments recommend discussing and visualising the hospital experience in concrete terms (Stichting Kind & Ziekenhuis, n.d.). The WACH experts agreed: "All the small steps they go through, not just the actions of the healthcare professionals. So also, for example, when the children have to undress". However, knowing that hyperfocus can trigger fear responses and can result in the perception of pain, one WACH expert explains that parents should be careful when providing details: "Preparing children for [the steps of the] procedure might put more focus on the actions and thus might not be desirable in some cases".

Furthermore, parents are advised to prepare their children for everything they will consciously experience, see, feel, hear, smell or taste. The four websites do not go into more detail about these aspects. When parents want to comply with this advice, they need to find the information themselves. In contrast, parents are advised to be cautious in their explanations, avoiding conceived notions and assumptions of what the child may experience. A WACH expert explained the following: "Everyone experiences things differently. So you shouldn't describe how something is going to feel, because we don't know that".

Timing and Interval of Preparation

Children have a different sense of time than adults; they live in the here and now (UMC Utrecht, n.d.). Therefore, paediatric departments and experts recommend starting preparation shortly before the hospital visit. The appropriate duration of this preparation period depends on the age and the characteristics of the child. Some children prefer to be prepared on the day itself, while other children need more time to process the information. Parents are encouraged to consider the characteristics of their children before deciding on the timing. A medical pedagogical care worker provided more specific details: "For 4-6 year-olds, preparation must be done shortly before the hospital visit, often on the day itself. With older children, preparation can often take place a little earlier. Then we're talking about one day in advance".

Paediatric departments and experts encourage parents to repeat the information multiple times over small intervals. Especially for younger children, repetition is important and can avoid (the anticipation of) imaginary fears.

Providing the Child with a Feeling of Control

Besides information transmission, preparation should also consist of making achievable agreements with the child about certain controllable aspects. The website of the Wilhelmina children's hospital provided the following recommendation: "Discuss at home how you can help your child during the hospital visit, think of holding his hand or telling a story" (UMC Utrecht, n.d.). No other examples of 'achievable agreements' are provided.

3.2.3 Existing Preparation Materials

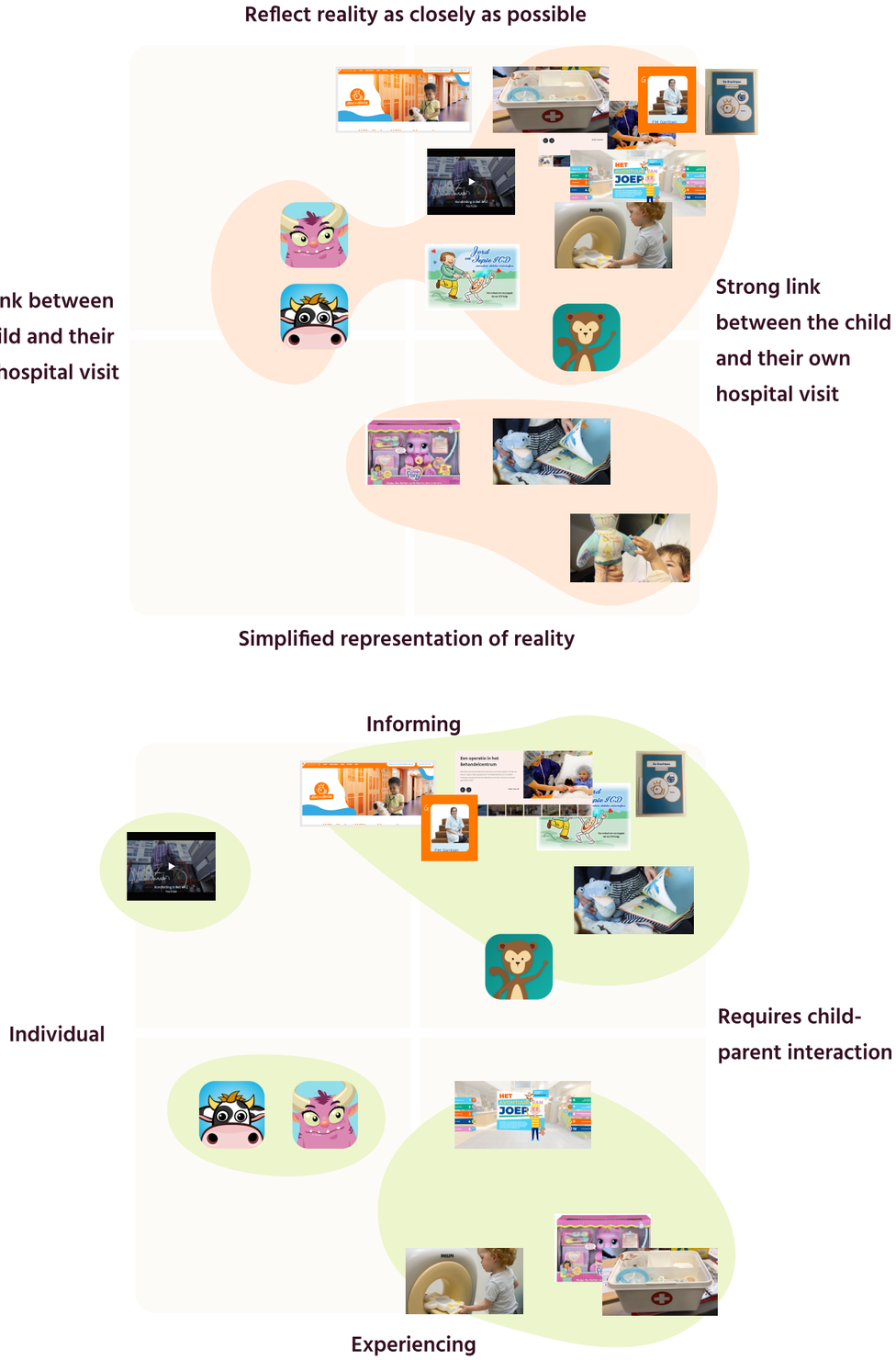
RQ5 – How do existing preparation materials, including the Hospital Hero application, prepare children for their hospital visits?

All paediatric departments recommended preparation materials to support the verbal explanations of parents. These preparation materials included reading books, pictures, informative movies, hospital-related applications, (toys resembling) medical equipment, and web pages specifically designed for children. An overview of these materials can be found in Appendix D.

In order to get a general understanding of how the existing materials can support verbal explanations, all materials were sequenced on two opposite axes, see Figures 25 and 26. Preparation tools either seem to support verbal communication by additional child-friendly information in the shape of visuals, audio or video, or by experiencing hospital-related stimuli. The materials that help children experience stimuli focus on two senses: sight and touch. Smell, hearing, and taste are often not discussed in the preparation materials.

The majority of the preparation materials reflect the reality of the hospital visit as closely as possible. The preparation materials make use of actual photographs, realistic descriptions, or tools closely resembling the actual equipment.

Finally, most of the materials require child-parent interaction to transform the information into meaningful preparation. Most of the materials do not provide guidelines for parents about how to transform this information.



▲ **Figures 25-26**. Existing preparation materials were clustered and sequenced on opposite axes. All mapped preparation materials can be found in Appendix D.

The Hospital Hero Application

Figure 27 visualises aspects of the Hospital Hero application that meet the recommended preparation aspects (defined in section 3.2.2) as well as points out aspects that can be improved according to the recommendations.

Similar to the majority of analysed existing preparation materials, the Hospital Hero app does not provide parents with preparation guidelines.



▲ **Figures 27**. Analysis of the Hospital Hero application.

3.2.4 Conclusion

Answering RQ4 resulted in an overview of the essential preparation aspects, which were analysed from the perspective of parents. These insights were compared with the results of RQ5. This in-depth analysis resulted in the accumulation of the following design opportunities that can support home-based preparation:

• Supporting parents during the preparation process

A noteworthy insight of the performed analysis was the overall generalisation of the suggested preparation approach. Recommendations about how to personalise the preparation specific to the situation of the child in question were (often) not mentioned. As a result, parents need to figure out themselves how to interpret and combine these recommendations with the specifications of their child's hospital visit. Hence, the opportunity was found to support parents in the preparation process, not only when preparing their child, but also when preparing themselves. Section 3.3 further examines the problems parents encounter during the preparation process, in order to customise the support.

• One preparation tool that can be used by both the parent and child

Most of the existing preparation materials support verbal explanations by parents but do not provide parents with information. In order to provide verbal explanations, parents need to educate themselves with another medium, such as internet searches. Therefore, in the current situation, a mismatch can occur between the information obtained by the parent and the intended use of the preparation material. To support home-based preparation, a preparation tool should be designed that can be used by both the parent and child.

• Providing customised preparation

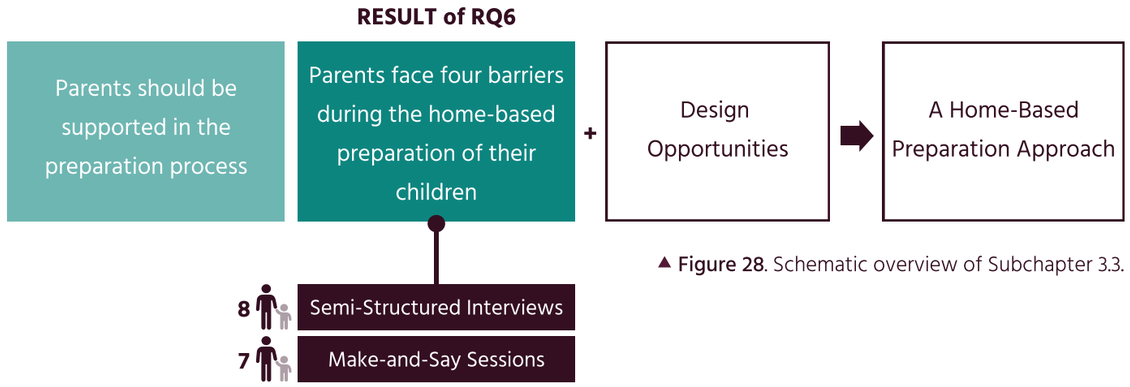
Paediatric experts emphasise that every paediatric patient and their situation is unique and requires a customised preparation approach. Hence, a stand-alone generalised preparation tool will therefore not reach the desired goal. To allow for customised preparation, the to-be-designed preparation tool should encourage parents to add information based on the innate knowledge they possess about their children.

• Providing parents and children with context-specific details and sensory information about the outpatient visits

During the preparation of paediatric patients, it is important to mention context-specific details and sensory information. The current Hospital Hero application provides general information about the procedures and highlights concrete steps of the entire hospital visit, but does not provide the details recommended by paediatric experts. Chapter 4 will explore the hospital experience in depth to map the context-specific details of an outpatient visit to the cardiology department from a child's perspective. By providing this information to both the parent and child, parents can also make achievable agreements with their child.

3.3 Barriers Faced in Home-Based Preparation

This section maps the barriers parents encounter during the home-based preparation of their children. These insights were combined with the previously defined design opportunities, ultimately resulting in the generation of a home-based preparation approach. A schematic overview of this subchapter is visualised in Figure 28.



▲ **Figure 28**. Schematic overview of Subchapter 3.3.

3.3.1 Methods

The aim of the employed methods was to collect insights into the practised preparation methods and the corresponding problems parents encounter during the home-based preparation of their children.

Make-and-Say Sessions with Parents

A make-and-say session is a qualitative research technique where respondents are provided with (physical) tools to help explain themselves and/or support idea generation (Van Boeijen et al., 2020).

The sessions were conducted during an organised event titled 'Discover the secrets of the hospital'. The purpose of the event was to show and have children experience what the WACH offers paediatric patients in terms of anxiety and fear reduction. The event was held at the BplusC Library in Leiden, Netherlands. Parents and children could voluntarily participate in the make-and-say sessions during this event. The respondents were either presented with a hospital-related question or a general open question (see Appendix E1), contingent upon their experience with hospitals. The parents were asked to draw or write down their answers to the question followed by a more in-depth conversation about their practised preparation approach.

In total, seven parents participated in the make-and-say sessions. An overview of the respondents and the corresponding age of their child can be seen in Table 3. Quotes and notes were documented during the session and the created materials were collected afterwards. All materials can be found in Appendix E2.

RESPONDENT	CHILD
Mother (n=6)	3 y.o.
	4 y.o.
	6 y.o.
	>18 y.o.
Father (n=1)	6 y.o.

▲ **Table 3**. Respondents of the make-and-say sessions.

Semi-Structured Interviews

Seven parents were approached in the outpatient clinic of the WACH. After verbal approval, a semi-structured interview was conducted face-to-face. Depending on the preferences of the respondents, the session was either held in a private location or in the general waiting room of the WACH. In depth-questions were asked about home-based preparation and the corresponding effects on

the hospital experience of their child. Each session took between 10-15 minutes. Notes and possible quotes were anonymously collected and written down.

One parent of an 8-year-old CHD patient was recruited via email, followed by a semi-structured interview of approximately one hour. The interview was conducted online by means of video calling. In-depth questions were asked about the practised home-based preparation and the used preparation materials. The interview protocol can be found in Appendix F.

RESPONDENT	CHILD
Mother (n=5)	3 y.o.
	6 y.o.
	7 y.o.
Mother (n=1)	8 y.o.
Father (n=2)	4 y.o.
	6 y.o.

▲ **Table 4.** Respondents of the semi-structured interviews.

Data Analysis

The gathered insights from the make-and-say sessions and the semi-structured interview were analysed following the context mapping principle (Sanders & Stappers, 2012). The gathered information (i.e. quotes, notes and make-and-say materials) was collected in the form of statement cards. These statement cards contain the original quote of the respondent and a corresponding interpretation made by the researcher. All cards were colour-coded based on the method used to obtain the information. First, all cards were clustered based on the method by which the information was obtained, creating two overviews. During the second iteration, the overviews and corresponding clusters were merged. Insights obtained from the semi-structured interviews with paediatric experts (see section 3.2) were added to these clusters. The entire process required multiple iterations. The finalised clusters can be found in Appendix G.

3.3.2 Results

RQ6 – Which barriers do parents encounter when preparing their children for an outpatient visit?

Based on the data analysis, four barriers were found. The following sections detail each barrier.

1. Not being able to find (the right) information

Parents that were aware of the benefits of preparation, shared that they feel the need to educate themselves first before providing information to their children. Some parents reported that they struggled with finding information about the procedures and the activities performed during a procedure. "Oh I didn't know that [a hospital-related website for children] existed, I've been looking for it though". Parents also mentioned struggling with finding the correct information. Parents expressed their concerns about unnecessarily burdening their children with incorrect explanations. Parents report that when the preparation differs from reality, it evokes fear and confusion, making them hesitant in sharing information at all.

In addition, parents indicated that they do not know in advance which procedures are going to take place: "In all those years, the hospital has never provided any information about the procedures that will happen during her outpatient visit." This uncertainty makes it difficult for parents to prepare their children for a hospital visit.

2. Not knowing what information to share

Parents reported struggling with the number of details they need to share with their children. Multiple respondents explained that when they prepare their children, they tend to leave out details since they believe too many details can evoke unnecessary anxiety. In contrast, experts recommend preparing children for every detail (see section 3.2.2). This insight shows a juxtaposition between the recommended way to prepare children and the practised preparation methods.

Additionally, parents reported feeling conflicted about providing honest information. Explaining to your child that something might hurt or be uncomfortable feels bothersome and sometimes unnecessarily cruel. Especially when children have experience with the medical procedure, neglecting to tell if something is going to hurt feels like lying. "You cannot say that it will not hurt, because if it hurts, even just a little bit, the child thinks you have lied."

3. Not knowing how to share the information

The majority of the parents indicated that the foremost practised preparation method is verbal explanation. More than half of the respondents (8 out of 14 parents) reported limited/no use of supporting preparation materials. When providing verbal explanations (without supporting materials), parents encountered problems with translating the found information into child-friendly preparation: "But that's information I provide myself, so it might not be told in a way that would suit a young child, you know, that pedagogical touch that makes information more pleasant to hear".

4. Lack of emotional guidance during the preparation process

The last problem parents encountered during the preparation process is the lack of emotional support. Parents acknowledged that their emotional status during preparation influences how their children anticipate and engage in the hospital visit (i.e. modelling). During the semi-structured interviews, some parents reported being nervous before and during the hospital visit. These parents indicated that they missed emotional support and guidance during the preparation process.

"Yes, you know, parents also have to deal with all the accompanying emotions. I also needed EMDR therapy after the entire process, […]. Better information provision from the hospital would have helped."

3.3.3 Conclusion

From the literature and desk research, we know that young children (i.e. between two and seven y.o.) strongly rely on their parents in terms of preparation. As a result, the quality of the preparation children receive partially depends on how well parents are prepared themselves. During the home-based preparation process, parents encounter four barriers: (1) Not being able to find the right information, (2) not knowing what information to share, (3) not knowing how to share the information, and (4) a lack of emotional guidance. To accommodate these barriers, the to-be-designed preparation tool should provide parents with context-specific information as well as support them with translating (the obtained) information in a child-friendly manner. This home-based preparation approach is described in the following section.

3.4 A Home-Based Preparation Approach

The defined home-based preparation approach is visualised in Figure 29. The approach consists of four interaction arrows and a preparation tool visualised as a black box. It is important to note that the preparation tool is encompassed in the interaction system between parent and child, thus minimising the change of the tool becoming a stand-alone preparation method.

Preparing the Parent 🟢

In order for parents to prepare their children, they should be prepared themselves. Based on the insights and barriers found in the previous sections, this interaction arrow has to prepare the parent in three domains:

1. (Practical) Information provision
2. (Emotional) Support to step into the role of the preparer
3. Communication guidelines

Preparation by the Parent 🔵🟡

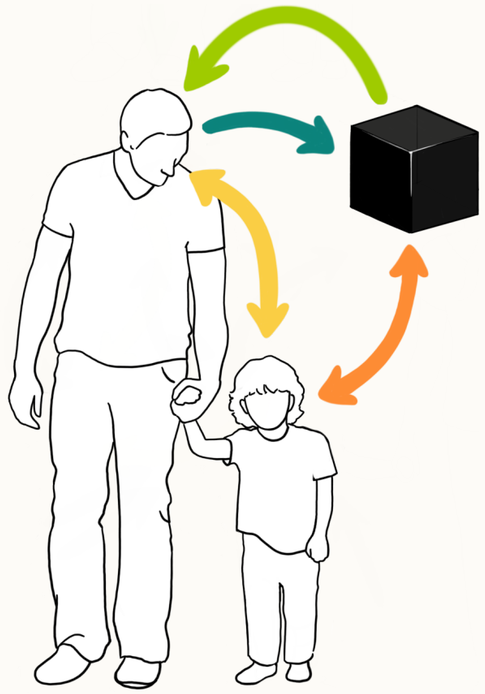
These two interaction arrows refer to the customised input of the parent, making use of the innate knowledge parents possess about their child. Together with the provided knowledge obtained during the previously described interaction, parents can provide additional and customised information during the preparation of their child. The dark green interaction arrow refers to the input of parents into the black box. For example, when parents notice that their child does not understand the information provided by the tool, they can step in.

Previous insights indicate that preparing young children should not consist of one moment, but rather multiple moments spread over several time intervals. The preparation approach, therefore, includes the yellow interaction arrow. This interaction arrow refers to small child-parent interactions without the active use of the preparation tool. These interaction moments are made possible by 'Preparing the Parent'. Examples include explaining that they will visit the outpatient clinic tomorrow while biking, or making references between the hospital visit and things they encounter in daily life.

Preparation of the Child 🟠

The final interaction arrow refers to the preparation of the child by means of the black box and the customised input provided by the parent.

This home-based preparation approach functions as the baseline for the remainder of the project. The preparation tool should prepare parents and paediatric patients for their outpatient visits with context-specific details. These details are mapped in Chapter 4.



▲ **Figure 29**. The defined home-based preparation approach.

3.5 Limitations

Desk Research

The explorative and randomised Google searches might not have resulted in a realistic overview of all existing preparation materials. In addition, some preparation materials were only accessible to paediatric patients and their parents (e.g. by logging into a patient portal). Therefore, the overview of existing preparation materials might be incomplete.

Make-and-Say Sessions

A limitation of the make-and-say sessions was the recruitment process during a hospital-related event where the importance of preparation was emphasised. This might have resulted in an overall more positive outlook on preparation.

Semi-Structured Interviews

A limitation of the semi-structured interviews was the timing. The majority of the respondents were approached in between the medical procedures of their children. Hence, the length of the interview was contingent upon the fluctuating amount of waiting time between appointments. In addition, the timing of the interviews did not allow for personal reflection prior to answering the questions. The discussed topic (i.e. preparation) is somewhat abstract, making on-the-spot answers difficult.

Takeaways from this chapter

- The recommendations provided by paediatric departments about preparation are general. Parents need to figure out themselves how to interpret and combine these recommendations with the specifications of their child's hospital visit.

- Every paediatric patient and their situation is unique and requires a customised preparation approach. Hence, a stand-alone generalised preparation tool will therefore not optimally prepare children.

- The current Hospital Hero application provides general information about the procedures and highlights concrete steps of the hospital visit, but does not provide the details recommended by paediatric experts.

- Parents encountered four barriers when preparing their child for a hospital visit, including (1) not being able to find (the right) information, (2) not knowing what information to share, and (3) how to share the information, and (4) a lack of emotional guidance during the preparation process.

- All aforementioned insights resulted in the generation of a home-based preparation approach. This approach consists of three interactions and a preparation tool. The three interactions include: (1) Preparing the parent, (2) Preparation by the parent and (3) Preparation of the child.

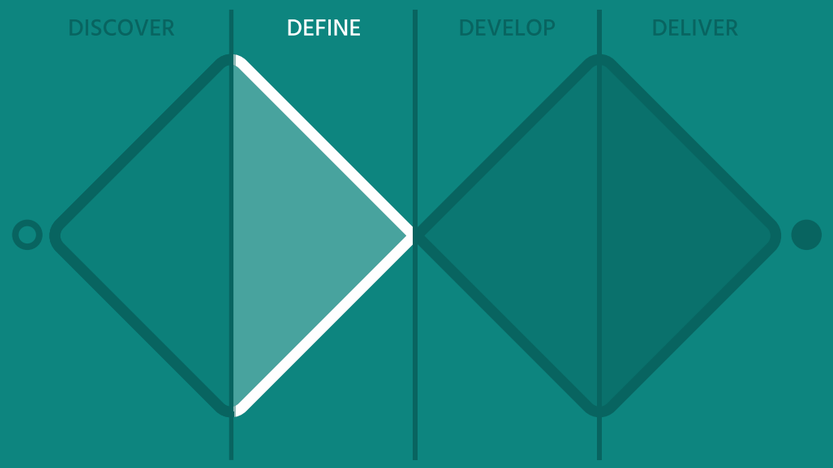
Chapter 4. Mapping the Hospital Experience

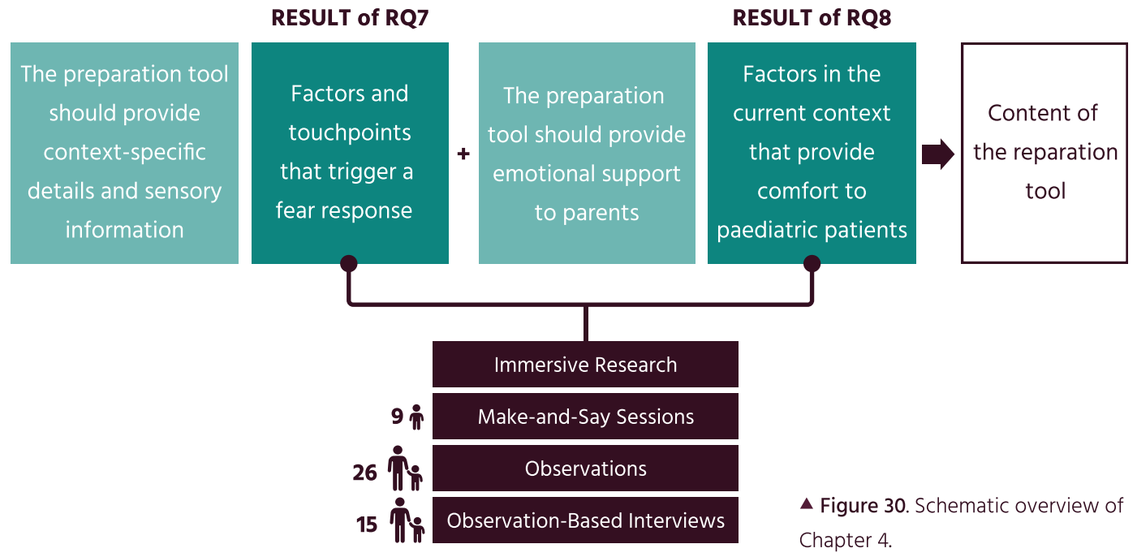
4.1 Study Purpose

In the previous chapter, a home-based preparation approach was defined. This chapter explores the hospital context and maps the experience from the perspective of paediatric patients between the ages of four and seven. The explorations focus on the triggers of fear as well as comforting elements. These insights resulted in the content of the to-be-designed preparation tool. The following research questions were answered:

RQ7 – Which factors and touchpoints of an outpatient visit to the WACH trigger a fear response in children between the ages of four and seven?

RQ8 – Which factors in the current context provide comfort to paediatric patients during their outpatient visits to the cardiology department of the WACH?





▲ **Figure 30**. Schematic overview of Chapter 4.

4.2 Methods

4.2.1 Immersive Research

The aim of this immersive research was to obtain a deeper understanding of how it is to experience medical procedures intended for paediatric cardiac patients.

The medical procedures I experienced were blood pressure and blood saturation measurements, needle insertion with and without local analgesia, and the experience of electrocardiogram and echocardiogram stickers on my skin. These medical procedures were carried out by paediatric healthcare workers in the same treatment rooms intended for paediatric patients. Besides medical procedures, I also experienced several distraction methods that are currently used to reduce anxiety and fear in the WACH, such as a VR headset, the Buzzy, and playing equipment like the balancing bird.

These insights are not reported and were only used as a tool to support the design process, in order to avoid misconceptions or possible mix-ups between the perspective of paediatric patients and my own experiences.

4.2.2 Make-and-Say Sessions with Children

The aim of the make-and-say sessions was to create an understanding of hospital-related fears and comforting elements based on the perspective of children. The make-and-say sessions were conducted with nine children between the ages of six and ten, during the same event described in section 3.3.1.



▲ **Figure 31**. A picture taken during the make-and-say sessions with children.

Respondents were either presented with a hospital-related question or a general open question (see Appendix E1), contingent upon their experience with healthcare institutions. Depending on their age, the respondent was either asked to draw or write down their answer to the question themselves followed by a more in-depth conversation or the question was read out loud, followed by an interactive conversation about the topic. Quotes and notes were written down during the session and the created materials were collected afterwards, see Appendix E3.

RESPONDENT	HOSPITAL EXPERIENCE
3 y.o.	no
5 y.o.	no
6 y.o.	being vaccinated (n=1)
7 y.o.	family doctor
9 y.o.	no
10 y.o.	outpatient clinic

▲ **Table 5**. Respondents of the make-and-say session with children.

4.2.3 Observations

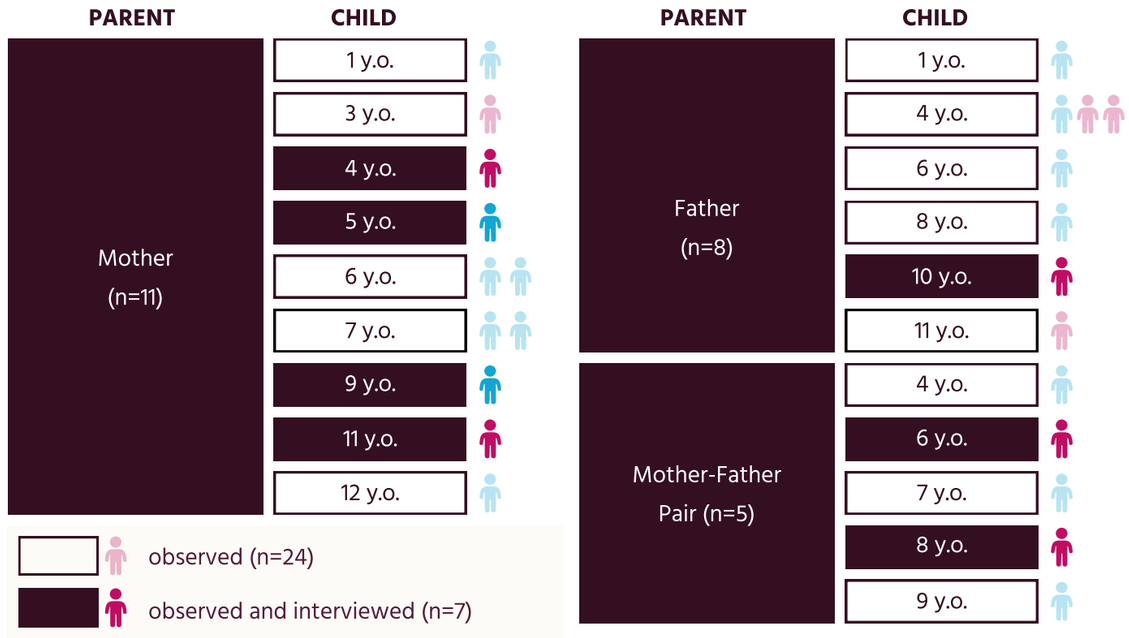
The aim of this research method was to (1) map out the touchpoints children encounter during a visit to the outpatient clinic, and (2) explore how these touchpoints, interactions and other factors of the outpatient visit affect the experience of the paediatric patients and their parents.

In consultation with the treating physician and other involved healthcare workers of the WACH, paediatric patients that fit the target group (i.e. children with congenital heart disease around the age of four to seven) were selected. After verbal approval of the parents and when possible the approval of the child, first-hand observations were carried out. In total, 24 paediatric patients were observed during (parts of) their outpatient visit to the paediatric cardiology department of the WACH (see Table 6). It was possible to be present in the treatment rooms, allowing for close observations of the different steps of the medical procedures and corresponding patient reactions, patient-HCW interactions, and child-parent interactions. Notes and possible quotes were anonymously collected and written down. Pictures of the room and medical equipment were taken, making sure no patients, parents or healthcare workers were in the frame.

4.2.4 Observation-Based Interviews

The aim of these observation-based interviews was to get a more in-depth understanding of how paediatric patients (and their parents) experience an outpatient visit.

Based on the observations and time management of the hospital appointment, 7 out of the 24 observed child-parent pairs were approached in the waiting room between check-ups or after the consultation with the treating physician, see Table 6. After verbal approval of the parents and when possible the approval of the child, short informal interviews based on the observations were carried out. Questions such as "I noticed that you did not like the echo, can you maybe explain why?" were asked of the child. Depending on the answers, probing questions followed. More in-depth questions about the observations and corresponding emotional status of the child were asked of the parents. The age of the child, notes and possible quotes were anonymously collected and written down.



▲ **Table 6**. Overview of the child-parent pairs that were observed and interviewed.

4.2.5 Data Analysis

All materials and insights from the previously described methods were analysed following the context mapping principle. The obtained information was collected in the form of statement and observation cards. Statement cards contain the original quote of the respondent and a corresponding interpretation. Observations cards contain the interpretation of the situation or emotional status of the respondents.

All cards were colour-coded based on the source of the information: HCW, parent or child. Additionally, the cards were colour-coded based on the method used to obtain the information. First, all cards were clustered based on the method in which the information was obtained, creating two overviews of the insights obtained by (1) the make-and-say sessions and (2) the observations and observation-based interviews. During the second iteration, the cards were divided into two categories based on their content: (1) cards related to fear, and (2) cards related to comforting elements. Next, all cards within the categories were clustered based on their theme. This process took multiple iterations. The process and finalised clusters can be found in Appendices H and I.

4.3 Outpatient Visit to the Paediatric Cardiology Department of the WACH

The previous chapter established that the to-be-designed preparation tool should provide context-specific details and sensory information about the outpatient visit. This sub-chapter maps out the general context of the outpatient clinic of the WACH and explores the triggers of fear. In order for the preparation tool to provide emotional support, this sub-chapter explored the comforting elements associated with an outpatient visit from the perspective of children.

4.3.1 Context

The medical procedures of a general outpatient

visit include weight- and length measurements, blood pressure measurements, saturation measurements, an electrocardiogram (ECG), and an echocardiogram. The procedures are followed up by a consultation with the treating physician who interprets the results of the procedures. The procedures that are performed during an outpatient visit depend on the age, health status, and medical history of the paediatric patient. This means that an outpatient visit to the cardiology department looks different for every child and can vary over time for the same patient.

The WACH divides the check-up procedures over different treatment rooms. When all procedures are necessary, a paediatric patient will see five different rooms, including the waiting room (demarcated with purple in Figure 32), and at least four different healthcare workers. Before and in between the medical procedures, paediatric patients and their parents have to wait in the general waiting room. They are notified by a digital screen and a notification sound that it is their turn to enter one of the treatment rooms. The WACH organises outpatient visits in a set order. First, paediatric patients are scheduled to undergo procedures connected to the teal room, followed by the red room, and then yellow (see Figure 32). Due to the needed flexibility of working with people, the collaboration of multiple healthcare workers, and ad-hoc situations, the set order might differ. The outpatient visit is always concluded with a consultation in the green room.

Inside the different treatment rooms, paediatric patients come in contact with a range of different touchpoints, visualised in Figures 33-40. Senses related to the touchpoints are visualised with icons. The actions paediatric patients actively need to perform are summarised for each treatment room.

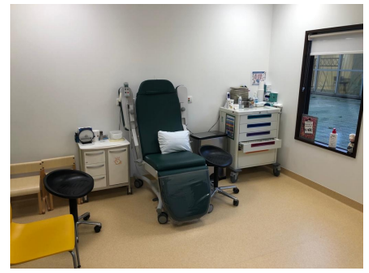
BLOOD SAMPLING

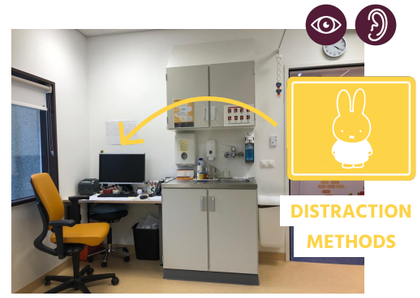
A paediatric healthcare worker puts a tourniquet around the arm of the patient, while their arm rests on a pillow, chair or comfortably at their side. When applicable, band-aids with local analgesia are removed (with adhesive dissolvent). The area of the skin is cleaned with disinfectant before the HCW inserts the needle in the arm/finger of the patient. Tubes are filled with blood, whereafter the penetration mark is covered up with a bandaid. Paediatric patients can choose to be actively distracted by materials present in the room.

Remove clothing if applicable - Remove local analgesia bandages - Climb on the examination table - Choose a distraction method

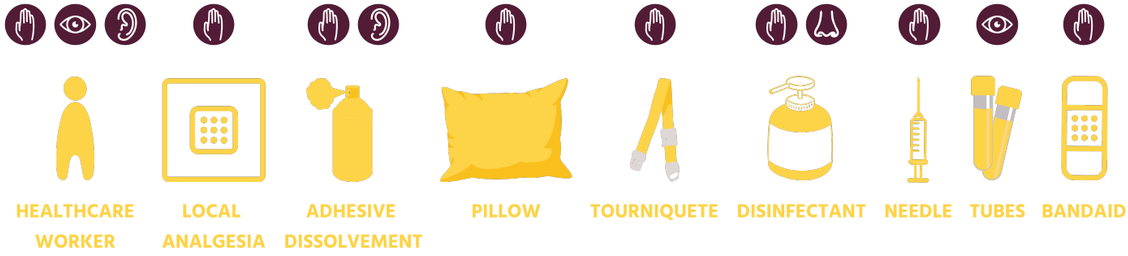


▲ **Figure 33**. A WACH treatment room where blood sampling takes place.





▼ **Figure 34**. Touchpoints of blood sampling.





▲ **Figure 35**. A WACH treatment room where the consultation with the treating physician takes place.



Figure 32. Schematic blueprint of ▶ the outpatient clinic of the WACH.

Figure 36. Touchpoints of the consultation with the physician. ▶

CONSULTATION

The treating physician examines the patient's heart with a stethoscope, explains the test results, informs about the (social, cognitive and physical) progress of the patient, and answers possible questions. Follow-up steps are discussed and when applicable, a hospital appointment is made.

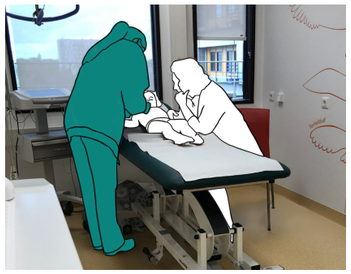
Undress/get dressed - Climb on the examination table - Ask and/or answer possible questions



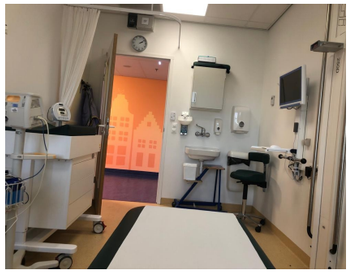
ELECTROCARDIOGRAM & OTHER MEASUREMENTS

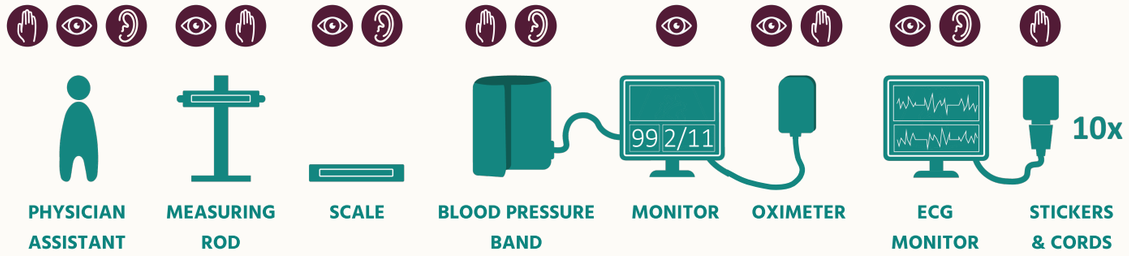
In this room, multiple procedures can be performed: ECG, weight-, length-, blood pressure-, and saturation measurements. The length and weight of the patient are measured with a scale and measuring rod. For the ECG, a physician assistant (PA) places 10 ECG stickers on the chest, arms and legs of the patient and connects them to cords. Blood pressure is measured by applying a band around the upper arm of the patient. Saturation measurements are taken via a small device clipped to the pointer finger of the patient.

Undress/get dressed - Step on the scale/under the measuring rod - Climb on the examination table - Lie and/or sit still (ECG, blood pressure) - Remove stickers (ECG)



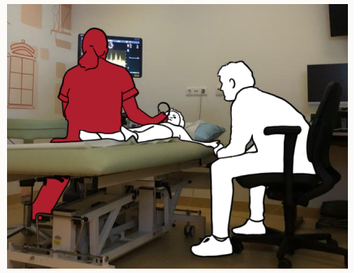






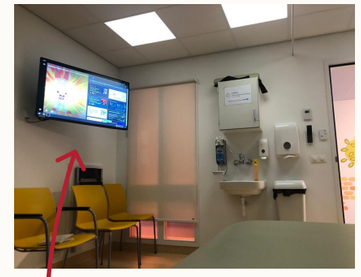
◀ **Figure 37**. A WACH treatment room where ECGs take place.

▲ **Figure 38**. Touchpoints of this treatment room.

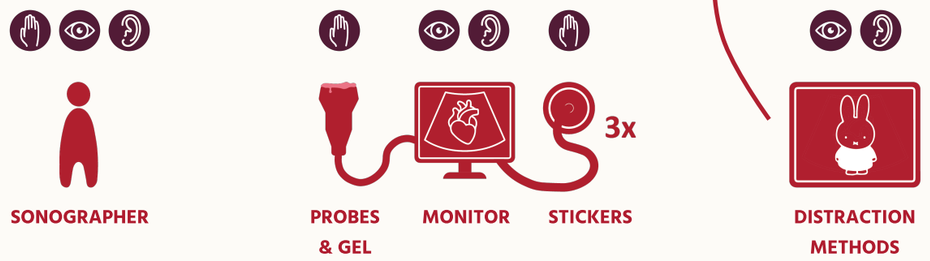


▲ **Figure 39**. A WACH treatment room where echos take place.





▼ **Figure 40**. Touchpoints of an echocardiogram.



ECHOCARDIOGRAM

A sonographer physically examines where to put three echo stickers on the chest of the patient. Next, the sonographer connects three corresponding cords to these stickers. The sonographer applies gel on an echo probe and/or directly on the skin of the patient. Whereafter, he/she presses the probe against the chest of the patient in different positions and angles. Meanwhile the patient can interact with different distraction methods present in the room.

Undress/get dressed - Climb on the examination table - Choose a distraction method - Change positions based on the directions of the sonographer - Remove stickers - Remove gel from chest

4.3.2 Triggers of Fear

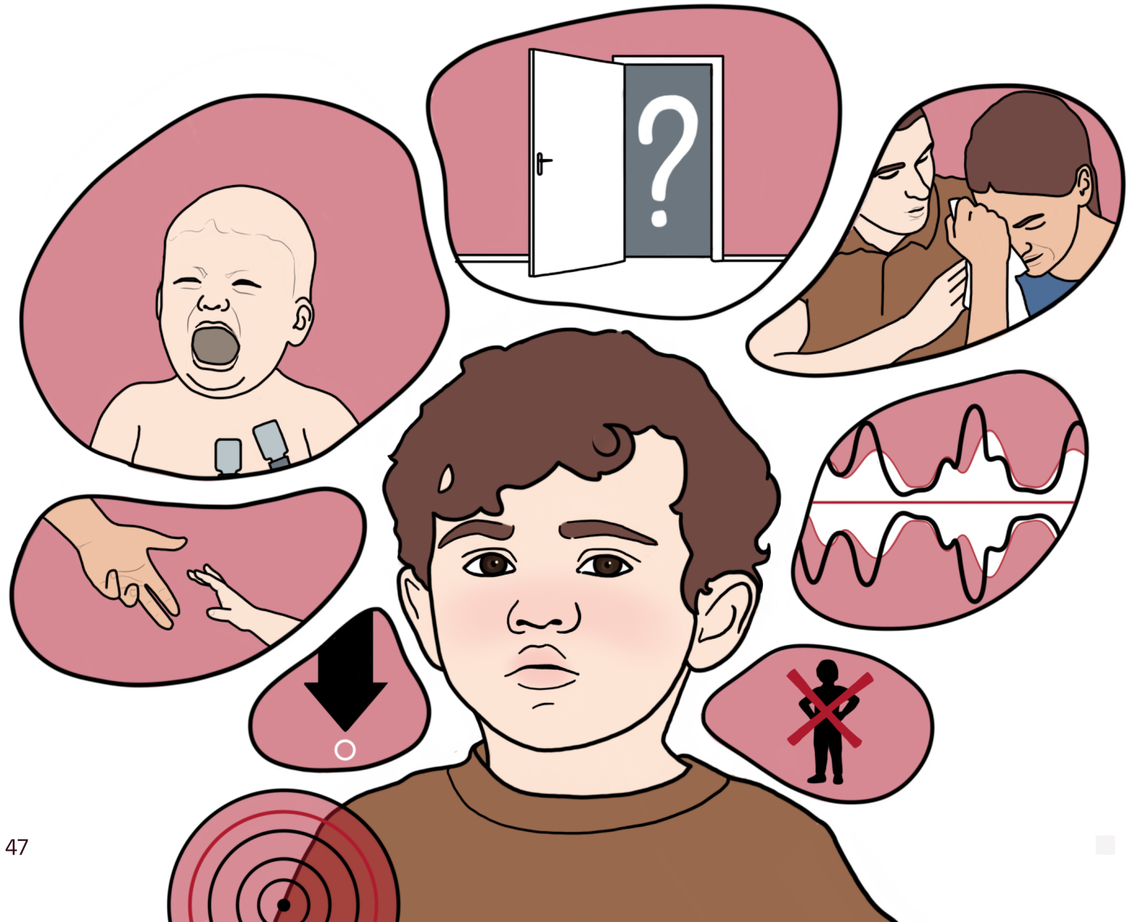
RQ7 – Which factors and touchpoints of an outpatient visit to the WACH trigger a fear response in children between the ages of 4 and 7?

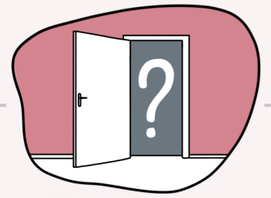
Figure 41 summarises the results. The observed and/or reported triggers of fear have been clustered into eight categories (from left to right):

1. Procedures that are (perceived as) painful
2. Hyperfocus
3. Being (left) alone
4. Knowing (from experience) that something unpleasant is going to happen
5. Not knowing what will happen
6. Distress of parents
7. Unexpected and unfamiliar stimuli
8. Not feeling in control

From these eight clusters of fears, three can be relatively easily tackled by means of preparation: (1) Distress of Parents, (2) Not knowing what will happen, and (3) Unexpected and unfamiliar stimuli. Hence, these categories were selected as a framework for the content of the preparation tool. The following paragraphs will go into more depth about these three categories. Appendix H can be consulted about the remaining categories.

▼ **Figure 41**. Overview of the observed and/or reported triggers of fear before and during a visit to the outpatient clinic. The content of the visual is based on the insights reported in Appendix H.





Not knowing what will happen

"This is the scariest thing for me because I've never done this before" (5 y.o. boy).

One of the major triggers of fear that was observed and reported was not knowing what would happen inside the treatment rooms. Due to the cognitive level of young children, previous hospital experiences might be forgotten or altered due to their rich imagination. Children visiting the hospital for the first time have no references at all. Entering a room without knowing or clearly remembering what it looks like inside can be scary for many children. During an outpatient visit, paediatric patients might need to enter up to four different treatment rooms in a relatively short time.

"What is that [ECG stickers]?" (6 y.o. boy)

Almost all touchpoints mapped in the previous section, triggered fear responses at least once during the observations. Touchpoints that came in immediate contact with the paediatric patient, i.e. the touchpoint is clearly felt on the skin, were observed to trigger the most (extreme) fear responses. These touchpoints include a needle, a stethoscope, an echo probe, a blood pressure band, and medical stickers. The derived reason behind this fear was not knowing or recognising the touchpoint resulting in the anticipation of something unpleasant.

"Are we going to wash away the gel?" (7 y.o. boy)

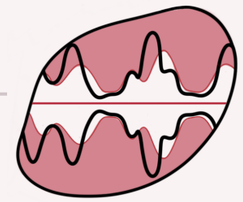
Paediatric patients also verbally expressed their fear of object permanence; not knowing if medical attachments would be removed before going home.



Distress of parents

"This is our first time in the hospital, so we are a bit nervous" (Father of a 10 y.o.)

As explained in Chapter 2, the emotional status of parents before, during, and after hospital visits is a crucial factor in the fear reduction for paediatric patients since children naturally mirror their behaviour to that of their parents (i.e. modelling). During the first-hand observations, parents were observed to show physical signs of anxiety. Parents that reported feeling anxious pinpointed three main reasons: (1) Not knowing what to expect, because it was their first time visiting the outpatient clinic; (2) Expecting bad news about the health status of their child, or; (3) Observing and/or the expectation that their child would experience procedural distress.



Unexpected and unfamiliar stimuli

"I don't want a vacuum cleaner [ECG cords]". Mother reassures her child: "No, nothing is going to make noise." (Mother of a 3 y.o.)

One of the developmental fears of children between the ages of two and seven is unfamiliar and excessive stimuli. This developmental fear was observed and reported to be triggered by three main factors: (1) The conductive gel used during an echocardiogram; (2) Unexpected noises originating

from medical equipment, and; (3) A large contrast between the amount of light.

The gel is generally described as cold and startles paediatric patients when it comes in contact with their skin. The most observed fear trigger in terms of sound was the echocardiogram monitor emitting (mechanical) sounds of the heartbeat of the patient. These sounds are not constant and start unannounced. Other noteworthy sounds originating from (medical) equipment that were observed to trigger fear responses included sounds related to blood pressure measurements and ECG equipment as well as the relatively loud notification sounds audible in the waiting room. Human sounds were also observed to startle paediatric patients. These sounds include HCWs (loudly) calling the name of the paediatric patient, often in an otherwise quiet waiting room, and sounds originating from the treatment rooms. It was observed multiple times that sounds of distress (e.g. crying, screaming) behind closed doors of treatment rooms were audible in the waiting room.

Finally, it was observed that whenever a treatment room was relatively dark in comparison to the hallway, children were hesitant to enter the room. The treatment rooms where echocardiograms take place are often dark, so sonographers can see the nuances on the monitor better. Some HCWs leave out the lights permanently, while other HCWs prefer to switch off the lights during the session. Fear was observed when the lights were turned off unannounced.

4.3.3 Comforting Elements

RQ7 – Which factors in the current context provide comfort to paediatric patients during their outpatient visits to the cardiology department of the WACH?

Figure 42 summarises the results. The observed and/or reported elements that provided comfort to children have been clustered into nine categories (from left to right):
1. Pain reduction methods
2. Feeling in control
3. Knowing what will happen
4. A moment of reflection
5. The presence of parents
6. Stuffed animals
7. A bond of trust
8. Distraction
9. A child-friendly environment

The following paragraphs will highlight how some of the found insights can supplement the preparation. Appendix I can be consulted about the remaining categories.

►**Figure 42**. Overview of the observed and/or reported triggers of fear before and during a visit to the outpatient clinic. The content of the visual is based on the insights reported in Appendix I.



Distraction

"An echo is the least fun because it can hurt, but it's also the most fun because I can watch a movie." (6 y.o. boy)

Pain reduction methods help children feel more comfortable during medical procedures that are (perceived as) painful. Pain management can include the use of local analgesia or drug-free alternatives such as distraction. Parents are allowed and even encouraged to actively distract their children during medical procedures. Some of the observed distraction methods used by parents include interactive conversations, physical touch, food, and play. Many parents were observed to hold the hand or stroke the head of their child during the procedures.

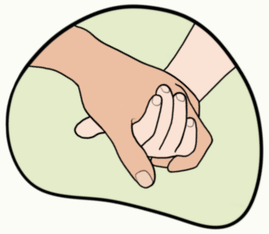


Stuffed animals

“Pietje [favourite stuffed animal] has to come with.” (6 y.o. girl)

It was observed that many paediatric patients brought stuffed animals to the outpatient clinic. Some patients even held on to them during the medical procedures, only letting go of them when strictly necessary. During an observation-based interview, a mother of a 6-year-old boy visiting the outpatient clinic for the first time explained that he never used his stuffed animal at home, but he wanted to bring it to the hospital. Children report feeling more at ease when facing scary situations with their stuffed animals.





Presence of parents

"I want mommy to do it." (3 y.o. girl)

The presence of parents is a major comforting element for children. Paediatric patients are observed seeking comfort from their parents through physical touch and eye contact. Most of the younger paediatric patients were observed to use their parents as a mediator for contact with the healthcare worker in the room; directing their questions or remarks to their parents instead of the healthcare worker. "Mommy it [what the healthcare worker is doing] stings a little." (5 y.o. boy)

Parents were observed taking on mediating roles during procedures that helped children feel comforted, so healthcare workers can efficiently perform their tasks. A mother of a 7-year-old was observed giving a pacifier to her child. She explained that he is really active in everyday life and a pacifier helps him to lie still. This parent knew what was expected from her child during the procedure and helped him to achieve this.



Reward

The promise of a reward can help children focus on positive things during medical procedures. Getting a present or doing a fun activity before and/or after the outpatient visit can create positive associations with hospital visits.



Feeling in control

One reported and observed factor that helped paediatric patients feel in control was the visualisation of time. Many paediatric patients were observed asking how long the hospital visit was going to take. A mother of a 7-year-old explained that she helped her son visualise the passing of time by crossing off procedures from their appointment ticket. During the procedures, she was observed actively reminding her son that this was the second procedure on the list.



Child-friendly environment

"The decoration of the hospital really does a lot. The colours and the toys. In a clinical room, he feels that it is different, that something is going to happen." (Father of a 4 y.o.)

The environment plays a significant role in how children approach a situation. Parents reported that their children feel at ease in the waiting room of the outpatient clinic of the WACH because there are age-appropriate toys and playing equipment. Two parents indicated that they felt more at ease knowing that their child could play in the waiting room. Paediatric patients are observed reading, drawing or physically playing in the waiting room. The treatment rooms also feature age-appropriate decorations and often have toys or other distraction methods available.

4.4 Conclusion

Mapping the context-specific triggers of fear and comforting elements validated the insights obtained from the literature and the recommended essential aspects of preparation. Mapping the hospital experience provided a baseline for the preparation content. The following sections summarise the insights obtained regarding the content of the preparation tool.

• Overview of the general workflow of an outpatient visit

A visit to the outpatient clinic of the cardiology department looks different for every child and can vary over time for the same patient. Hence, the content of the preparation tool should allow for flexibility regarding the order of events.

The check-up procedures are divided into multiple treatment rooms. Entering a room without knowing what is inside was a reported and observed trigger of fear. The preparation tool should provide visual information about the inside of the treatment rooms, as well as the general waiting room. To comfort parents and children, the focus should be on the child-friendly environment and playing equipment.

• Overview of the procedure steps and touchpoints

The steps and touchpoints of the check-up procedures were mapped in detail. The preparation tool should highlight the touchpoints and sensory stimuli that triggered fear responses. Touchpoints and steps of the procedure that did not trigger any fear responses or positive reactions should not be prioritised.

Most of the sensory stimuli paediatric patients encounter are specific to the hospital context, meaning that children are not likely to encounter these stimuli elsewhere. The preparation tool should allow children to experience these unfamiliar stimuli in a safe environment.

• Overview of comforting elements

An observed and reported trigger of fear was the distress of parents. One of the reported reasons was observing and/or the expectation that their child would experience procedural distress. The preparation tool should inform parents about the way they can reassure and comfort their children during an outpatient visit. Parents should be informed that they are allowed and encouraged to actively distract their children during medical procedures.

In addition, the preparation tool should include the following comforting elements:

- Information and reassurance that parents and children are allowed (and encouraged) to stay together throughout the whole hospital visit.
- Confirmation that children are allowed to bring their stuffed animals or any personal belongings that make them feel happy.
- A visualisation of the passing of time. This helps children feel more in control, subsequently feeling more comfortable during the hospital visit.

4.4.1 Requirements

All insights gathered during the Define Phase (i.e. Chapters 3 & 4) resulted in the following list of requirements and guidelines for the preparation tool.

Fundamental Requirements

- The information offered by the preparation tool should be relevant for children with congenital heart disease between the ages of four and seven, who have to regularly visit the outpatient clinic.
- The preparation tool should remain relevant despite the number or frequency of outpatient visits.
- The preparation tool should be designed in such a manner that parent and child can use it together.
- The preparation tool should allow for personalised timing and (repeating) intervals of use.

Preparation of the Child 🟠

- The preparation tool should enable children between the ages of four and seven, to get acquainted with the steps of medical procedures.
- The preparation tool should enable children between the ages of four and seven, to get acquainted with context-specific touchpoints, emphasising the corresponding auditory and visual stimuli.

Preparation of the Parent 🟢

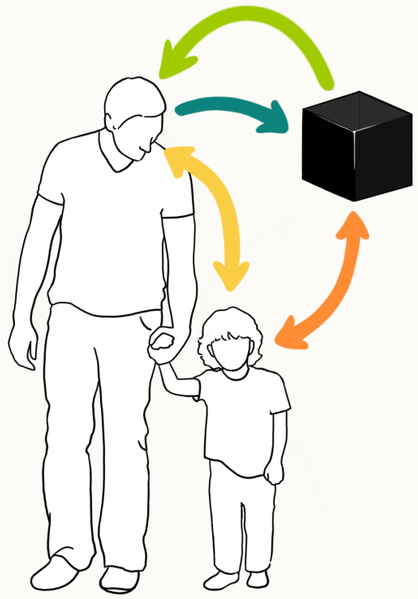
- The preparation tool should provide parents with comprehensible information about the medical procedures in terms of the following aspects:

1. What activities will be performed by HCWs during the procedures
2. Why these activities need to be performed
3. Which materials and equipment will be used during these activities

- The preparation tool should provide (emotional) support regarding how to avoid and/or deal with the (potential) procedural distress experienced by their child.

Preparation by the Parent 🔵🟡

- The preparation tool should provide parents with knowledge and tools that enable them to customise the preparation for their child.
- The preparation tool should encourage and provide space for parents to share (the obtained) information with their child during the preparation process.



▲ **Figure 43.** The defined home-based preparation approach.

4.5 Limitations

Observations

The first-hand observations were conducted inside the treatment rooms. The HCWs, parents and children in the room were aware of the presence of an additional person. An observer in the room with civilian clothes might have altered the behaviour of the healthcare workers, children and parents.

Another limitation was the selection of patients. It was not allowed to observe paediatric patients who were considered vulnerable by their treating physician. This might have resulted in skewed insights regarding the essential content of the preparation.

Observation-Based Interviews

A limitation of the observation-based interviews was the timing. The majority of the respondents were approached in between medical procedures. Hence, the length of the interview was contingent upon the fluctuating amount of waiting time between appointments.

Another limitation included the location of the interviews. Respondents were approached in the general waiting room. The presence of other people and other distractions might have affected the way respondents answered the questions.

Make-and-Say Sessions

One of the limitations that were encountered during the make-and-say sessions was the level of difficulty of the exercises (see Appendix E1). Respondents had to imagine a situation, whereafter they were asked to brainstorm out loud what they would have liked to know before the situation happened. During the sessions, it was discovered that the children, especially those under the age of five, struggled with imagining this situation and verbalising their answers. To mitigate this limitation, more probing questions were asked, possibly directing respondents in their answers.

Takeaways from this chapter

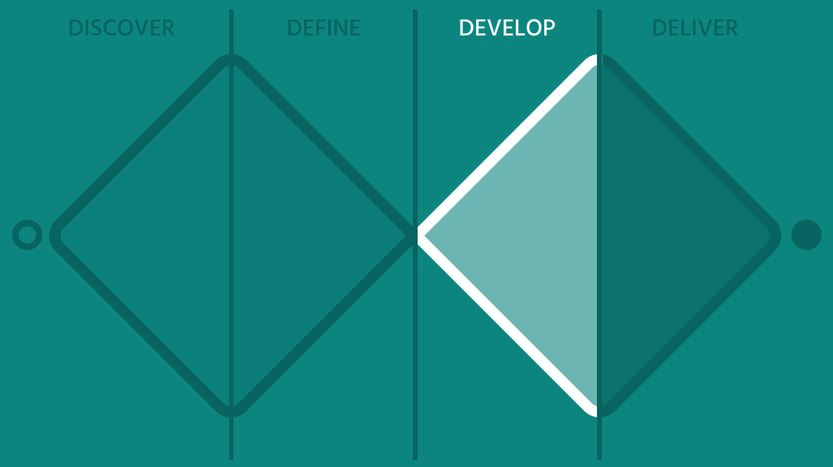
- A visit to the outpatient clinic of the cardiology department looks different for every child and can vary over time for the same patient. Hence, customised preparation is required.
- Paediatric patients and their parents can see up to five different rooms, including a general waiting room. Inside these rooms, children are confronted with different healthcare workers, medical equipment, and touchpoints.
- Child-reported and observed triggers of fear were clustered into eight categories. From these eight categories, three have been selected as essential preparation topics: (1) The distress of Parents, (2) Not knowing what will happen, and (3) Unexpected and unfamiliar stimuli.
- Child-reported and observed comforting elements were clustered into eleven categories. From these categories, elements have been selected as focus points for the preparation tool.

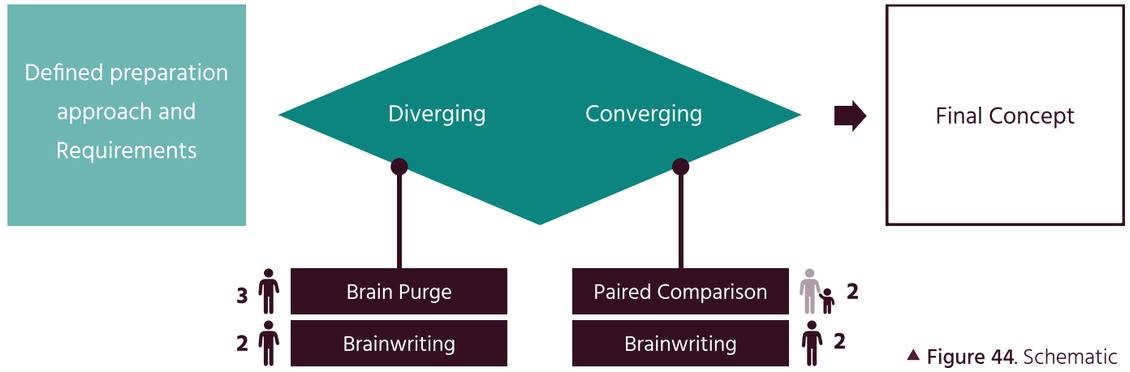
Chapter 5. Concept Generation

5.1 Approach

The goal of this chapter is to develop one concept based on the home-based preparation approach and requirements defined in the previous chapters, see Figure 44. The following pages discuss the ideation and conceptualisation process. Besides individual brainstorming and creative problem-solving techniques, multiple idea-generating sessions have been held with participants, either with a design background or a hospital-related background. Several diverging techniques have been used to create three concepts. In between the different stages of ideation and conceptualisation, the results were presented to the client. To ensure that the Hospital Hero's interests are taken into account, the final concept was chosen in consultation with them.

OVERVIEW OF THE FINAL CONCEPT p. 64





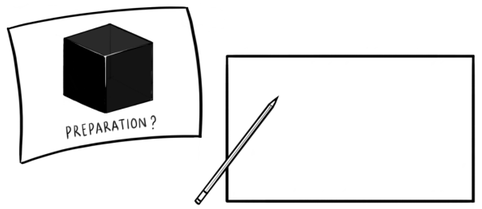
▲ **Figure 44**. Schematic overview of Chapter 5.

5.2 Methods

5.2.1 Brain Purge

To start the ideation process, a purge session was held with three participants with design backgrounds. Purging is a converging technique where all ideas that pop up are written down and/or visualised (Heijne & Van der Meer, 2019). During a purge, the participants share their existing ideas rapidly.

The purge session started with a short introduction to the information and insights collected from previous chapters. The defined preparation approach (see Figure 43) was presented as the focal point of the purge. Participants were asked to purge their ideas about the following question: 'What can the black box [visualised in Figure 43] be?'. The purge session lasted 40 minutes.



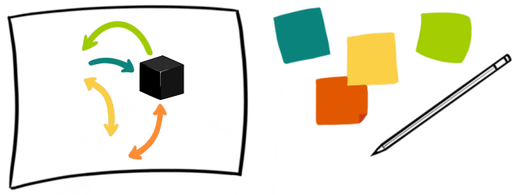
▲ **Figure 45**. Materials used during the Brain Purge.

5.2.2 Brainwriting

Brainwriting is a technique where participants generate ideas in silence and record them on post-its (Heijne & Van der Meer, 2019). After the brainwriting session, the post-its were collected and the participants were asked to share their ideas. In total, two brainwriting sessions took place, one during the diverging phase, and one during the converging phase.

Brainwriting during the diverging phase

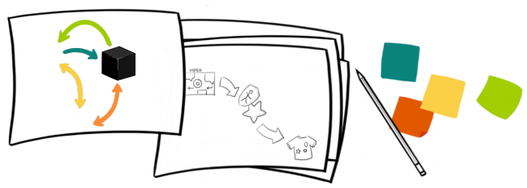
This brainwriting session was held with two members of the Hospital Hero foundation. The session was based on the defined preparation approach. In contrast to the previous method, the focus point of the brainwriting sessions was not the black box, but the four interaction arrows. The participants were asked to brainwrite for 10 minutes for each interaction arrow. After each brainwriting interval, the participants shared their ideas. In total, four brainwriting intervals took place, over the span of one hour.



▲ **Figure 46**. Materials used during the diverging brainwriting session.

Brainwriting during the converging phase

This brainwriting session was held with two participants with a design background. In contrast to the brainwriting sessions during the diverging phase, participants did not have to start brainwriting from scratch but were given four ideas as a starting point. At the start of the session, the ideas were explained. The participants were then asked to brainstorm about how each interaction arrow could be presented in the idea. The participants were asked to brainwrite five minutes for each interaction arrow. In total, 16 brainwriting intervals took place, over the span of two hours.

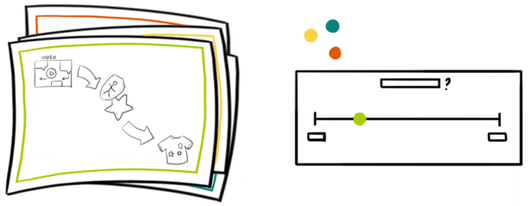


▲ **Figure 47**. Materials used during the converging brainwriting session.

5.2.3 Paired Comparison

Paired comparison analysis is a technique used to prioritise options by comparing them against each other (Heijne & Van der Meer, 2019). Four existing preparation materials and four generated ideas were presented to children with congenital heart disease, aged 11 and 13, during an online session. The children were individually asked to rank the eight preparation materials on a horizontal scale, based on the following question: 'Do you think that this material would have prepared you for a hospital visit when you were younger?'. The scale ranged from 'no, not at all' to 'yes, definitely'. After ranking the preparation tool on the scale, the respondents were asked to hypothesise out loud why this tool would have helped them. These explanations and the corresponding ranking of the preparation materials were analysed. The results were compared with previously performed literature and desk research (i.e. Chapters 2 and 3).

The parents of the respondents were present during the session and filled in a written consent form on behalf of their children. The questions and materials used during the session were created under the supervision of a special education generalist, and can be found in Appendix J1. Each session lasted around 40 minutes.



▲ **Figure 48**. Materials used during the paired comparison sessions.

5.3 Diverging

During the diverging phase of the second diamond, brain purge and brainwriting sessions were conducted. These sessions resulted in a high quantity of low-to-medium detailed ideas. From these generated ideas, different aspects were collected to create four frameworks of preparation, explained on the following two pages. These frameworks formed the starting base of the converging phase.

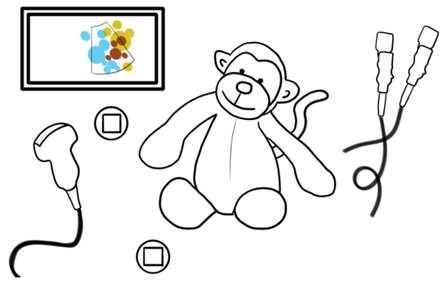
The ideation and brainstorming techniques were mainly focused on intervention-child interactions. During the next phase, these interactions were expanded to fit the whole defined preparation approach and all of its corresponding interaction arrows.



▲ **Figure 49**. Some ideas generated during the Brain Purge and Brainwriting session.

1.

Playing out medical procedures in the home situation



Children are provided with a stuffed animal and real-life materials they will encounter during the medical procedures. Parents will be educated about the steps performed during the procedures and are encouraged to play out the hospital visit with their children.

Story telling | Experiencing | Role Play

2.

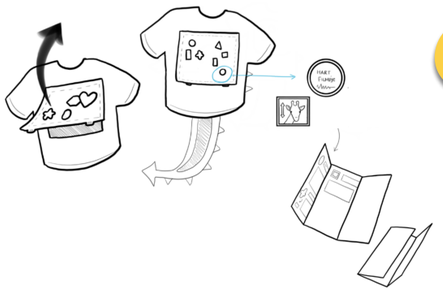
Actively collecting information by means of play



Children (and their parents) are challenged to collect information about the hospital visit through play. Preparation is combined with a physically challenging and interactive game to make the impending hospital visit overall more fun.

Active Play | Collecting | Discovering

Creating a routine by collecting informative rewards



3.

Children receive a blank t-shirt and patches that are linked to medical procedures. Parents are encouraged to talk about the patch and the corresponding procedure, actions, and stimuli that the child will encounter. During the hospital visit, the child can collect the patches.

Routine | Collecting | Rewards

Experiencing by means of storytelling



4.

Children are provided with materials they will encounter during the hospital visit. Utilising storytelling, the child is prepared for an adventure rather than a regular hospital visit.

Experiencing | Story telling | Discovering

5.4 Converging

The converging phase consisted of paired comparison sessions and a brainwriting session. These methods transformed the four preliminary ideas into three concepts that fit the defined home-based preparation approach. After careful deliberation of the requirements and wishes of the Hospital Hero foundation, elements of the different concepts were chosen and merged to create one final concept.

5.4.1 Paired Comparison Results

During the paired comparison sessions, the four preliminary ideas and four existing preparation tools were presented to two child-parent pairs. These sessions were focused on creating a general idea of the wishes of children regarding the practical interpretation of preparation. Figure 50 presents an overview of the reported aspects of the presented ideas. The aspects that were mentioned the most often or with the most enthusiasm are visualised in the middle of the circle. Reported aspects that were mentioned less often or with relatively less enthusiasm are located toward the outer ring of the circle. The child-reported aspects marked with a star were chosen as a focus to integrate into the concept: Animation vs. Realism, Discover, Play, and Storytelling. Aspects that were not selected as a focus were kept in the back of the mind during the conceptualisation phase. The following sections will detail the meaning of the individual aspects and share some of the corresponding quotes.

Animated vs. Realistic

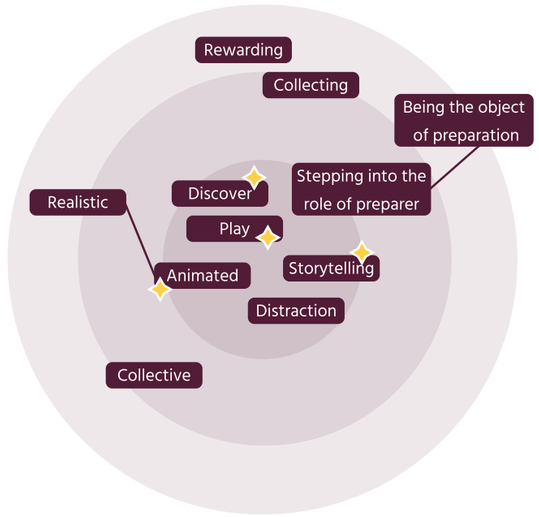
Both children shared a preference for animated visuals to communicate information about hospital-related equipment and activities. In contrast, the hospital environment, e.g. the treatment rooms, was preferred to be visualised realistically in order to get a sense of the actual surroundings.

"Then [if the room is realistically visualised] you know a little bit about what kind of devices are used. Not that there is suddenly a jackhammer or something in the room." (11 y.o. boy)

Discover

The discovery aspect was mentioned multiple times by both children. They reported a preference for discovering the information rather than the information being presented directly.

"You have to discover things. Personally, I quite like a scavenger hunt, just like the Hospital Hero thing." (11 y.o. boy)



Play

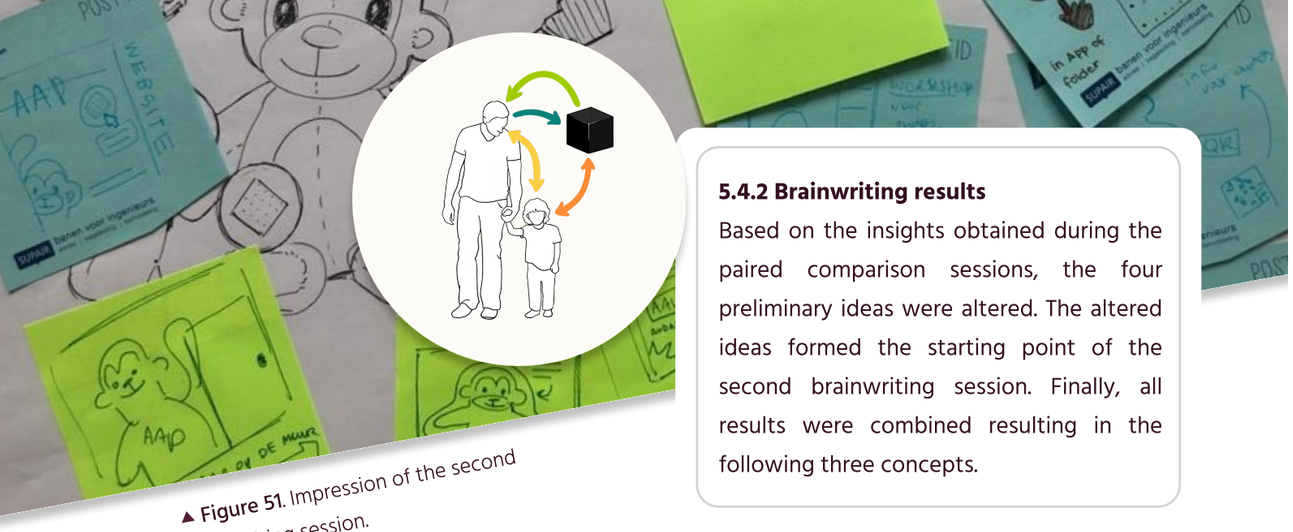
Both children enthusiastically reported the aspects of play and challenge, especially in combination with discovering information. Play is an important aspect for children. One of the respondents mentioned that preparation in a playful manner makes the hospital journey more enjoyable and less 'hospital-y'. Idea 2, "Actively collecting information through play", was reported as fun but the physical component was deemed unrealistic due to time constraints and the possible negative effects it would have on the test results of the medical procedures.

"Such a thing [a medical procedure] is fun to make a kind of game out of it. And at the same time, you see a bit of what happens and also like oh look that's going to happen to me too." (13 y.o. girl)

Storytelling

The storytelling aspect was not reported directly but was filtered out of the conversations and the preparation materials the children picked during the comparison session. Idea 4, "Experiencing through storytelling", was ranked relatively high. The respondents had a lot of experience with hospital visits and mentioned that it would have been more fun if the visits had been presented as an adventure rather than a necessity. When asked why idea 4 was picked over the other concepts, one of the respondents mentioned: "[…] I think it would be more fun than an app because you can just experience it yourself. Yes, that you can experience it yourself, going on an adventure with a map and a stethoscope […]. (13 y.o. girl)

◀ **Figure 50**. Overview of child-reported preparation aspects. Content based on the Paired Comparison method.

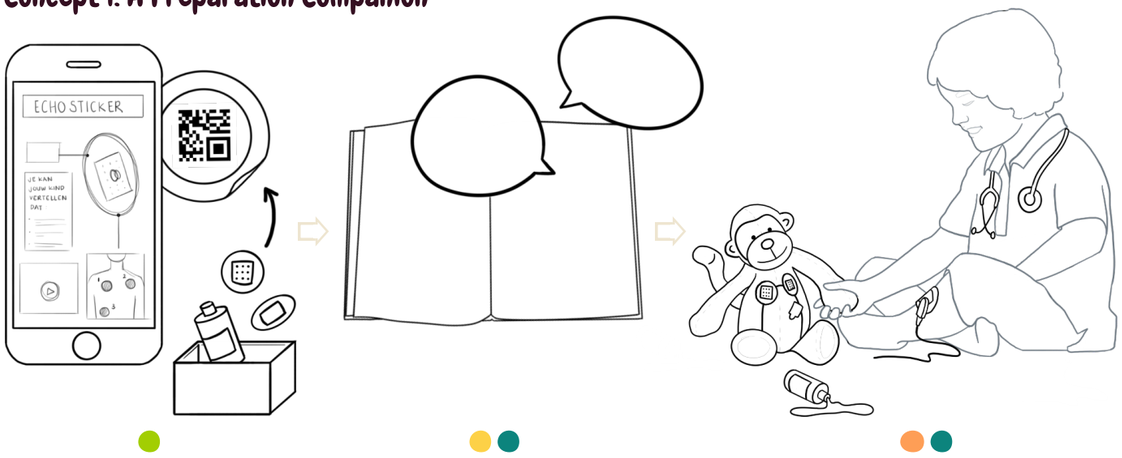


▲ **Figure 51**. Impression of the second brainwriting session.

5.4.2 Brainwriting results

Based on the insights obtained during the paired comparison sessions, the four preliminary ideas were altered. The altered ideas formed the starting point of the second brainwriting session. Finally, all results were combined resulting in the following three concepts.

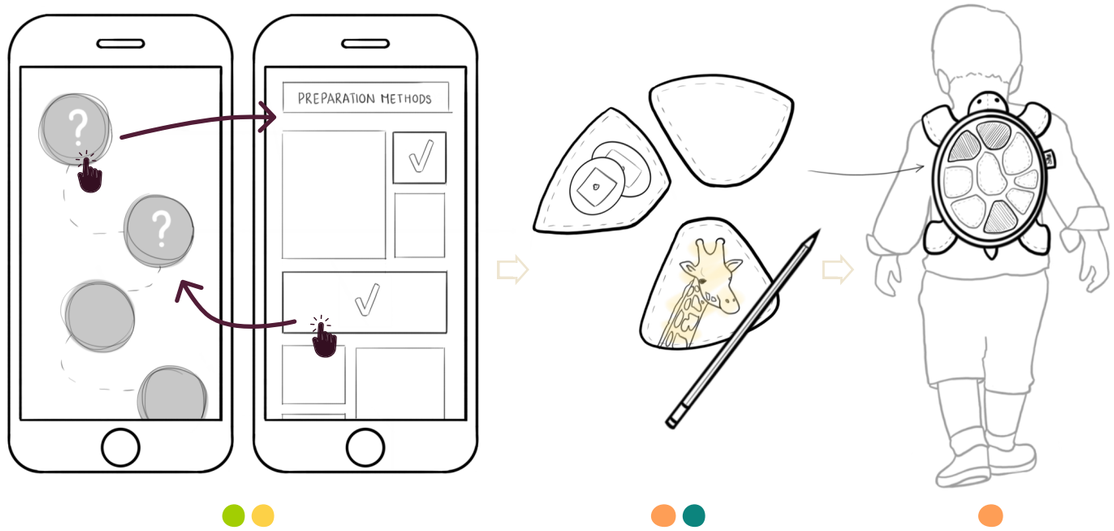
Concept 1. A Preparation Companion



▲ **Figure 52**. Elements of the first concept. The different colours refer to the interactions in the defined preparation approach.

This concept prepares children and their parents using roleplay. First, the parents are prepared by getting acquainted with the actual materials that will be used during the medical procedures. Parents can scan the QR codes present on the materials to find more information and tips about how to explain these materials to children. During the next phase of this concept, parents are encouraged to read a book together with their child. The book explains, in a child-friendly manner, what is going to happen during the hospital visit. The main character of the book is a monkey. Once the parent and child know what is going to happen, they can start playing this out with the provided stuffed monkey and the same hospital materials the parents used during the first phase. During the roleplay, where the monkey visits the outpatient clinic, parents can guide the storyline by explaining the materials and required actions. This concept allows the child to discover certain stimuli up close in a safe environment and get acquainted with the events happening during a hospital visit.

Concept 2. Building a Routine



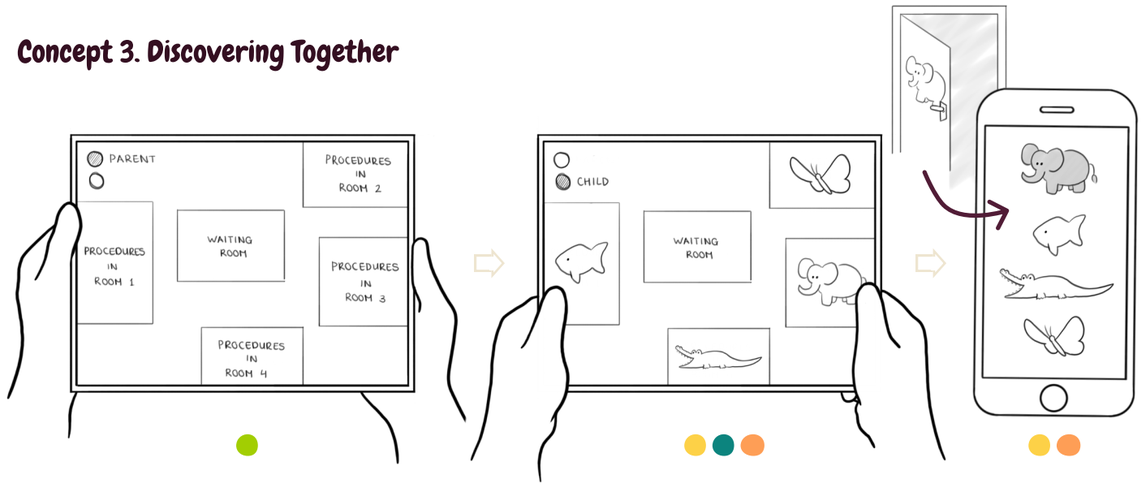
▲ **Figure 53**. Elements of the second concept. The different colours refer to the interactions in the defined preparation approach.

This concept consists of two elements: (1) parents building a routine together with their child and (2) children visualising this routine in order for them to collect tokens during their journey. In this concept, a routine is referred to as something bigger than the hospital visit itself, containing the hospital-related activities as well as the activities before and after the hospital visit.

First, parents are guided and encouraged to select a preparation method from a dashboard visualising all existing methods. Once the method has been chosen it appears in a visualised hospital routine. The application then informs and guides the parent during the preparation process. For example, the parent picks 'reading a book together with their child' from the method dashboard. A book icon appears in their visualised routine. When the parent clicks on this icon, they are provided with options and tips about the type of books and how to utilise this method when preparing children for medical procedures. Next, the application encourages the parents to add steps to the routine before preparation and after the hospital visit. For example, parents that want to reward their child with a present after the hospital visit can add a 'reward' icon to their routine. This allows the parent to create a simple yet clear overview of the activities that will happen during the day their child has to visit the outpatient clinic. To make the journey complete, the child can create tokens for each step of the routine. On the day of the hospital visit, the child can collect the tokens after the activity is completed. This helps the child to visualise the number of steps that have been completed and which activities still need to be performed.

In short, this concept encourages and supports parents in preparing their children for the medical procedures as well as the routine they build together. Sticking to this routine will help create predictability, making children feel in control.

Concept 3. Discovering Together



▲ **Figure 54**. Elements of the third concept. The different colours refer to the interactions in the defined preparation approach.

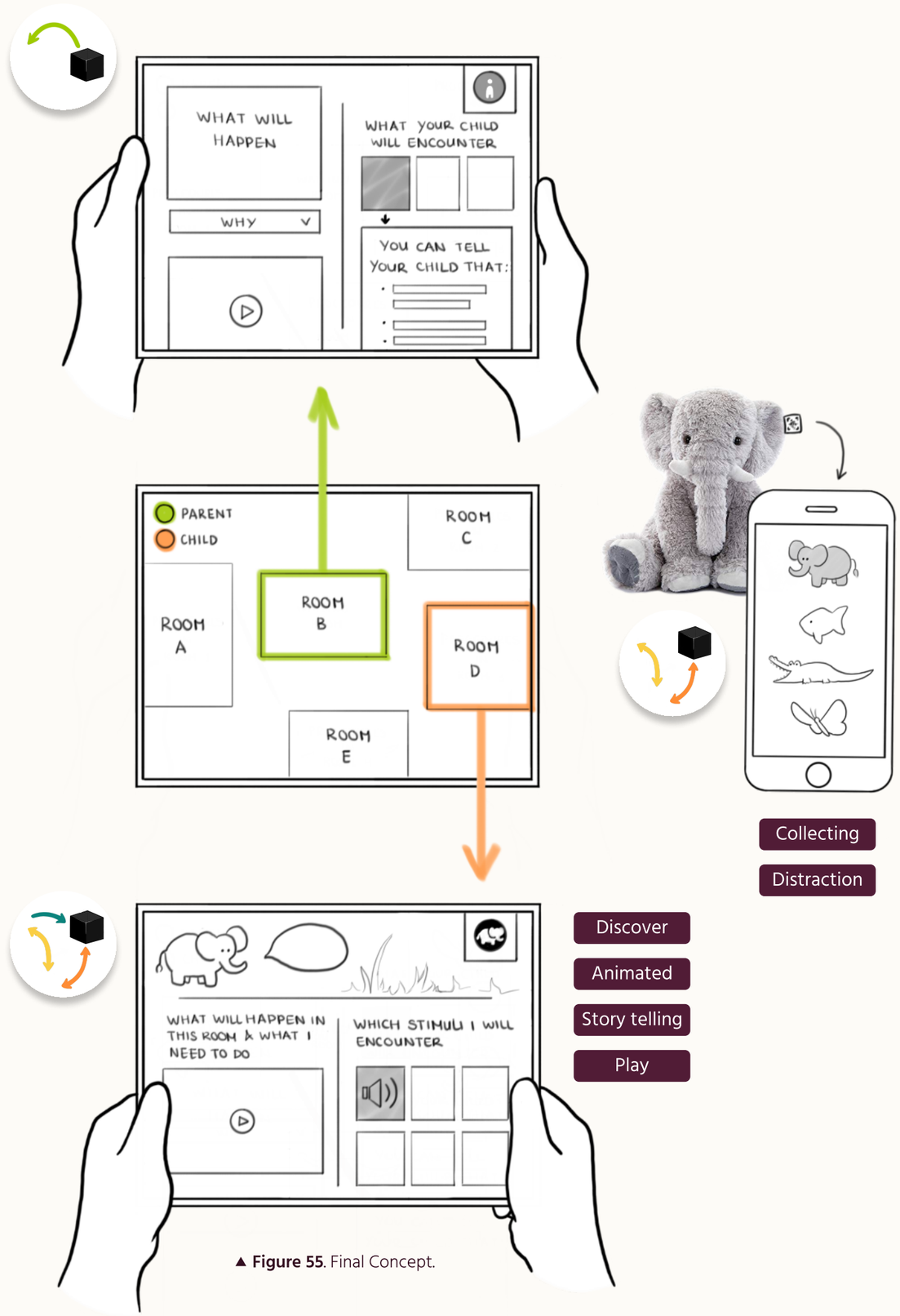
This concept integrates preparing parents and children in one online platform where they can discover hospital-related stimuli inside the treatment rooms. The platform features a toggle where users can either select parent mode or child mode. The child mode features rooms with animals that are connected to the medical procedures performed inside the room. Children can discover facts about this animal and the different touchpoints and their corresponding stimuli present in the treatment rooms. The parent mode provides information about the procedures and shows the same touchpoints present in the child mode. In contrast to the touchpoints in the child mode, the parent mode provides more detailed information about the touchpoints and tips about how to explain these to a child. When the child is discovering the stimuli in the child mode, parents can add this information and make it a more personalised experience. In the outpatient clinic, children can collect the 'procedure animals' on their phones to help repeat the information as well as create opportunities for storytelling.

5.5 Final Concept

The three concepts were discussed in a session with two representatives of the Hospital Hero Foundation. The concepts were assessed on the requirements and their overall feeling. Strong points and limitations of each concept were considered. At the end of the session, 'Discovering Together' (Concept 3) had been chosen as the most potential preparation tool. In the final stage of conceptualisation, this concept was merged with some of the strong points of the other concepts, creating the final concept visualised in Figure 55.

Online Module

The final concept is an online module that allows users to discover the procedure steps and unfamiliar stimuli in a safe and known environment at their own pace. The module features two layers. In the first layer, parents are provided with information and tips about preparing their children. In the second layer, parents and children can discover hospital-related stimuli together. Each treatment room is connected to an animal. This



▲ **Figure 55**. Final Concept.

animal will guide the users through the room using storytelling. While discovering together, parents are encouraged to share the obtained information (from the parent layer) with their children, consequently creating customised preparation.

Exploring Hospital-Related Stimuli

Several ways to explore stimuli have been considered. In order to combine all insights collected from previous chapters, the decision was made to visualise the treatment rooms and the touchpoints that come in direct contact with the skin of the paediatric patients. Users can get acquainted with the corresponding auditory stimuli while exploring the room. Chapter 6 will elaborate on this design choice.

Physical Component

In order to create a strong connection between the preparation and the child's outpatient visit, the concept features a physical component present in the outpatient clinic. This physical component is based on Concept 1 'A Preparation Companion'. To illustrate, the child is accompanied by an elephant while discovering the stimuli in an online simulated treatment room. The same animal will be present in the actual outpatient clinic in the shape of a stuffed animal. This creates opportunities for both parents and HCWs to initiate conversations with paediatric patients, repeat, and remind them about the preparation.

Due to the time constraints of this project, the decision was made to further develop the online module and neglect the physical component for the remainder of the project. Recommendations regarding the physical component can be found in Chapter 7.

5.6 Limitations

One of the limitations of the paired comparison sessions was the small sample group. Only two child-parent pairs participated due to the relatively small population and time constraints of the project. As a result of the small sample size, no significant results or conclusions could be drawn from the sessions. In addition, the two respondents, aged 11 and 13, were outside the age limits of the target group. In consultation with a remedial educationalist in training, the session focused on the past experiences of the respondents. Although children of this age have the cognitive development to do so, hypothesising if preparation materials would have worked for them in the past, might have resulted in distorted insights.

To mitigate these limitations, the results of the paired comparison sessions were compared with previously performed literature and desk research (Chapters 2 & 3) and overall used as inspiration rather than strict guidelines. Future qualitative research with a larger sample group should show if the hypotheses were correct.

Takeaways from this chapter

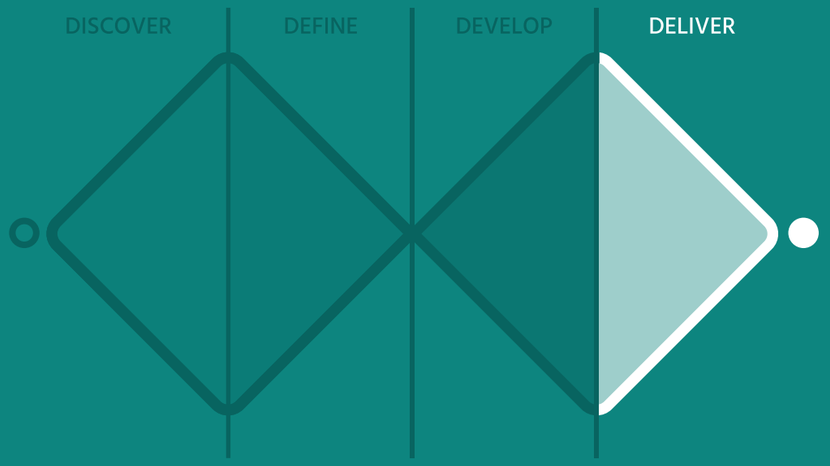
- Brain Purge and Brainwriting sessions resulted in four preliminary ideas, that concluded the converging phase.
- Paired Comparison and Brainwriting sessions transformed the four preliminary ideas into three concepts.
- As a result of the paired comparison sessions, four child-reported aspects (Animation, Play, Discover, and Storytelling) were chosen to be incorporated into the final concept.
- After careful deliberation of the defined home-based preparation approach, generated requirements, and wishes of the Hospital Hero foundation, elements of the three different concepts were chosen and merged to create one final concept.
- The final concept is an online module that allows children to discover unfamiliar stimuli in a safe and known environment at their own pace. The module features two layers. In the first layer, parents are provided with information and tips about preparing their children. In the second layer, parents and children can discover the procedure steps and touchpoints together. While discovering together, parents are encouraged to share the obtained information (from the parent layer) with their children, consequently creating customised preparation.

Chapter 6. Final Design

6.1 Approach

In the previous chapter, a final concept was chosen. Based on this conceptual framework, several iterative prototypes were made. Design choices of intermediate prototypes were evaluated by paediatric experts, resulting in one final design. This chapter will detail the design choices that were made and visualises the final design.

OVERVIEW OF THE DESIGN CHOICES p. 74
OVERVIEW OF THE FINAL DESIGN pp. 79-82



6.2 Design Choices

One of the fundamental requirements was that the preparation should be relevant for both parents and patients. The online module, therefore, features a toggle that can be used to switch between the respective parent and child layers.



▲ **Figure 56**. Home-screen of the parent layer.

The home screens of the parent and child layers are almost identical. The home screens feature four different treatment rooms and the general waiting room, tailored to the workflow of the outpatient clinic of the WACH. The home screen for the parent layer, see Figure 56, features the rooms with an animal and the name of the check-up procedures. The child layer only features the animal.

Each treatment room is assigned a 'procedure animal' that already exists within the Hospital Hero collection. These animals possess characteristics that are helpful during the procedure(s). For example, Nellie the Hippo (Dutch: Nellie de Nijlpaard), accompanies the child (and parent) during an echocardiogram where children have to lie still for a relatively long time. Conveniently, a hippo is exceptionally good at lounging. Additionally, hippos like water, referencing the gel used during the echocardiogram. These characteristics provide parents with tools to explain the procedure and make the procedural steps more comprehensible and fun for children.

CONTEXT-SPECIFIC INFORMATION AND PREPARATION TOOLS FOR PARENTS

After selecting one of the procedure animals in the parent layer, users are directed to a general information page, see Figure 57. This page provides parents with general information about (the steps of and tools used during) the procedure and the procedure animal. The page also features several informative movies that support the textual information. When scrolling down, a door appears. This design choice is explained on page 71.

From Chapter 3, we know that parents struggle with four main things regarding the preparation of their child: [1.] Not being able to find (the right) information, [2.] Not knowing what information to share, [3.] Not knowing how to share the information and [4.] Lack of emotional guidance during the preparation process. The general information page provides parents with all the information they need to know about this specific procedure, therefore supporting parents in finding the right information that they can confidently share with their children. To make the page comprehensible, the different information topics can be accessed via a drop-down structure.

comprehensible information about the check-up procedure in one place



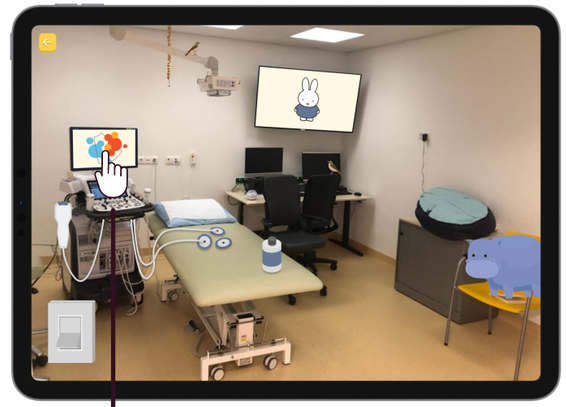
▲ **Figure 57.** The general information page; Follow-up screen after selecting a procedure/animal.

After clicking on the closed door, users enter the treatment room. Design choices regarding the visualisation of the room and the materials are explained on page 72.

Inside the room, several materials are visualised. These clickable materials are the touchpoints paediatric patients encounter during this specific check-up procedure, as mapped in Chapter 4. While exploring the room, users can click on the materials to get more textual information about them. This information includes context-specific details about the medical equipment and tips about how to explain certain elements to their children. The provided information is based on the mapped hospital experience and incorporates the three selected triggers of fear (see Chapter 4). For example, the information provided after clicking on the echocardiogram machine explains that the machine emits auditory stimuli that can be scary for children.

The textual support helps parents with preparing their children for the hospital experience flow in a child-friendly manner.

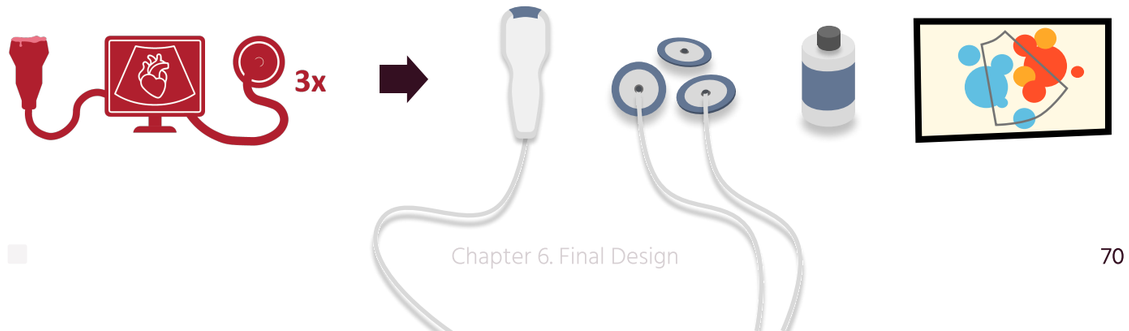
overview of the treatment room and the touchpoints



information about the touchpoints and tips about how to communicate this in a child-friendly manner

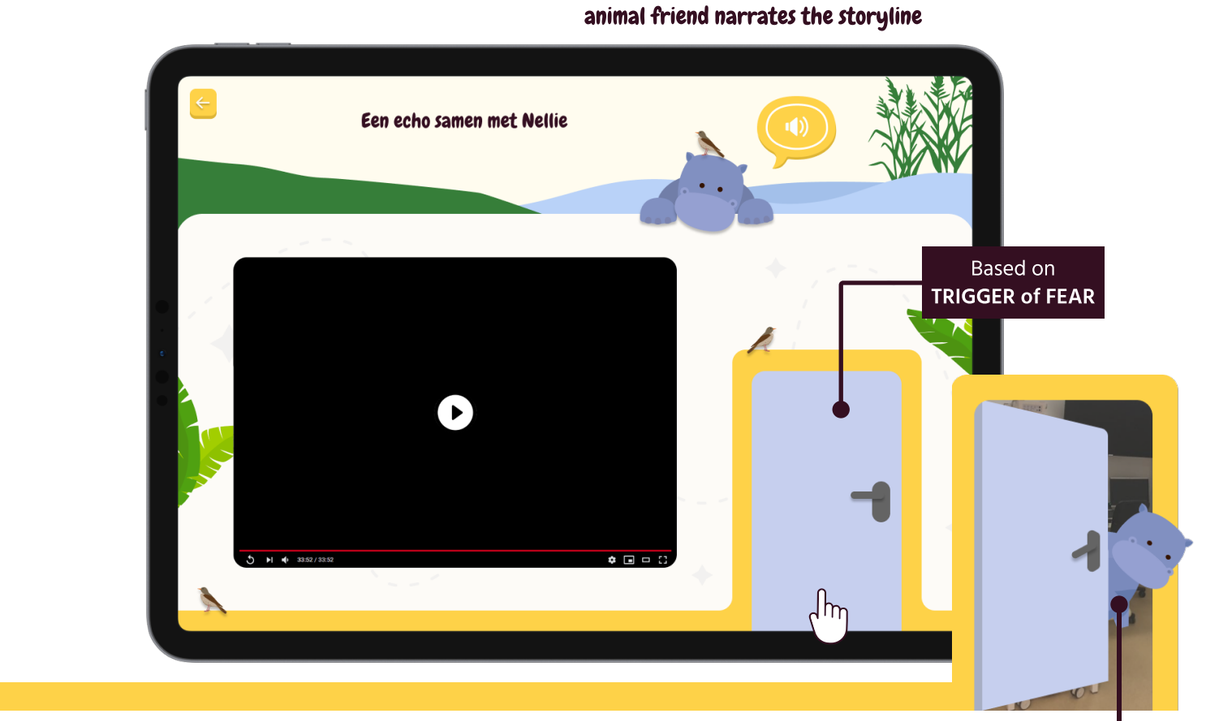


▶ **Figure 58.** Treatment room with materials; follow-up screen after clicking on the closed door.



DISCOVERING CONTEXT-SPECIFIC STIMULI

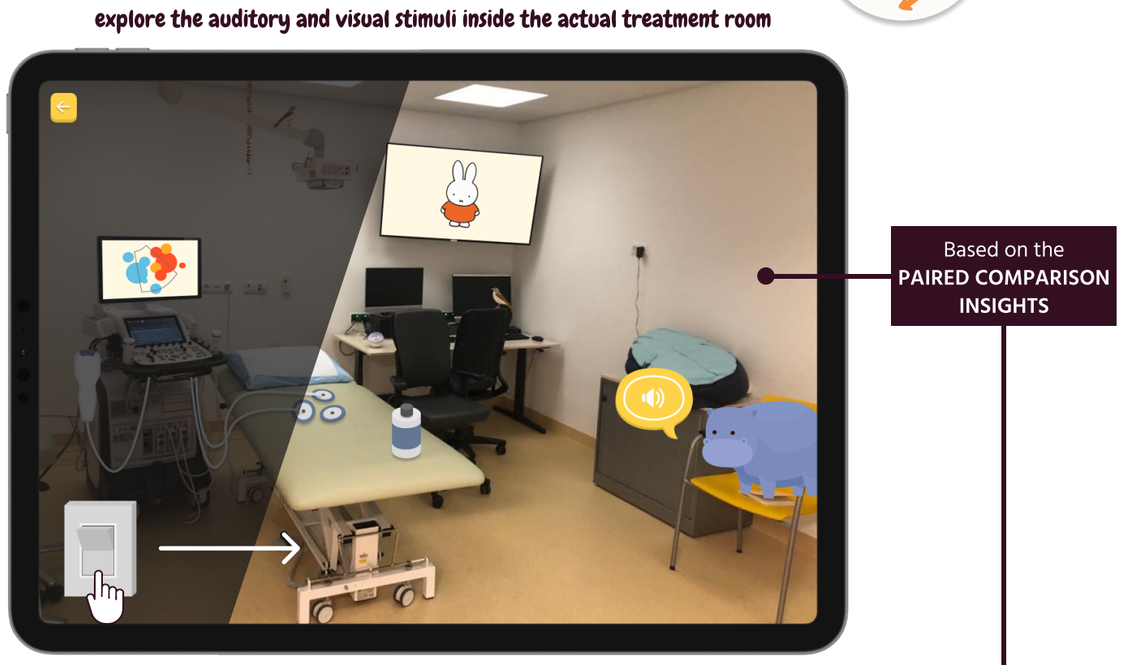
After selecting one of the procedure animals in the child layer, users enter the natural living environment of that animal featuring a video and a closed door. The informative video shows the process of an outpatient visit. The door simulates reality, i.e. paediatric patients have to enter multiple treatment rooms during their outpatient visits. This feature is based on the parameters of preparation selected in Chapter 4. The online module makes the experience of entering a room without knowing what is inside more fun and engaging.



▲ **Figure 59**. Follow-up screen after selecting the hippo in the home screen in the child layer.

The animal narrates the storyline and guides the users while discovering the online module. As a result, the child layer does not feature any written text other than the name of the animal. This design choice is based on the characteristics of the target group found in the literature (Chapter 2). The narration script can be found in Appendix K1.

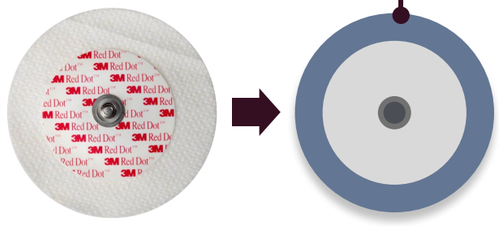
The animals adopt a persona as a friend, emphasising that children are never alone during their hospital visits. This design choice is based on a comforting element found in Chapter 4. The animal indicates that when entering the door, he/she will be present inside.



▲ **Figure 60**. The Exploring Page; follow-up screen after clicking on the door.

After clicking on the closed door, users enter the 'exploring page' similar to what would happen in the parent layer. This is the actual room the paediatric patients will see during their outpatient visit, visualised by means of a picture. To make it engaging to explore touchpoints in the room, the clickable materials are animated. These design decisions were based on insights obtained during the paired comparison analysis (see Chapter 5). To make it even more engaging to explore the room, the procedure animal asks questions such as: 'Can you discover all the materials in my room?' or 'Can you find the switch to turn on the light?'.

Similar to the parent layer, users can click on the animated touchpoints to learn more about it. The animal will explain what the material is, and how and why it is used during the procedure. For example, Nellie the Hippo explains the following

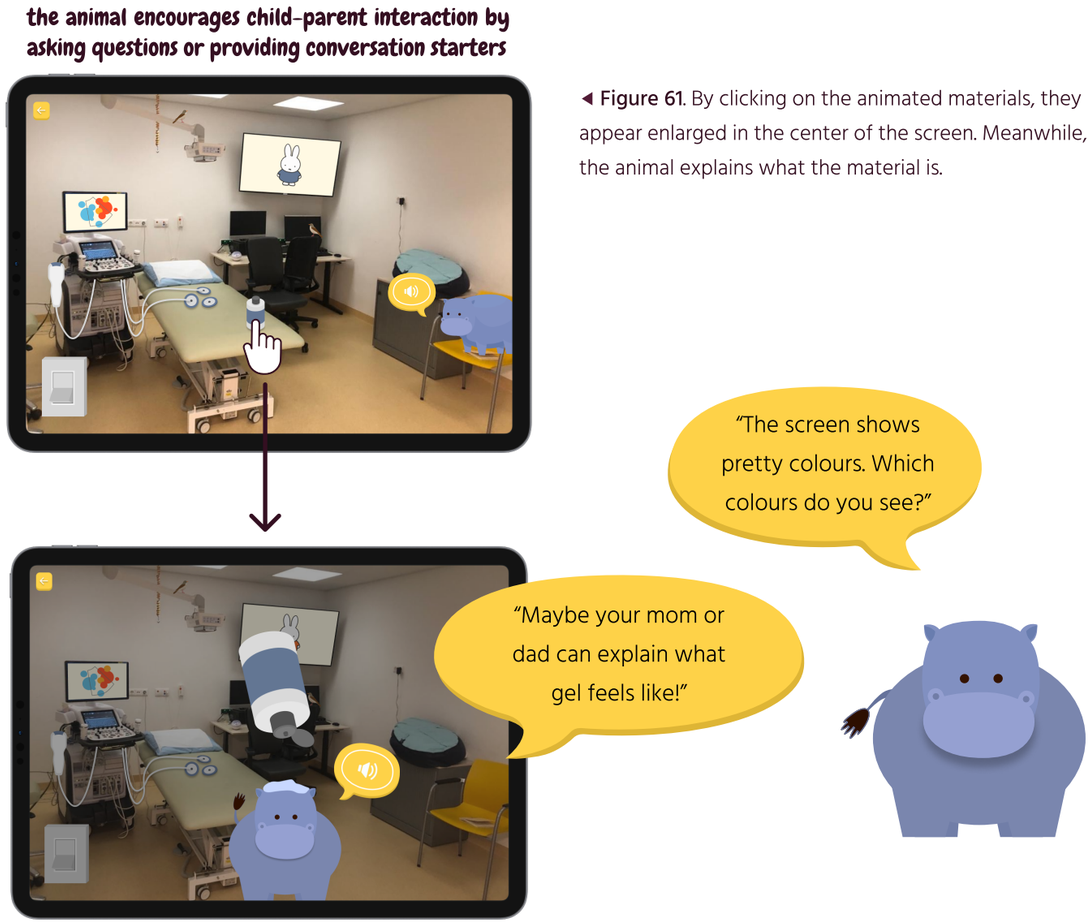


about the echo probe: 'This is the device the doctor uses to look at your heart. This is only possible with a little bit of gel' (see Appendix K1 for the remainder of the script). Additionally, the animal introduces the sounds and some visual aspects of the touchpoint. This allows children to discover the room, corresponding unfamiliar stimuli, and the steps of the procedure at home in a fun and safe environment. Users can click on any animated touchpoint, but can also follow a set order; one touchpoint at a time starts moving and changing colour to attract attention. This set order resembles the sequence of steps of the actual procedure.

ENCOURAGING CHILD-PARENT INTERACTION



One of the defined requirements was that the preparation tool should encourage and provide space for parents to share (the obtained) information with their children during the preparation process. To meet this requirement, the child layer is designed to be used together (i.e. not individually by the child). The animal narrating the story encourages interaction by asking questions or providing starting points for conversations. For example, Nellie the Hippo explains the following about the gel used during an echocardiogram: 'This is a bottle with gel. The gel might feel a bit weird. Maybe mom or dad can explain what gel feels like!'. Information about how the gel feels and what parents can say about this is found in the parent layer. Additionally, the procedure animal leaves enough time for parents to explain things or point things out in between the narration.



◂ **Figure 61**. By clicking on the animated materials, they appear enlarged in the center of the screen. Meanwhile, the animal explains what the material is.

Overview of the design choices

PREPARATION APPROACH	DESIGN CHOICES	BASED ON/INSPIRED BY
Informing parents and providing context-specific preparation tools	• One central page with general textual information supported by videos; • including tips about how parents can support their children during the procedure. • Specific information about the individual steps/materials of the medical procedures shown inside the actual treatment room.	**Barriers Parents Encounter** | CH. 3 **Comforting Elements** | CH. 4 **Barriers Parents Encounter** | CH. 3
Enabling the discovery of context-specific stimuli (auditory & visual)	• Users need to 'open' a door before they can explore the treatment room. • A picture of the actual room with animated touchpoints. • Clickable materials specific to the medical procedure. • Visual and auditory aspects of the selected touchpoints are explained. • Animals accompany the users while they explore the room. • Auditory support (i.e. narration by animals) instead of textual information.	**Triggers of Fear** | CH. 4 **Paired Comparison Insights** | CH. 5 **Experience Flow & Triggers of Fear** | CH. 4 **Triggers of Fear** | CH. 4 **Comforting Elements** | CH. 4 **Characteristics of the target group** | CH. 2
Encouraging child-parent interaction during the preparation process	• Information provided in the parent and child layer have a similar framework (i.e. inside the treatment room). • Animal provides auditory cues (i.e. asking questions and providing conversation starters). • Textual information in parent layer emphasises the importance of preparation.	**Analysis existing materials** | CH. 3 **Designers input**

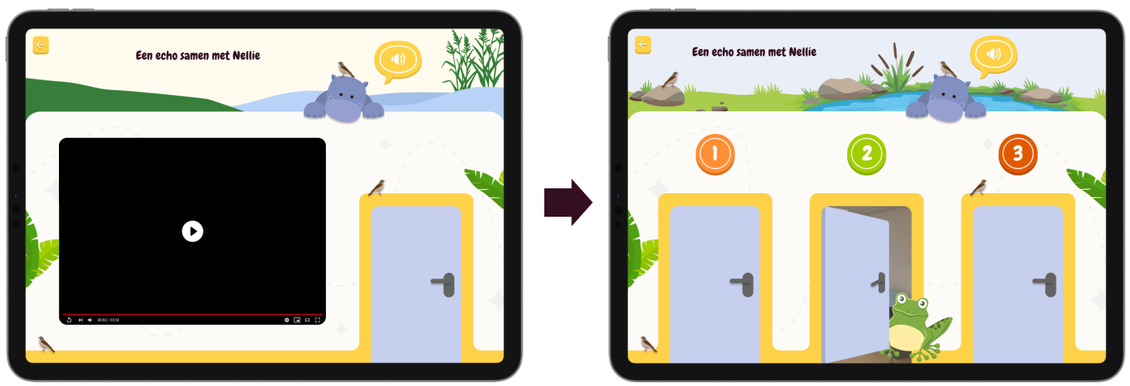
6.3 Intermediate Evaluation of the Design Choices

6.3.1 Method

The aim of the intermediate evaluation was to assess the design choices that were made in order to improve any lacking aspects. The evaluation sessions were held with a medical pedagogical care worker and a paediatric clinical psychologist of the WACH (n=2). The two respondents were selected based on their expertise regarding the preparation of paediatric patients.

At the start of the evaluation sessions, the defined preparation approach was explained as background information. Next, the respondents were walked through the prototype on an external device highlighting the design choices (explained in the previous section). Before transitioning to a new page of the prototype, semi-structured questions related to the design choices were asked. Each session took between 20-60 minutes and was conducted face-to-face. Notes and audio recordings were taken during the sessions. The semi-structured evaluation protocol can be found in Appendix L.

▼ **Figure 62**. Design adaptation inspired by the input of pediatric experts: small interactive game with closed doors.



"Hippos make quite a funny sound. Listen carefully! [real hippo noises]. I have my own space in the hospital. Can you discover which door is mine?"

6.3.2 Results and Design Adaptations

The evaluation sessions provided an overall validation of the conceptual framework. The majority of the design choices were evaluated positively. Three design choices left room for improvement. The following sections explain the results and how these were translated into design adaptations.

1. Design choice: Users need to open a door before they can explore the treatment room.

Both experts saw the value of preparing children (and parents) for entering unfamiliar rooms by opening a closed door. During the evaluation session, one of the respondents mentioned the following: "It doesn't have to fully conform to reality, […] you can make some kind of game out of it or a small joke. That makes the situation less heavy and then you actually normalise the hospital visit. That's what you want to achieve".

Based on this remark, the decision was made to emphasise the exploration of closed doors by means of an interactive game. Instead of simply opening one door, users have to find the correct door of the procedure animal by matching the sounds of the animals.

2. Design choice: Specific information about the individual steps and materials of the medical procedures shown inside the actual treatment room - Parent layer

The experts indicated that the provided information was too concise. Based on their expertise regarding the preparation of parents and children for hospital procedures, they explained that the majority of the parents they worked with wanted to know more information than was presented in the current prototype. Therefore, both respondents suggested adding more information and medical details about the touchpoints. The respondents also suggested supplementing the information with visuals of the actual touchpoints.

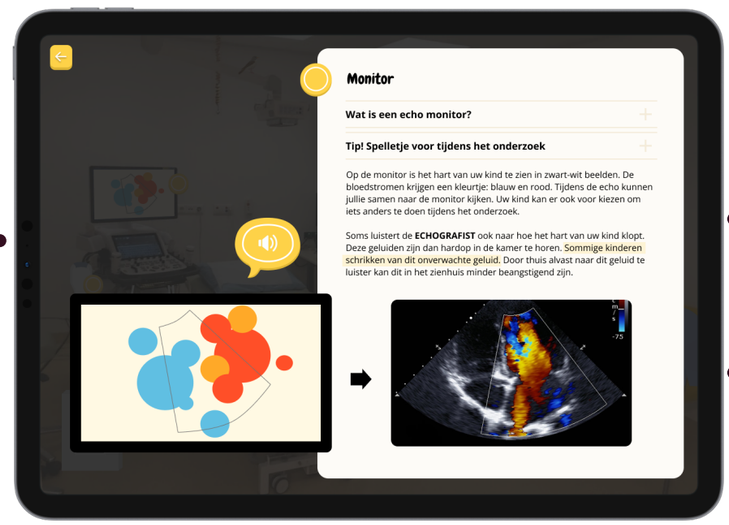
"The explanation for parents is quite concise. I like that they get the information in the same way as the children [in the child layer], but I think parents also want to actually see the equipment and materials".

The specific information about the touchpoints included tips about how to explain these in a child-friendly manner. Both respondents agreed that this could be emphasised.

▼ **Figure 63**. Design adaptation based on input pediatric experts: more information with visual support.



[actual sound of echocardiogram device]



more emphasis on auditory stimuli

more (detailed) information

real life picture of touchpoint

3. Design choice: Auditory support (i.e. narration by animals) instead of textual information.
The experts agreed that the design choice regarding auditory support fit the target group, making the online module overall more child-friendly. Both experts indicated that the content of the spoken text could be improved by emphasising the link between the preparation and the own hospital visit more and by integrating Comfort Talk (see Chapter 2). The audio script was discussed in detail during the evaluation session and iterated based on the suggestions and materials the experts provided. The new script can be found in Appendix K2.

"Changing it [the sentences] in such a way that you still explain what it is, but also how the children can benefit from it. [...] You can also already prime the children with comforting words such as easy, quick, or fun".



OLD SCRIPT: "This is the device the doctor uses to look at your heart. This is only possible with a little bit of gel."

NEW SCRIPT: "The doctor uses this small device to look at your heart. This works best if there is a little bit of gel on it. The gel is needed to easily move the device over your chest."

WHAT IT IS
COMFORT TALK
WHAT IT MEANS FOR THE CHILD

6.4 Final Design

After the adaptations based on the evaluation sessions, one final iteration of the prototype took place. The changes are explained in the following sections.

Interface Design

The design of the home screen of the child layer was changed in order to make it more engaging for children between the ages of four and seven, see Figure 64. The procedure animals were kept as the focus of the home screen, to keep a strong resemblance with the home screen of the parent layer.



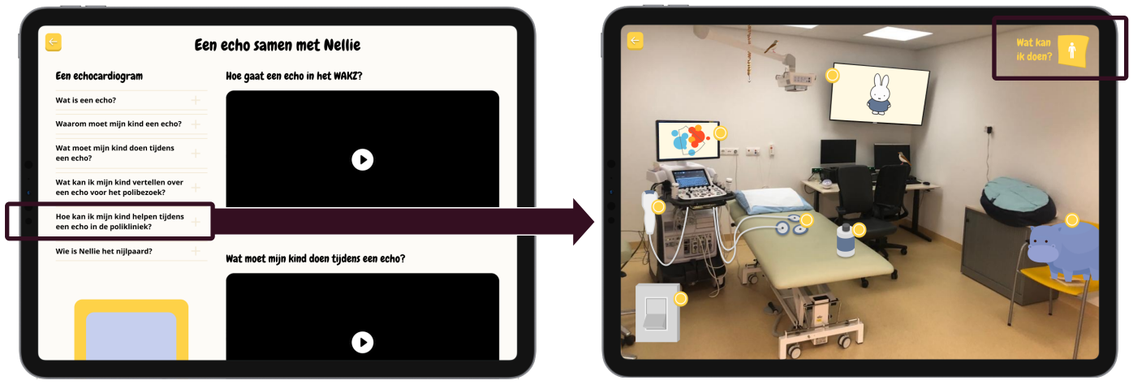
▶ **Figure 64**. Top: Old home screen. Bottom: New home screen of the child layer.

Adding a Button

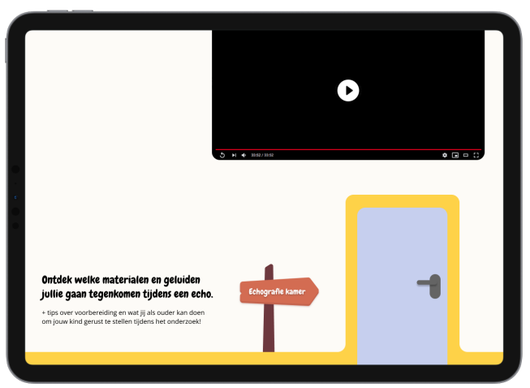
One of the topics of the general information page was 'What can I do as a parent to help my child during an echocardiogram?'. The information and tips provided about this topic refer to elements inside the treatment room. For example, one of the tips explains that parents are allowed and encouraged to move the chairs inside the room to be closer to their children during the check-up procedure. To help parents form an image of the tips (e.g. the chairs they can move), the location of this information was moved to the 'exploration page', see Figure 65. In this way, parents can see the room while reading about what they can do inside this room to help their child.

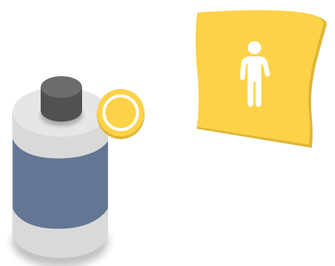
Usability

The overall usability of the prototype was improved by adding more guiding cues, either textual or visual. For example, an explanation about what can be found when clicking on the closed door was added, see Figure 66. Another iteration included adding yellow dots in the exploration page in the parent layer. This allowed users to see all touchpoints inside the room in one glance and decrease the change of missing information due to oversight. These yellow dots were not added to the child layer since it would restrict the exploration aspect.



▲ **Figure 65**. In the final design, information about what parents can do to help their child during the procedure is featured in the exploration page (right) instead of on the general information page (left).





◀ **Figure 66**. The usability of the online module is improved by adding textual and visual guiding cues.

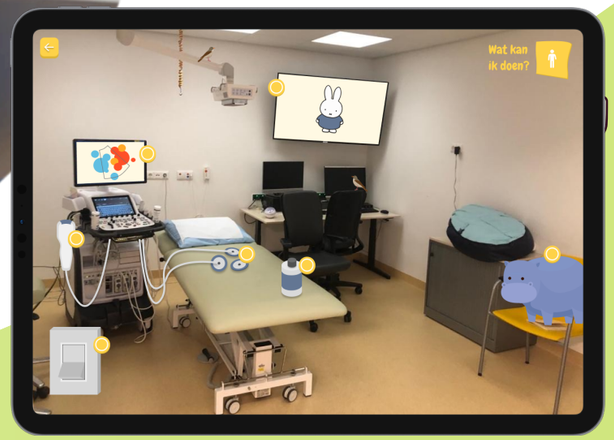
Overview of the Final Design

Parent Layer



OVERVIEW OF HOSPITAL FLOW AND PROCEDURES





OVERVIEW OF CONTEXT-SPECIFIC TOUCHPOINTS AND PROCEDURE STEPS

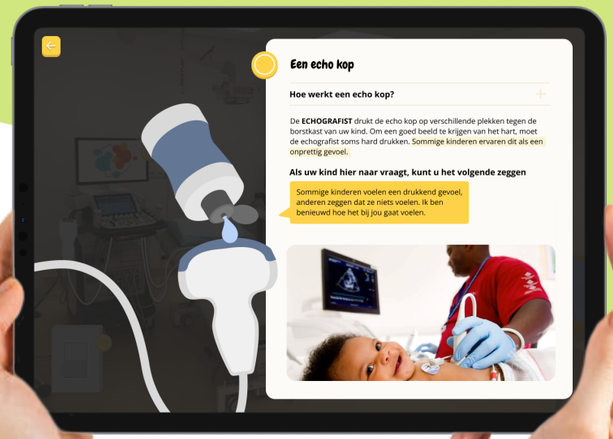
TIPS ABOUT HOW PARENTS CAN COMFORT THEIR CHILD DURING THE PROCEDURES







GENERAL INFORMATION PAGE

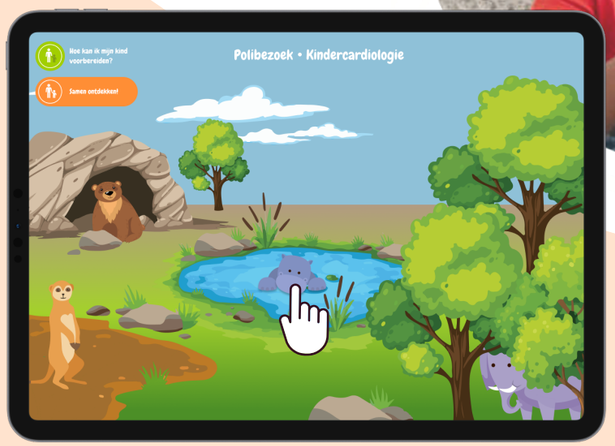


PREPARATION TOOLS AND COMMUNICATION GUIDELINES

Overview of the Final Design

Child Layer





INTRODUCING ALL PROCEDURE ANIMALS



"Hey! How nice to have you here!
My name is Nellie the Hippo."



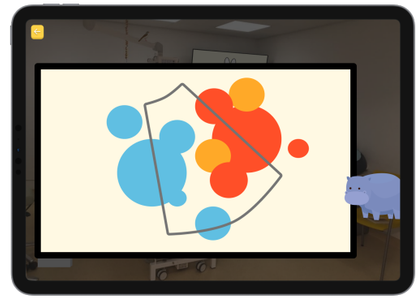
EXPLORING CLOSED DOORS

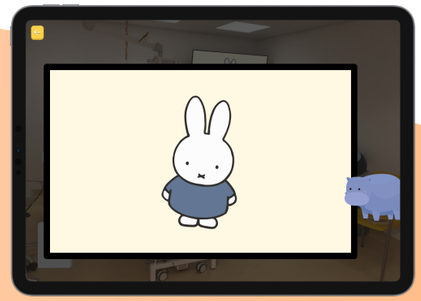


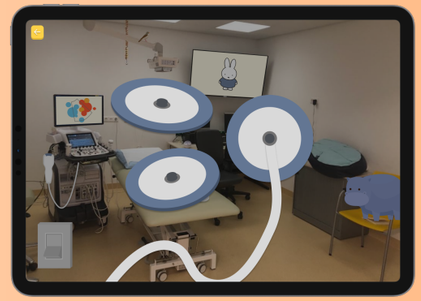
EXPLORING STEPS OF THE PROCEDURE AND SENSORY STIMULI INSIDE THE TREATMENT ROOM

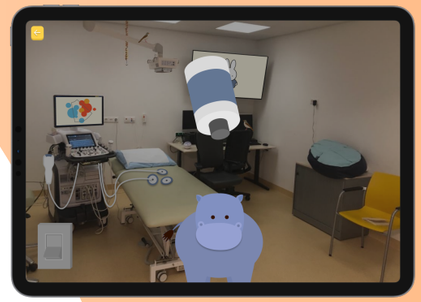


"Maybe your mom or dad can explain where the stickers will be placed on your body."











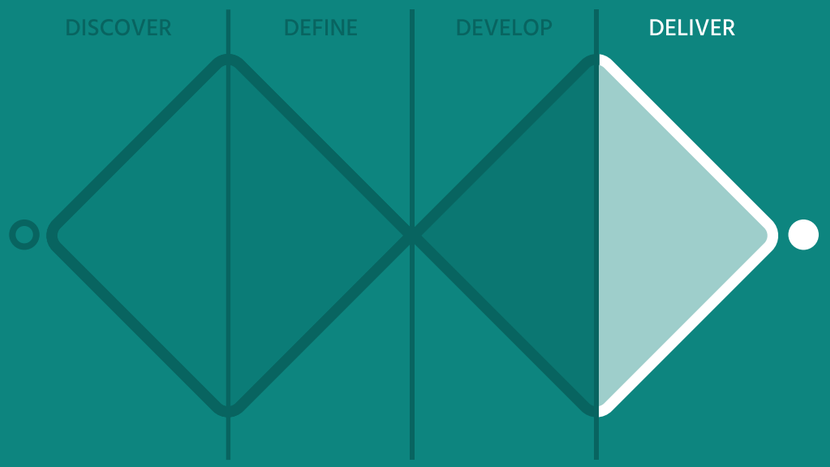
Chapter 7. Evaluation

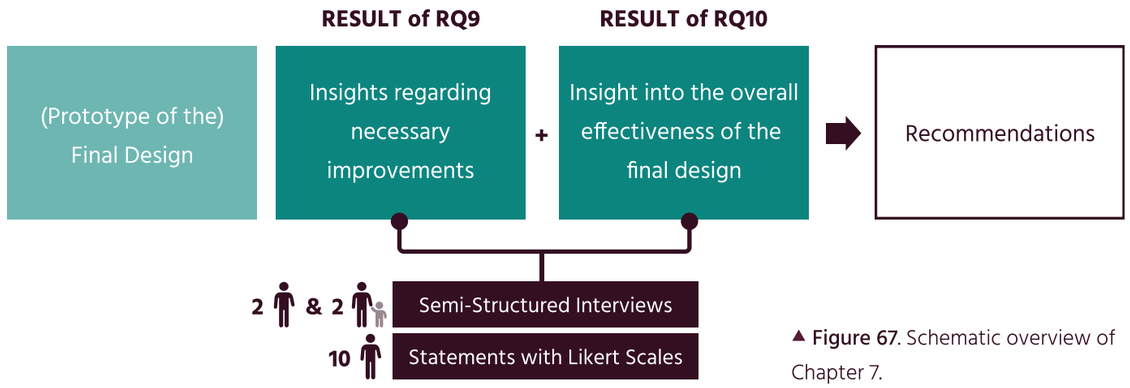
7.1 Study Purpose

The previous chapter visualised the final design. In this chapter, the design was evaluated with stakeholders and potential users. The aim of the qualitative evaluation was to gain insights regarding the defined preparation approach, design choices, and the overall desirability of the design. This chapter concludes with recommendations for future research. This chapter answers the following research questions:

RQ9 – Does the final design meet the defined requirements?

RQ10 – Does the final design have the potential to decrease fear and anxiety during outpatient visits to the cardiology department?





▲ **Figure 67**. Schematic overview of Chapter 7.

7.2 Method

An overview of the (number of) respondents, employed recruitment process, materials and procedures can be found in Table 7.

Respondents

The final prototype was evaluated with parents (n=2), and paediatric healthcare experts of the WACH (n=10) and the Sophia Children's Hospital (n=2). A description of the respondents can be found in Table 7. 11 out of the 14 respondents were familiar with the current Hospital Hero application. None of the respondents had prior knowledge about the final design of the prototype or the defined preparation framework.

▼ **Table 7**. Overview evaluation sessions.

	RESPONDENT	NO.	RECRUITMENT	MATERIAL	PROCEDURE
Potential Users	Mother of an 8 y.o. child with CHD	1	Via email	Semi-Structured Interview Questions (Appendix X)	One hour session, via video calling
	Mother of a 4 y.o. child	1			
HCWs of the SCH	Physician Assistant	1			
	Pediatric Nurse	1			
HCWs of the WACH	Pediatric Cardiologist	2	On the spot during working hours	Statements with Likert Scales and Corresponding Probing Questions (Appendix X)	20-30 minute session, face-to-face
	Pediatric Heamatologist	1			
	Sonographer	1			
	Physician Assistant	3			
	Pediatric Nurse	3			

Respondent was unfamiliar with the current Hospital Hero application.

Material

The final prototype (see the overview on pages 79-82) was evaluated. No intermediate changes or adaptations took place between the evaluation sessions. The prototype was shown on an external device mimicking the intended online environment, see Figure 68.



▲ **Figure 68.** Evaluation session in the WACH.

To gain an in-depth understanding of why respondents think the design (does not) meet the requirements, qualitative data was collected by means of semi-structured interview questions, see Appendix M1. Respondents recruited on the spot during working hours had limited time. To make efficient use of their time, a mixed method was employed of statements with seven-point Likert scales and corresponding probing questions. The statements were adapted from the semi-structured interview protocol and can be found in Appendix M2.

Procedure

The parents and paediatric experts of the SCH were recruited via email, followed by an online evaluation session of approximately one hour. The following structure was conducted:

1. Introduction of the respondent
2. Introduction of the project and background information (introduction of Hospital Hero, the purpose of the design, the framework of design: parent and child layer)
3. Walkthrough of the prototype, i.e. the researcher clicked through the interactive prototype
4. Semi-structured interview questions

The respondents were encouraged to speak their thoughts out loud during the walkthrough of the prototype.

The respondents of the WACH were recruited on the spot during working hours, followed by an evaluation session face-to-face, lasting between 20 to 30 minutes. The following structure was conducted:

1. Introduction of the respondent (name, function)
2. Introduction of the project (the purpose of the design, the framework of design: parent and child layer)
3. Walkthrough of the prototype, i.e. the researcher clicked through the interactive prototype
4. Open question: 'What is your first impression of the design?'
5. 10 statements with a seven-point Likert scale, with corresponding probing questions
6. Open question: 'Are there any parts or elements of the design that can be improved?'

The Likert scales were handed out on paper and collected after each session.

7.3 Results

FIRST IMPRESSION

After the walkthrough of the prototype, each respondent was asked to share their first impression of the design. The descriptions the respondents used to describe their opinion were collected and visualised in one overview, see Figure 69. The size of the visualised words correlates to the number of times the description was used by different respondents to describe the design.

First reaction of a physician assistant of the Sophia's Children's Hospital: "I think it's a really good idea, really beautiful to do it in this way. […] this would save us so much time if this were actually realised, that would be awesome. Because that's just what we run into in our daily lives, children and parents who just don't know how to handle this [an outpatient visit]".

▼ **Figure 69.** Word cloud of the first reaction of respondents.

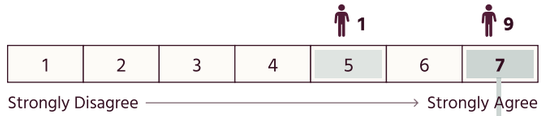




FIT THE TARGET GROUP

Requirement: The online module should be relevant for parents and children with CHD between the ages of 4 and 7, who have to repeatedly visit the outpatient clinic.

Statement: This online module is relevant for children with a congenital heart defect between the ages of 4 and 7.



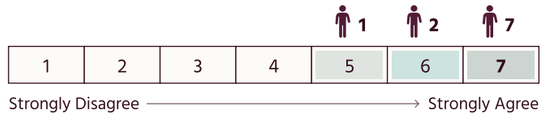
"I think this is actually the most important age. I think that you can also use parts of it with children from the age of three, but definitely not younger. Up to eight years old would be suitable too, I believe".

All paediatric healthcare experts agreed that the online module was relevant for the defined age category. "I think that this is very nicely tailored to this age group". Respondents mentioned the following aspects: child-friendly voice, comprehensible information, visual and auditory aspects, and the interactiveness while exploring the room.

6 out of the 12 HCWs mentioned that the age category could be expanded to older children up to primary school age. "There are many children with a congenital heart defect that have a cognitive delay, so what does age mean? [...] This afternoon I saw a child of 14, and he was terrified. He would have greatly benefited from this tool".

In contrast, both parents reported that certain elements of the design were most suitable for children between the ages of three and four. They pinpointed the following two aspects: (1) visual cues i.e. the cartoon character Miffy (Dutch: Nijntje) on the television screen and (2) the level at which the procedure animal explains certain touchpoints in the room. "I think this is very good, but if you do it this way, you also provide information [for children] younger than 4. [...] children aged 5, 6, 7 might lose their interest because they can already see that there are three".

Statement: This online module is relevant for parents with children who have a congenital heart defect.



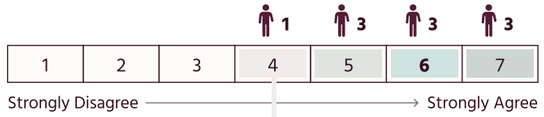
7 out of 12 HCWs mentioned that the online module would be most relevant for parents visiting the outpatient clinic for the first time, i.e. not necessarily based on the age category of their child. Parents who visit the outpatient clinic shortly after the birth of their child know what will happen during the procedures once their child turns four. Explanations about the touchpoints and the room were deemed irrelevant to these parents. Tips about how to communicate this information remain relevant, according to the HCWs.

Both potential users indicated that the online module would have been relevant for them when visiting the outpatient clinic for the first few times. "Definitely the information 'why does my child need an ultrasound' and the purpose of an ultrasound, that would have removed a lot of questions and also worries and uncertainty. [...] I wish this had been around a few years ago".

Besides answering questions, other reported aspects that made the online module relevant for parents included: general information and context-specific information in one place, easy-to-follow guidelines, conversation starters, and reassurance.

Besides being relevant for parents, the online module was also unpromptedly deemed relevant as an explanation tool for external users by a potential user. "And friends and family who want to know more can also use it so that they also know what it means. It is actually quite a struggle to explain that sometimes".

Statement: This online module is relevant for children who have to visit the outpatient clinic repeatedly.



"The tool only shows the essential aspects; what does the room look like, what is going to happen. They will know that at a certain point. So I can imagine, that children would think 'yes I did that last time', that the challenge is no longer there".

The majority of the HCWs saw the value in using the child layer of the online module repeatedly, due to the age range of the target group. Respondents mentioned the importance of repeating information, comforting children who (recently) had major medical interventions, or setting straight any fantasies or misconceptions about the hospital visit.

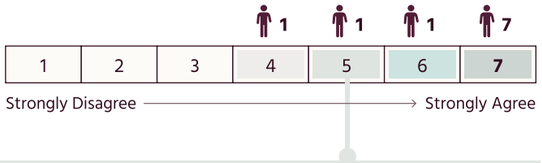
Respondents that scored the statement lower, mentioned the increasing age of the target group and the lack of new information. In addition, HCWs mentioned that the hospital experience would become familiar to the children at a certain point and therefore, the online module would lose the exploration feature.

The mother of an 8-year-old child with CHD reported that she would have used the parent layer of the online module repeatedly; "Maybe sometimes to freshen things up". Both parents indicated that their children would have used the online module multiple times too, especially shortly before visiting the outpatient clinic (for the first time).

INFORM PARENTS

Requirement: The online module should provide parents with comprehensible information that is specific to the check-up procedures performed during an outpatient visit.

Statement: The provided information in the parent layer of the online module is easy to understand for parents.



"There are still some difficult words here and there, but overall clearly written".

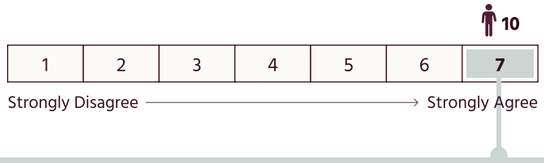
Both the HCWs and potential users agreed that the information provided in the parent layer was comprehensible. The reported aspects that contributed to the comprehensibility were: the small amount of text, no use of medical terminology, simple words, and a pleasing text-to-image ratio. One of the potential users unpromtedly stated the following about the comprehensibility: "The great thing about this app is that it is bundled. It is short but powerful and I think that is very valuable. It is written in easy language. I think it is very understandable and I think that is a very big plus".

HCWs unpromtedly mentioned the following aspects to increase comprehensibility: the option to change the language of the parent layer and child layer individually (n=5), the option to read the textual information out loud (n=4), and adding explanations about the importance of the communication tips, i.e. not only the what but also the why (n=2).

SUPPORT PARENTS: ENABLE CUSTOMISED PREPARATION

Requirement: The online module should provide parents with preparation tools and encourage parents to share (the obtained) information with their child during the home-based preparation process.

Statement: The online module supports parents during the home-based preparation process.



"Totally agree. But I think it depends on the parent how much they add themselves. You have parents who involve their child in everything and you have parents who just say 'here's the iPad' and are done with it".

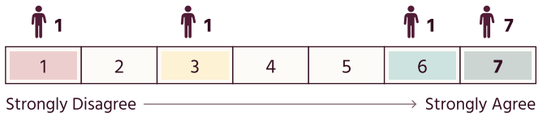
All HCWs agreed that the online module could support parents during the preparation process. When asked which aspects contributed to this, the following things were reported: parents and child are informed in a similar way, the online module highlights important moments and materials, the procedure animal and integrated jokes provide conversation starters, and the parents are offered communication guidelines. When asked if the parent layer provided preparation tools, one of the potential users answered the following: "Yes, for example, those things 'if your child asks about this, you can say the following'. Because when you are a little lost due to the situation, it is nice that you see 'oh this is something I could say'."

Both potential users reported that they would probably only add information when their child would actively ask for it. The reported rationale for this was the clear storyline, comprehensible explanations by the procedure animal, and the independent character of their children.

PREPARE CHILDREN

Requirement: The online module should provide the opportunity for children to explore auditory and visual context-specific stimuli and get acquainted with the steps of medical procedures.

Statement: I think the design of the child layer of the online module works well for preparing children (between the ages of 4 and 7).

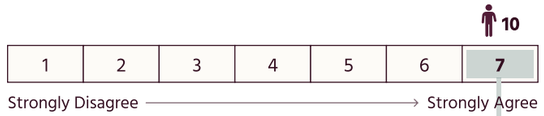


All respondents agreed that the design choices of the online module work well when preparing children. The HCWs that scored the statement with an one and a three, did so because they did not agree with the defined age group. Respondents mentioned the following contributing aspects: discovering, empowering, engagement, visual and auditory aspects, repetition, small jokes, and the interactive game with the doors. "And I think adding those doors is genius because all those doors that are closed here [in the outpatient clinic] result in a big question mark".

Both potential users and three HCWs suggested adding more information to the child layer, specifically about how the child will interact with the touchpoints. "I think if they see the procedure, it will be less scary to see it there [in the hospital]".

DESIRABILITY

Statement: I would recommend the online module to the children and parents I see during my work as a pediatric healthcare worker.



"Yes, I would definitely recommend this. I think this module is a huge addition to our work".

All HCWs indicated that they would recommend the online module to the paediatric patients and parents they see in the clinic. HCWs mentioned that it would save time during the procedures and increase the comfort of parents and children. Both potential users indicated that they would have used the online module themselves as well as with their children.

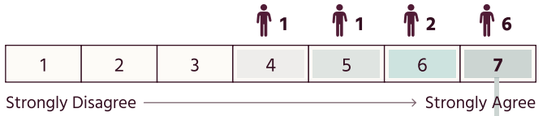
One HCW unpromptedly remarked that the online module would also provide communication tools for HCWs; "I think it can be a very nice tool for children, but also for us. We can use it to point out certain aspects and communicate about the procedure in the same way [the online module does]".

IMPLEMENTATION

Most of the HCWs saw opportunities in incorporating the online module into their daily work. The most reported opportunity was asking the child questions about the procedure animal. 6 out of the 12 HCWs unpromtedly suggested adding a physical component, like a stuffed animal or sticker, to the room as a conversation starter for HCWs. Both potential users found this physical component a must.

HCWs who scored this statement lower (n=2) attributed this to the time constraints of an outpatient visit, changes in the workflow, and not knowing which paediatric patients would have prepared themselves with the module and which ones did not.

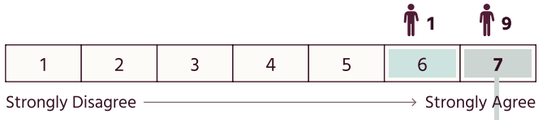
Statement: I can easily incorporate the online module in my daily work with pediatric patients.



"I think it is very easy to incorporate. Ultimately we just need to know what's in it and what we can use. We can ask questions like 'have you watched it, what do you know about the hippo?'."

OVERALL GOAL: FEAR-FREE OUTPATIENT CLINIC VISITS

Statement: I think this online module can help children (between the ages of 4 and 7) experience less fear during a visit to the outpatient clinic.

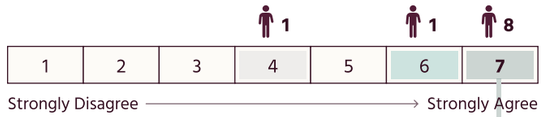


"I think it would definitely decrease their fear because it is no longer a surprise what's behind that door. Things are explained, and parents are talking with you about it. I think this would help a lot".

All 14 respondents reported that they think the online module can potentially help (their) children experience less fear during their outpatient visits.

Respondents reported that the online module offers preparation in a fun and engaging manner for children. In addition, the majority of the HCWs mentioned that parents would be more relaxed, in turn positively affecting the emotional status of their children.

Statement: I think this online module can help parents experience less anxiety and fear during outpatient clinic appointments of their child.



"Parents go through this [online module] with their child so they are both more prepared. Most of the time, parents are more anxious than their children. When children realise 'oh it is not that bad', parents can let it [anxiety] go".

12 of the 14 respondents agreed that the online module would reduce parents' feelings of anxiety. Respondents mentioned that the communication tools provided by the online module help parents feel more confident about the hospital visit, in turn decreasing the feelings of anxiety. Other aspects mentioned were knowing what will happen yourself and knowing that your child is prepared. "If their child is well prepared as a result, parents are also a bit more relaxed".

One HCW (i.e. who scored the statement with a four) and one potential user attributed the fear of parents to the health status of the child; "My fear mainly concerns the outcome of those procedures. And unfortunately, you can't take that away". This potential user, however, did report that the online module would have helped with decreasing her anxiety in the early stages of her daughter's diagnosis.

7.4 Conclusion

• **RQ9** – Does the final design meet the defined requirements?

FIT THE TARGET GROUP

Overall, the child layer of the online module fits the characteristics of the age group. However, certain aspects (i.e. visual cues and level of explanations) were deemed to be tailored towards the younger half of the age group. This would possibly affect the preparation outcomes for the older half (i.e. 6-7 year olds).

The evaluation results show that the parent layer is relevant for parents with children with CHD between the ages of four and seven. The offered information about the procedure (on the general information page) is mostly relevant for parents that are going to visit the outpatient clinic for the first time. The offered preparation tools and communication guidelines that are tailored toward children between the ages of four and seven remain relevant for all parents regardless of the number of times they have visited the outpatient clinic.

Depending on the interval of the outpatient visit, the online module remains relevant for repeated use. When paediatric patients are required to visit multiple times within a short interval of time (e.g. every three months), the respondents indicated that the online module would lose its relevancy due to the lack of new information. However, the majority of paediatric patients visit the outpatient clinic once every year or once every two years. For these children, repetition of the same information was deemed beneficial.

INFORM PARENTS

The parent layer informs parents about context-specific information in a comprehensible manner. The offered information details the essential aspects of the medical procedures. Respondents pointed out small elements or additions that could be added to this information. These elements are discussed in the recommendations.

SUPPORT PARENTS: ENABLE CUSTOMISED PREPARATION

The parent layer provides sufficient preparation tools and communication guidelines to enable child-parent interaction during home-based preparation. Respondents expected that there would be enough space for parents to share (the obtained) information with their children. Future research should find out if the online module should encourage child-parent interaction more.

PREPARE CHILDREN

All respondents expected that the child layer would prepare children for the visual and auditory stimuli they would encounter during the procedures. However, respondents expected that the online module would not optimally prepare children for the steps of the procedures. They indicated that the child layer should not only explain what the steps of the procedures (i.e. touchpoints) are but also provide more in-depth information about how children will interact with these touchpoints.

• **RQ10** – Does the final design have the potential to decrease fear and anxiety during outpatient visits to the cardiology department?

The online module has the potential to diminish fear and anxiety of paediatric patients and their parents. Parents get their questions answered in a comprehensible manner and get support during the home-based preparation of their child. Children can explore hospital-related stimuli and the steps of the procedures at their own pace in a child-friendly environment. The online module empowers parents and children with home-based preparation.

Implementation of the online module was deemed desirable by healthcare workers and potential users. The design fits within the current workflow of the paediatric outpatient clinic of the WACH and has the potential to be tailored to other paediatric hospitals and medical procedures. In addition, it was found that the online module has the potential to support HCWs during communication with paediatric patients and can support parents in explaining the heart defect of their child to external parties.

7.5 Limitations

Respondents

A limitation of the evaluation was the small number of respondents. Second, the respondents did not include any paediatric patients. As a result, conclusions were made based on the second-hand (i.e. indirect) information of the respondents. A proposal for the evaluation approach with paediatric patients can be found in the recommendations.

Third, the potential users that did participate in the evaluation sessions, did not fit the specifications of the target group (i.e. age of the child or no congenital heart defect). One of the potential users also participated in a previous study (i.e. semi-structured interview about practised preparation methods), resulting in possibly biased answers.

Finally, the majority of the respondents were familiar with the Hospital Hero foundation. This might have resulted in a more positive response to the prototype.

Material

The materials used during the evaluation might have affected the answers of the respondents. First, the prototype that was tested had a limited interaction (i.e. not all functions worked). As a result, respondents were not able to click through the prototype themselves. For this reason, the walkthrough of the prototype might not have progressed at the desired pace of the respondents, possibly affecting their answers.

Second, Likert scales are susceptible to response biases such as social desirability. The bias of the results was attempted to be minimised by asking probing questions about the provided answers.

7.6 Future Recommendations

The following sections contain recommendations regarding the improvements of the design, a recommended evaluation approach for the target group, and implementation recommendations.

7.6.1 Improvements Based on Qualitative Evaluation

Based on the qualitative evaluation, the following improvements are recommended:

• More information about the procedure steps should be added to the child layer. The online module now only verbally explains the touchpoints, but should also visually indicate how the touchpoints will interact with the child. My recommendation would be to provide this information by means of interactive games, e.g. children need to drag the three echo stickers to their intended places on the chest. Adding these interactive games can also make the online module more suitable for the older half of the age group (i.e. 6 to 7-year-olds).

• More background information should be added to the parent layer. The provided information explains how things can be done (e.g. provide comfort inside the treatment room) but does not detail why these things are important. The added rationale can help parents better understand the guidelines and the importance of preparation in general.

• The order of the procedure steps and used terminology (in the online module) should be discussed in detail within the team of healthcare workers. The order of the procedure steps featured in the final design is based on the conducted observations. Some details (e.g. how echo gel is applied) are left out due to personal differences between the practised method of HCWs (e.g. some apply the gel directly on the chest of paediatric patients, while others apply it on the echo probe). When one guideline regarding the steps of the procedure is established within the HCW team, the online module can specifically prepare children for this. This also applies to the used terminology (e.g. 'plakkers' vs. stickers).

• The usability of the online module should be improved. The evaluation studies indicated that the level of guidance (i.e. what the user needs to do) could be improved, specifically in the parent layer. In addition, the overall preparation approach of the online module should be communicated; The module should encourage parents to use the parent layer before using the child layer.

• The online module should be completed. The current version of the prototype only features information regarding the echocardiogram. Information about the other check-up procedures that are part of an outpatient visit and general waiting room should be added.

7.6.2 Future Evaluation with Child-Parent Pairs

The online module should be evaluated with child-parent pairs in a real-world context. The following sections detail a recommended evaluation approach. The content of the materials should be defined and discussed with paediatric experts.

Respondents

Child-parent pairs that fit the characteristics of the target group (i.e. defined age group, CHD) and have a planned visit to the outpatient clinic within the next two weeks.

Material

• High-fidelity prototype of the (improved) online module
• Observation topic list
• Semi-structured interview protocols for children and for parents

Procedure

• Shortly after recruitment, the child-parent pairs should be provided with a high-fidelity prototype of the online module, at least one week before their planned hospital visit. Parents should be asked to go through the parent layer of the online module, and then go through the child layer together with their child. Parents should be free to decide when, where, and how often they do this. Respondents of the evaluation study should be asked to take notes or pictures to map any insights obtained during this process.

• To map the possible effect of the home-based preparation, researchers should observe the child-parent pairs during their outpatient visits. The researchers should write down any observations regarding child-parent interactions and the emotional states of the child-parent pairs.

• Shortly after the outpatient visit, preferably within the same day, a face-to-face meeting should take place with the child-parent pair. During this meeting:

1. In-depth questions should be asked about the home-based preparation with the online module. Parents should be encouraged to share the pictures and/or notes they took. When applicable, parents should be asked to reflect on previous hospital visits and point out possible differences compared to the most recent visit (i.e. with the online module). An example of a question for children is: 'Can you explain to me what you learned from [name of procedure animal, e.g. Nellie]?'.

2. In-depth questions should be asked about if/how the online module affected the hospital experience. The written-down observations of the researcher can function as conversation starters. Example questions for children include: 'How did you experience searching for [name of the procedure animal]?' and 'Did you recognise some things that [name of procedure animal] told you about?'.

The gathered interview data should be analysed together with the observations.

7.6.3 Implementation

Current Hospital Hero Application

The online module can be integrated into the current Hospital Hero application, either as an integral part of the application itself or as a link to an external website. My recommendation would be to integrate the online module in the application as an integral part, so it can utilise existing aspects of the application. An integration proposal can be found in Appendix N.

Two aspects can be utilised: (1) personalisation of the hospital journey and (2) scanning QR codes. In the current Hospital Hero application, users can indicate which check-up procedures are scheduled. The online module can utilise this feature to only show the check-up procedures the child will encounter. Children can also use the current Hospital Hero application to find animals by means of scanning QR codes. QR codes of the procedure animals featured in the online module can be hidden inside the treatment rooms and function as a reward (i.e. comforting element).

Another reported and observed factor that helped paediatric patients feel in control was the visualisation of time (see section 4.3.3). By scanning QR codes and collecting the procedure animals, children can visualise the progress of their outpatient visit (see Appendix N). For example, after their echocardiogram, they can scan the QR code and Nellie the Hippo appears in an overview showing that they still need to collect the remaining procedure animals.

Physical Component

Besides a QR code inside the treatment rooms, it is recommended to add a physical component so one coherent experience is created for children and parents. The initial concept suggested a stuffed animal, based on the mapped comforting elements. Multiple respondents of the evaluation suggested a 2D sticker on the wall, due to hygienic reasons. Future research should look into the best option for the type and placement of the physical component.

Besides creating a coherent experience, a physical component inside the treatment rooms can have the potential to enrich the preparation approach of healthcare workers shortly before/during the medical procedures (i.e. on top of home-based preparation). In addition, the physical component can provide active distraction (i.e. avoiding (hyper)focus) during medical procedures, which can in turn contribute to a decrease in the procedural distress experienced by paediatric patients. Future research should explore how the hypothesised effects manifest in the real-life context and how these effects can be enhanced.

Informing HCWs

Before implementing the online module, the content should be presented to relevant stakeholders. HCWs should be encouraged to implement the online module in their daily workflow. The evaluation sessions already indicated that there is a need for this.

HCWs repeating the home-based preparation and/or integrating it into their daily work can positively affect the bond of trust they develop with paediatric patients. Strengthening this bond of trust can, in turn, result in children experiencing less pain, fear and anxiety, showing better compliance, healing faster, and having fewer traumatic memories (see Chapter 2). Future research should not only look into the effects of home-based preparation but look at the whole hospital experience including the preparation approaches of HCWs.

Scalability of the Design

The aim of the Hospital Hero foundation is to reach as many paediatric patients as possible, meaning that the online module should have the potential to be tailored to other (Dutch) children's hospitals. The online module can be relatively easily tailored to (the workflow of) other hospitals and medical procedures. When doing so, I recommend the following steps:

1. Observe and establish the touchpoints and (order of) procedure steps that are utilised.
2. Map the auditory and visual aspects of the touchpoints. These may differ depending on the medical equipment used.
3. Map the context-specific triggers of fear, so the online module can prepare parents and children for this. For example, a trigger of fear specific to the WACH is the echo gel used at room temperature. Other children's hospitals may heat the gel before use. The mapped comforting elements (see Chapter 4) will mostly remain the same for paediatric patients.
4. Implement pictures of the actual treatment rooms as a base for the 'exploration page'.
5. Tailor context-specific information to the hospital/medical procedure, e.g. parents are allowed to sit on the 'yellow' chairs.

The preparation approach and overall structure of the online module can remain the same.

7.7 Concluding Remarks

Qualitative evaluations indicated that the designed intervention has the potential to positively impact paediatric healthcare, supporting many children and their parents with their hospital journey. When the recommended aspects are integrated into the current design, the preparation tool has the potential to address all components of procedural distress, possibly resulting in a sustainable multimodal intervention that diminishes paediatric hospital-related fear and anxiety. The online module can be tailored to (the workflow of) other hospitals and medical procedures, possibly extending its reach beyond children with CHD.

BIBLIOGRAPHY

Amsterdam UMC, Emma Kinderziekenhuis. Information on this website was retrieved on November 8 2022, from https://www.erasmusmc.nl/nl-nl/sophia/pages/bereid-uw-kind-voor-op-een-bezoek#770fcc9d-b803-49a9-82f8-9a7ade55f4c7

Babakr, Z., Mohamedamin, P., & Kakamad, K. (2019). Piaget's cognitive developmental theory: Critical review. Education Quarterly Reviews, 2(3).

Comfort Talk®. The leading Voice in Patient Comfort. (n.d.) Retrieved October 6 2022, from https://comforttalk.com/

Design Council. (2019). Framework for Innovation: Design Council's evolved Double Diamond. Retrieved September 10 2022, from https://www.designcouncil.org.uk/our-work/skills-learning/tools-frameworks/framework-for-innovation-design-councils-evolved-double-diamond/

Gillis, A. J. (1990). Hospital preparation: the children's story. Children's Health Care, 19(1), 19-27.

Heeren, A. (2020). On the Distinction Between Fear and Anxiety in a (Post) Pandemic World: A Commentary on. Clinical Neuropsychiatry, 17(3), 189.

Heijne, K., & Van der Meer, H.(2019). Road Map for Creative Problem Solving Techniques: Organizing and Facilitating Group Sessions. Boom.

Jeroen Bosch Ziekenhuis. Uw kind voorbereiden. Information on this website was retrieved on November 8 2022, from https://www.jeroenboschziekenhuis.nl/hallo-ziekenhuis/uw-kind-voorbereiden

Knipping, S. (n.d.). Angst en reacties bij een ziekenhuisopname. De speelboom: Kindertherapie & Hypnotherapie. Retrieved October 3 2022, from https://despeelboomkindertherapie.nl/inspiratie/angst-en-reacties-rondom-een-ziekenhuisopname/

Lazdrus, R. S., & Folkman, S. (1984). Stress, appraisal and coping. New York Springer.

Lerwick, J. L. (2016). Minimizing pediatric healthcare-induced anxiety and trauma. World journal of clinical pediatrics, 5(2), 143-150.

Leroy, P. L. (2021). Van trauma naar vertrouwen: Procedurele comfortzorg als missing link voor goede zorg. Praktische Pediatrie 2021;15:2.

Luyckx, K., Goossens, E., Rassart, J., Apers, S., Vanhalst, J., & Moons, P. (2014). Parental support, internalizing symptoms, perceived health status, and quality of life in adolescents with congenital heart disease: influences and reciprocal effects. Journal of behavioral medicine, 37(1), 145-155.

Mayo Clinic. (n.d.) Congenital heart defects in children. https://www.mayoclinic.org/diseases-conditions/congenital-heart-defects-children/symptoms-causes/syc-20350074

Mendels, E., Zirar-Vroegindeweij, A., Waagenaar, G., Versteegh, J., & Leroy, P. (2022). Kindgerichte zorg bij medische verrichtingen. Huisarts en wetenschap, 65(9), 31-35.

Muris, P., Merckelbach, H., Gadet, B., & Moulaert, V. (2000). Fears, worries, and scary dreams in 4-to 12-year-old children: Their content, developmental pattern, and origins. Journal of clinical child psychology, 29(1), 43-52.

Nickerson, C. (2022). How Observational Learning Affects Behavior. Simply Psychology. Retrieved from https://www.simplypsychology.org/what-is-observational-learning.html

Perusini, J. N., & Fanselow, M. S. (2015). Neurobehavioral perspectives on the distinction between fear and anxiety. Learning & Memory, 22(9), 417-425.

Petrillo, M., & Sanger, S. (1980). Emotional care of hospitalized children. (2nd ed.). Philadelphia Lippincott.

Rachman, S. (1977). The conditioning theory of fear acquisition: A critical examination. Behaviour research and therapy, 15(5), 375-387.

Rodriguez, C. M., Clough, V., Gowda, A. S., & Tucker, M. C. (2012). Multimethod assessment of children's distress during noninvasive outpatient medical procedures: Child and parent attitudes and factors. Journal of pediatric psychology, 37(5), 557-566.

Smith, M. L. (2014). Interventions to minimize distress during pediatric primary care visits: A systematic literature review.
Stichting Hartekind. (n.d.). Home. Referenced August 9 2022, from https://www.hartekind.nl/

Stichting Kind en Ziekenhuis. Information on this website was retrieved on November 7 2022, from https://kindenziekenhuis.nl/voor-tijdens-na-ziekenhuis/

Sanders, EBN., & Stappers, PJ. (2012). Convivial toolbox: Generative research for the front end of design. Bis.

Sun, R., Liu, M., Lu, L., Zheng, Y., & Zhang, P. (2015). Congenital heart disease: causes, diagnosis, symptoms, and treatments. Cell biochemistry and biophysics, 72(3), 857-860.

UMC Utrecht, Wilhelmina Kinderziekenhuis (WKZ). Information on this website was retrieved on November 8 2022, from https://www.hetwkz.nl/nl/uw-kind-voorbereiden

Van Boeijen, A.G.C., Daalhuizen, J.J., & Zijlstra, J.J.M. (Eds.), (2020, Rev. ed.). Delft Design Guide: Perspectives-Models-Approaches-Methods. Amsterdam: BISPublishers.

Vernon, D. (1973). Use of modelling to modify children's responses to a maternal potentially stressful situation. Journal of Applied Psychology, 58, 35-1365.

Vleugel-Ruissen, S., & Keijzer, M. (2019). Voorbij de angst: Distress bij kinderen in de paramedische setting. Gompel&Svacina.

FIGURES

[1] Pictures retrieved from https://wakz-kids.nl/

[2] Picture retrieved from https://www.pzc.nl/gent/kinderen-die-te-bang-zijn-voor-vaccin-krijgen-vr-bril-op-tijdens-prik-in-gent-bij-ons-geven-ze-geen-kik~ab79ab70/?referrer=https%3A%2F%2Fwww.google.com%2F

[3] Picture retrieved from https://uihc.org/childrens/health-topics/distraction-action

[4] Picture retrieved from https://shopee.sg/Buzzy-Mini-Drug-Free-Pain-Relief-for-Injections-Injuries-and-More-i.436541051.7088017117

APPENDIX

	A • **Design Brief**	p. 100
Chapter 3	**B** • **Clusters of Recommended Home-Based Preparation Aspects**	p. 105
Chapter 3	**C** • **Semi-Structured Interview Protocol** | Paediatric Experts	p. 107
Chapter 3	**D** • **Overview Existing Preparation Materials**	p. 108
Chapter 3	**E** • **Make-and-Say Sessions** | Parents and Children	p. 110
Chapter 3	**F** • **Semi-Structured Interview Protocol** | Parents	p. 113
Chapter 3	**G** • **Context Mapping Clusters** | Barriers Faced During Home-Based Preparation	p. 114
Ch. 4	**H** • **Context Mapping Clusters** | Triggers of Fear	p. 116
Ch. 4	**I** • **Context Mapping Clusters** | Comforting Elements	p. 118
5	**J** • **Paired Comparison**	p. 120
Ch. 6	**K** • **Narration Script**	p. 122
Ch. 6	**L** • **Intermediate Evaluation Protocol** | Paediatric Experts	p. 125
Ch. 7	**M** • **Evaluation Protocol** | Stakeholders & Potential Users	p. 126
Ch. 7	**N** • **Integration Proposal**	p. 130

Design Brief

Personal Project Brief - IDE Master Graduation

TU Delft

Reducing fear and anxiety during visits to the pediatric cardiology — project title

Please state the title of your graduation project (above) and the start date and end date (below). Keep the title compact and simple. Do not use abbreviations. The remainder of this document allows you to define and clarify your graduation project.

start date 05 - 09 - 2022 — 06 - 04 - 2023 end date

INTRODUCTION **

Please describe, the context of your project, and address the main stakeholders (interests) within this context in a concise yet complete manner. Who are involved, what do they value and how do they currently operate within the given context? What are the main opportunities and limitations you are currently aware of (cultural- and social norms, resources (time, money,...), technology, ...).

In the Netherlands, four children are born daily with Congenital Heart Disease (CHD) [1]. CHD is a general term for a range of birth defects that affect the heart structure. Congenital heart defects are the most common type of birth defect, affecting 1 in 100 children [1]. Approximately two-thirds of these children undergo one or more life-saving medical procedures shortly after birth. But their medical journey does not end there; "For many of these patients, congenital heart disease is accompanied by substantial stressors and challenges throughout their lifespan" [2]. A heart defect is a lifelong burden.

CHD patients often require medical interventions and regular check-ups to monitor their health, starting from birth. These hospital visits have a big impact on a child's life. Research and practice show that children experience anxiety and distress during healthcare visits [3] which can even result in post-traumatic stress and developmental issues [1]. Children experiencing feelings of anxiety and distress often demonstrate physiological and behavioural distress, including difficulty coping with and recovering from procedures [3]. When anxiety is decreased, "children are able to approach medical situations with a sense of comfort, achievement, and control" [3].

This is where Hospital Hero steps in. The Hospital Hero application is specifically designed with and for children to support children and their families in their hospital journey. It optimizes the preparation process before the hospital visit and provides active distraction through fun and engaging games, including searching and collecting animals through QR code scanning, thereby creating an overall positive experience. The current application only features one healthcare path: Blood sampling.

My graduation assignment is part of a long-term project focused on reaching as many children as possible by integrating multiple healthcare pathways in order to reduce fear and anxiety among all children undergoing medical procedures. I will focus on the healthcare path of children with CHD to make their hospital journey, as well as that of their parents/guardians and close-family members, more comfortable.

[1] Stichting Hartekind. (n.d.). Home. Referenced August 9 2022, from https://www.hartekind.nl/

[2] Luyckx, K., Goossens, E., Rassart, J., Apers, S., Vanhalst, J., & Moons, P. (2014). Parental support, internalizing symptoms, perceived health status, and quality of life in adolescents with congenital heart disease: influences and reciprocal effects. Journal of behavioral medicine, 37(1), 145-155.

[3] Smith, M. L. (2014). Interventions to minimize distress during pediatric primary care visits: A systematic literature review.

[4] Stokmans, S. (n.d.). Hartekind Puck [Photograph]. Sandra Stokmans Fotografie. https://www.documentairefamiliefotografie.nl/ziekenhuis-reportage-openhartoperatie-wkz-hartekind/

[5] n.d. (n.d.). Met de Hospital Hero app op safari door het ziekenhuis. [Photograph]. Willem-Alexander Kinderziekenhuis. https://wakz-kids.nl/2021/12/04/met-de-hospital-hero-app-op-safari-door-het-ziekenhuis/

space available for images / figures on next page

Personal Project Brief - IDE Master Graduation

TU Delft

introduction (continued): space for images



image / figure 1: The hospital journey of CHD patients starts from an early age [4].



image / figure 2: The Hospital Hero application supports children and their parents in their hospital journey [5].

PROBLEM DEFINITION **

Limit and define the scope and solution space of your project to one that is manageable within one Master Graduation Project of 30 EC (= 20 full time weeks or 100 working days) and clearly indicate what issue(s) should be addressed in this project.

Children with heart problems follow a unique healthcare path (together with their guardians) that depends on the type of defect and its severity. The healthcare path of CHD patients starts at a young age and is characterized by recurring hospital visits. In other words; recurring feelings of distress and anxiety [1]. To make the hospital journey of CHD patients more comfortable, it is essential to know which factors cause these feelings before, during and after outpatient visits to the pediatric cardiology department. Challenges include the (lack of) primary sources of information since young children may find it hard to express their feelings, and the multitude of different pathways within one's hospital journey.

The next step is to translate the findings and use this information to make a tailored intervention that makes the hospital journey for the patients as well as their close family members more comfortable. Challenges include the age range of the target group; children aged 4 cope differently with stress than 10-year-olds. The intervention should accommodate children from 4 to 10, in such a way that each child can make use of the intervention in an age-appropriate manner.

ASSIGNMENT **

State in 2 or 3 sentences what you are going to research, design, create and / or generate, that will solve (part of) the issue(s) pointed out in "problem definition". Then illustrate this assignment by indicating what kind of solution you expect and / or aim to deliver, for instance: a product, a product-service combination, a strategy illustrated through product or product-service combination ideas, ... In case of a Specialisation and/or Annotation, make sure the assignment reflects this/these.

To design an intervention (service or product-service combination) that alleviates children's feelings (aged 4 to 10) of fear and anxiety during outpatient visits to the pediatric cardiology department.

The main research question is: What is needed to alleviate children's feelings of fear and anxiety during outpatient visits to the pediatric cardiology department?

To answer this question, several sub-questions have been formulated.
1. What does the patient journey of children with CHD, who come to the pediatric cardiology department for an outpatient visit, look like?
    a. What role do healthcare personnel, parents/guardians, and family members play in this patient journey?

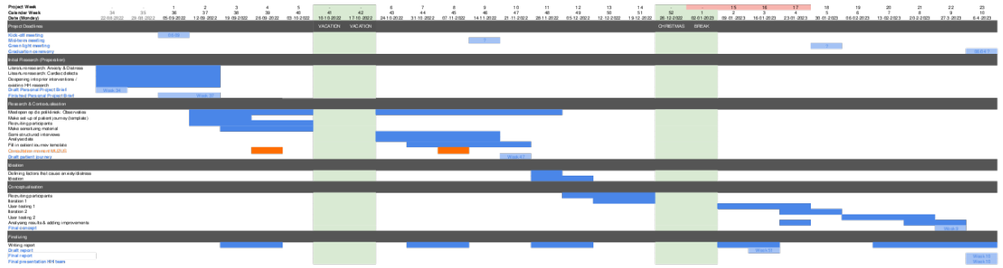
2. What factors play a role in creating feelings of anxiety before, during and after outpatient visits to the pediatric cardiology department?

Methods: Observations, Sensitizing Booklets, Interviewing, Journey Mapping, Low- and High Fidelity Prototyping

PLANNING AND APPROACH **

Include a Gantt Chart (replace the example below - more examples can be found in Manual 2) that shows the different phases of your project, deliverables you have in mind, meetings, and how you plan to spend your time. Please note that all activities should fit within the given net time of 30 EC = 20 full time weeks or 100 working days, and your planning should include a kick-off meeting, mid-term meeting, green light meeting and graduation ceremony. Illustrate your Gantt Chart by, for instance, explaining your approach, and please indicate periods of part-time activities and/or periods of not spending time on your graduation project, if any, for instance because of holidays or parallel activities.

start date 5 - 9 - 2022 6 - 4 - 2023 end date



I plan to work as a teaching assistant for 4 hours every week, meaning that 4.5 workdays are left to work on my graduation project. My project will span the course of 23 weeks and is divided into 5 phases: (1) Initial research, (2) Research & Contextualisation, (3) Ideation, (4) Conceptualization, and (5) Finalization. To allow for enough time in the creative phases and some flexibility when working with people/patients, I tried to split my time in two. The first ~50 workdays will be dedicated to creating the patient journey, and the remainder of my time will be dedicated to ideation, conceptualization and user testing. I plan to document my findings and write the report in blocks of 2 weeks, parallel to other activities.

I plan to start my graduation project with observations (among other activities) and want to continue observing outpatient visits during the first phases of my project since I believe I can obtain valuable information by doing so. Depending on the time and resources of the hospital, I hope to be present for at least one check-up or examination per week.

Richard Goossens will not be available for the entire month of January. This is indicated in the planning with a red colour. An alteration I made because of this is the break in calendar weeks 41 and 42. This allows me to get the recommended time off and provides enough time in February to finish my project with the supervision of Richard.

Lastly, I want to highlight the consultation moments with MUZUS, which are indicated in orange colour in the Gantt chart. These consultation moments are free from obligations for all parties involved and serve as an additional expert source regarding patient journey mapping.

MOTIVATION AND PERSONAL AMBITIONS

Explain why you set up this project, what competences you want to prove and learn. For example: acquired competences from your MSc programme, the elective semester, extra-curricular activities (etc.) and point out the competences you have yet developed. Optionally, describe which personal learning ambitions you explicitly want to address in this project, on top of the learning objectives of the Graduation Project, such as: in depth knowledge a on specific subject, broadening your competences or experimenting with a specific tool and/or methodology, ... Stick to no more than five ambitions.

Over the years, I discovered a fondness for design research; I want to better understand the underlying desires, needs and challenges of the end user. This project allows me to do that in a new and challenging manner but also leaves room for me to translate my findings into a fitting design intervention. The master elective Context Mapping Skills provided me with extensive knowledge about qualitative analysing techniques and the elective Health Psychology taught me how to analyse behaviour and design for behaviour change. I used these new skills during my master internship at Leiden University Medical Centre (LUMC). This is where I truly understood what impact a design researcher can have in the medical field. I aspire to keep doing just that.

This project fits in well with my interests and current skill set as a designer but provides enough challenges that allow me to keep growing as a designer and person.

Firstly, I have never worked with children before. During my bachelor's, I have designed for children but never actually with children. Children, especially between the age of 4 to 10, have to be approached in a different manner than adults. I am looking forward to exploring and learning how to adapt design research tools and broaden my skill set as a designer to also accommodate young children.

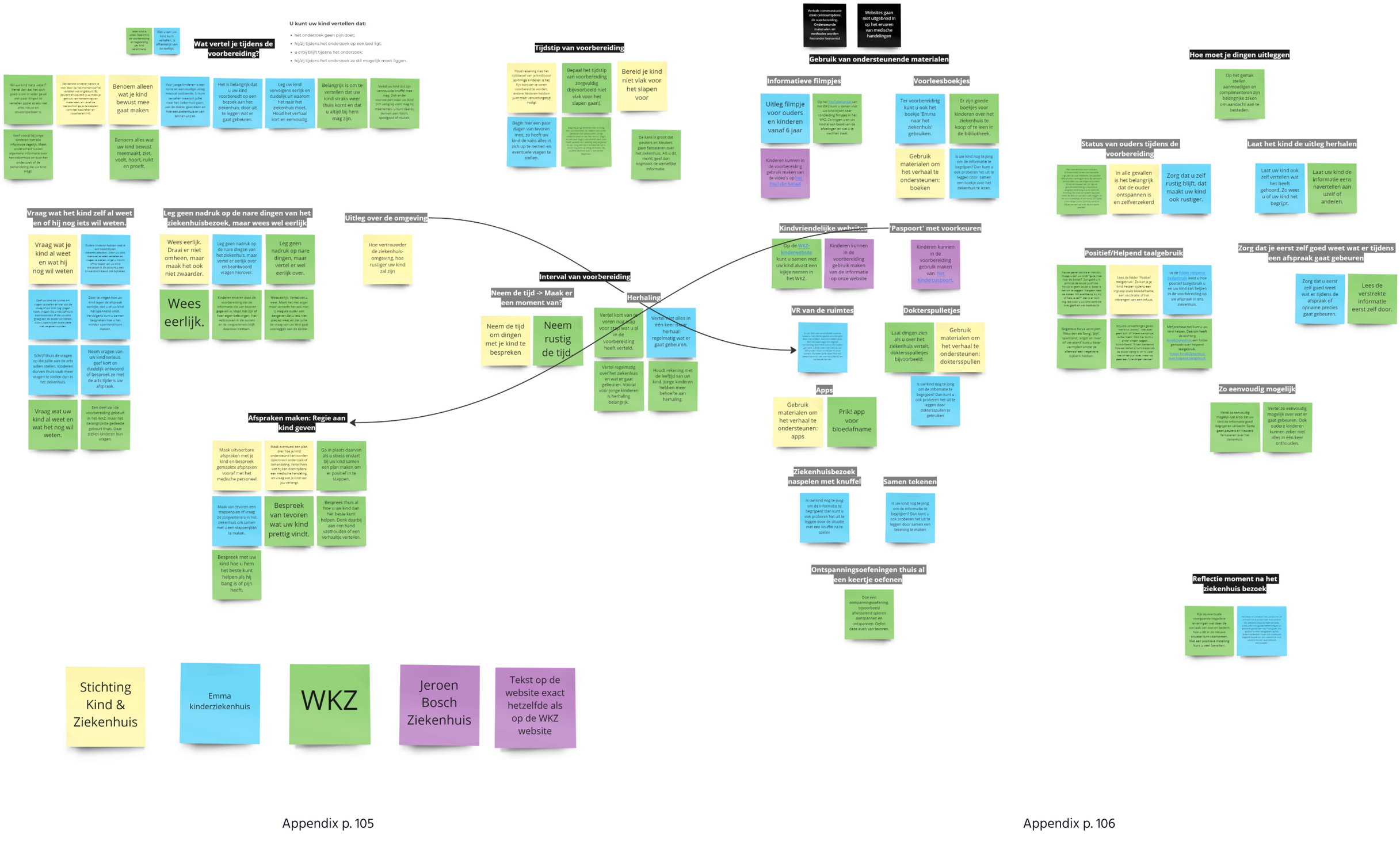
Secondly, I want to strengthen my analysis skills. I will be in contact with children, their parents/guardians, immediate family members and medical personnel. Each with their own opinion, needs and experiences. I want to strengthen the skills needed to differentiate between the most important information and side issues; Which factors are important to integrate into the final intervention and which ones should be disregarded?

Lastly, I am looking forward to becoming more familiar with hospital culture. During my internship, I noticed some barriers; the biggest ones being time management and medical jargon. I aspire to work with hospitals since it allows me to get in close contact with patients. Knowing the hospital culture and how to cope with its barriers are skills I deem important. Additionally, I want to gain more confidence in communicating and explaining design methods to people without a design background.

FINAL COMMENTS

In case your project brief needs final comments, please add any information you think is relevant.

APPENDIX B • Clusters of Recommended Home-Based Preparation Aspects



APPENDIX C • Semi-Structured Interview Protocol | Paediatric Experts

- Hoe definieert u stress (voor ziekenhuisbezoek)? Hoe definieert u angst (tijdens ziekenhuisbezoek)? Ziet u een verschil tussen stress en angst?

- Wanneer ervaren kinderen angstmomenten?
  - Tijdens het ziekenhuisbezoek? (angst)
  - Voor en/of na het ziekenhuisbezoek? (stress)

- Ziet u een correlatie tussen leeftijd en angst?
  - de mate/intensiteit van angst
  - de soort angst

- Welke rol spelen ouders/brussen?
  - Hoe reageren ouders/brussen op een kind in ziekenhuis en op een gestrest kind?

- Zijn er plekken/attributen die angst en stress veroorzaken?

- Zijn er verschillen qua type behandeling/leeftijd?

- Hoe uiten kinderen stress voornamelijk? Wat voor een gevolgen kan dit hebben?
  - Gevolgen voor huidige en toekomstige ziekenhuisbezoeken
  - Gevolgen voor welzijn kind/ouders

- Hoe gaan kinderen om met stress? Ziet u ook dat kinderen zelf coping mechanisms voor stress hebben?

- Vanaf welke leeftijd worden kinderen bewust van hun eigen ziektebeeld? Verandert er dan iets in hun gedrag/coping mechanism/stressmomenten?

- Wat voor een interventies/strategieën passen jullie toe om stress te verminderen? Wat maakt een interventie effectief?
  - Werkt dit in alle gevallen? Wanneer/waarom niet?

- Wordt er ook veel in voorbereiding gedaan? Hoe en bij wie kan voorbereiding een rol spelen/helpen? Worden er handvatten gegeven?

- Weet u of kinderen nog veel stress achteraf ervaren? Heeft het zin om achteraf dingen te verwerken/hier handvatten voor te geven?

- Wat mist er nog op de polikliniek? Waar zou een verbeterslag kunnen plaatsvinden?

- In hoeverre speelt pijn een rol in angst?
  - Zijn kinderen ook bang als pijn niet een rol speelt? Waardoor denkt u dat deze angst ontstaat?

APPENDIX D • Overview Existing Preparation Materials

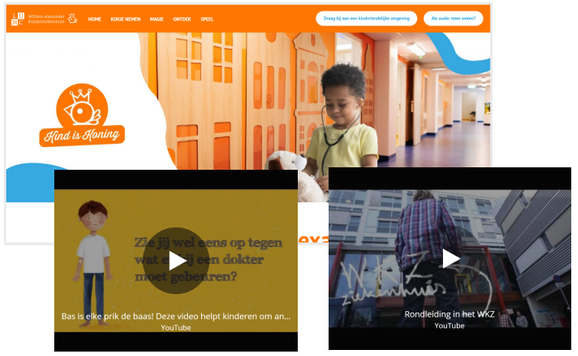


Reading Books



Kris Krokodil

Informative Websites



Videos



Pictures of HCWs



Real Hospital Materials

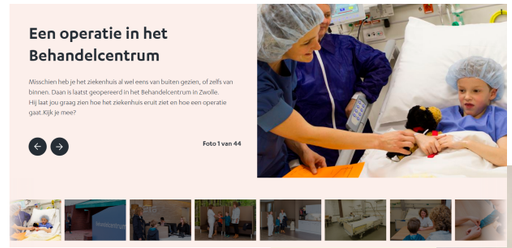




Hospital-Related Toys

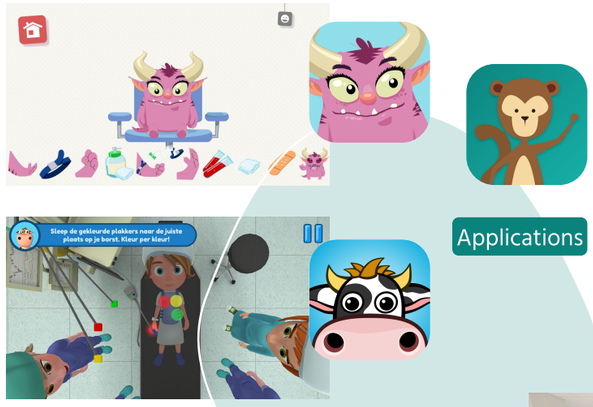
De Krachtpas







Picture Books with Text



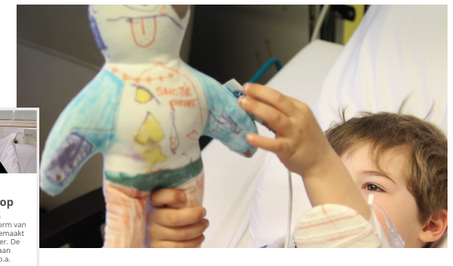
Applications



360° Scan of the Treatment Rooms



Philips MRI-Scanner + App

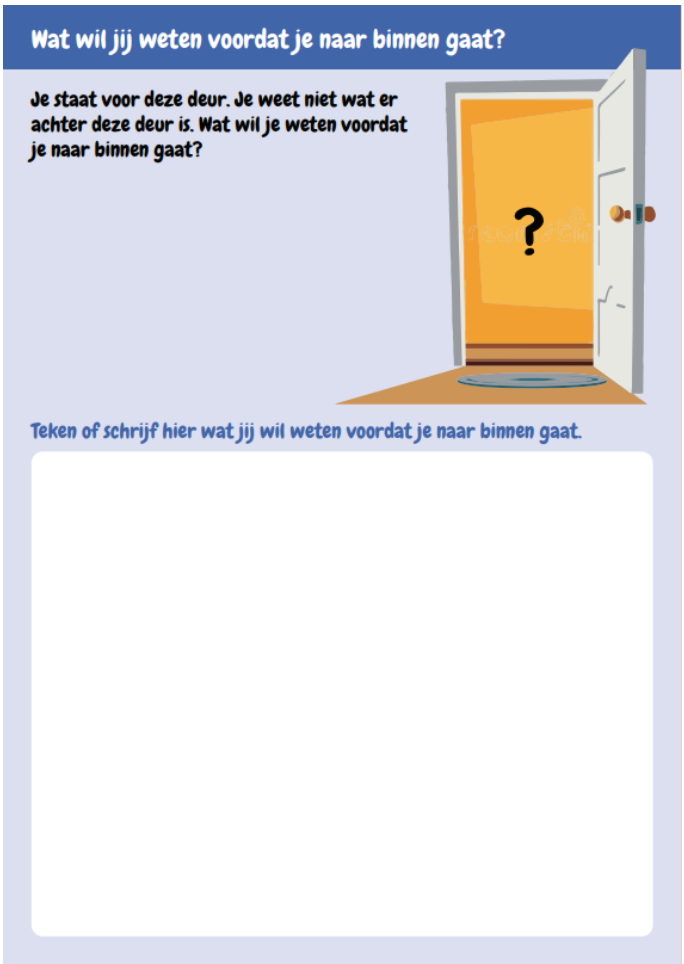


Kiwanis Doll



APPENDIX E1 • Make-and-Say Sessions | Materials Parents and Children

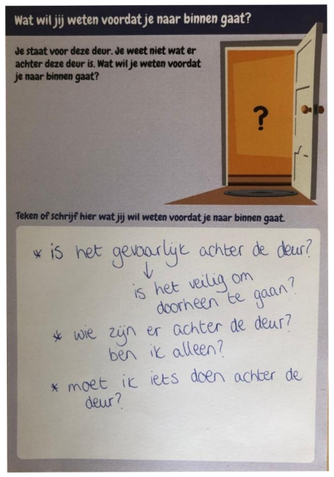
General Open Question

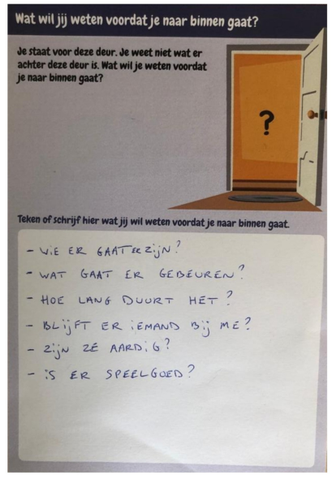


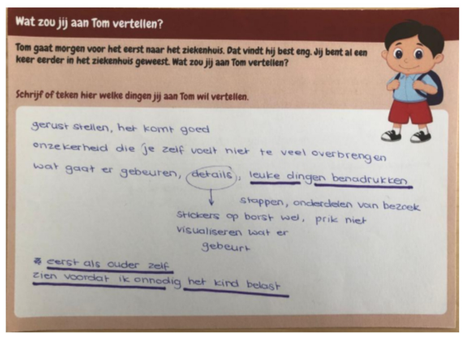
Hospital-Related Question

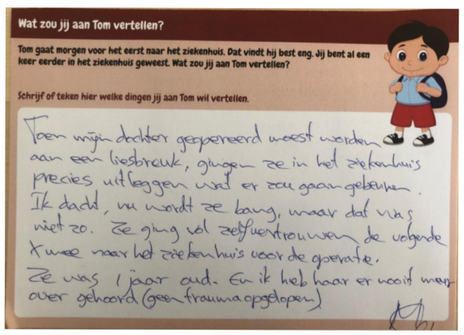


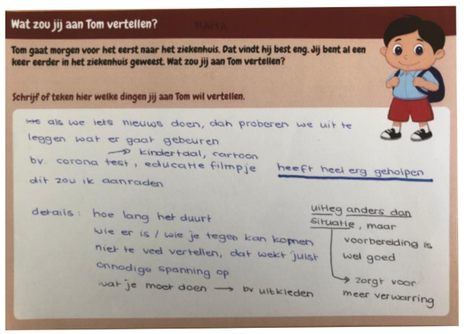
APPENDIX E2 • Make-and-Say Sessions | Results Parents

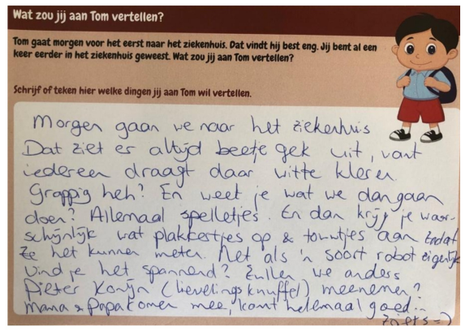


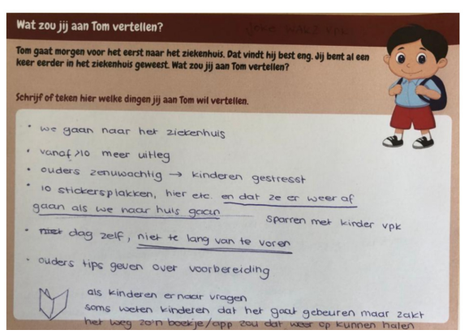




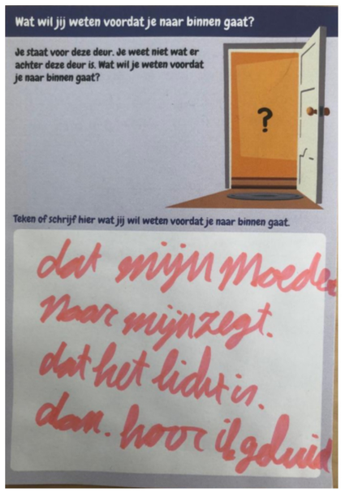


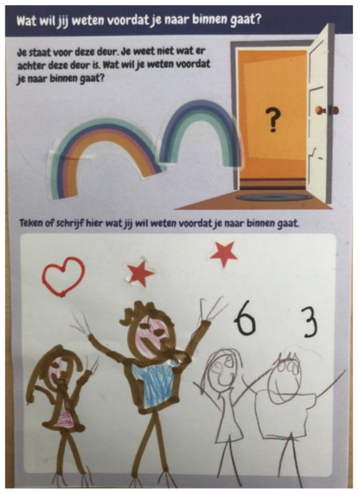


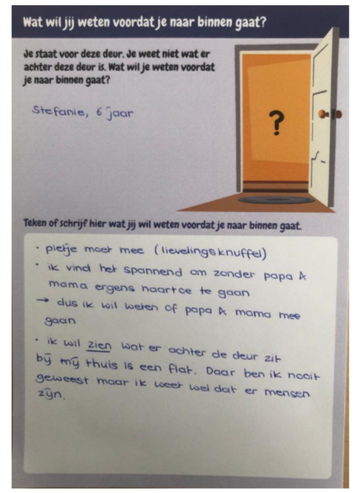


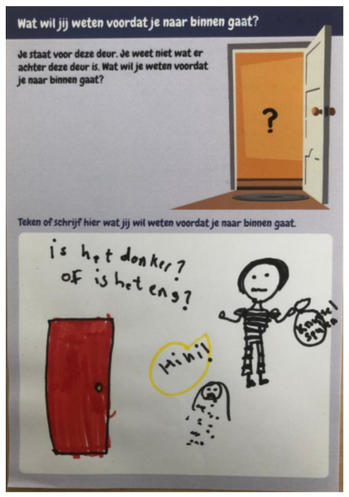


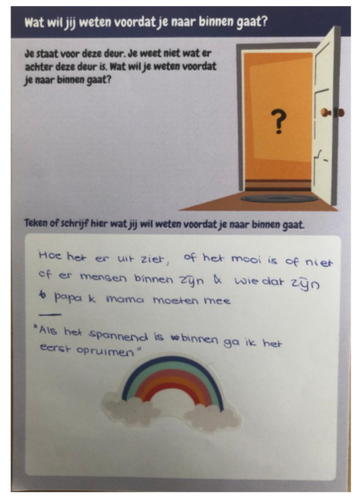
APPENDIX E3 • Make-and-Say Sessions | Results Children

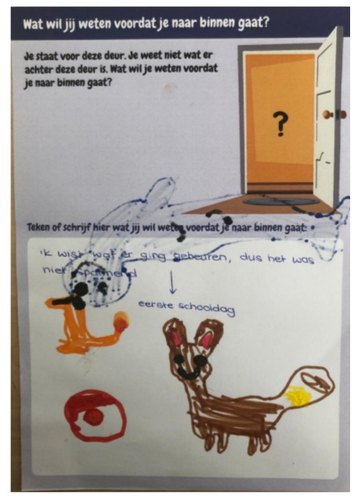


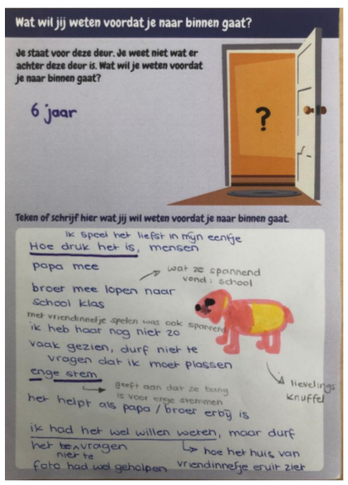


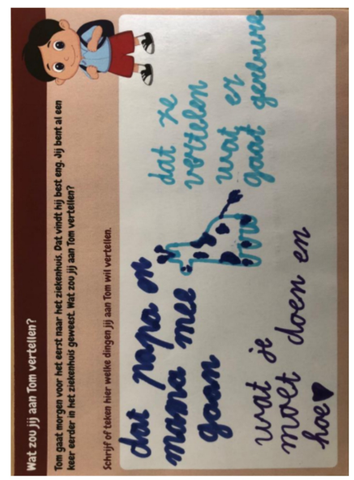


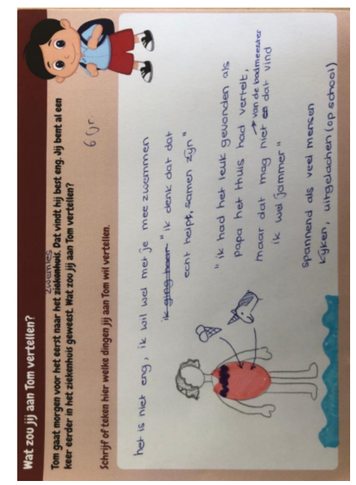








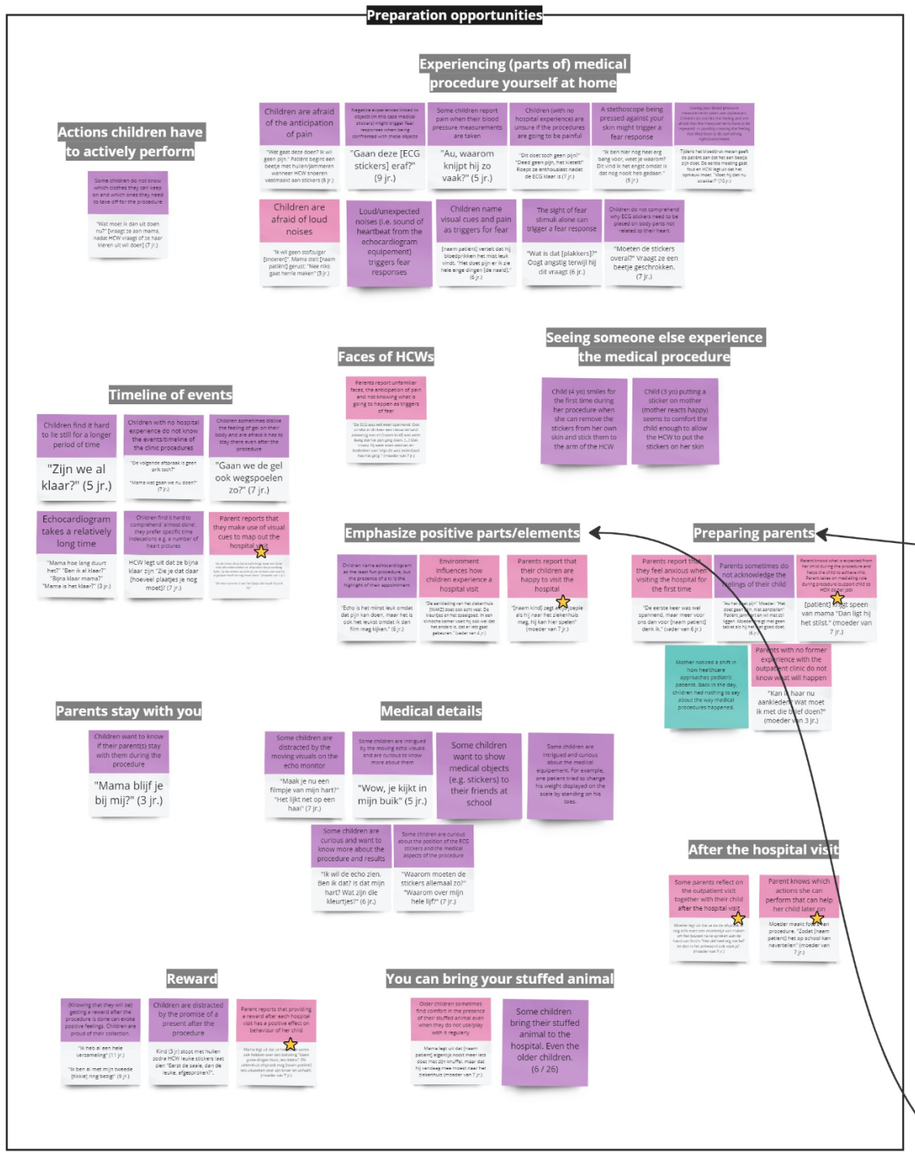




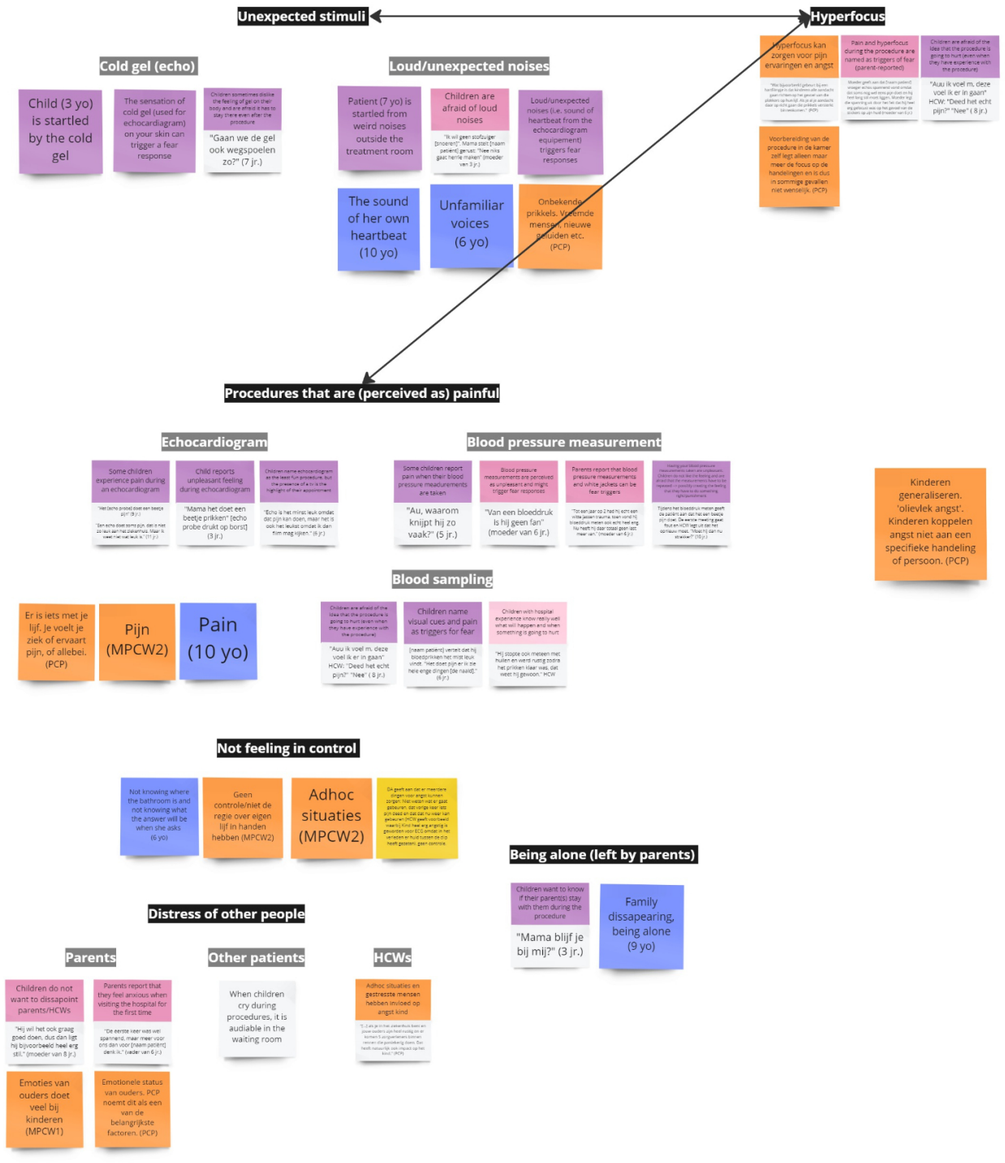
APPENDIX F • Semi-Structured Interview Protocol | Parents

SEMI-STRUCTURED INTERVIEW VRAGEN OUDERS | 30 min
INTRODUCTIE 1. Mijzelf introduceren 2. Kunt u misschien uzelf kort introduceren? 3. Kunt u misschien iets meer vertellen over uw kind? | *leeftijd, naam* 4. Welke (aangeboren) hartafwijking heeft uw kind?
BEZOEK AAN HET ZIEKENHUIS (POLIKLINIEK) 1. Kunt u omschrijven welke ervaring u kind heeft met de polikliniek? 2. Hoe zou u de emotionele status van uw kind tijdens een bezoek aan de polikliniek omschrijven? a. Waardoor denkt u dat dat komt? 3. Hoe vond uw kind het vroeger om naar het ziekenhuis te gaan? a. Waardoor denkt u dat dat komt?
VOORBEREIDING 1. Merkt u dat uw kind gespannen is voor een bezoek aan het ziekenhuis? a. Waarom wel/niet? b. Waardoor komt dit? 2. Als uw kind een afspraak in de polikliniek heeft, weet u dan van te voren welke testjes uw kind moet doen? a. Hoe weet u dit? b. Vind u het belangrijk om te weten? 3. Vertelt u ook aan uw kind wat hij/zij in de polikliniek gaat doen? Stap voor stap beschrijven hoe je je kind voorbereid a. Waarom wel/niet? b. Hoe doet u dat? c. Wat zegt u dan? d. Wanneer verteld u dit aan uw kind? | *Thuis, in de auto, wachtkamer* 4. Heeft u het gevoel dat uw kind begrijpt en weet wat wat er van hem/haar wordt verwacht tijdens een bezoek aan het ziekenhuis? 5. Kent u materialen/technieken die helpen bij de voorbereiding? Kunt u die aan mij beschrijven? 6. Gebruikt u deze technieken of heeft u deze technieken wel eens gebruikt? 7. Waar heeft u behoefte aan bij de voorbereiding? a. Zijn dit andere behoeften ten opzichte van het eerste bezoek aan de polikliniek? 8. Waar heeft uw kind behoefte aan denkt u? Is dit anders dan waar u behoefte aan heeft? 9. Wat mist u als ouder? Wat heeft u nodig?
SPARREN OVER BESTAANDE INTERVENTIES
AFSLUITING - Bedanken - Invullen toestemmingsformulier - Toestemming benaderen vervolgonderzoeken?

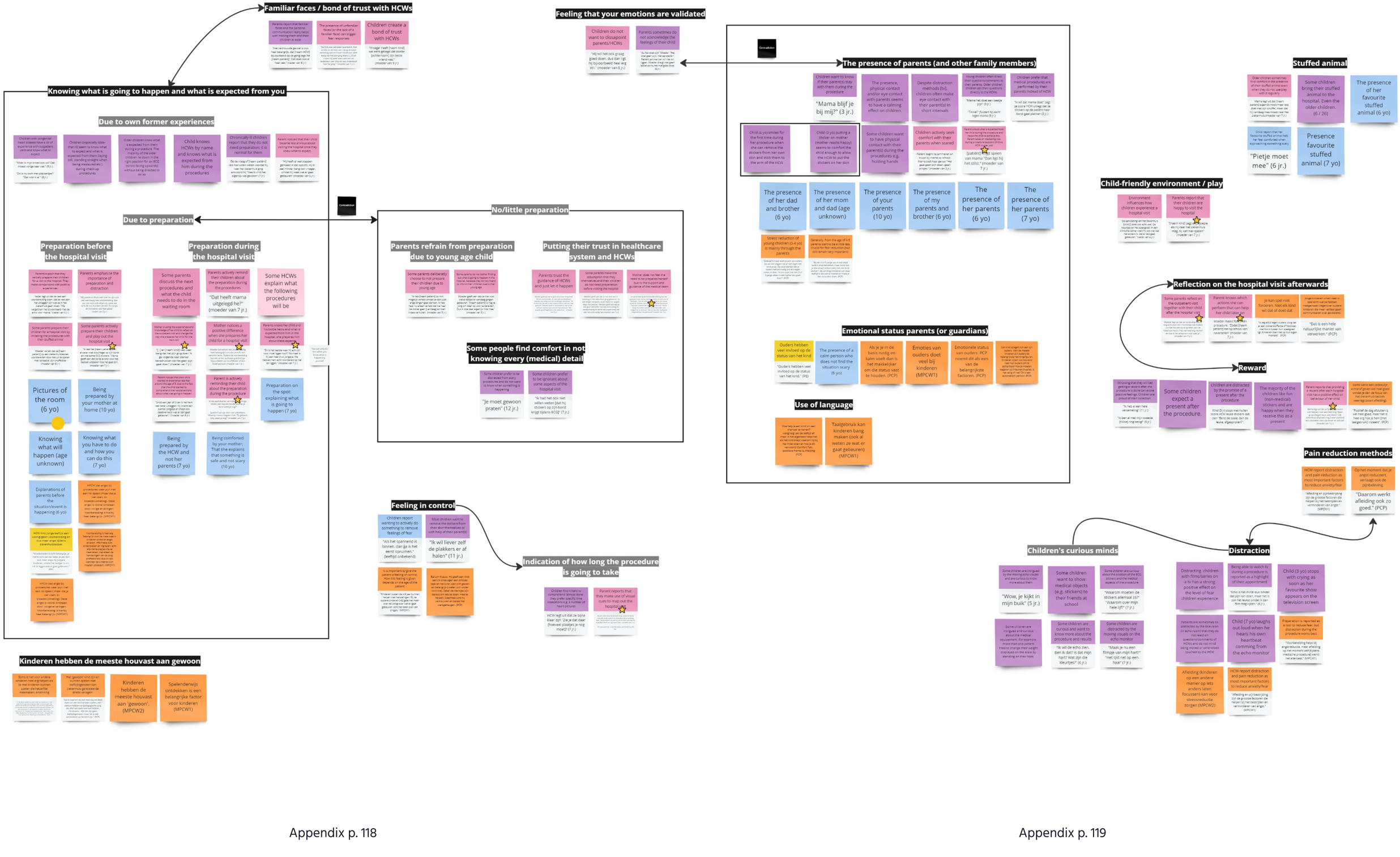
APPENDIX G • Context Mapping Clusters | Barriers Faced During Home-Based Preparation



APPENDIX H • Context Mapping Clusters | Triggers of Fear

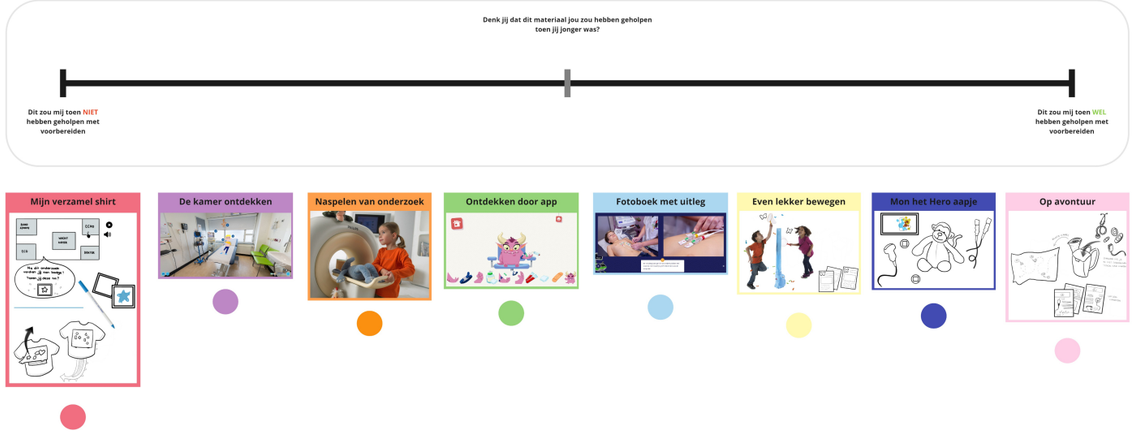


APPENDIX I • Context Mapping Clusters | Comforting Elements



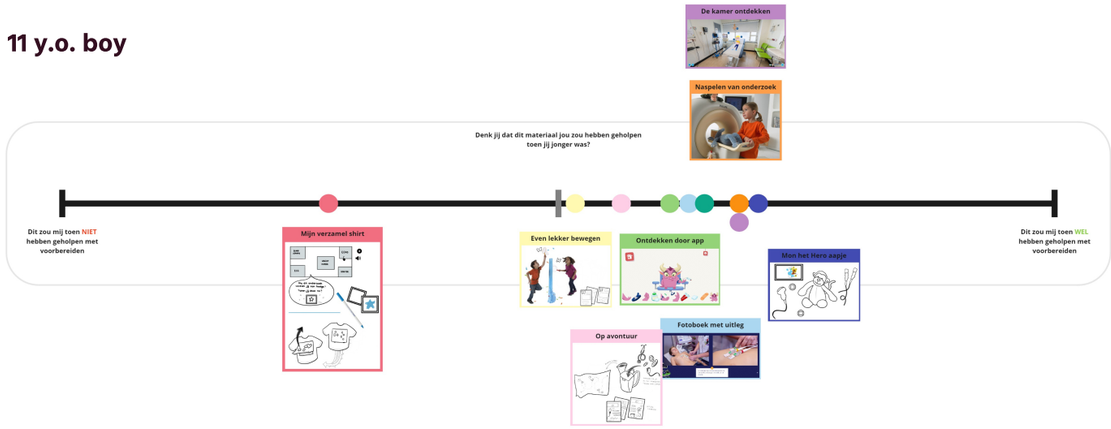
APPENDIX J1 • Paired Comparison | Material and Results

SEMI-STRUCTURED INTERVIEW VRAGEN KIND + OUDER | 10 min
INTRODUCTIE 1. Mijzelf introduceren 2. Wil jij misschien iets over jezelf vertellen?
VOORBEREIDING 1. Jij bent onlangs nog in het ziekenhuis geweest toch? Weet jij je nog hoe jij je voelde tijdens deze afspraak? a. Ja / nee → Kan je dat misschien aan mij uitleggen? 2. Wist je toen van te voren wat er ging gebeuren tijdens dit bezoek aan het ziekenhuis? a. Kan je mij uitleggen wat je wist? 3. Heb jij je toen voorbereid op dit bezoek? a. Wat doe je dan? b. Wanneer doe je dat? c. Doe je dit samen met iemand? | *ouders*, *vriendinnen*, *etc.* 4. Zag deze voorbereiding er ook anders uit dan eerdere afspraken? 5. Zou jij iets willen veranderen aan de voorbereiding?
SPARREN OVER BESTAANDE INTERVENTIES - MIRO
AFSLUITING - Bedanken

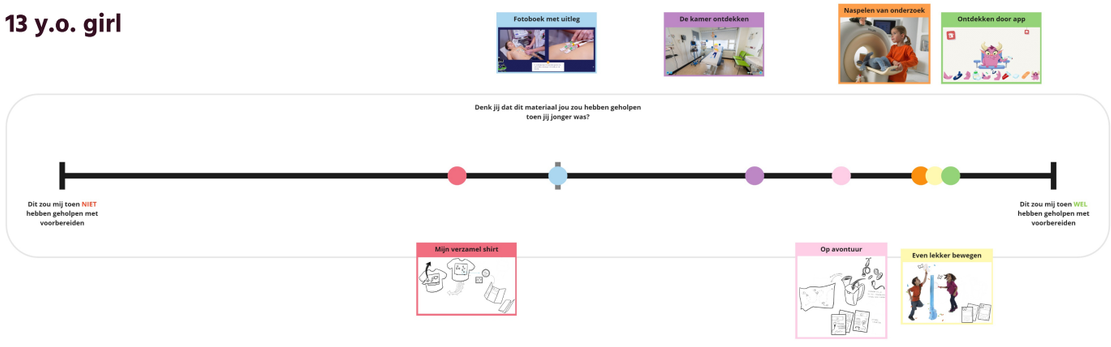


APPENDIX J2 • Paired Comparison | Results

11 y.o. boy



13 y.o. girl



APPENDIX K1 • Narration Script | First Iteration

Audio script Nellie the Hippo - Echocardiogram

[Pagina 1] - Hallo, wat leuk dat je er bent! Ik ben Nellie het Nijlpaard. Ik ben dol op lekker luieren en modder op mijn kop.

Ik heb mijn eigen plekje in het ziekenhuis. Kan jij ontdekken welke deur van mij is?

[Pagina 1 - deur gevonden] Ja wat goed! Je hebt mijn deur gevonden. Door nog een keer op de deur te klikken kunnen wij samen de binnenkant van mijn kamer ontdekken. Ga je mee?

[Donkere kamer - intro] In mijn kamer is het vaak een beetje donker. Wist jij dat nijlpaarden overdag veel slapen en in het donker opzoek zijn naar eten? Doordat het een beetje donker is in mijn kamer zijn de schermen goed zichtbaar. Kan jij ontdekken welke schermen er in mijn kamer zijn?

[Echo] - Dit is het scherm van een echo apparaat. Met een echo apparaat kijkt de dokter naar jouw hart. Op het scherm zijn mooie kleuren te zien. Welke kleuren zie jij?

Ook maakt dit apparaat soms gekke geluiden. Goed luisteren!

[tv scherm] - Dit is een tv scherm. Hier kunnen wij samen een leuk filmpje op kijken terwijl de dokter naar jouw hart kijkt. Ik ben heel erg goed in lekker luieren, jij ook?

Wat goed! Je hebt de schermen in mijn kamer gevonden. Nu kan het licht aan. Kan jij het lichtknopje vinden?

[lichte kamer] Zo, in het licht kunnen we de andere spulletjes in deze kamer wat beter zien. Kan jij ontdekken welke spulletjes er allemaal in mijn kamer te vinden zijn?

[Stickers] - Dit zijn echo stickers. Zullen we samen tellen hoeveel het er zijn?

1 - 2 -3! Het zijn 3 echo stickers.

[Gel] - Dit is een flesje met gel. Gel voelt een beetje gek. Misschien kan papa of mama wel uitleggen hoe dit voelt! Door op het flesje te klikken komt er gel uit.

Hahah maakte jij dat scheet geluidje?

Er viel zomaar een druppel gel op mijn kop. Gelukkig is dat niet erg, de gel gaat er weer makkelijk vanaf.

[probe] - Door dit apparaatje kan de dokter naar jouw hart kijken. Dit lukt alleen als er een beetje gel op zit.

Je hebt alles in mijn kamer ontdekt! Je bent een echte hero. Kom, laten we terug gaan naar onze andere dierenvriendjes.

APPENDIX K2 • Narration Script | Final Iteration

Audio script Nellie the Hippo - Echocardiogram

1[Nellie] Hallo, wat leuk dat je er bent! Ik ben Nellie het Nijlpaard. Ik ben dol op lekker luieren en modder op mijn kop. Nijlpaarden maken best wel een grappig geluid. Goed luisteren! [Nijlpaarden geluid] Ik heb mijn eigen plekje in het ziekenhuis. Kan jij ontdekken welke deur van mij is?

(Door op het spraakwolkje te klikken kunnen kinderen de vraag nog een keer horen)
[Nijlpaarden geluid] + [Nellie] Kan jij ontdekken welke deur van mij is?

[kikker] Hoi! Het kikker gekwaak wat je net hoorde was van mij. Nellie zit niet achter deze deur.

[koe] Halloo! Dat geloei was van mij. Nellie zit niet achter deze deur.

[Nellie] Ja, wat goed! Je hebt mijn deur gevonden. Door nog een keer op de deur te klikken kunnen we samen de binnenkant van mijn kamer ontdekken. Ga je mee?

[Nellie] In mijn kamer is het vaak een beetje donker, hierdoor zijn de schermen goed zichtbaar. Ben jij wel eens in de bioscoop geweest? Daar gaat ook het licht uit en dan kan je het grote scherm erg goed zien.

[Nellie] Kan jij ontdekken welke schermen er in mijn kamer zijn?

[Nellie] Dit is het scherm van een echo apparaat. Met een echo apparaat kan de dokter naar jouw hart kijken. Op het scherm zijn mooie kleuren te zien. Welke kleuren zie jij?

Ook maakt dit apparaat soms gekke geluiden. Goed luisteren! [echo geluiden]

[Nellie] Dit is een tv scherm. Hier kunnen wij samen een leuk filmpje op kijken terwijl de dokter naar jouw hart kijkt. Ik ben benieuwd of jij jouw filmpje ook extra goed kan zien in het donker.

[Nellie] Wat goed! Je hebt alle schermen in mijn kamer gevonden. Nu kan het licht aan. Kan jij het lichtknopje vinden?

[Nellie] Zo. In het licht kunnen wij mijn kamer wat beter bekijken. In het midden van de kamer staat een onderzoekstafel. Hier mag jij op gaan liggen. Doordat jij goed stil ligt, kan de dokter goed werken. Ik ben heel erg goed in lekker luieren, jij ook? [korte pauze] De dokter heeft een paar spulletjes nodig om goed naar jouw hart te kunnen kijken. Kan jij ontdekken welke spulletjes dat zijn?

[Nellie] Dit is een flesje met gel. Gel voelt misschien een beetje koud, gek of kriebelend. Ik ben benieuwd hoe dit voor jou gaat voelen. Door op het flesje te klikken komt er gel uit.

[Nellie] [Scheet geluidje] 'Nellie giechelt' Maakte jij dat scheet geluidje? [korte pauze] Er viel zomaar een druppel gel op mijn kop. Gelukkig is dat niet erg, de gel gaat er weer makkelijk vanaf.

[Nellie] Dit zijn echo stickers. Zullen we samen tellen hoeveel het er zijn? 1 - 2 - 3! Het zijn drie echo stickers. Misschien kan papa of mama aanwijzen waar deze echo stickers geplakt worden.

[Nellie] Met dit apparaatje kan de dokter naar jouw hart kijken. Dit lukt het beste als er een beetje gel op zit. De gel is nodig om gemakkelijk met het apparaatje over jouw borst te glijden.

[Nellie] Je hebt alle spulletjes in mijn kamer ontdekt. Je bent een echte hospital hero!

[korte pauze]

Door op het gele knopje te drukken, kunnen wij terug gaan naar onze andere dierenvriendjes. Wil jij nog een keer horen welke spulletjes de dokter nodig heeft om naar jouw hart te kijken? Klik dan op het rode knopje

ZELF ONTDEKKEN

GEL
[Nellie] [Scheet geluidje] 'Nellie giechelt'. Dit is een flesje met gel. Gel voelt misschien een beetje koud, gek of kriebelend. Vertel eens aan papa of mama hoe jij denkt dat gel gaat voelen.

ECHO STICKERS
[Nellie] Dit zijn echo stickers. Weet jij waar deze geplakt gaan worden?

TV SCHERM
[Nellie] [Liedje van nijntje] Ik vind het super leuk om een filmpje van Nijntje te kijken. Wat ga jij doen als de dokter naar jouw hart kijkt?

PROBE
[Nellie] Met dit apparaatje glijdt de dokter over jouw borst. Om goed bij jouw borst te kunnen, moet jouw t-shirt of trui even uit. Nadat de dokter klaar is, mag jij jouw kleren weer aan doen.

ECHO SCHERM
[Nellie] Dit is het scherm van een echo apparaat. Op dit scherm kan de dokter jouw hart goed zien. Ook maakt dit apparaat soms gekke geluiden [Echo geluiden]

VOGEL
[Vogel geluiden]

NELLIE
[Nijlpaard geluiden]

APPENDIX L • Intermediate Evaluation Protocol | Paediatric Experts

Semi-Structured Interview - Walkthrough of Prototype

- Audio opnemen?

Aanname: Ouders zijn in staat tot het reproduceren en overbrengen van de opgedane kennis
Aanname: Kinderen onthouden en herkennen geluiden die ze eerder hebben gehoord, waardoor ze de voorbereiding kunnen matchen met ervaringen in ziekenhuis

1. In hoeverre zijn deze aannames waar?

Voorbereiding
2. Hoeveel referenties naar het eigen ziekenhuis bezoek moeten er in zitten?
3. Hoe gedetailleerd moet de uitleg ingaan op medische details?

Volgorde
3. Moet er een volgorde inzitten? bv. bij een echo is er een duidelijke volgorde in stappen. Moet ik hier juist wel of niet op inspelen?

Details
4. Zijn de ‘animaties’ duidelijk voor jonge kinderen? Moet het juist levensecht of meer geanimeerd?
5. Hoe erg is het als de kamer niet precies hetzelfde is als de 'daadwerkelijke' kamer die het kind tegenkomt in het ziekenhuis?
6. In hoeverre moet de voorbereiding matchen met de wekelijkheid? bv. Begrijpen kinderen tussen 4 en 7 dat de gel op de kop van het nijlpaard hetzelfde is als op hun borst in het ziekenhuis?

- Sparren over details ‘ouder-laag’

- Doorspreken van het script. Zijn er dingen die Nellie juist wel of niet moet zeggen?

- Karakter eigenschappen van de onderzoeksdieren

APPENDIX M1 • Evaluation Protocol | Semi-Structured Interview

Evaluatie Protocol - Ouders [40-60 min]

- Mag ik dit gesprek opnemen? (audio)

[Introductie van project: Stress en angst verminderen bij kinderen met een aangeboren hartafwijking die herhaaldelijk naar het ziekenhuis moeten voor onderzoek → dmv voorbereiding]

- Zou u zichzelf kort willen voorstellen?
- Bereidt u uw kind voor op een bezoek aan het ziekenhuis? Hoe doet u dat?
- Heeft uw kind ervaring met het ziekenhuis?
- Hoe zou u uw kind voorbereiden op een bezoek aan het ziekenhuis?

[Doorlopen prototype]

1. Ik ben benieuwd naar uw eerste reactie over deze online module?

2. In de situatie dat uw dochter naar de polikliniek moet. Denkt u dat deze online module relevant is/was geweest voor u persoonlijk? (leeftijd van kinderen, veel/weinig ervaring met het ziekenhuis, gemoedstoestand)

3. Hoe denkt u dat deze online module u zou hebben geholpen? (in de rol van voorbereider stappen, alle informatie op 1 plek, context-specifiek)-> Hoe zou het u hebben geholpen?

4. Wat vindt u van de informatie die ouders (in de ouder-laag) krijgen? (Hoeveelheid details, mate van detail, begrijpbaarheid)

5. Denkt u dat deze online module (in de 'kinder-laag') interactie stimuleert tussen u en uw kind?→ Zo ja, waardoor komt dit? / Zo nee, waardoor kan dit versterkt worden?

6. Denkt u dat deze online module u zou hebben geholpen met het voorbereiden van uw kind? (ouders ruimte om eigen invulling te geven)→ Welke aspecten van de tool dragen hier volgens u het meest aan bij?

7. Denkt u dat deze manier van voorbereiden zou hebben geholpen voor uw kind? → Waarom wel/ waarom niet? (Geluiden uit de ontdekkingswereld koppelen aan die van de onderzoeken, materialen die gebruikt worden)

8. Denkt u dat deze online module zou hebben geholpen bij het verminderen van angst en stress bij uw kind voor, tijdens, en na een polibezoek? Waarom wel/niet?

9. Denkt u dat deze online module zou hebben geholpen bij het verminderen van angst en stress bij u en/of uw partner voor, tijdens en na een polibezoek? Waarom wel/niet?

10. Zou u deze online module zelf hebben gebruikt/gebruiken?→ Waarom?

11. Zijn er onderdelen die verbeterd kunnen worden?

12. Zijn er nog zaken die we niet hebben besproken maar wel belangrijk zijn om te vertellen?

APPENDIX M2 • Evaluation Protocol | Statements with Likert Scales

[open vraag] Ik ben benieuwd naar uw eerste reactie over deze online module?

[*introductie stellingen*: aantal stellingen waar ik dieper op in ga]

1. Deze online module is relevant voor **kinderen** met een aangeboren hartafwijking tussen de 4 en 7 jaar oud.

Helemaal mee oneens — Helemaal mee eens

1	2	3	4	5	6	7

→ **Kunt u uw antwoord toelichten? Welke aspecten dragen hier aan bij?**

2. Deze online module is relevant voor **ouders** met kinderen die een aangeboren hartafwijking hebben.

Helemaal mee oneens — Helemaal mee eens

1	2	3	4	5	6	7

→ **Waarom?**

3. Deze online module is relevant voor **kinderen** die herhaaldelijk naar de polikliniek moeten.

Helemaal mee oneens — Helemaal mee eens

1	2	3	4	5	6	7

→ **Welke aspecten dragen hier aan bij?**

4. Ik denk dat de informatie die ouders krijgen begrijpbaar is.

Helemaal mee oneens — Helemaal mee eens

1	2	3	4	5	6	7

→ **Waarom?** *(Hoeveelheid details, mate van detail)*

5. Ik denk dat deze online module ouders helpt om hun kind voor te bereiden.

Helemaal mee oneens — Helemaal mee eens

1	2	3	4	5	6	7

→ **Welke aspecten van de tool dragen hier volgens u het meest aan bij?** *(ouders ruimte om eigen invulling te geven, in de rol van voorbereider stappen, alle informatie op 1 plek, context-specifiek, stimuleren ouder-kind interactie)*

6. Ik denk dat deze manier van voorbereiding goed werkt voor kinderen tussen de 4 en 7 jaar oud.

Helemaal mee oneens — Helemaal mee eens

1	2	3	4	5	6	7

→ **Waarom?** *(Geluiden uit de ontdekkingswereld koppelen aan die van de onderzoeken, materialen die gebruikt worden)*

7. Ik denk dat deze online module **kinderen** kan helpen om minder angst en stress te ervaren tijdens een polibezoek.

Helemaal mee oneens — Helemaal mee eens

1	2	3	4	5	6	7

→ **Waarom?**

8. Ik denk dat deze online module **ouders** kan helpen om minder angst en stress te ervaren tijdens een polibezoek.

Helemaal mee oneens — Helemaal mee eens

1	2	3	4	5	6	7

→ **Waarom?**

9. Ik zou deze online module aanraden aan de kinderen en ouders die ik op de werkvloer zie.

Helemaal mee oneens — Helemaal mee eens

1	2	3	4	5	6	7

→ **Kunt u uw antwoord toelichten? Welke aspecten zorgen hiervoor?**

[open vraag] Zijn er onderdelen die verbeterd kunnen worden?

CONTEXT-SPECIFIEKE KENNIS AAN OUDERS VERSCHAFFEN
PERSOONLIJKE VOORBEREIDING
ONTDEKKEN VAN ONBEKENDE PRIKKELS: GELUIDEN / ZIEN
RELEVANT VOOR KINDEREN DIE HERHAALDELIJK NAAR HET ZIEKENHUIS MOETEN

APPENDIX N • Integration Proposal



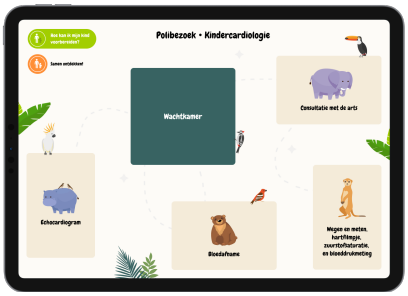
Application shows a distinction between the steps that are intended to be performed at home vs. in the outpatient clinic (colour gradient & text).

NEW

Similar to the current HH app, users can personalise their journey by selecting the procedures scheduled during their appointment. This step determines which procedure (animals) are visible in the online module.

ADAPTED

Note: This feature only works when hospitals communicate this before the scheduled appointment.



NEW

Similar to current HH app, users can search and collect animals in the general waiting room by means of scanning QR codes.

During/after the procedure, users can search for the procedure animal (e.g. sticker) inside the treatment room. When the corresponding QR code is scanned, the animal appears in the overview showing that they still need to collect the remaining procedure animals.

NEW



Similar to current HH app, the journey ends with 'Going Home!'