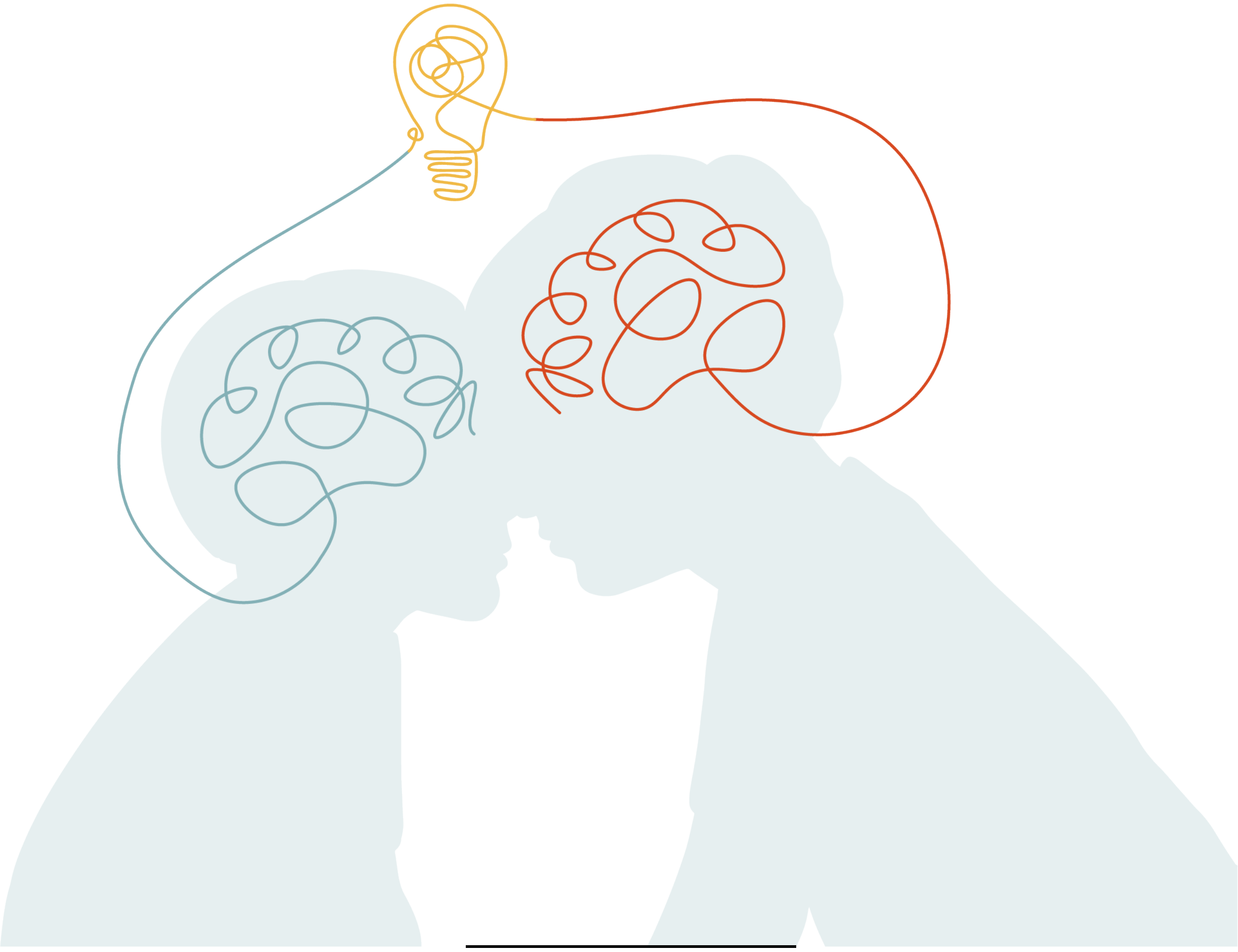
EMPOWER YOUNG EXPERTS

Co-designing a peer sharing tool for Child Brain Lab participants



Master Thesis | Charlotte Hemmes

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Faculty of Industrial Design Engineering
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This master thesis is written

by Charlotte Hemmes

Under contract of
Play Well Lab

In collaboration with
Child Brain Lab (part of the Paediatric
Brain Centre at Erasmus University Medical
Centre, Sophia Children's Hospital)

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Charlotte

SUMMARY

The Child Brain Lab (CBL), a part of the Paediatric Brain Centre at Sophia Children's Hospital within the Erasmus Medical Centre, is a scientific research and testing facility dedicated to children with brain conditions (CB). These children frequently experience isolation and lack of social contact due to their situations. These observations lead to the following research question, *"How can design empower participants aged six to eighteen in the Child Brain Lab to use peer-sharing for preparation and support during their visits effectively?"*

As CB frequently visit the hospital and are familiar with the medical setting, a CBL visit does not trigger much stress. So, it became clear that the main challenge was not solely to reduce stress but to empower these children to share their experiences, gain control, and connect with their peers. The CBL provided an ideal opportunity to address these needs as it aims to test hundreds of CB annually. CB did express a desire to be informed about procedures and often felt alone during hospital visits.

The design goal is to empower participants of the CBL to recognise their expertise and support them to express their experiences and share them with their peers.

Methods

- Human-centered design approach
- Literature research on healthcare barriers and peer support for children
- Interview and creative sessions with children (including CB), parents, and CBL clinicians
- Creative facilitation and brainstorming sessions with other students
- Evaluation and user testing with CB and CBL clinicians

Key insights

- CB are experts-by-experience
- CB want to help others and learn new things
- Barriers CB experiences include bad information provision and the wrong kind of empathy
- Create a safe and supportive peer interaction environment
- Bridge information gaps and simplify medical language
- Empower children with a sense of control and autonomy

These findings led to Lab Maatjes, a peer-sharing app tailored to the CBL journey. It was designed around the principles of self-determination theory. For autonomy, the app allows users to explore what CBL involves and why it is important. It also offers guidance and support to navigate the app and express themselves independently. It promotes competence by allowing them to share their stories, feel heard and seen, and gather the information they want to know. Finally, it provides relatedness by creating a trusted environment where they can connect with peers and gain insight into their experiences and how they relate to their views. Lab Maatjes creates an engaging preparation process that puts participants in control, makes them feel valued for their contributions to the CBL and ensures that they do not feel alone as they connect with peers.

This thesis concludes with an evaluation of the app, using the feedback of the CBL participants for quick iterations. The final sections of this report identify areas for improvement and recommendations for implementing the design, including creating two versions of the app for different age groups, implementing advanced features such as audio recording, and doing more research on the sharing behaviours of the participants.

GLOSSARY

Brain conditions
In this report, the term 'brain conditions' is used as an overall term for all conditions that participants in CBL have. Brain conditions refer to neurological or psychiatric disorders or disorders of the head and senses.

CB
Children with brain conditions

CBL
Child Brain Lab, a part of the Paediatric Brain Center of Erasmus MC Sophia Children's Hospital

Children
In this report, 'children' encompasses individuals below 18. In some cases, it is pertinent to the data to distinguish between children and adolescents.

Clinicians
Clinicians is an overarching term in this report for all healthcare professionals responsible for the care of the CB.

CWB
Children without brain conditions. (Cavender et al., 2008)

Normal or normality
In this report, "normality" refers to the desire of CB not to be perceived as different from their peers (both with and without medical conditions) and to live in a way that aligns with typical expectations and experiences, often meaning without medical obligations. It is important to note that using "normality" here is not meant to exclude anything as 'abnormal'.

PBC
Paediatric Brain Center, part of Sophia Children's Hospital of Erasmus MC

Parents
In this report, parents refer to the legal guardians and caregivers of the child.

Peer support
"Using children and young people's knowledge, skills, and experience in a planned and structured way to understand, support, inform, and help develop the skills, understanding, confidence, and self-awareness of other children and young people with whom they have something in common." (Street & Herts, 2005).

Peers
Peers is a comprehensive term used in English to refer to individuals of the same age or those within the same profession or school environment sharing a similar status or experience. In the context of this report, "peers" specifically pertain to children with prior hospital experiences and brain disorders.

PWB
PWB stands for "peers without brain conditions." This distinction is essential as CB participants interact with two distinct groups: peers who share similar medical needs (referred to as "peers" in this report) and peers without brain conditions, such as classmates or friends in various activities like sports (Cavender et al., 2008).

SCH
Sophia Children's Hospital of Erasmus MC

Testers
Testers are the research employees of the CBL who conduct the tests with the CB. Three research employees are all three responsible for one of the lab rooms. These testers are solely involved in conducting the tests. Other clinicians do the data analysis, and the results are reported to the participants by their personal clinician.

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INTRODUCE

Note. ErasmusMC (n.d. a)

1. Introduction

This chapter introduces the project brief, which focuses on enhancing the CBL experience for its participants. The project intends to use children's natural curiosity to create a peer-sharing tool within CBL while incorporating child-centred and value-based healthcare principles. The goal is to empower participants aged six to eighteen using human-centred research methods. This chapter discusses the project's context, relevance, research methods, and main goals.

1.1 PROJECT INTRODUCTION

This project's foundation relies on children's curiosity and willingness to help each other as peer informants, a simple but powerful idea. By facilitating peer-sharing within the CBL, the objective is to enhance the testing experience for these children. To improve the test experience, the CBL should provide information about what will happen and why, which also relates to the preference of what the participants want to know and ensure that the information is understandable for them to prepare for the CBL. This information should enable them to actively participate in their healthcare by supporting them in expressing their views on the lab experience to their peers. Consequently, this contributes to improved communication with their clinicians. The design will empower CBL participants by providing them with a platform to express their thoughts and help others with their knowledge, giving them a sense of ownership over their healthcare journey. Additionally, it will offer the control to choose their interactions with peers and what they want to know to prepare for the CBL.

The context of the project is the CBL, a part of the Paediatric Brain Centre of the Erasmus Medical Centre Sophia Children's Hospital. The lab analyses the development of children, identifies any issues early, tests the efficacy of new interventions, and tries various solutions to assist. Before the lab visit, participants will complete questionnaires and have their brains scanned to create 3D images (Level 1 of the lab). Participants will undergo testing in the laboratory to assess cognitive, emotional, and motor functions. The tests will be carried out in three different rooms, each addressing one of the specific functions (Level 2 of the lab). The facility has recently welcomed its first participant on 1 May 2023. Before this, the CBL performed trials with children who did not have brain conditions (CWB).

The following section taps into why it is important to give the participants of the CBL a sense of control and ownership and sets the background context of this project.

1.2 BACKGROUND INFORMATION

1.2.1 HOSPITAL EXPERIENCE FOR CHILDREN

Hospital visits can be stressful for anyone, and children are especially vulnerable to stress from hospital visits. This vulnerability is because they are more prone to disruption in their routines and unfamiliar surroundings (Lerwick, 2016). Hospital information is often not presented understandably, leaving children feeling anxious and powerless (Coyne et al., 2014; Coyne, 2006). Clinicians focus on minimising this and making medical situations understandable to children by explaining their treatment processes and ensuring they know what will happen. When children are not involved in their healthcare, they feel neglected, which frustrates them. They like to be listened to and for adults to consider their perspectives (Schalkers et al., 2015). The quote from Lucy (Coyne, 2006, p.66) reflects the desire to be heard as a child.

"Well, I don't like them talking to my mum all the time… People just ask what's wrong with me? but then they ask my mum what's wrong with me… and what's my name and stuff like that and I know what's wrong with me, not my mum… I know how old I am and what my name is. We're the ones who know what's wrong with us because it's wrong with us. I'm getting used to it, but I don't like it." (Lucy, nine years old, speaks in an angry voice.)

This quote illustrates that children often desire to be involved in decisions about their healthcare and want to be heard (Cavet & Sloper, 2005; NCB, 2021). Children wanting to participate in the discussions about their care aligns with a significant shift in healthcare decision-making. In the past, decisions were typically made by a child's legal guardian in consultation with clinicians, often excluding the child from the process. However, current understanding, supported by a growing body of evidence, emphasises the child's capacity to actively participate in medical decision-making and advocate for his or her involvement (Wyatt et al., 2015). Within the legal framework of the Netherlands, the Medical Treatment Agreement Act (Dutch: WGBO) classifies children into three categories: 0-11 years old, 12-16 years old, and 16+. Although children under 16 require parental consent, those aged 12 and above have the right to be informed and express their opinions during the decision-making (Art. 7:450, BW, 1995). Importantly, involving children in the decision-making process holds significant value, potentially reducing anxiety levels and enhancing self-empowerment, even before the age of twelve (Coyne, 2008). Children as young as six have shown the ability to actively engage with and understand the information about their medical situation and the available choices (KNMG, 2016).

Involving children in the medical decision-making process is only possible if the information is presented to them in an accessible and understandable way. Despite the best efforts of medical personnel, children are often bypassed, and their caregivers are addressed instead. One of the reasons for the children being neglected in this communication is misunderstandings between parents and clinicians, as clinicians are often interrupted by parents who want to ask questions themselves. On the other hand, parents may see it as a failure by clinicians if they do not focus more on the child. Another reason a child may be ignored is if they seem shy or uninterested and avoid attention (Tielen, n.d.; Meulendijks, 2020). To promote a positive healthcare experience, hospitals should focus on reassuring children and giving them a sense of control, which can be done through child-centred healthcare (Coyne et al., 2014).

1.2.2 RELATED PROJECTS

The CBL is aware of the shortcomings of current healthcare systems and, therefore, focuses on child-centred healthcare. They are constantly striving to improve the experience of CBL participants. To this end, the CBL has collaborated with both Erasmus University and Delft University of Technology on several research studies focusing on making the tests more child-friendly and getting the results back to the participants in an understandable manner. Figure 1 shows all these studies, their connection, and where this project is positioned.

The dashed box also shows Benthe Plat's thesis, a parallel project for the 'Self-Portrait' app. This thesis builds upon the studies of Paul Meulendijks and Loes Tielen (also shown in Figure 1). Meulendijks' research focused on encouraging paediatric patients to participate actively in their doctor's consultations. By increasing the children's understanding of their condition and outcomes, an improvement in the patient's ability to ask questions during the consultation was achieved. Based on the results of this project, the Play Well Lab (PWL) and the CBL started a project to create an app called 'het Zelfportret' ('the Self-Portrait'), which is currently being developed by MCW / creative agency on behalf of the CBL. This app is a virtual patient file where CBL participants can view their test results after their visit. Tielen conducted a user research study to discover how paediatric patients, their parents, and experts would like this app to come to life. Benthe Plat's thesis is currently centred on three specific test results to visualise them comprehensively and ensure they are presented responsibly for children. The app 'the Self-Portrait' is an integral part of the CBL and, therefore, part of this project's scope, as the final concept of this project could integrate into this app.

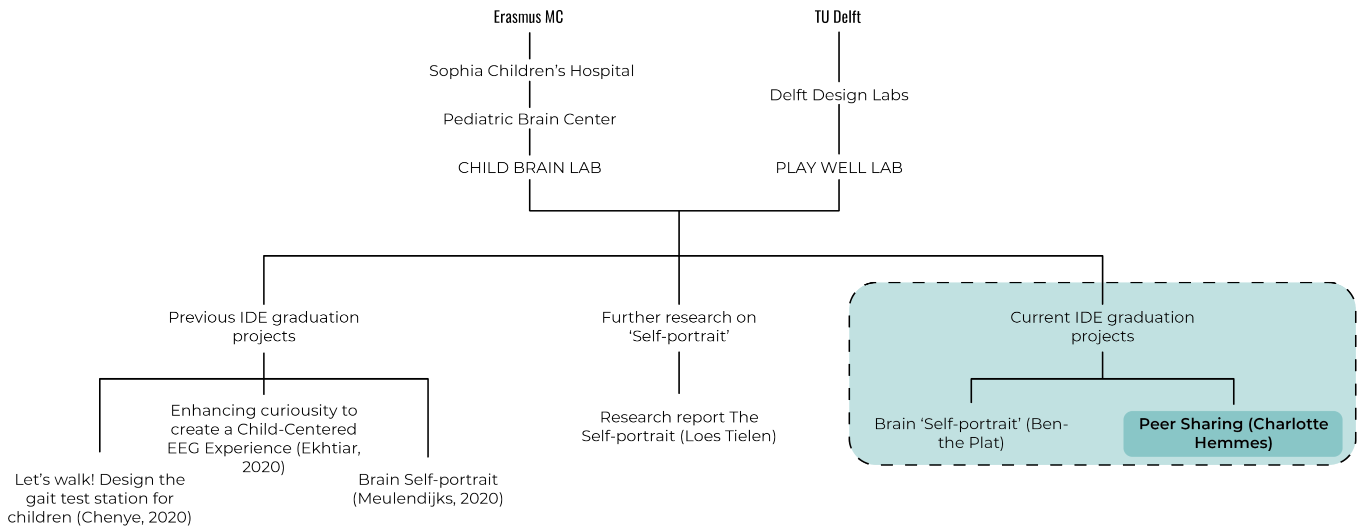

Figure 1 | Previous projects

1.2.3 VALUE-BASED HEALTHCARE

The CBL describes itself as a bridge between value-based healthcare and scientific research (Erasmus MC, n.d.). Value-based healthcare (VBHC) aims to enhance patient outcomes while optimising cost efficiency (Erasmus MC, 2017)(Figure 2).

$$\frac{\text{Outcomes + experiences that matter to the patients}}{\text{Costs + energy needed to achieve the outcomes}} = \text{VALUE}$$

Figure 2 | Value-based healthcare model

As healthcare costs rise globally, numerous countries, including Sweden and the Netherlands, align with VBHC components. However, many others are beginning to create an environment conducive to value-based healthcare. While a few countries are making notable progress, others are starting to restructure systems around patient-centred value delivery (Shah, 2016).

Patient-reported outcomes (PROs) reflect patients' perspectives on their health, encompassing health-related quality of life and treatment perceptions. Standardised tools, such as patient-reported outcome measures (PROMs), are utilised for these outcomes. PROMs offer a broader view of patient value beyond medical indicators and serve as instruments to gauge patient quality of life (Oemrawsingh, 2021). These indicators are what hold significance for patients. In the case of children, specific tools have been developed to assess PROs, capturing children's viewpoints on their healthcare and quality of life (Ravens-Sieberer et al., 2007):

KIDSCREEN, measures the following domains:
- Physical well-being
- Psychological
- Autonomy
- Peers and social support
- Parents & home life
- School life
- Bullying
- Finances

DISABKIDS measures similar domains:
- Mental
- Independence
- Emotional
- Social
- Inclusion
- Exclusion
- Physical
- Limitations
- Treatment

These tools consist of questionnaires aimed at children of all ages. In medical settings, children are often given questionnaires to be completed under the supervision of their parents. Questionnaires can be a valuable method that provides a structured approach for gathering information about children's views. However, it is important to consider age-appropriate questionnaire design carefully and to conduct thorough pre-testing to ensure effective communication and meaningful responses from children (Borgers et al., 2000).

In summary, this project uses children's natural curiosity to encourage peer-sharing within the CBL to improve the testing experience. Hospital visits can be stressful for children because of the unfamiliarity. Involving children in healthcare decisions aligns with their desire for participation and empowerment. To achieve this, the project's goal is a peer-sharing tool that provides a platform for children to connect, share experiences, and offer support; this is elaborated upon in the project brief (Appendix A). Creating a child-centred environment, where children are heard and information is presented in an understandable manner, aligns with the move towards patient-centred care and value-based healthcare, ultimately improving well-being and enhancing the overall healthcare experience.

1.3 PROJECT BRIEF

The PWL and CBL collaboratively created the assignment to explore peer-sharing benefits for CBL participants. As mentioned earlier, the two reasons were to reduce pre-visit stress and use children's desire to share experiences (Van Schelven et al., 2021b). The design made in this project can help to prepare and support children for their CBL visit. The inspiration for this initiative came from the elective 'Co-design and research with children'. At this project's beginning, a project brief was written to set the context and aim of this Master's thesis (see Appendix A). This section highlights some of the details of this brief that are necessary to understand how this project came about.

Lambert et al. (2013) explain how information provision is often too complicated, and children prefer it when their perspective and child-friendly language are considered. One study also had children stating that a peer could write the medical information provided better (Grootens-Wiegers et al., 2015). Children know the vocabulary of children the best and what kind of information they would like, and probably other children as well. The quote given by a parent in the research of Meulendijks (2020): *"We did not find the flyer very helpful, so we did a bit of searching online and found a video from this other hospital. It helped a lot! Especially because it was explained by another child."* highlights that children have a profound interest in learning from their peers. Also, this quote shows that paediatric patients find information more enjoyable and understandable when someone they can relate to explains it.

Children typically interact regularly with their peers in daily life, interacting with classmates, friends, and neighbours. However, children dealing with chronic conditions often experience heightened isolation due to disruptions in these interactions, both during and after school hours (Krulik & Florian, 1995). This contrast between children who regularly attend hospitals and those who do not underscores the significance of facilitating peer interaction for the children facing these challenges.

All of this was seen as an opportunity for the CBL to explore bringing together the participants to share experiences and knowledge and enhance a more pleasant encounter with the hospital. This project has taken a broader look at peer support in a healthcare context focused on CB. The following research question is posed to explore the broader context:

RQ: "How can design empower participants aged six to eighteen in the CBL to effectively use peer-sharing for preparation and support of their CBL visits?"

Furthermore, the project brief outlines the aim of developing a design concept that enables CBL participants aged six to twelve to make meaningful connections. The age group expansion is explained in Chapter 2. The concept aims to increase their self-confidence and curiosity about being part of the CBL. The research focuses on creating a tool that meets the needs and wishes of the CBL participants and integrates their perspectives into the context.

All these requirements are summarised in one overarching design goal:

"The design goal of this project is to create a 'tool' that enables CBL participants (aged six to eighteen) to make meaningful connections with their peers in order to learn."

By creating these connections, the tool aims to build participants' confidence and provide a platform to share experiences and knowledge about their brain condition. The tool should empower participants to feel like experts and helpers in CBL research, giving them a sense of ownership and curiosity about their condition.

In the PWL project assignment, the aim was to use peers as informants and use the eagerness of children to share. While drafting the project brief for this thesis, it was noted that peer support could be a significant benefit in enabling peer information and peer-sharing. Peer support is defined as follows:

"Peer support involves harnessing the knowledge, skills, and experiences of children and young people in a deliberate and structured manner. Its purpose is to facilitate understanding, provide support, offer insights, and aid in the development of skills, confidence, and self-awareness among fellow children and young individuals who share similar experiences" (Street & Herts, 2005).

It encompasses two main components: peer-sharing and peer learning. Peer-sharing pertains to the emotional element of peer support, entailing sharing personal experiences to create empathy. In contrast, peer learning is centred on sharing knowledge and information among peers, aimed at enhancing awareness and understanding. Enabling peer-sharing in the eventual design not only provides clear information but also inherently promotes peer support. Peer support is a valuable added benefit to the project, as outlined in the original project brief for this thesis (refer to Appendix A).

1.4 PROJECT APPROACH

The approach used in this project is the double diamond, which provides a structured framework for the design process. It emphasises the importance of divergent and convergent thinking at different stages to generate innovative solutions (Design Council, 2019). In Figure 3, each stage is presented in relation to the chapters of this report. The project deliverables are also shown in between. Here is a summary of each stage and what it entailed in this masterplan project.

Diamond 1
The first diamond represents the discovery phase, where the focus is on gaining a deep understanding of the problem space. This phase involves conducting research, gathering insights, and exploring different perspectives.This process of gathering valuable information from various viewpoints will be accomplished through desk research, field research with CBL participants, and semi-structured interviews with testers.
The second half of diamond one represents the definition phase, which focuses on narrowing the problem space and defining the design challenge. In this phase, the findings from the discovery phase are synthesised into a clear problem statement.

Diamond 2
The second diamond represents the delivery phase, focusing on developing and implementing the design solution. This phase examines the design vision and how it can be translated into a concept. Iterations are then made based on different perspectives from CBL clinicians, peers, parents, and CB. In order to create a more appropriate concept, this is developed in an interactive prototype to evaluate more holistically than the rapid iterations. Resulting in recommendations that could be improved in future development and an implementation plan for the CBL if they develop the design.

1.5 METHODOLOGY

Research on, with, or by children
Research on children often focuses only on parents or paediatric experts, often leading to insightful findings. However, they are not from the perspective of the children themselves. This project aims to do research by children, involving them throughout the process from problem definition to design evaluation. In retrospect, it became more research with children as they were consulted throughout the process but were not enabled to form the design objectives and scope of the project (Clavering & McLaughlin, 2010).

Human-centred design
The project prioritises the needs, experiences, and perspectives of the CBL participants using a human-centred design (HCD) approach. HCD is based on three key principles: desirability, feasibility, and viability (see Figure 4). Thoroughly exploring what all stakeholders want and need helps to determine which aspects should be prioritised. The challenge is to combine these elements into a concept that is feasible and, most importantly, desirable for the CBL participants. In addition, as the participants are children who often live within the rules set by adults, it is also crucial that the other stakeholders desire the final concept.

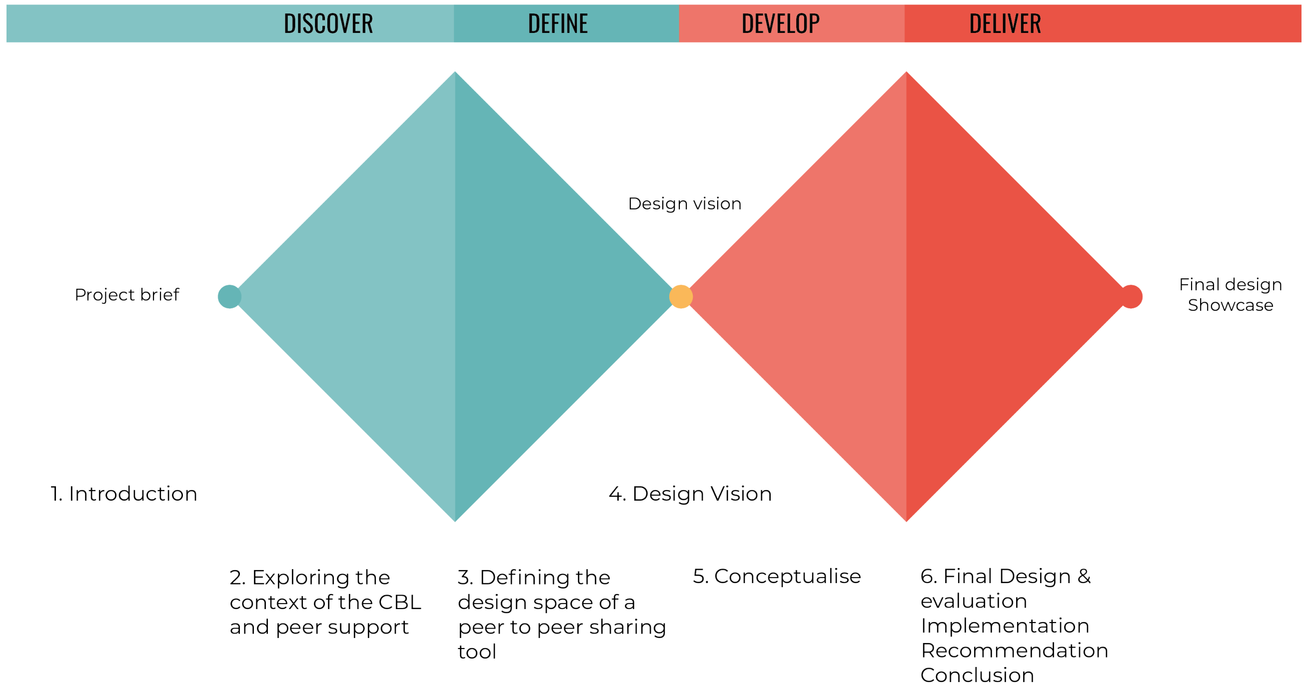

Figure 3 | Overview of how this project is divided in the double diamond approach

Finally, the design must be viable, ensuring that it provides value while being mindful of the cost. For example, the design should not increase the workload of the SCH excessively while providing little value.

1.6 RESEARCH ACTIVITIES

To gather insights, a flexible approach was adopted, this was done to make use of all the participants that were recruited throughout the process. As there was not a linear research phase at the beginning with interviews of the target audience, different research activities were carried out at each stage. In order to make this report easier to read, the research activities and their timing are described in Table 1. Each activity has been given a reference name, RA (research activity), and a number. These are referenced throughout the report to make each decision easier to understand.
See Appendix D for the research materials used in each session.

Survey
At the start of the project, the CBL proposed including a supplementary question in their trial survey. Specifically for this project, the question was: “What would you tell a peer who is also going to the CBL?” The survey returned eight responses, and the added question and the CBL’s original inquiries were evaluated.

Semi-structured interviews
Semi-structured interviews are chosen because they are conducted early in the design process. This approach allows insights and perspectives to be gathered from the testers in an exploratory way. It allows the interviewer to delve deeper into interesting directions as the design direction still needs to be set.

Make-and-say sessions
Make-and-say sessions are a qualitative approach that gathers insights by having participants create something and then explain their creation. This method is used to gain a deeper understanding of the underlying thinking. Also referred to as latent and tacit knowledge, this is the participant’s knowledge that is not directly observable and cannot always be accessed through questioning alone. (Sanders & Stapper, 2012)

Storytelling
The Delft Design Guide storytelling method uses narratives to communicate design concepts, ideas and user experiences (Van Boeijen et al., 2020). The method prioritises creating compelling stories that effectively speak to different stakeholders, allowing them to understand the design context at an early stage of development. In this project, for example, cartoons and idea drawings were utilised to illustrate the proposed design concept.

Privacy and consent
Consent and privacy are essential factors in research, especially within this research context. Given the vulnerability of CB, ethical considerations are emphasised through the application for approval by TU Delft’s Human Research Ethics Committee (HREC). The application guidelines ensure careful treatment of human subjects, particularly those under 16 (who also require parental consent).
For this research, a consent form approved by the HREC was used for both the child and the parent. The form contained all project details, including dedication to their rights, well-being, and data privacy. The form was often provided in advance or allowed sufficient time for reading and discussion.

Obtaining ethical approval in advance emphasises a transparent approach to mitigating risks to participants and creating a safe and confidential environment for all involved.

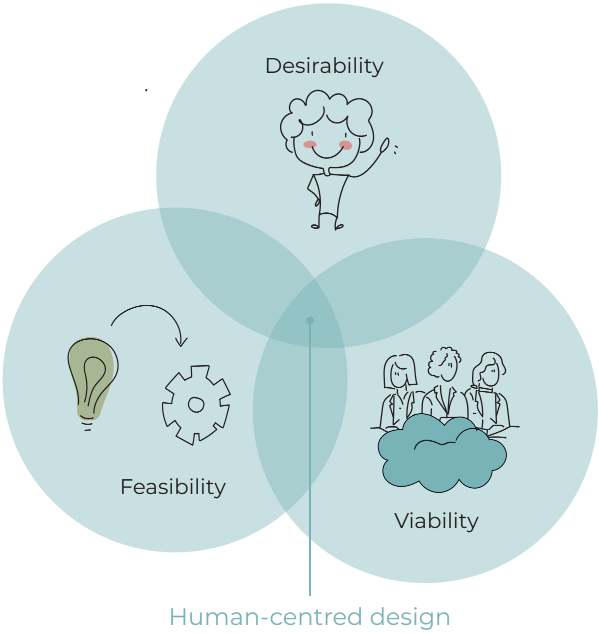

Figure 4 | Three pillars of human-centred design

Table 1 | Research activities

● 60 min

What	Who	Goal	Duration*	Reference
Survey (added question)	5 (8, 10, 10, 13, 13 yo) CWB	*What would participants share with a peer who was also going to CBL?*	● ◖	FR1
Semi-structured interview	3 testers	*What is CBL, what are the procedures? How did participants experience it, how did they feel afterwards?* *What are their needs and preferences for an enjoyable CBL experience?*	●	FR2
Make and say sessions	6 (6, 8, 10, 13 yo) CWB + 1 parent	*Explore what the children experienced during their CBL visit.* *What is their perspective on sharing with their peers? How would they help their peers (what kind of support)? ***	●	FR3
Observations	4 (11, 12, 13, 16 yo) CB	*How do they behave when interacting with clinicians and parents?* *What is their attitude and how do they feel during a consultation?*	● ◖	FR4
Short conversation	1 CB (12 yo)+ parent	*What are the CB's preferences regarding preparation information and peer contact?*	◔	FR5
Brainstorm session	7 CBL clinicians	*To explore together the possibilities of a peer sharing tool for CBL participants. And to observe where their preferences lead. Also to get more inspiration.*	●	FR6
Semi-structured interview Remote questionnaire Miro board ***	1 CB (18 yo) 1 CB (12yo) + parent 1 CB (18 yo)	*What are the preferences, needs and current experiences of CBs regarding hospital information provision, peer interaction and sharing?* *The aim is to gain insight and understand CB's views on how they currently prepare for hospital visits. What is their perspective on peer sharing/interaction and evaluate the scenario?*	●	FR7
Intermediate feedback meeting	1 CB (17 yo)	*Evaluate concept idea and brainstorm on improvements*	●	FR8
	2 CBL clinicians	*Feedback on concept idea and assessment of feasibility, particularly in terms of privacy and clinician workload.*	●	FR9
Final evaluation (usertests)	2 CWB (8, 10 yo) 2 CB (9, 13 yo) 1 parent of CB	*Evaluate final design for desirability, usability and design qualities*	●	-
	3 CBL clinicians	*Evaluate final design for desirability and feasibility*	◔	-

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* The times given in the table are for one session, so if there were four observations, this would be four times 1.5 hours. Except for the make and say sessions, it was divided into three sessions of 1-1.5 hours each, shared between the researcher and Benthe Plat. The last session was shorter (20 minutes) because the participant lost interest, probably due to his age and the structure of the questions and activities.

** After the first session, a new session plan was made because the focus was too much on what they had experienced in CBL. This was changed to focus more on expressing and sharing perspectives.

*** This participant was not comfortable with an online or physical interview, but was open to answering questions. These were formatted like the other online sessions on a Miro board.

Considerations

As this research has a sensitive target group, the following considerations are taken into account:

Diversity
When creating the design, it is important to consider the diverse range of children who will be using the tool. This includes age, cognitive and physical abilities, and personalities. In order to ensure that the design caters to the specific needs of all participants, it may be necessary to develop various versions and modes of interaction. This approach will promote inclusivity and accessibility for everyone involved.

Clear communication and understandable information
The target audience could have implications with communication due to intellectual disabilities. Also, the age of the children is relevant for the design in choosing communication methods. By making the information more accessible and easily understandable, children in the CBL can actively engage with the design and benefit from its intended purpose.

Accessibility
To ensure the quality and reliability of information in peer learning and sharing, it is vital to balance accessibility and moderation. Therefore, the design should establish clear guidelines on how to use the tool in an appropriate way. Moderation protocols should be in place if it is decided to allow more freedom of use and to let CBL participants choose what to share. Otherwise, what they can share should be controlled in itself, so that moderation is not necessary. In addition, these protocols and guidelines should address the sharing of personal data, to reduce the privacy and misinformation risks.

Engagement
By making the design visually appealing, interactive, and rewarding, participants are more likely to be actively engaged and feel motivated to participate in sharing. This can contribute to a more fun experience for all participants.

Flexibility and adaptability
Recognising that research processes and stakeholder needs may evolve, the design solution should be flexible and adaptable. This allows for adjustments to the design, data collection methods, and communication strategies throughout the project. By incorporating flexibility, the design can remain relevant and effective, accommodating potential changes in research requirements and meeting participants' evolving needs.

Positive impact
The overall aim of the project is to impact all stakeholders involved positively. The design of peer-sharing should contribute to enhancing the experiences of the participants in the CBL. It should promote self-confidence, curiosity, and meaningful interactions among participants. Additionally, these enhanced experiences could affect the CBL positively in reaching their goal of child-centred care and involving their participants more in the process of the lab. Lastly, the design should not put additional strain on the CBL, the hospital and parents.

SUMMING UP

To summarise, the hospital experience for children, particularly during tests and procedures, can be stressful, and addressing this stress through informed preparation is critical. Children's curiosity and openness prior to tests and waiting times between procedures provide opportunities to engage and inform them. The potential of peer communication among children has been recognised, with their ability to relate and share experiences on an equal level without the presence of an authority figure (e.g., a parent or clinician). The goal of this project is to use peer communication to improve CBL participant readiness and decrease nervousness before CBL visits. This research contributes to the broader goal of enhancing the CBL participant journey through well-informed and positive experiences.

TAKEAWAYS

- Children want to feel heard and seen.
- Children are often competent in sharing their perspectives, so leverage children's curiosity and openness.
- Use the power of peer communication to build trust and preparedness (reducing possible stress).
- Consider PROs and VBHC principles to create value for the CBL participants.
- Develop a platform for peer-sharing and learning to empower CBL participants and enhance their understanding of their condition.
- The Self-Portrait app could serve as a platform for sharing information.
- Children are interested in peers' experiences and trust their judgments.
- Children can communicate on an even level with each other.

Note: For readability of the report, pseudonyms are used for the three CB (RA7 & RA8) as they are often quoted. In chronological order, the names used in the report are Ilse (18 years old), Nando (12 years old), Isabella (18 years old) and Merel (17 years old). See Appendix E for more details of these CB. The quotes and findings of the research done in this project are highlighted in colour; quotes found in the literature are only cursive.

EXPLORE

Note. Willemse (2022a)

2. Exploring the context of the CBL and peer support

The CBL is constantly working to refine and improve the testing experience, for example by working with graduate projects. This project focuses on how using peers as informants could positively impact the CBL experience. The lab aims to test hundreds of participants each year, which is a great opportunity. Many of these participants will have had similar encounters with clinicians and will be undergoing the same tests at CBL. This is in contrast to their other hospital visits, where peer interaction is limited. Therefore, enabling them to share information with their peers can improve their overall healthcare experience in a number of ways: information about their daily challenges can provide emotional support, sharing medical information can increase their knowledge about care and their condition, and, in particular, sharing CBL experiences and perspectives can prepare them in a more personal and understandable way. This chapter explores this possibility by delving into the context of the project, looking at what CBL entails, who is involved, and the existing challenges and needs of participants that provide opportunities for improvement. This exploration provides a broader understanding of the project context.

2.1 CBL

The CBL is a scientific research lab for CB as mentioned in the introduction. The testing trajectory is as child-friendly as possible by using avatars (Wavy, Neuro, and Brainy) and a playful way of doing the tests to make it a fun and positive experience for the participants. The lab consists of three rooms, listed below. They have the official name and a more descriptive and understandable name used by the testers when communicating with the younger participants (see between brackets):

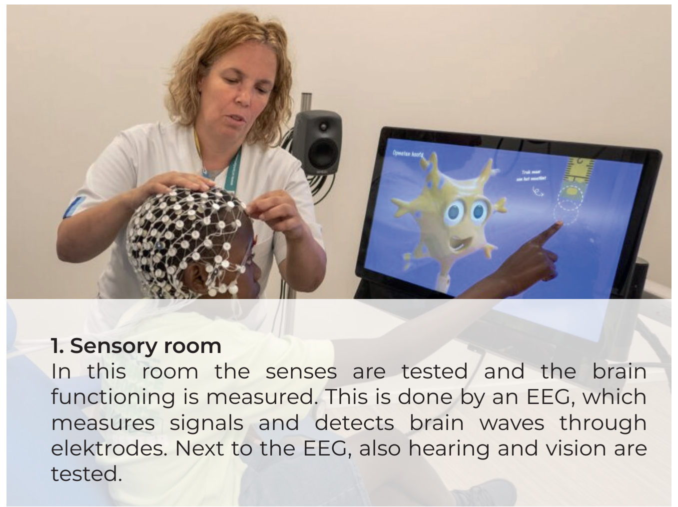
- Cognition Room ("Thinking Room")
- Sensory Room ("Machine Room")
- Mobility Room ("Moving Room")

It is not relevant to this project's scope to go into detail about each test carried out, so a global overview is given in Figure 5. An overview of all the tests is included in Appendix B for reference if any of the tests come up.

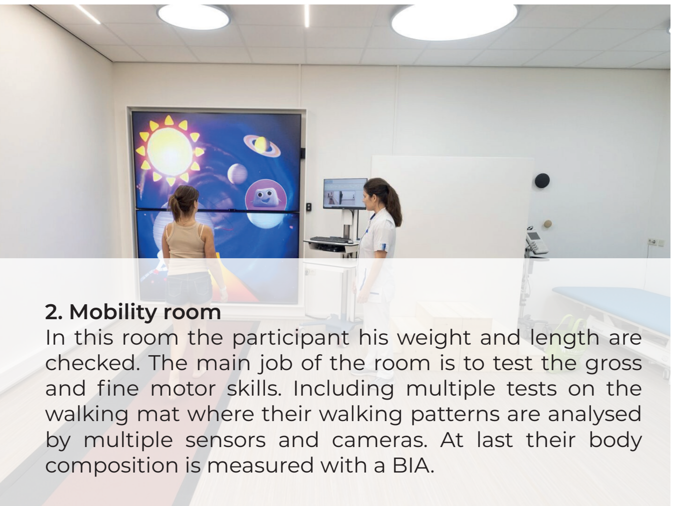
2.1.1 WHAT DOES A CBL VISIT? ENTAIL?

This section provides a global overview of the testing procedure employed by the CBL. While the specific details of the tests and their execution are not covered here, as this thesis focuses on participant interaction rather than the tests themselves, it remains essential to acknowledge how these tests impact the target group. This overview is presented to highlight the context. The emotions and experiences of participants before, during, and after their visits to the CBL form the foundation for determining their needs and preferences, thereby guiding the scope of this study. The design scope is visualised through possible intervention points, depicted in the diagram, see Figure 6. These points show when and how peer-sharing could enhance the lab experience.

Participants are often tired at the end of the visit because the procedure takes at least 4.5 hours, excluding the 3D scan, breaks, and travel time. In addition, the tasks are intensive

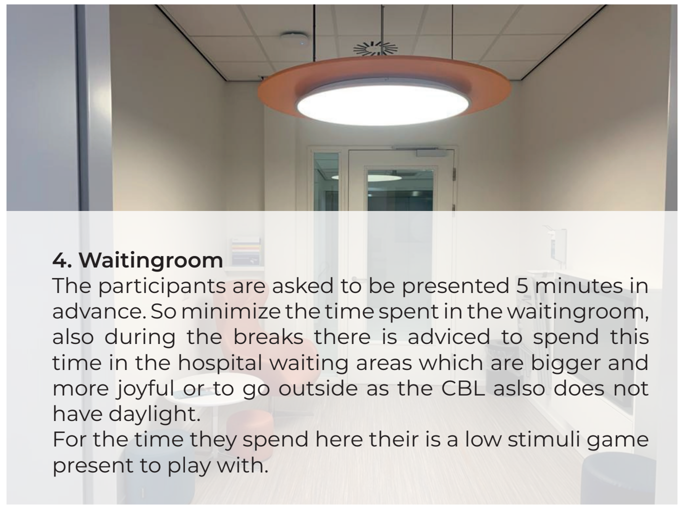


1. Sensory room
In this room the senses are tested and the brain functioning is measured. This is done by an EEG, which measures signals and detects brain waves through elektrodes. Next to the EEG, also hearing and vision are tested.



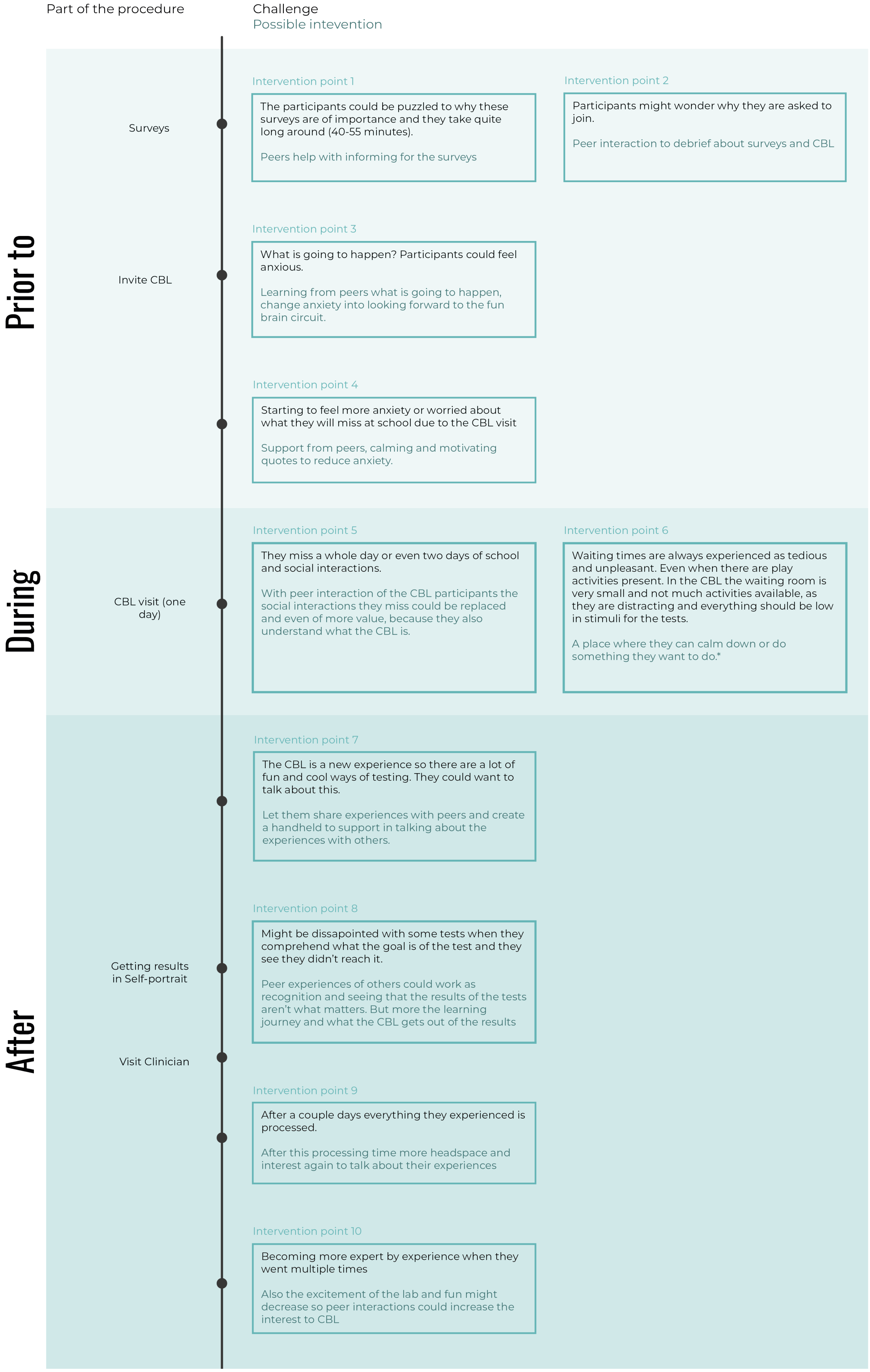
2. Mobility room
In this room the participant his weight and length are checked. The main job of the room is to test the gross and fine motor skills. Including multiple tests on the walking mat where their walking patterns are analysed by multiple sensors and cameras. At last their body composition is measured with a BIA.

3. Cognitionroom
In this room cognition and development of the particpant is studied. They measure the intelligence and linguistic comprehension. They also look into behaviour and do an parent-child interaction test.



4. Waitingroom
The participants are asked to be presented 5 minutes in advance. So minimize the time spent in the waitingroom, also during the breaks there is adviced to spend this time in the hospital waiting areas which are bigger and more joyful or to go outside as the CBL aslso does not have daylight.
For the time they spend here their is a low stimuli game present to play with.

Figure 5 | Descriptions of the rooms in CBL (1. Willemse (2022b.); 2. ErasmusMC (n.d. b); 3. Willemse (2022c.))



Intervention point 1
The participants could be puzzled to why these surveys are of importance and they take quite long around (40-55 minutes).
Peers help with informing for the surveys

Intervention point 2
Participants might wonder why they are asked to join.
Peer interaction to debrief about surveys and CBL

Intervention point 3
What is going to happen? Participants could feel anxious.
Learning from peers what is going to happen, change anxiety into looking forward to the fun brain circuit.

Intervention point 4
Starting to feel more anxiety or worried about what they will miss at school due to the CBL visit
Support from peers, calming and motivating quotes to reduce anxiety.

Intervention point 5
They miss a whole day or even two days of school and social interactions.
With peer interaction of the CBL participants the social interactions they miss could be replaced and even of more value, because they also understand what the CBL is.

Intervention point 6
Waiting times are always experienced as tedious and unpleasant. Even when there are play activities present. In the CBL the waiting room is very small and not much activities available, as they are distracting and everything should be low in stimuli for the tests.
A place where they can calm down or do something they want to do.*

Intervention point 7
The CBL is a new experience so there are a lot of fun and cool ways of testing. They could want to talk about this.
Let them share experiences with peers and create a handheld to support in talking about the experiences with others.

Intervention point 8
Might be dissapointed with some tests when they comprehend what the goal is of the test and they see they didn't reach it.
Peer experiences of others could work as recognition and seeing that the results of the tests aren't what matters. But more the learning journey and what the CBL gets out of the results

Intervention point 9
After a couple days everything they experienced is processed.
After this processing time more headspace and interest again to talk about their experiences

Intervention point 10
Becoming more expert by experience when they went multiple times
Also the excitement of the lab and fun might decrease so peer interactions could increase the interest to CBL

Figure 6 | Intervention points of CBL visit and mentally taxing for the CB. Participants can feel exhausted after being tested, which sometimes leads to them being hyper, high in emotion, or easily irritable, which can affect test results (RA2). Also, the participants differ in how they might feel about their experience in the CBL due to external factors, such as the previous day's journey to the CBL, their personalities, and what they are missing out on at home during their stay.

Test visits
The CBL participants have already been diagnosed and are patients at SCH or another hospital. The participants have been coming from a young age to the hospital and are familiar with this medical environment, reducing their anxiety about visiting the hospital (RA7 & RA8).

Furthermore, their familiarity contributes to their knowledge of the tests used in the CBL since these are commonly used in other hospital consultations or training. One tester commented, *"For example, if they just had to pile some blocks downstairs and then come to the CBL and we have to do the same test, they [CB] could be like 'again… [sigh]'." - tester of the mobility room.* This quote illustrates how this familiarity could cause them to feel bored (RA2).

The CBL tests a child five times during childhood, from infancy to adolescence. The first two visits occur before age six; children cannot remember these visits because their brains are still developing memory (Meulendijks, 2020; see Appendix C). Some children may remember bits and pieces, indicating that they have been to the lab, but they are unlikely to have much active memory of these first two CBL visits (Figure 7). A CB who visits five times during childhood is the ideal situation for CBL, but sometimes CB are recruited at a later age and, therefore, have fewer visits.

2.1.2 HOW IS A CBL VISIT EXPERIENCED?

This section presents the main findings from the children's experiences, both from the perspective of the testers and the CBL trial participants (unconditioned). See Appendix F for a full overview (RA1 & RA2).

Almost all trial participants rated the mobility room as the most enjoyable. The main reason the participants picked this room as the most pleasant was the opportunity to move around and not sit still. One of the testers also suggested that the mobility room was perceived as the most enjoyable because participants could choose their own testing order, so they experienced more flexibility and freedom.

The cognition room was found to be the most boring by the children. The experimenter explained that the tasks are repetitive and often remind them of 'exams' (Dutch: 'Citotoetsen'). They have the feeling of being assessed, which is negatively experienced, and in other rooms, they less frequently encounter this feeling.

Most of the test participants found it challenging to remember all the events, but the fact that they received a gift after the test day was vividly remembered (RA7 & RA8). The testers also explained that they often kept the children's positive attitude towards the tests, even when they were not in the mood, by giving them small rewards, such as breaks, wanting to sit on the tester's chair, and running around the hall (RA2). Based on these two insights given by the CWB participants and the testers, it can be assumed that children respond positively to rewards, and these incentives play a significant role in maintaining their enthusiasm and positivity when engaging in various activities.

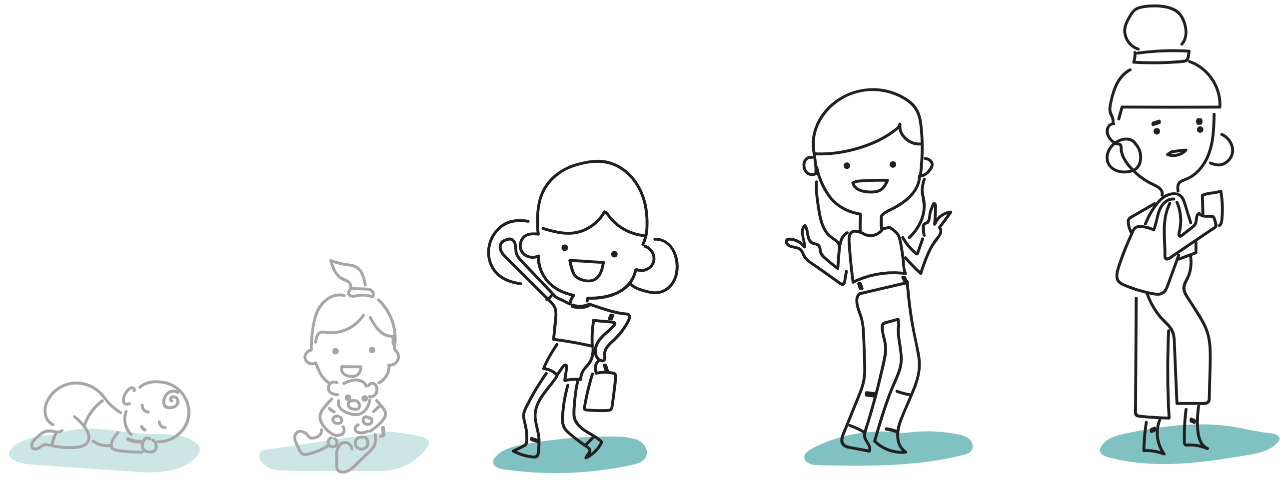
Even though the tests are for research purposes and every result is positive, children do see it differently. Children understand when they do 'well' or 'badly' in tests from their perspective. For example, consider children attempting to toss a ball at a target fixed to a wall. If they continue to miss the target, they may experience negative emotions, as apparent in one of the answers to the surveys (RA1), even if they are unaware of the scoring system and the test results. From their perspective, they feel they have done poorly in this test, which may lead to disappointment or annoyance.

In summary, this instance illustrates how children can experience emotions regardless of their understanding of the task. It is crucial to acknowledge that outcomes influence emotional responses.

2.1.3 PARTICIPATING IN SCIENTIFIC RESEARCH

Observations from consultations with CB show that they are often asked to participate in studies and research (RA4). For some children, participating in research could feel like an extra burden on their condition because the tests remind them of their condition. It also adds to the disruptions of their daily lives and routines because they must go to the hospital again (Staphorst et al., 2015). The visit to the CBL even takes two days, which can result in missing two days of school as the tests are long and the child also has to go to the hospital.

It is not possible to conclude whether the CBL tests are perceived as positive or negative by the participants, as only a few participants visited the lab, and not all of them were interviewed in this thesis. However, one tester mentioned that the first participant (a six-year-old boy) enjoyed it and was quite tired afterwards. In the observations of this research, most children were more than happy to help and looked pleased to be asked about their experiences. However, participating in studies can take much energy from the children and the parents (RA4). The CBL participants interviewed at the end of the project (see Chapter 6) were also positive about CBL.


Visit 1
0-12 months

Visit 2
30-42 months

Visit 3
5-8 years old

Visit 4
9-14 years old

Visit 5
15-18 years old

Figure 7 | Age categories per visit (adapted from 123rf (n.d.))

In addition, studies of the perspectives of children on medical research found the children were often very positive about (Swartling et al., 2011; Staphorst & Van de Vathorst, 2015):

- Learning new things about themselves (their bodies and abilities)
- Helping other children and having fun doing it
- Children with a chronic illness also mentioned that it could influence improving their care (better medicines and treatments).

The CB interviewed shared these views, which were not explicitly linked to research participation (RA7 & RA8). However, they generally mentioned their desire to help others and improve care. Ilse (18 years old) said about her social media profile on her condition, *"I get messages from parents saying, 'Oh my God, you help my child so much,' and that makes everything worth it,".* Merel (17 years old) mentioned, *"I enjoy working with them [the child advisory board] because you can just make the hospital a better place because of it."* They derive a sense of value from actively listening to and helping others. (Ilse: *"[When introducing herself] I love listening to stories and helping people by listening to their stories").*

2.2 STAKEHOLDERS

This section highlights the key stakeholders, with the target audience being the most important stakeholder for this project, the CBL participants (CB), Figure 8 also shows how tight the relationship is between the child and the other stakeholders.

2.2.1 PARENTS

In hospital settings, many medical resources, including hospital websites, letters, and consultations, are designed with a focus on parents. Parents play a pivotal role, particularly during the early stages of a child's development, serving as the primary source of care and information. Consequently, their influence significantly contributes to the overall well-being of their children. However, despite their inclination to advocate for their children's needs, parents often lack the necessary support and expertise, primarily due to their unfamiliarity with the healthcare situation (Yates et al., 2010). The role of advocate can be a source of stress and anxiety for parents, adding to their already considerable responsibilities.

Balancing the best with control
The parents' desire to care for their child is closely linked to the need to maintain control, especially when a parent's child is in a vulnerable position, such as a brain condition. As a precaution, parents may be reluctant to stay in control to avoid exposing their children to distressing information about their condition (Heah et al., 2006).

Knowing abilities
Parents, motivated by their instinct to protect their child, sometimes unintentionally hinder their child's growth and development. Despite their well-intentioned efforts, they may inadvertently create barriers that limit the child's opportunities for personal growth and independence (MCW, 2022).

Contrasting attitudes
Parents have different views on peer support. Some are reluctant to allow children to share information freely, but they may also understand the benefits of encouraging relationships and collaborative learning (Aufegger et al., 2020). When children are aware of or understand their condition, parents are no longer solely responsible for managing it, as the child can help by providing guidance and support in various circumstances. This shared responsibility makes parents feel more prepared and less alone, ultimately reducing stress. One parent mentioned the following; *"That's what I see, say, as a mother is that he struggles with that right that he feels like he is the only one who has this? And, that also causes him to always mope when he has to go to the hospital. 'No one has to do this'. It might be nicer, but I always say just be glad your friends do not all have it. But it does make him feel alone in that" – The parent of Nando (12 years old)*

It is an example of how, even when surrounded by friends, CB can still feel alone if no one is going through the same experiences as them. This parent also mentioned how hard it is to look for peers sometimes because everyone has a different age and condition. Some children have a more severe condition, which can be difficult to indicate. She said:

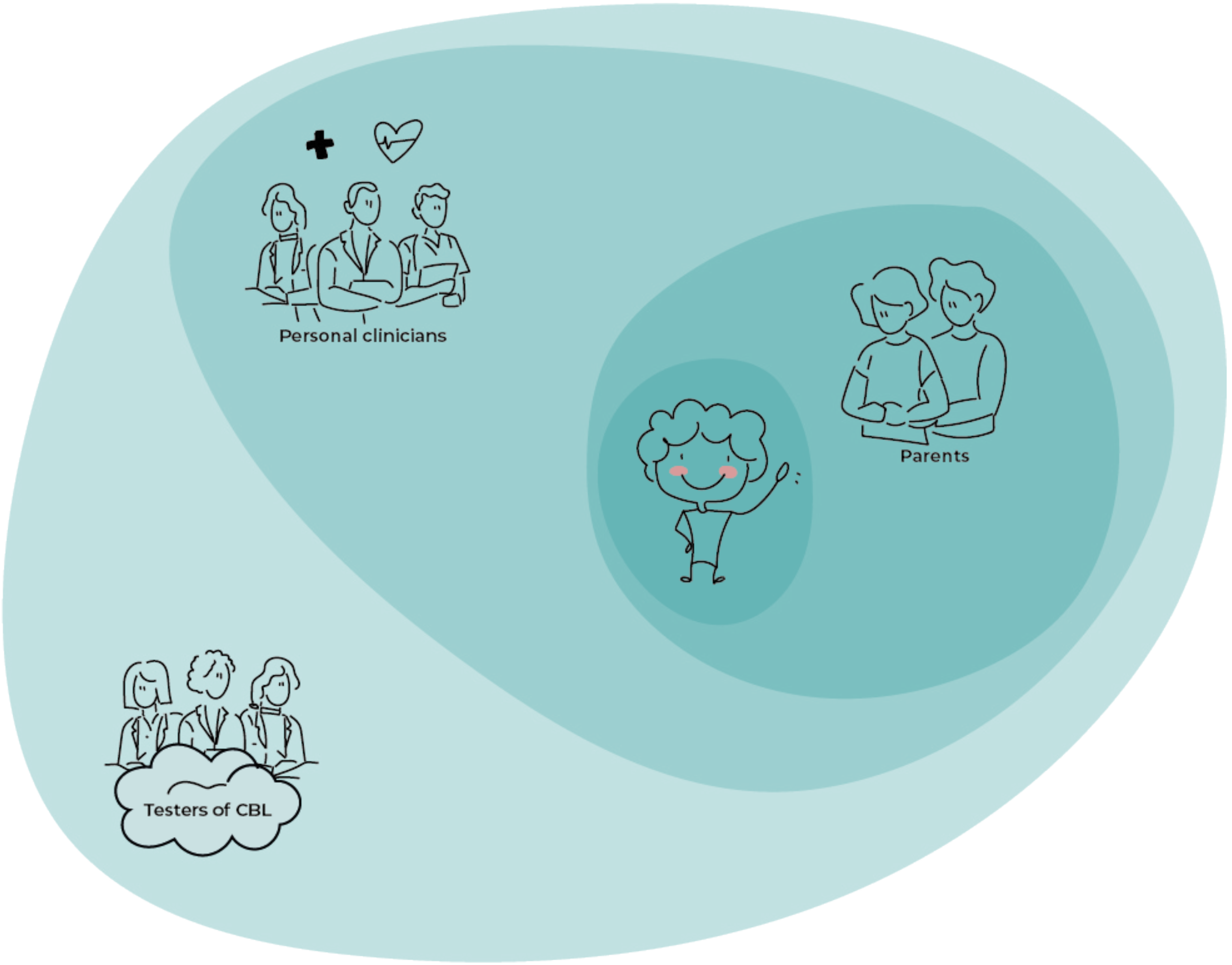


Figure 8 | Stakeholders and their distance to the CBL participant

"I know, I myself once thought of well I will look through Facebook or something with him to see if there are peers. But that did scare me. I quickly took it down. So then you get that everyone has it a bit different. You see very extreme forms and with him it's just - we got lucky how he developed. So it can help you sometimes, others, but sometimes it's also better not to see it, so to speak." -Parent of Nando (12 years old)

The stories of more severe conditions may frighten a child or give them the wrong idea that something similar will happen to them. On the other hand, observing other children with milder conditions may make children with more complex conditions feel bad about their abilities. Parents may be reluctant to seek out peers after reading numerous reports that do not apply to their child.

2.2.2 TESTERS

The testers are responsible for carrying out tests with the CBL participants. As they only observe the target group (CBL participants aged six to eighteen) within the CBL, they have a different perspective than the other stakeholders, and they 'need' the child's voluntary participation.

The cognition room tester noted: *"A child with a task-oriented attitude"*, would be desirable. The children's participation is completely voluntary, and the participants cannot do anything wrong, as the laboratory is for research, so any result is desirable. However, the tests must be completed for the results to be considered valid and contribute to meaningful conclusions. As coercion cannot be used to get children to participate, if the children are reluctant, the test will be stopped, as this may lead to incomplete test results, which could hinder the research. Children need to be actively engaged and focused on the tasks to ensure they complete all the tests, which can be challenging.

Another tester (from the mobility room) emphasised the importance of a child's willingness to take part in the tests, saying, *"a child who wants to [enjoys] taking part in the test"*. Testers strive to create a positive and enjoyable experience for the children they work with, encouraging participation while minimising stress. To facilitate this, creating a fun and engaging atmosphere within the CBL that motivates children to approach tasks with a positive attitude is important. Ideally, children should be excited about their CBL experience and actively look forward to participating in the tests.

2.2.3 CLINICIANS

In addition to the testers, the participants of the CBL are also affected by other clinicians. For instance, a personal doctor will discuss the results of the CBL tests with the CB. Additionally, multiple other caregivers are included in this report under the term clinicians, including physiotherapists, psychologists, and all other healthcare providers involved in the care of the CB. While they have some overlapping needs, they also have different requirements from the testers and the parents, as elaborated below.

Best for the child
The main desire of the clinicians is the same as that of the parents of the CB: to promote overall well-being and improve quality of life by actively involving patients in the treatment process. But often the clinician's priority is still the physical complaints and the medical problem, rather than all the other daily factors that can affect the CB's emotional well-being (Van Schelven et al., 2021a).

Reducing anxiety and stress
Secondly, they want to reduce patients' and parents' anxiety and stress. Decreasing the potential stress is done by keeping parents well informed so they can better understand the clinical approach, potential complications, and other details of the procedures (Wanzer et al., 2004; RA4).

The patient-doctor gap
They also face the challenge of communicating complex medical information while simultaneously trying to minimise the knowledge gap between patient and doctor. Clinicians must balance information accuracy and the clinician's and patients' comprehensibility to ensure they understand the risks and complications (Sisk et al., 2021; RA4).

To meet the wide range of patient needs, healthcare providers need to change their communication tactics. They can effectively engage patients and their families, promote informed decision-making, reduce stress and anxiety, and ultimately improve patient outcomes by considering developmental age, unique circumstances and avoiding overly technical terminology.

2.3 PARTICIPANTS OF CBL

The CBL participants (aged 6-18 years old) are the target group of this project and, as such, are the main stakeholders in the design. Designing for this target group is complex as these children are still at the peak of their development, and the age range covers multiple significant developmental stages. The design of this project is primarily influenced by the growing need for autonomy among children as they become more independent with ageing. Additionally, the impact of peer influence on development is addressed. This section also considers the developmental skills that must be considered in the design to ensure accessibility for children of all ages.

Independence

CB face the challenge of balancing their desire for independence with the need for assistance. Creating an environment that promotes growth requires allowing them agency over their lives while ensuring their safety and well-being. If they can do things by themselves, it helps improve their self-esteem (Heah et al., 2006). A contrast emerges when comparing the views of these children with those of their parents, especially concerning achievable independence. This phenomenon is not unique to chronic illnesses; children generally want to demonstrate their ability to make independent decisions, and sometimes parents are not yet ready. However, chronic conditions add extra complexity to this dynamic, as parents, driven by a protective instinct, may inadvertently limit the child's perception of potential opportunities (Peeters et al., 2014).

When parental perspectives restrict the range of possibilities, children may internalise these limitations, ultimately restricting their perspectives. As expressed by a teenager with a chronic condition, *"If your parents raise you with the idea that 'you have fewer options,' then as a young person, you might start to think* that about yourself" (Van Hal et al., 2019, p. 73). The significance of peer relationships in children's developmental journey cannot be underestimated. Interactions with peers enhance social competencies and holistic growth. Nonetheless, this aspect becomes complicated when PWB (un)intentionally exclude CB or when they never had the same life experiences as CB. This gap hinders a comprehensive learning journey.

As CB often develop in a different way to CWB, for example, some brain conditions can make a child feel and act younger than they are. This difference in developmental age can sometimes make it difficult for them to adapt to their PWB, for example, by spending more time with adults or being alone (Bøttcher & Dammeyer, 2016).

Understanding independence and social relationships is crucial for the development and well-being of CB.

The effect of ageing on interest in information

When CBL participants age (10 years and above), they want to obtain information about their medical conditions. They may also be afraid to ask 'stupid' questions. Concerned about their parents' feelings, some children may prefer visiting their doctor's appointments without their parents to avoid causing them pain or anxiety (Meulendijks, 2020). In addition, these negative feelings may influence the child's attitude. For example, the parent may be anxious about the outcome of an operation and stressed about being late and other practical matters, making the journey less pleasant for the child (RA4). As children become older, they are more interested in information about their condition and medical treatments, but at the same time, they do not want to be confronted with their condition outside the hospital and prefer to focus on other things (Meulendijks, 2020; RA7 & RA8).

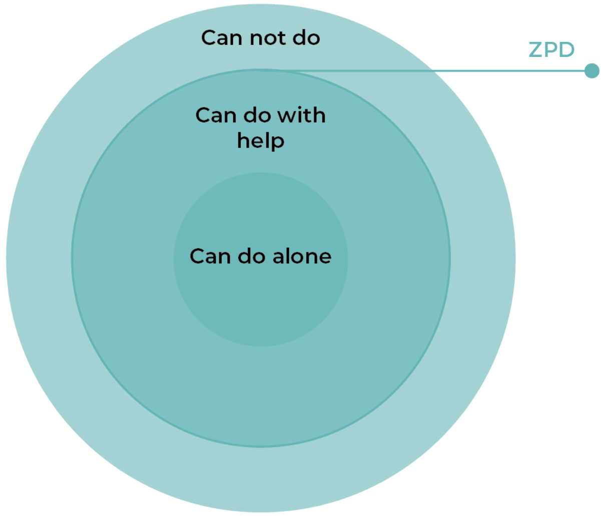


Figure 9 | Model of the Zone of proximal development

Zone of proximal development

A child's learning and development depend not solely on age but also on the resources provided. Vygotsky's theory of development highlights this through his zone of proximal development (ZPD) model (Vygotsky & Cole, 1978; Chaiklin, 2003)(Figure 9). The child's developmental stage enables them to complete certain tasks and learn new skills more efficiently than in a previous stage of development. However, the ZPD model examines how a child can surpass their developmental stage with adequate resources and support from a more knowledgeable other. The ZPD model contains three areas: the tasks children can do without help, a zone of tasks children will not be able to do, and the ZPD, activities children can do with support. This last zone is an expert-novice interaction involving a more knowledgeable other in the learning process. The expert is often seen as an adult but could also be a more knowledgeable peer.

Additional research shows that peers of equal ability can support each other in the ZPD. When peers possess the same level of knowledge, they can learn from one another by establishing new ZPDs for each other and collaborating to achieve their set targets. They can assist by discussing unfamiliar topics with one another (Khatib & Ahmadi, 2011). This collaboration of finding solutions and achieving both new skills indicates how peers can support development and learning in a mutually beneficial manner.

Peer influence

Next, peers have a beneficial role in learning; it is also a significant factor in children's social development. As children grow older, they often seek knowledge and skills from adults, whom they perceive as more knowledgeable. However, as they become older and desire more independence, peer influence becomes more significant, and the authority of parents decreases (Bar-Tal et al., 1991). An estimate of what this influence would look like has been sketched in Figure 10, based on the development tables of Meulendijks (2020) (included in Appendix C) and the study of Bar-Tal et al. (1991).

2.3.1 AGE GROUP EXTENSION

Although the initial focus was on children aged six to twelve, research on CB and the development of children suggests that including older children in the age range may be beneficial.

Greater scope for intervention

Participants visit the CBL only five times during the trajectory, with only three deliberate encounters. Only one visit between the ages of six and twelve is made, making the design's application and solution space very limited. As a result, the age range has been extended to allow for more design freedom and to explore possibilities for use over a longer period (more CBL visits).

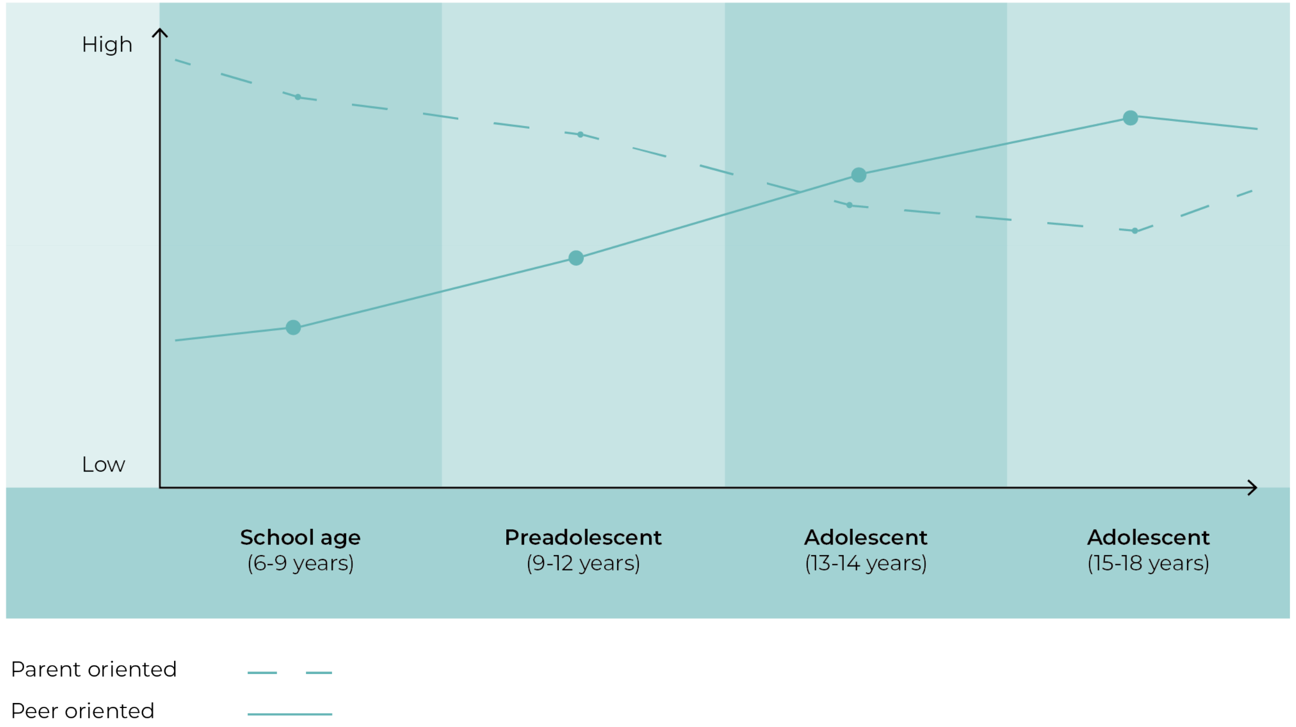


Figure 10 | Anticipated shift in child's orientation from parent to peers

Developmental-age
CB participants often have developmental delays due to their condition. These delays may also affect the age range of this project, as children chronologically aged six may be developmentally aged three, for example. In addition, these conditions are also associated with behavioural problems, which also means that children are more likely to socialise with peers of different ages (French, 1987). Therefore, a wider age range was considered in order not to exclude possible peer matches.

Benefits for older and younger age groups
Peer relationships are important for developing social skills such as communication, empathy, and cooperation (Chailkin, 2003; Piaget, 2000). Peer relations are, therefore, crucial for younger children who are still developing social skills the most. On the other hand, when children get older, they are also more influenced by peers. Adolescents want more independence and autonomy from adults, so they often orient more towards their peers at this age (Berndt, 1979). This increased peer influence makes peer-sharing attractive to older and younger children. Younger children can learn from their peers, and adolescents can feel more autonomous as they can explore information through their peers independently of adults.

Peer mentoring
Following these appeals, involving older children in the design allows younger children to learn from and be mentored by older children (Smith & Inder, 1990). As a result, younger children could use the tool to ask questions and seek advice from their peers. It could also be beneficial to see older children with the same condition and observe how they deal with situations to get a sense of the future.

2.3.2 DESIRES & NEEDS

It is important to consider the needs and wishes of CB. Understanding their lives and perspectives is necessary to create an appropriate concept that is desirable for them (human-centred design approach). As said in the considerations, the group remains diverse, so each child must be seen as an individual with different needs and desires (Yates et al., 2010).

New Normal
Firstly, CB view hospitals differently than children who have less experience with hospital visits than they do. CB see the hospital often as normal: one respondent even said, 'It felt like home.' However, the feeling of familiarity should be distinct from the idea that a hospital visit is experienced as a joyful moment.

Ilse (18 years old) expressed this sentiment, reflecting on her perception of hospitals: *"This is very strange, my feeling is that you feel somehow at home in the hospital. … And I see it as the most normal thing in the world. So I'm not so afraid of the hospital, nor of the doctors. Although I have noticed that this is something my peers have less."* Later in the interview, she ensures, *"That does not mean I like it [going to the hospital]."* This quote shows how she notices that she is different from her peers in her view of the hospital. A parent made the same point, emphasising the normality despite the lack of enjoyment: *"It has become normal for him, although it's not fun, is it?" [She looked at her son, who nodded in agreement.]* -Parent Nando (12 years old)

For CB, the fear of the hospital does not stem from the unfamiliarity of the hospital environment, as they are accustomed to multiple visits per year. However, it can still be perceived negatively due to the necessity of undergoing treatments and the possibility of receiving distressing news during these visits. Additionally, the fear may be compounded by their desire to enjoy their childhood and simply engage in typical daily activities. However, Isabella mentioned, *"I think I already know a lot [about the hospital and my condition], and yes, going to the hospital remains stressful ('spannend' in Dutch).*", highlighting that they can still experience stress from a hospital visit even though they know a lot and are familiar with the medical environment.

Therefore, it is important to provide clear information and preparation to reduce the anxiety associated with hospital visits for CB, also shared by Isabella; *"Explanations are very important to me; without them, I am tense and don't know what is going to happen."*

Desire for normality
This desire for normality is a recurring theme among CB, complicated by their medical conditions. As Yates et al. (2010) note, they sometimes need to recognise that extra support from others is necessary.

Nando (12 years old) expressed his desire for normality, saying, *"But it's [having a drain] just different from other people."* His parent, in agreement, added, *"In short, [Nando wants] not [to] be different from others,"* while talking about her son.

Interestingly, the desire for normality can evolve with age, as described by another Ilse who became more accepting as she got older (over sixteen years old). She shared, *"I did not want to display myself too much as a girl with a disability, just because I've had that feeling you shouldn't be different for a very long time, so I did not want to portray myself like that either."* She continued, *"Now I am more in the phase where you start to accept it. And more. More in the phase where I think you start to accept it and see it more as something beautiful."*

Feeling vulnerable and alone
Children with a chronic condition, such as a brain condition, are constantly aware that something could go wrong. These medical conditions introduce unpredictability into their lives (Yates et al., 2010). Often, children strive to lead as normal a life as possible, but they must contend with the unpredictability of sudden hospital visits or surgeries. During these moments, they often find themselves alone and do not have the opportunity to interact with many of their peers, as described in the quote from Ilse (18 years old): *"But what I can mainly remember is that when you do those tests, you are alone, so you don't see many other children who go through that. So you really had to rely on, well, the children you meet from my surgeries, but just, you know, during check-ups, you don't really get to know other children."*

Support is a process, perspectives change
One study mentioned the significance of providing ongoing support to children (Söderbäck et al., 2011). It is important to recognise that children may not fully express all their needs and desires during the initial interactions with someone or something. However, over time, as they are asked and engaged with more than once, they gradually reveal more about what they genuinely think.This principle is particularly relevant to this project, as the CBL interacts with the participants several times during their childhood, providing an opportunity to gather their perspectives on the CBL over time.

Furthermore, their responses may vary each time when children are asked questions such as "How are you?" or "How did you feel about it?" during these interactions. Several factors could influence their answers, including their current mood, the journey to the lab, or recent life events.To understand the children's experiences comprehensively, it is essential not to depend solely on one-time check-in points.

2.4 PEER SUPPORT

This section explores the benefits and concerns associated with the use of peer support, and peer-sharing in particular. Furthermore, it will explore children's attitudes regarding peer support.

2.4.1 BENEFITS

There have been several studies on peer support for people with chronic conditions. Not all these studies have addressed the benefits of CB specifically. However, the main benefit of peer support in general is that people with similar chronic conditions (peers) can share knowledge and experiences that clinicians do not have (Baumann & Dang, 2012). Other benefits found (Olsson et al., 2005; Lewis et al., 2016; Dale et al., 2012) are as follows:

Coping strategies
Observing and exchanging experiences with people in similar situations to develop new ways to cope with the difficulties and stress of chronic illness. It may also aid in some conditions with self-management, and they can analyse their feelings and why some are present together.

Advocacy and social skills
Improving communication skills, assertiveness, and social identity to impact social contexts and advocate for the rights and needs of people with chronic illnesses.

Perceptions and attitudes
Investigating other points of view and widening the scope of what is considered normal to decrease stigma and boost confidence and self-efficacy. Additionally, developing skills like problem-solving and goal-setting improves their future attitudes.

Stress reduction and a sense of belonging
Reduced isolation, enhanced social connectedness, and confirmation of good attitude change for increased resilience and self-confidence.

Providing help and support to peers
Assisting and supporting others struggling to find a feeling of purpose and independence.

2.4.2 CONCERNS

As mentioned above, there are many benefits to connecting CB with their peers. However, some concerns need to be mentioned. Not to avoid but to mitigate and use them to make the tool more powerful (Ollson et al., 2005).

Misinformation
The main challenge is who will monitor the participants' tool use. As children do not have all the correct knowledge and information is often provided to them from several different sources, this can lead to different pieces of information meaning the same thing. This could lead to children giving each other incorrect information or information taken out of context. However, peer-sharing aims to give children some control and independence, so having it moderated by experts or adults is contradictory, as this takes away some of the privacy and freedom. Research should be done to determine if children feel this way and how this can be addressed without taking away their control.

Shocking information
Peers could also inform each other about shocking details that they did not know or might not even apply to them, as the future is often unpredictable in these conditions.

Socially excluded as a group
As CB meet more peers, they may feel even more socially excluded from their PWC. They have a new definition of 'normal', meaning they feel more on the outside during their daily lives, knowing they fit in somewhere else. CB might see themselves as a 'disabled' subgroup to which they belong, more rejected by society.

Social comparison
Children like to compare themselves and have a competitive drive. They want to know if they are doing better or worse than others. Allowing them to do this gives some children a positive feeling because they see that their condition is not as severe. However, other children are made to realise they have even less ability than they previously knew (Tielen, n.d.).

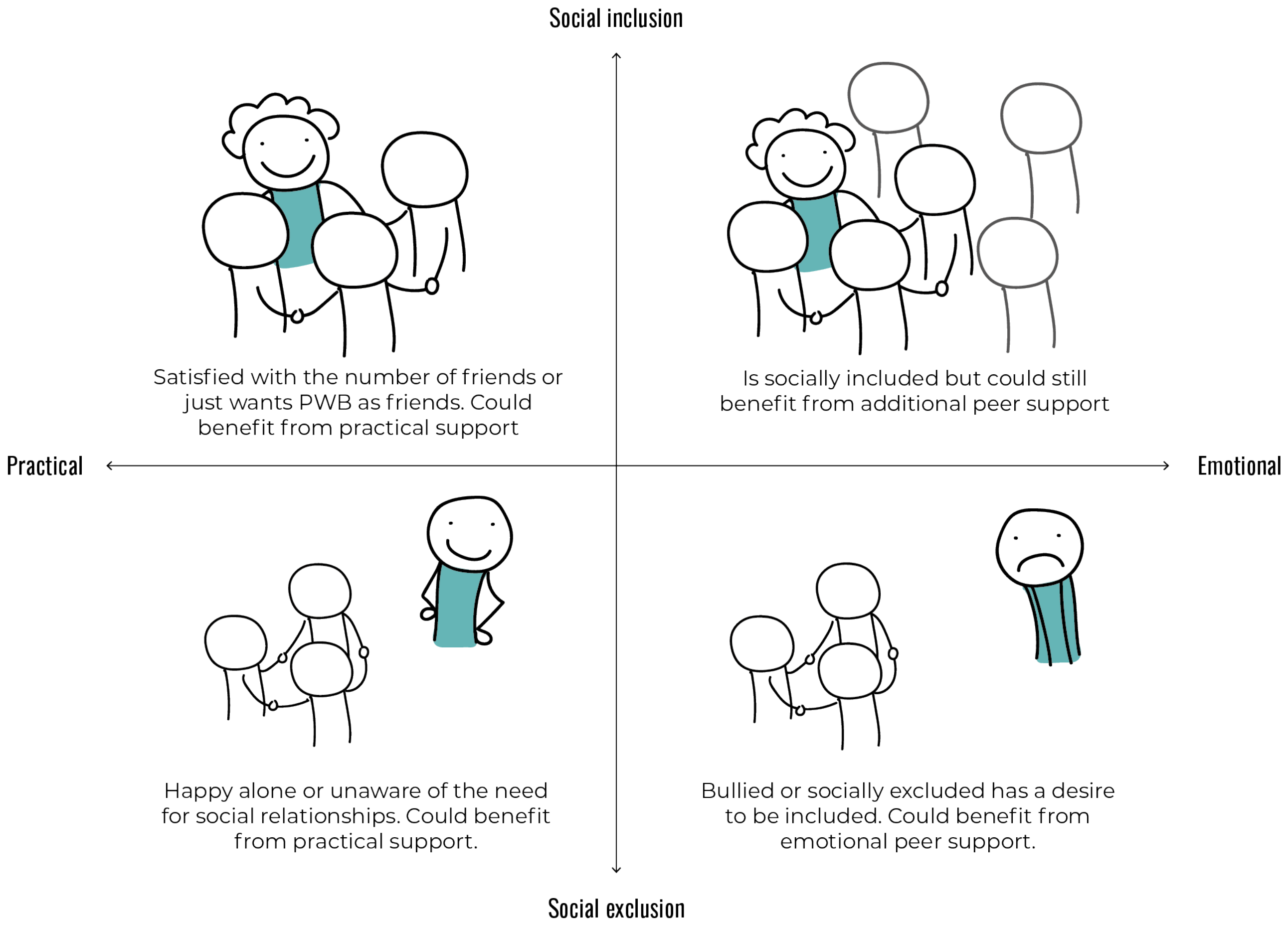


Figure 11 | Different attitudes towards peer support

2.4.3 ATTITUDES

The target group is diverse due to children's ages and personalities in general. They may have different attitudes towards a peer-to-peer-sharing tool. While some children would be happy to use such a tool if it allowed them to interact with their peers, others do not see the need for it. The disinterested perspective of some children may stem from their satisfaction with their current social status, as they prefer not to stand out from their PWB. These children have a strong desire for normality, as evidenced by the following statements *"It's not important to me; I already have enough friends" and "No, everything is fine. I do not feel that anything is wrong with me, so I prefer to interact with people who are also free of any conditions"* (Van Staa et al., 2006, p.30).

The study also indicates that certain children occasionally seek peer support, as one participant expressed, *"Sometimes yes, sometimes no. Sometimes you can talk about it, but sometimes it holds you back when you want a moment to be free of illness"* (Van Staa et al., 2006, p. 30). This suggests that some children do not perceive themselves as ill, reflecting their aspiration for normality. Furthermore, another group may not even seek peer support due to age or intellectual limitations. This group may lack awareness of their illness and its social implications, hence not recognising the need for peer support. Additionally, some children generally prefer solitude.

In the study by Crompton et al. (2023), autistic young adults reported feeling particularly isolated following their diagnosis. The young patients expressed a desire to spend time with others who shared similar experiences, stating: *"Sometimes it is nice . . . I always think it is nice to have really similar experiences that you can share and talk about . . . and sort of click on a particular level"* (Crompton et al., 2023, p. 81) This indicates the value they place on connecting with people who can relate to their journey.

In addition, De Clercq (2012) explores how different personality traits influence children's positioning within a group. Many factors influence social relationships. Children acknowledge the challenges of being outgoing when living with a chronic illness. However, they also recognise that confidence increases their likeability within a group, which can be challenging when medical limitations undermine their self-efficacy.

All these different attitudes are summarised and grouped into four types in the matrix (Figure 11). The matrix shows that children who want peer support often want emotional connection and sharing. In contrast, the two groups on the left may benefit more from practical and informational support with less emphasis on interactive elements. The latter group typically seeks information and expertise without sharing their own experiences.

CONCLUSION

In conclusion, this chapter explores the context surrounding the CBL and its impact on the CB. The CBL offers a child-friendly testing environment, enhancing engagement and interaction. The CBL visit is currently positively experienced by CB, although it takes up quite some energy.

Participating in research introduces benefits and drawbacks for children. The key benefits for them are helping others and learning new things (about their condition, care and themselves). The perspectives of various stakeholders highlight the complexity of the context. The extended age range, from six to eighteen, acknowledges the evolving needs and aspirations of CBL participants, emphasising the value of peer mentoring and community support.

Ultimately, understanding the desires and needs of CBL participants is essential to designing effective interventions that support their well-being and developmental journey. This chapter has explored the broad context of this project, and the next chapter takes this knowledge and converges it into a more defined design space for the peer-sharing tool.

TAKEAWAYS

Values

- Hospital settings can negatively influence children, CB often experience a diminished sense of control and a growing desire for more independence. The design should give them a new sense of control over their healthcare experience to address this problem.
- CB have a unique understanding of their situation, making them the expert-by-experience, so it is important to recognise this and give them some autonomy in explaining their conditions and decision-making.
- The main benefit of participating for children in research was the opportunity to learn about themselves and help others.

Design opportunities

- Children do not encounter many peers in the hospital; meeting points with peers could be facilitated in this design.
- Freedom of choice makes it more enjoyable for the children to do the tests.
- The need for a safe space without judgement, to find information or ask questions.

Considerations

- The CBL participants are already diagnosed and, therefore, familiar with the hospital and some of the tests they perform at the CBL.
- The long testing times should be considered as a child might feel tired afterwards, leading to the question of when the design would be used.
- Although making the tests playful adds an element of engagement, it does not necessarily give control back to the children. They do not have influence over the sequence of the tests and may still have to do something they find unpleasant or undesirable.
- All adult stakeholders want what is ‘best’ for the children, but the best should not be confused with what the children want themselves.

03

DEFINE

Note. Unsplash (n.d.)

3. Defining the design space for a peer-sharing tool

This chapter defines what peer-sharing could improve in the current context. By examining existing challenges CB face and identifying potential solutions through peer-sharing, this chapter lays the groundwork for developing an effective tool and leading the way to the design vision.

3.1 CHALLENGES OF CB AND THE ROLE OF PEER-SHARING

The initial assumption that children experience stress from not knowing what will happen in the CBL is no longer seen as the main problem, as shown by the findings in section 2.4.1. From the interviews and literature, it was found that the main challenges CB face in their healthcare journey and daily lives range from barriers to accessing information to forming relations with their PWB and participating in social activities. For these challenges, peer-sharing could be a solution. To make the peer-sharing tool enhance the overall CBL experience of the CB, it should help them in overcoming these barriers. This section defines the key challenges identified through research and outlines the corresponding options for a peer-sharing intervention.

3.1.1 INFORMATION CHALLENGES

Providing adequate information to children regarding their medical conditions can help their care. The internet offers much information about brain conditions; however, this abundance can overwhelm patients, specifically children. CB may become demotivated to delve deeper into their research or experience confusion due to difficulty interpreting complex medical information (Yates et al., 2010; NCB, 2021). This demotivation and confusion can reduce willingness to dedicate time and effort to understand their condition. Additionally, it is challenging for CB to decide what information is pertinent to their specific case, even when sharing the same diagnosed condition, given the uniqueness of each condition (RA7 & RA8).

Opportunity
Peer-sharing can bridge information challenges by providing information in a format that is tailored to their age and comprehension level. It can offer simplified explanations, visual aids, and personal stories shared by peers who have experienced similar situations.

3.1.2 BARRIERS TO PARTICIPATION IN DAILY LIFE

Physical barriers
The world is mostly built for people without disabilities, so CBL participants have to live in an environment with many physical barriers that hinder their participation in daily activities (Goering, 2015; Peeters et al., 2014). Examples include stairs, transport and participating in school or sports activities. These physical barriers also affect their social lives, as peers (and PWB) are sometimes out of reach.

Mental barriers
Mental barriers include both cognitive and psychological challenges. (Yates et al., 2010; NCB, 2021)

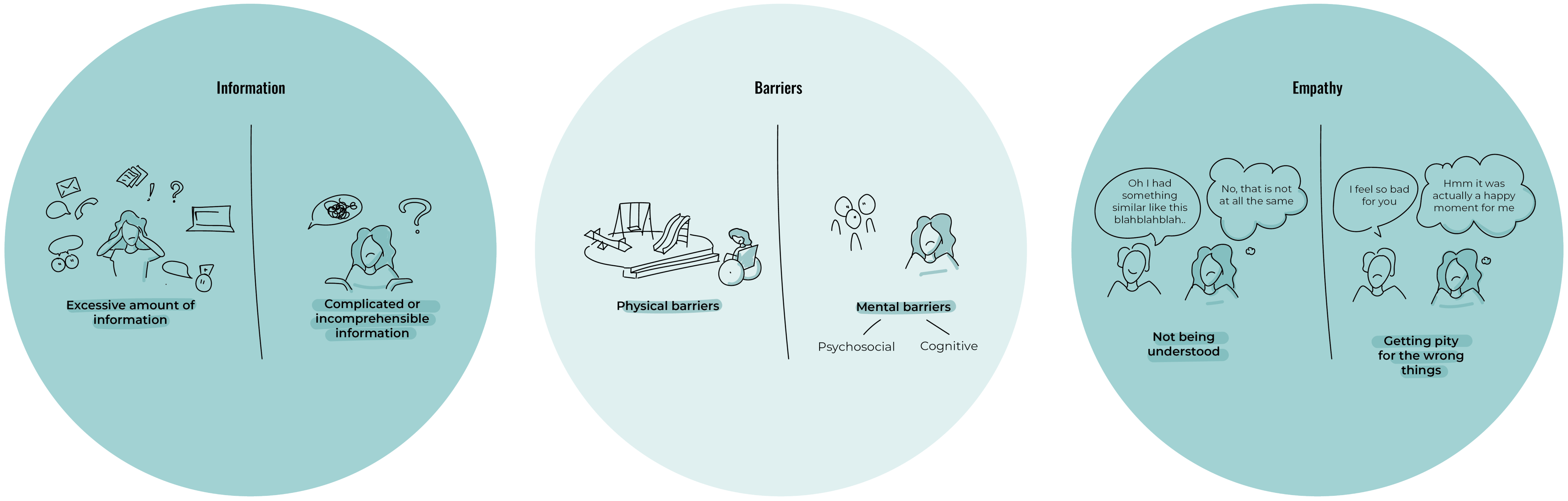


Figure 12 | The challenges of CB

- **Cognitive**
  Some brain conditions can lead to learning difficulties, creating cognitive barriers for children who struggle to keep up with their peers in educational settings. These barriers also affect a child's confidence and increase the feeling of loneliness (Peeters et al., 2014).

- **Psychosocial**
  These barriers can result from health setbacks or social exclusion, which could lead to disruptions in the CB's family, social and educational lives. Feelings of isolation and bullying are common experiences for CB (Yates et al., 2010; Olsson et al., 2005).
  Children also experience many internal barriers that must be overcome or addressed to support them in expressing their experiences (Söderbäck et al., 2011; Shier, 2001). They may find it difficult to express their views due to a lack of self-confidence, shyness, or not seeing the benefit of voicing their perspectives. In addition to internal barriers, past experiences of not being listened to or talked over by adults can lead to a reluctance to speak up. These elements can hinder communication and make it difficult for them to express themselves clearly and assertively. These factors are even more pronounced in CB because, as mentioned above, their abilities are limited, and they are often seen as 'different' by PWB.

Opportunity
Peer-sharing can offer a platform where participants can engage in discussions and share experiences without the limitations posed by physical barriers. Children can build a sense of belonging and empowerment by contributing to the tool's content and interacting with peers. However, this opportunity is only possible when the tool does not also challenge their intellectual or motor skills, creating further obstacles. The psychosocial barriers can only be overcome if the tool builds peer trust. Otherwise, CB would still not feel comfortable interacting or sharing with peers.

3.1.3 EMPATHY ISSUES

Interactions with PWB, family members or other well-meaning people may result in empathy that does not match the CB's experience. Despite sincere efforts to comprehend the challenges faced by CB, a substantial gap in understanding may persist, potentially giving rise to feelings of isolation and disconnection. As Heaven, a young adult living with a chronic illness, articulated, *"I don't think anyone understands, I really don't. Unless you've had [a chronic illness] and you go through it... there's no real word I can think of to describe the pain, and there's no real word to describe the depression or... losing all your friends... it just completely ruins your life"* (Yates et al., 2010, p.44).

Furthermore, well-intentioned advice, while intended to offer support, can sometimes trivialise the experiences and challenges faced by CB. An example of this is illustrated by the statement made by an eighteen-year-old female participant in the study by Van Schelven et al. (2021a, p. 15): *"Sometimes it's nicer for people to say 'I just feel really bad for you'... my mum is always there for me. But she does not understand my situation... So I am really alone. And well, my dog really helps with that, which might be very stupid, but sometimes a dog understands you better than people"*. This quote underscores how even well-meaning parents may struggle to fully empathise with a person navigating the complexities of medical experiences associated with brain conditions.

Opportunity
Peer-sharing can foster a community where genuine empathy is grounded in shared experiences. By connecting with peers who truly understand their challenges, children can receive support based on empathy

without pity, promoting emotional well-being.

This project focuses on information provision and empathy because the design assignment explores the possibilities of using peers as informants and empathy as it is easily achieved through peer support. The mental and physical barriers are essential to note as they influence the design requirements (as physical accessibility and the design should be supportive and motivating enough to convince children with internal barriers to participate in peer-sharing).

3.2 INFORMATION PROVISION

This section looks at how information is currently provided to children in healthcare settings and within the CBL, to elaborate on the previously found challenge of information.

The difficulty of communicating information to children in a way they can understand has become a known and critical problem in medical treatment (Diaconescu & Moisa, 2015). Children's different cognitive abilities and the complicated nature of the medical field require new approaches to ensure effective communication. Patient Information Sheets (PIS) have been developed to address this issue and are aimed at parents and children.

Research by Bray et al. (2019) sheds light on the diverse information needs of children, highlighting their desire for autonomy in constructing their own 'information scripts' to satisfy their curiosity. Traditional information delivery methods, which rely heavily on non-interactive techniques, fail to engage children in the way they need.

The CBL has focused on tailoring communication styles for different age groups. The PIS developed by the CBL uses carefully chosen language and accompanying visuals, with the complexity of information increasing with age. Visuals, such as photographs and realistic 3D images, have proven to be powerful tools for capturing the attention of young readers and helping them understand medical concepts (Grootens-Wiegers et al., 2015). However, these PISs are written by a clinician (with expertise in paediatric care), so an adult assumes what children want to know and read.

One suggestion that has emerged from the research is the inclusion of children's perspectives in producing information materials. By involving children in the design process, it becomes possible to bridge the communication gap and present information that resonates with their unique experiences. This approach has shown promise in increasing children's comfort and understanding, as evidenced by positive feedback from participants who found booklets featuring other children who had participated helpful (Grootens-Wiegers et al., 2015).

3.3 MODELS AND FRAMEWORKS

The design process incorporates the framework of subjective well-being in CB, intertwined with the principles of self-determination theory proposed by Ryan and Deci in 1985, to ensure a positive impact on the final design. This theory posits that people have three basic psychological needs: autonomy, competence, and relatedness. Autonomy involves having choices and initiative, competence relates to mastery and efficacy in one's actions, and relatedness pertains to feelings of closeness to others. Satisfying these needs contributes independently to positive effects on well-being (Véronneau et al., 2015). These components align with the following key themes found for influencing the subjective well-being of children with a chronic condition, also shown in Figure 13 (Foley et al., 2012; Yates et al., 2010; Ravens-Sieberer, 2014);

1. **Feeling of value**
   Children, including those with brain conditions, want to feel valued through recognition of their contributions and accomplishments in daily life. To find this value, a sense of competence is essential, meaning the feeling of accomplishment and capability. It could be achieved by helping others through sharing their knowledge, but also learning new things from their peers enhances their feelings of self-efficacy improving their perceived quality of life.

2. **Positive social relationships**
   CB's emotional well-being depends on supportive friendships and a sense of belonging, which is consistent with relatedness within self-determination theory. This togetherness could be supported by facilitating community among CBL participants.

3. **Opportunities for reflection**
   A quiet space for emotional regulation and reflection is also valuable for CB. They can quickly be overwhelmed as their brains sometimes find it difficult to process a lot of stimuli. A space for reflection allows them the processing time they need to think independently, which contributes to their overall well-being.

4. **Participation**
   This fourth theme relates to the physical and mental barriers to participation mentioned in the previous section. For CB, being able to participate in activities that bring them joy and fulfilment, despite their specific health conditions, contributes greatly to their well-being. Participating in desired activities gives them a sense of autonomy and addresses the lack of control that is often associated with their conditions. They are often excluded from participation because of their condition. So, in addition to participating in daily activities they want to do, such as exercising or playing outside when they want to, the theme of participation also extends to decision-making in healthcare settings.

In conclusion, aligning with the desires and needs of CB enables the creation of a peer-sharing tool that empowers them. By creating an environment where they can connect with peers (relatedness), feel in control (autonomy), develop skills, acquire knowledge about their conditions, and support one another (competence). The project will build upon these insights in the design process.

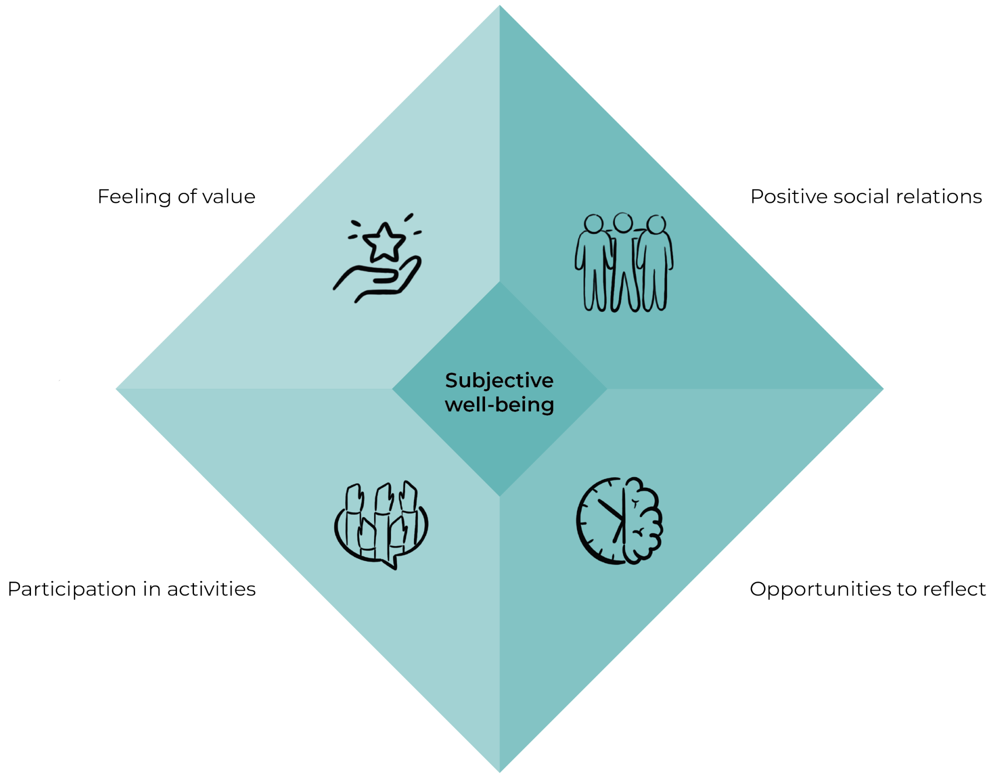


Figure 13 | The key themes of well-being from the perspectives of children

3.4 ADDITIONAL RESEARCH FINDINGS SHAPING THE DESIGN VISION

3.4.1 WHAT SHOULD THE TOOL ENTAIL?

Integration with Self-Portrait
All CBL clinicians in the input session saw the peer-sharing tool as a future part of the Self-Portrait app. With the CBL visits leaving little or no space for real-life interactions, it was decided to make the peer-sharing tool a digital tool.

Design guideline 1

The design should be able to be integrated into the Self-Portrait app.

Value of sharing
An 8-year-old CWB noted that sharing her feelings and emotions gave her a sense of relief. Her 14-year-old sibling said they often kept their feelings to themselves, viewing this tendency as undesirable, and would recommend that all children share and communicate about such situations.
These observations collectively imply a benefit in sharing emotional content, as it relieves.

Value of the children's perspective
Both the CB and the CWB were excited to be involved in the research activities of this project. Their excitement shows they enjoy being involved and are willing to help when asked. The children also named numerous ideas for the CBL during the sessions (RA3), demonstrating their desire to help improve the CBL and providing valuable feedback. During this project, the CBL had already made changes based on the trial runs mentioned by some of the children (such as the name of the rooms on the door because the windows were too high for the children to look in). The responses demonstrated the importance of gathering children's perspectives and involving them in reflective processes about how child-centred the CBL was in their eyes.

Design guideline 2

The design should allow the CBL participants to share their perspectives and engage them in CBL.

Age differences
The creative sessions revealed differences in the children's understanding and expression of emotions and feelings influenced by their age. Some children demonstrated a deeper understanding and ability to discuss emotions, while others struggled to recall emotional events. Attitudes towards emotions also varied, with one child (boy, 10 years old) mentioning that he did not see any benefit in talking about emotional events when people were not around. So, depending on their age and emotional understanding, children's attitudes and abilities to share experiences and emotions will vary.

Design guideline 3

The design should provide the means for CBL participants of different ages to express themselves in a manner that suits their capacities and understanding.

Going together
When asked how CBL participants could help each other, several CWB suggested that attending CBL with their peers would reduce anxiety and create a more enjoyable experience. Also, two CWB mentioned they saw the three avatars used in the tests of the CBL (Neuro, Wavy and Brainy) as a 'maatje' (buddy), suggesting some sort of companionship would improve the experience.

Design guideline 4

The design should create a sense of support and companionship.

Child in control
Several CBL clinicians gave examples of informing participants that they can ask questions and have a say in what they are doing, for example, asking for a break, 'Why is the test done?' and 'What is next?'.

Design guideline 5

The design should empower the CBL participants and let them feel in control.

Learning opportunities
CBL clinicians mentioned as a benefit that children can learn about themselves and at the same time help the CBL learn about them. The responses to the survey of the CBL done after the trial runs (filled in by CWB)(RA1) also mentioned some points about learning new things about themselves, which was perceived as positive. These insights show how mutual learning can enrich the value for the participants and the CBL.

Design guideline 6

The design should enable the CBL participants to see what they learn about themselves and what CBL learns from them.

3.4.2 WHAT SHOULD THE CONTENT COVER?

Giving tips and advice
Children recognised the value of offering tips and advice to their peers, emphasising the importance of actively listening to instructions for optimal participation in the CBL tests. "Listen carefully to something; things are quite difficult if you have not listened properly".

Experiences and feelings
The children were positive about their experience of CBL, describing it as 'social' and fun. They emphasised the importance of creating an environment where sharing emotions and feelings is encouraged and comfortable.

Design guideline 7

The design should enable the CBL participants to share what they find meaningful and exciting for others.

Ensuring preparedness
Hospitals are widely perceived as intimidating or scary despite efforts to create a child-friendly environment. Recognising and addressing these fears can help reduce anxiety and promote a positive experience.
Providing information about potential challenges and negative experiences while maintaining a balanced perspective can

help participants cope more effectively with unexpected situations.
Children acknowledged that CBL visits could be lengthy and busy, describing them with quotes such as: "It takes a long time" and "It is full of tasks" (RA1), highlighting the need for adequate preparation to manage expectations and reduce potential anxiety.

Introducing the CBL team
The CBL clinicians mentioned that it could be beneficial to introduce the CBL team so that the children foster a sense of familiarity, leading to a development of trust and comfort within the lab environment.
Several CB were also curious to at least know the names of the clinicians they would meet (RA4 & RA5).

Design guideline 8

The design should prepare the children and manage their expectations before they go to the lab.

3.5 EXISTING INTERVENTIONS

This section analyses existing support tools for providing information, voicing perspectives and peer support. Only tools within the healthcare system are considered, but not only tools for the specific target group. It also includes tools for other chronic conditions and, for example, peer support tools for parents. An overview is provided in Appendix G.

Three tools, in particular, provide valuable insights and ideas for the design of a peer-sharing tool within CBL; Cyberpoli, Bodymap tool and Hospital Hero (see Figure 14). Building on their strengths and addressing their limitations, the proposed design aims to achieve the following improvements:

Inviting & supportive
As shown in the Body map tool, simply asking a question is not enough to invite a child to share (even in a consultation setting where the purpose is to find out how the child is doing).

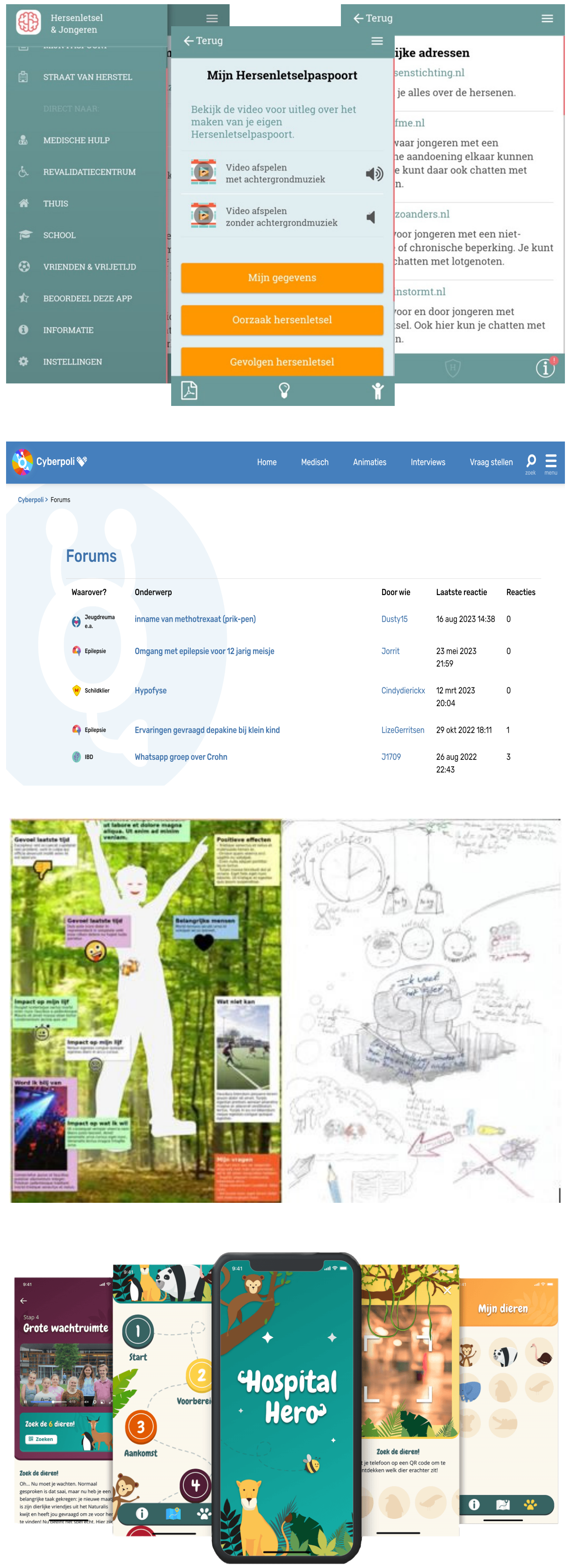
Balance guidance and exploration
Users can freely explore while receiving guidance to ensure a meaningful and engaging experience.

Guided use
The purpose of the tool is clearly defined to avoid overwhelming the user. In the other tools, children often could not find their specific interaction when they needed it (empty chat rooms or overloaded platforms). Using a format like the Hospital Heroes app shows when to use what.

Working with children
Evaluation and feedback from the children will be the design's main part. The tool should address and support individual needs, as these often change. The design should be flexible so that interaction with the child can be used to adapt it.

In addition to addressing their feedback, the design should support them in more technical features such as speech-to-text functionality, accommodating different reading levels and providing text descriptions for images to support their needs.

By incorporating these improvements, the proposed design aims to stimulate curiosity and empower children to feel in control of their CBL journey. This empowerment could lead to a sense of worth and self-efficacy by increasing the perception of the participant's abilities.



Bekijk de video voor uitleg over het maken van je eigen Hersenletselpaspoort.

Waarover?	Onderwerp	Door wie	Laatste reactie	Reacties
Jeugdreuma e.a.	inname van methotrexaat (prik-pen)	Dusty15	16 aug 2023 14:38	0
Epilepsie	Omgang met epilepsie voor 12 jarig meisje	Jorrit	23 mei 2023 21:59	0
Schildklier	Hypofyse	Cindydierickx	12 mrt 2023 20:04	0
Epilepsie	Ervaringen gevraagd depakine bij klein kind	LizeGerritsen	29 okt 2022 18:11	1
IBD	Whatsapp groep over Crohn	J1709	26 aug 2022 22:43	3

Figure 14 | Existing tools (top to bottom; Breinstaat (Appadvice, n.d.), Cyberpoli (Cyberpoli, n.d.), Bodymaptool (van Schelven et al., 2021a), Hospital Hero (Hospital Hero (n.d.)))

CONCLUSION

This chapter defines the design space for a peer-sharing tool that addresses the challenges faced by CB. It shifts the focus from stress to understanding their internal motivations and barriers, focusing on access to information through peer-sharing. The goal of positive impact can be achieved by addressing the factors that influence the emotional well-being of the CB from their perspectives. These factors are linked to the three values of the self-determination theory, which are now considered the core design pillars to use in the design process.

The findings from the research activities and the evidence from existing interventions identified the key design guidelines on which to focus. This approach has the potential to have a positive impact and empower CB within the CBL.

TAKEAWAYS

- Peers have a unique perspective and knowledge because they have been through similar experiences. Their insights from living through the same situations give them the empathy and expertise to know what CB want to know and where they need support.
- A visual way of sharing information is a preferred tool for children. However, the visual style should be carefully chosen, as it should not be too abstract or childish for older participants.
- The CBL participants should be supported in expressing their views to enhance the comprehensiveness of their perspectives. Otherwise, internal barriers may hinder them.
- Supporting the CBL participants is essential because internal barriers (e.g. lack of self-confidence) might hinder them from sharing their experiences. The support offered should include emotional and facilitative support. Emotional support is crucial as it boosts their self-assurance, while facilitative support enables them to express themselves more fully.
- The CBL participants should be able to be actively involved in the CBL journey to shape the information according to their needs.

04

ENVISION

Note. Unsplash (n.d.)

4. Design vision

This chapter draws together all the insights from the previous chapters into a conclusion to the convergence phase: the design vision. It describes the two focus groups of this design, what they need and the design goal. Also, the intended use of the application and the reasoning behind the decision to create an app is explained. Additionally, it presents the interaction vision, which represents the key interaction qualities and how the design should feel to the user, using a metaphor or analogy.

4.1 TWO FOCUS GROUPS

Given the varying attitudes of children towards peer support, given in section 2.5.3, they are combined into two distinct focus groups within the CBL: the expert-by-experience and the novice participants (see Figure 15). The design should facilitate a platform where the expert participants inform the novices and create a supportive environment where the novice feels confident to become the expert.

NOVICE PARTICIPANTS

Novice participants refer to children visiting the CBL for the first time or having limited experience with the lab. They do not know what to expect during their CBL visit. Novice participants often seek guidance and information to help them navigate their initial experiences.

Characteristics

- **First-time visitors**
  Novice participants typically visit the CBL for the first time and may feel uncertain about the process.
- **Limited prior knowledge**
  They may have limited prior knowledge about the CBL, its activities, or what to expect during their visit.
- **Desire for information**
  Novice participants are often eager to gather information and seek guidance to make their CBL experience more comfortable and enjoyable.
- **Possible anxiety**
  Due to their limited familiarity, novice participants may experience anxiety or apprehension about the unknown.
- **Benefit from guidance**
  They benefit from clear and accessible information that aids in preparing them for their CBL experience, helping to elevate their awareness and empower them to participate more actively in their healthcare journey.

EXPERT-BY-EXPERIENCE PARTICIPANTS

Expert-by-experience participants are children who have visited the CBL multiple times and have gained a deep understanding of the lab's activities and procedures. These participants are more experienced and knowledgeable about their medical condition and the CBL. If they can share their expertise, this can increase their self-confidence. They are often older than the novice participants, but this is not exclusively the case as a participant can also be recruited later in age to join the CBL and still feel like a novice participant.

Characteristics

- **Multiple visits**
  Expert-by-experience participants have been to the CBL multiple times and are familiar with the lab's routines and activities.
- **Expertise**
  They have a deeper understanding of their medical condition and how it relates to the CBL's research and tests.
- **Desire to help others**
  Expert participants often want to use their experience and expertise to assist novice and less experienced participants.
- **Independence**
  While they may seek information, expert participants value their independence and may prefer to access information autonomously.
- **Community**
  They value contributing to a sense of community among CBL participants by sharing their insights and experiences and fostering a supportive environment where their insights are valued and their experiences are acknowledged.

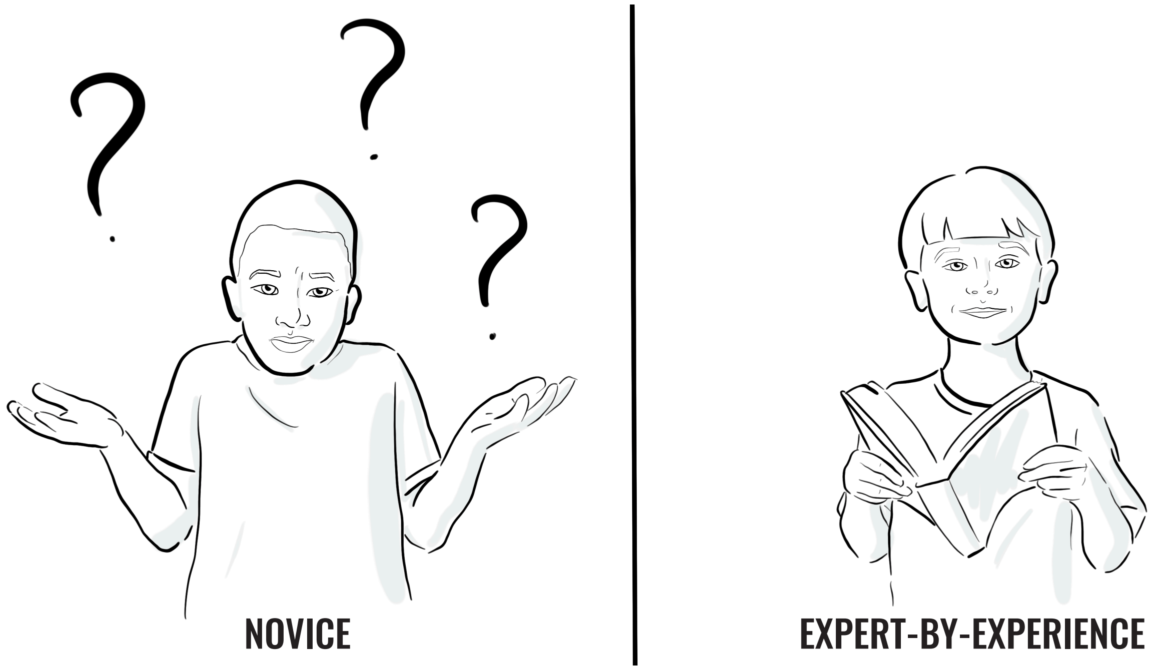


Figure 15 | Two focus groups

4.2 DESIGN GOAL

The design goal is to **empower** participants of the CBL to **recognise their expertise** and **support them to express** their experiences through **peer-sharing**.

This goal envisions the design as a dynamic space where participants actively share their insights, experiences and perspectives.

Two scenarios are predicted: the ideal scenario and the passive scenario. The perfect situation, shown in Figure 16, illustrates a triple interaction where participants learn from each other and from the CBL, which requires active engagement, meaning sharing their perspectives with the other participants. In the second scenario, the CBL participant is more passive; they simply receive information without engaging in sharing their experiences (see Figure 17). While the design should respect individual preferences, the ultimate success lies in realising the potential of active engagement. Without participants sharing, there is nothing to see on the platform.

Autonomy
Empowerment allows participants to feel control over what they want to do and when. The app should enable them to see why the CBL is important for them. Support should help them overcome barriers to success while maintaining their independence.

Competence
Being recognised for their expertise can boost their self-confidence and the feeling they are valued and contribute to the CBL and their peers.

Relatedness
Including the participants' peers promotes a sense of community and creates an environment where they can recognise themselves in others and see they are not alone.

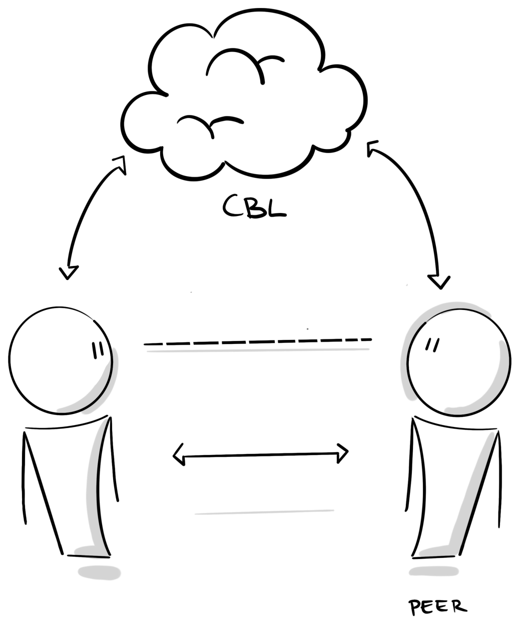


Figure 16 | The optimal scenario

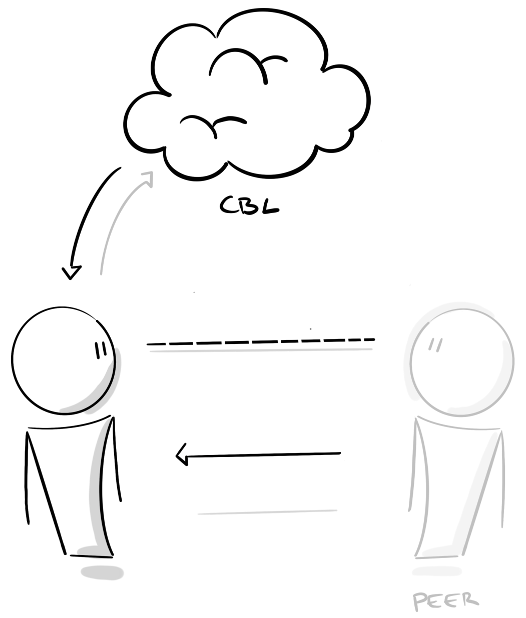


Figure 17 | The second also desirable scenario

4.3 ENVISIONED USE OF THE DESIGN

For the design process, three areas discover, connect and express, divide the design space, facilitating idea generation within the confines of this space (refer to Figure 18). Each area centres on a value of the self-determination theory: autonomy, competence, or relatedness, and corresponds to a component of the design goal while also integrating previously identified design values. These three areas are the primary focus of the design, with any additional possibilities deemed beyond the project scope.

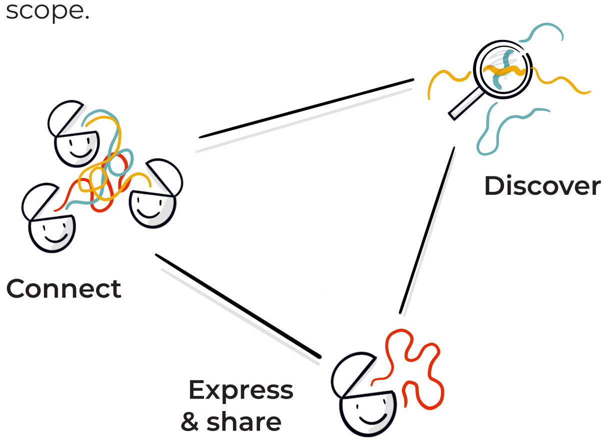


Figure 18 | Three areas for designing; discover, express & share and connect

Discover stories of peers (autonomy and relatedness)

- The design should enable the participants to explore and spark curiosity about the CBL.
- The design should enable the participants to find and understand the information they need and find important autonomously (independent from external help, e.g. parents) on 'what will happen during the visit' and 'why it is necessary for them'.

Connect to peers (relatedness)

- The design should create a sense of community among participants, encouraging them to connect and engage with their peers meaningfully. This sense of belonging should be built on shared experiences, mutual support, and the opportunity for participants to learn from one another.
- The design should provide possibilities for direct interaction, meaning they could react and connect when desired.

Share and express their own stories with their peers (competence and autonomy)

- The design should create an environment that encourages participants' confidence, making them feel comfortable sharing their perspectives and experiences of their CBL visit and encouraging even hesitant participants to participate.
- The design should enhance the understanding of participants' expressions by others within the community, providing tools or features that help to facilitate deeper insights for more meaningful sharing.

The sessions with CB gave some indication of how the design would be used, using the previously defined design areas. Figure 19 illustrates how all these areas would be used. It shows the possible questions the design could address and when these questions would arise during the CBL journey. The discover line peaks before a new phase of the CBL journey starts, indicating that participants want to know what will happen. The express & share line is after they have completed a part of the journey. Then, they know how they experienced it and may want to share it. The connecting line increases initially and stays the same as participants may want to interact with their peers at any time and see what they think.

Figure 20 shows the anticipated use of the tool across all five visits. It depicts a decrease in discover as familiarity with the CBL grows and an increase in engagement with the connecting and sharing part. As the CB said, once they know what will happen during the CBL visit, they will no longer desire this information, so the discover line decreases, but they may still be interested in sharing their stories to help others (RA7 & RA8).

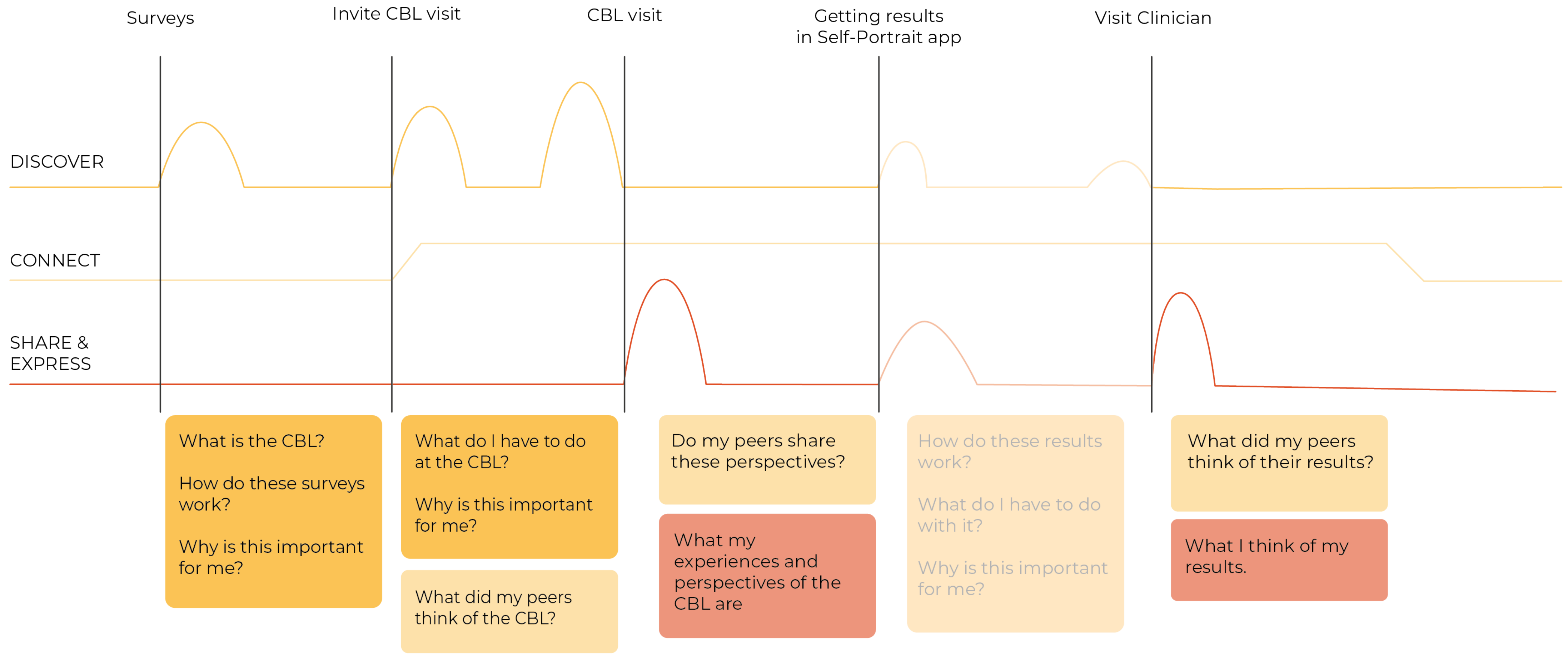


Figure 19 | Assumption of use described for one visit in detail for one visit

Figure 20 | Assumption of use described for all five visits

4.4 INTERACTION VISION

When CBL participants use the app, they should feel as if they are entering the common area of a backpackers' hostel. This metaphor captures the five qualities of interaction that the user should feel;

Part of a community
The design should evoke a sense of belonging and connection, just as a solo traveller finds similarities with all other solo travellers while being unique.

Invited
As backpackers welcome others to join them, the platform should encourage participation by making participants feel included and valued.

The freedom to choose
Solo travellers select their adventures on their own, aligning with the participants' autonomy to tailor their engagement.

Supported
Just as backpackers share advice and stories, participants should be able to share their experiences and insights and learn from each other.

Independent
Like solo travellers navigating their way, participants should be able to find information independently.

The interaction vision embraces the idea of participants engaging with peers, experts and information at their own pace and comfort level. In Figure 21, the interaction vision is shown, and the main focus is on peer-sharing (yellow-green box), but it also includes self-reflection and exploring information on your own (grey boxes).

4.5 WHY AN APP?

In the previous chapters, the option of a digital tool, or more specifically, an app, was briefly highlighted. The main reason for this choice was the integration with the Self-Portrait app, which is already in development and feasible. It would be convenient to integrate this design as an additional functionality of the digital patient record. In the input received from the CBL clinicians, they all also highlighted numerous possibilities for integration with the Self-Portrait app (RA6). This integration or combination of both projects into one app was also mentioned several times in meetings during this project. Together with the benefits discussed below, the final design was chosen to be an app.

REASONING FOR CB

Empowering Independence (autonomy and competence)
CB often have a strong desire for independence. They want to feel in control of their healthcare journey. Creating an app that provides them with accessible tools and information empowers them to take ownership of their preparation, enabling them to do this independently from external support.

The extent of this empowerment relies on the availability of digital tools within the child's home environment and the guidelines set by their parents. For instance, during the research activities (RA3), some parents said that their children could use the computer or tablet when the interview was over. Having access to a smartphone also varies by child, meaning that, particularly for younger children, their sense of autonomy is influenced by the rules established by their parents. To enhance accessibility, it might be worth considering the possibility of featuring the app in the waiting room of the CBL.

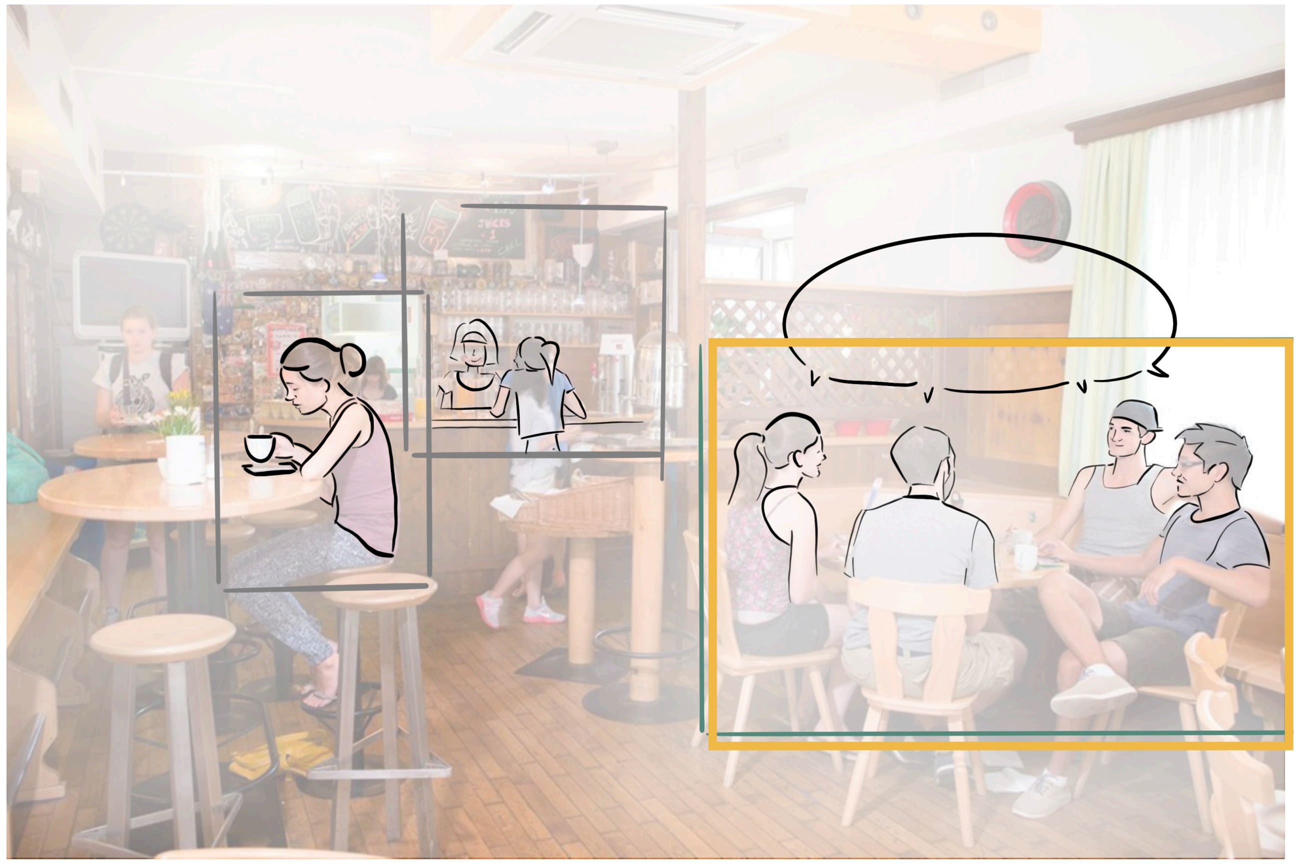


Figure 21 | Interaction Vision

Fostering a sense of normality
Feeling 'normal' is a fundamental need for CB, as mentioned in Chapter 2. An app can help bridge the gap between their medical condition and a sense of normality. It allows them to access information discreetly, blending the preparation for the visit and finding support into their daily lives. Unlike physical tools, an app is available everywhere. This level of accessibility ensures that vital information and support are available when they want and need it most.

Building connections and community (relatedness)
CB often suffer from feelings of isolation, so they have a high desire for relatedness, such as feeling they belong. A supportive community is built by creating an app that connects children with similar experiences. No one should feel alone on their healthcare journey. With an app, they have a buddy to go with, providing companionship and emotional support. An app offers direct interaction, the real-time interaction the lab often does not have and can be filled with interactions online to feel less alone.

Personalisation and flexibility
Apps offer a lot of personalisation and adaptability. Every child is unique and has different needs. An app can adeptly accommodate these requirements. This adaptability and personalisation often make physical tools more complex, while in an app, it stays one tool with different features implementable. For instance, consider a scenario where a physical tool, such as a printed booklet, provides information to children with varying needs. In this case, producing multiple versions of the booklet to cater to different preferences and requirements can take time and effort.

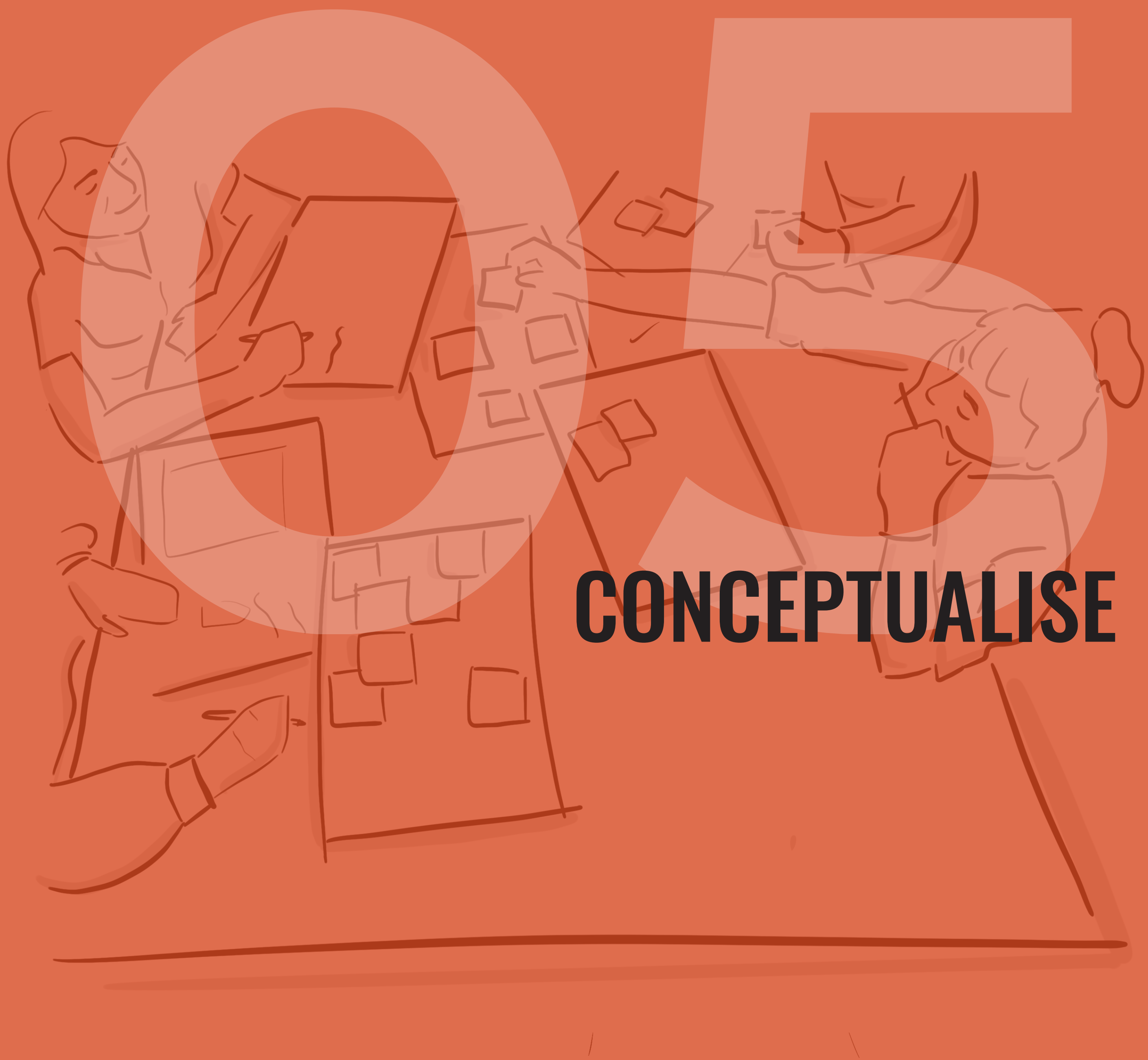
Conversely, content can be dynamically tailored to each user's preferences within an app. For example, users can adjust text sizes, language preferences, and accessibility features directly within the app, ensuring they receive content in a format that suits their unique needs. This streamlined personalisation enhances the user experience while reducing the complexity of managing multiple physical versions of a tool.

Making learning fun
An app offers opportunities for gamification and interactive learning, making the process engaging and enjoyable, for example, by integrating multimedia tools such as videos, animations and playful ways to interact with the information. Children are increasingly drawn to various digital products and applications in the digital age. This digital age is making them familiar with various digital tools, which makes them exceptionally good at comprehending and adjusting to an app compared to adults who did not grow up with digital devices (Prensky, 2001). Therefore, integrating the Self-Portrait with an app aligns with the technological preferences of modern-day children. This alignment can potentially enhance engagement levels and enthusiasm for the app.

REASONING FOR CBL

Flexibility
The content of the app can be easily adapted to provide information to new participants. And if participants are linked to a unique code, the CBL can even personalise or add information as required.

Cost-effective
When integrated into the Self-Portrait application, the additional cost is minimal as it becomes an integral part of the existing system, with only the cost of incorporating additional technical features.



05

CONCEPTUALISE

5. Concept generation

This chapter explains the design process that led to the final design. Showing how the creative process of generating and refining ideas to create an engaging and meaningful experience for the CB has been performed. The conceptualisation consists of ideation, concept development and further concept detailing. Different ideas are explored, each addressing different design values. The strong features of the ideas are combined into a concept, which is further detailed with the main aim of enabling peer-sharing and empowering participants. In addition, privacy, moderation and practical implementation considerations are discussed to balance user engagement and security.

5.1 IDEATION

During the research phase, ideation was carried out to explore the possibilities for creating a peer support tool. The primary focus was to determine what form of support the design should focus on; knowledge sharing or emotional support. It is important to note that these initial five ideas, described in Appendix J, were primarily used for exploratory purposes, to identify the directions that would best align with the needs of the participants.

From this ideation, the following key characteristics were extracted from each idea:

- **'Support Pets':** The concept of having a companion accompany the participant to the lab, for support and fun during the visit.
- **'Babble Bal':** Facilitating easy and playful reflection on one's experiences.
- **'Brain Cafe':** A digital environment gives many options insharing and doing other activities together with peers.
- **'Brain Helpers':** Stimulating CB's curiosity by connecting with the lab through clues.
- **'Friendwall':** Promote a sense of community among participants.

Combining the above characteristics with the design vision, a second ideation was carried out (for clarification, these ideas were chronologically developed before the interaction vision was created, so the interaction vision is not reflected in these ideas). This ideation led to the following three ideas. The first idea was based on the input session with CBL clinicians, where social media platforms such as TikTok and vlogs were mentioned, which eventually evolved into the idea of 'Brain Chatter', a dedicated space where participants could introduce themselves, share information about their upcoming CBL experiences, engage in chat discussions, view photos and videos of others, or contribute their own content. Additionally, Brain Chatter features entertaining challenges and polls for active participation.

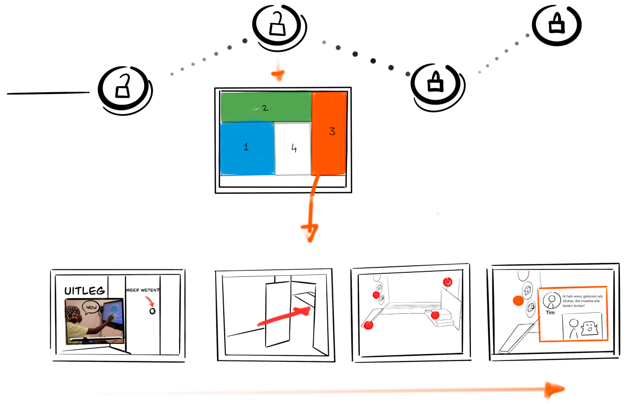
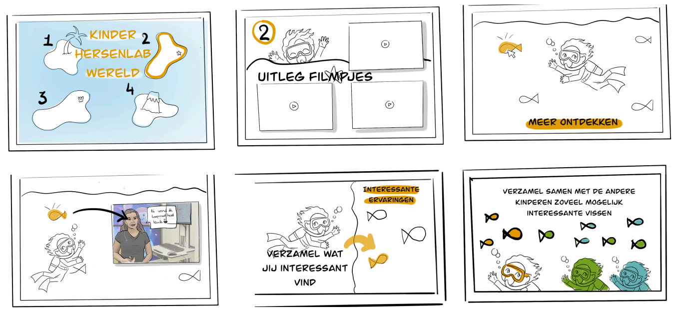
The second idea focused on the insight that the tool should be coherent with the journey children undergo when visiting the lab, resulting in the creation of the "Children Brain Lab Trail". Within this virtual environment, the app unlocks content corresponding to the specific phase of the lab visit. Initially, it provides information about the level 1 surveys, and as an upcoming lab visit is approaching, the app unlocks access to different rooms within the lab where users can explore and discover. Users can click on items in these rooms to see how their peers have perceived these tests.

Lastly, the idea of "Brain Search" was created to see how the design could be engaging and fun. The app was made into a discovery game within a virtual deep-sea environment. Users go on a quest to search for information that is located on different islands. During exploration they can find an 'interesting' fish, which provides an experience of a peer, they can save it in their virtual "net" and collaborate with their peers to achieve common goals (e.g. collect ten fish) by sharing their perspectives.

These three ideas are evaluated by the PMI method from the Delft Design Guide (van Boeijen et al., 2020), where intuitively, the ideas' pluses (P), minuses (M), and interesting (I) aspects are named, see Table 2.

To summarise the freedom of use and overview of 'Brain Chatter', the guidance that the 'Child Brain Lab Trail' offers and the collecting stories from the 'Brain Search' idea have been combined into a new concept.

Table 2 | Evaluation three ideas for peer-sharing apps

	Brain Chatter	Child Brain Lab Trail	Brain Search
			
P	+ It provides a platform for children to share their personal experiences with CBL, such as the tests they enjoyed or interesting facts they learned. Together with different multimedia means to enhance the story. + Allows the CBL to ask for direct feedback via polls and stays engaging when the platform is often updated with new experiences and polls. + It fosters community and connection among participants, as they can discuss their upcoming CBL experiences and share their excitement.	+ It offers a captivating virtual tour that mimics the layout and atmosphere of the actual CBL, building anticipation and excitement for the real visit. + It has a good overview, as all the peer stories are connected to the objects in the room.	+ Engages children in an exciting quest-like adventure, making learning about the CBL enjoyable and adventurous. + Promotes collaboration and teamwork as participants work together to achieve common goals, such as collecting virtual "fish."
M	– It has limited space for expressing perspectives due to large images with only small captions. – It is quite an overwhelming platform where it is not easy to navigate what a user wants to find out.	– After the first visit to the CBL, the different levels can be constraining and frustrating. – The virtual tour may provide less engagement than other interactive methods, potentially decreasing interest. – Lack of collaborative elements within the tour may miss the opportunity to encourage connectedness among participants.	– After the first visit the game is probably not engaging anymore as the participants know what is going to happen, with the collecting the fish making it an even higher treshold to explore. – The game could be complex for younger children and too easy for older children. – As the format is more playful and chaotic compared to the other ideas, it is quite hard to self-explore the information.
I	! Social media platforms are already trendy and familiar to children	! Opening a new level each time sparks curiosity	! A challenge or collaborative goal to reach gives meaning to the use of the app and enhances the sense of community.

5.2 CONCEPT

5.2.1 INSPIRATION

The final concept draws inspiration from a combination of elements found in the previous three ideas, as well as insights gained from "The Scrapbook" concept developed by MCW, a creative agency responsible for the Self-portrait app.

Scrapbook concept
The MCW "Scrapbook" concept served as a source of inspiration, focusing on creating a digital collection of memories and experiences. This concept strongly aligned with the goals of engaging children with the CBL and making their experiences interactive and memorable.

Guestbook
The idea of a guestbook led to the incorporation of a feedback mechanism in the final concept (taken from the interaction vision). It emphasises the importance of allowing children the freedom to express their thoughts through writing or drawing to personalise their CBL experience.

Time capsule
Inspiration from the time capsule concept led to considerations that a CBL visit is quite special and children could revisit it. This concept influenced the exploration of using memoirs as a means for children to look back on their childhood moments, with the CBL serving as a repository.

Vriendenboekje (English: friend-booklet)
Taking inspiration from the tradition of "vriendenboekjes" (English: friend-booklets) in Dutch elementary schools, the final concept aims to provide children with a similar opportunity to collect and reflect on their CBL experiences. Much like these books, the concept guides users in expressing and allows for customisation of their input. Also, it collects all friends in one place, just like the "Brain Quest" idea of collecting the stories ("fish").

Emotion diary
Children can have difficulty expressing themselves, so reflection booklets on emotions were created to assist them. The aids provided in these booklets allow children to express themselves quickly and simply. These aids are also used in the final concept to support the CB.

Figure 22 | Inspiration sources

5.2.2 THE CONCEPT AND EVALUATION

This section presents the final concept and the evaluation with two CBL clinicians and three CBs, Merel, Isabella, Nando and Nando's parent (see Appendix I). In the session with Nando and Isabella, only a storyboard of the model on which this concept was based was shown. However, this model was very close to the concept sketches and conveyed the idea clearly through storytelling. Figures 23A-H show the concept idea sketches alongside an explanation of the app feature and the iterations recommended based on the feedback from the evaluation sessions.

'What is going to happen?' shows instruction videos of the CBL (e.g. surveys, 3D scan, all testing rooms and test results plus the consultation of test results). In these videos, the children explain why these things are all necessary and why this is helpful for them (Figure 23B).

Give a general overview and some details, but do not give everything away, as this could lead to participants preparing for the tests and they are not interested in all the details (RA7 & RA8).

'I have a question' lets the participant ask questions easily before and after the visit. It also presents the most asked questions on the side to make navigating easy (Figure 23C).

Let children answer instead of doctors, as doctors often lack time. The children in the app can easily answer the questions asked (within their knowledge) at the same communication level as the question asker (RA8).

'Who is also going?' is where the participants are connected when willing to interact to show who is also going within a time frame of (week to month). Here, both participants who already went and those who still have not had their visit. In this way, they are directly connected from novice to expert by experience (Figure 23D).

Keep the chat room private between the children; otherwise, it is a higher threshold to talk (RA8).
How do we keep this positive and not a spiral of anxiety due to multiple anxious participants (RA8 & RA9)?

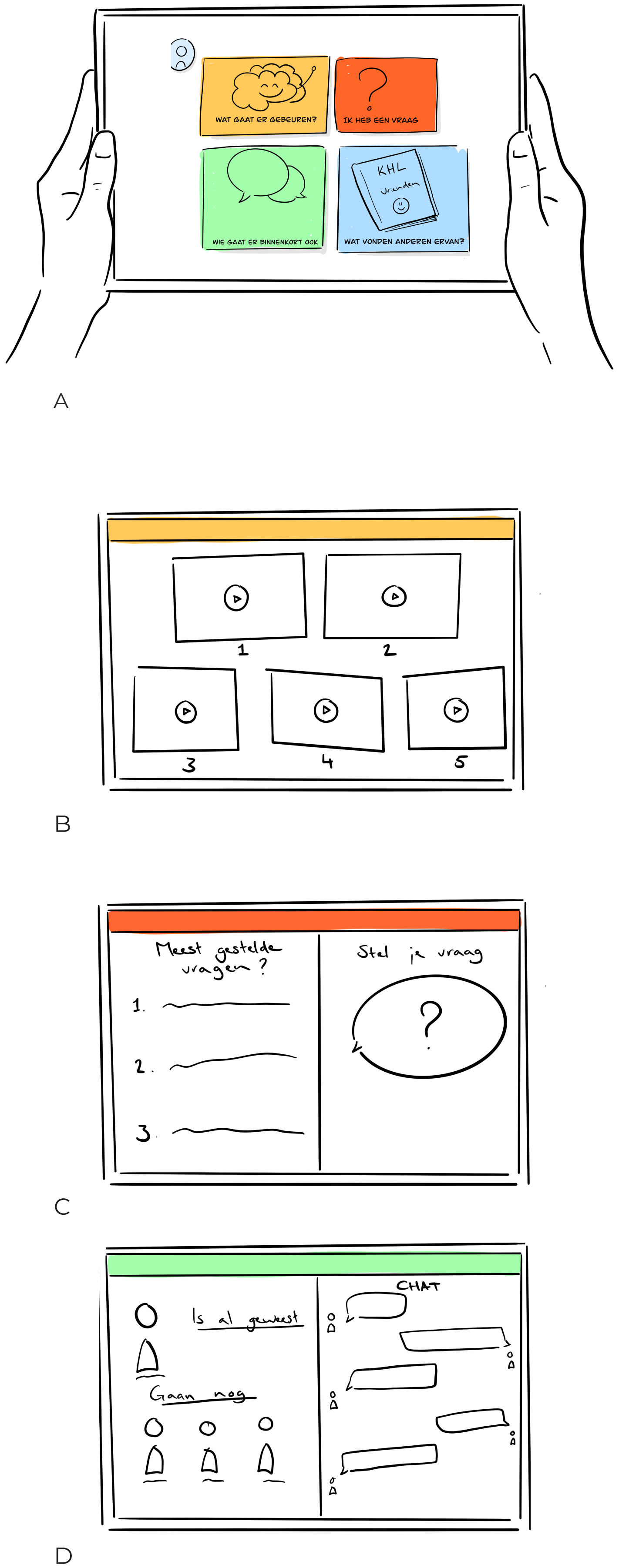


Figure 23 | Overview of concept (A-H)

The diary function is intended as a time for self-reflection. Participants take a photo in the lab, which is uploaded to the app. The notification with the photo is seen as a nudge: 'Hey, remember to fill in your experience'. They can choose whether they want a format with guiding questions or total freedom by recording a video. Both formats are also offered as some children with speech impairments may have difficulty recording videos and may be much more shy than others. Both situations should be catered for (Figure 23 E-F).

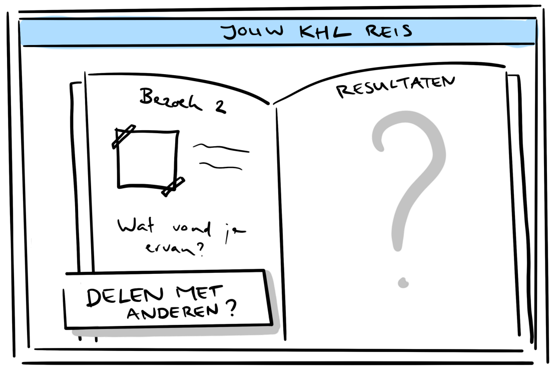
Also, ensure parental consent is obtained before sharing (RA9).
In the formatted version, adding some tools (e.g. emoticons) to make it easier and lower the threshold for the CB to share. Also for children who need guidance in expressing their stories (e.g. younger participants) (RA8).

With the stickers, the participants can give votes to others on their experiences to show if they were 'helpful', 'relatable' or 'funny'. In this way, they get feedback if these were valuable to others (Figure 23G).

Keep the voting anonymous or only visible to CBL clinicians. The voting option is a nice filter for both the CBL and the participant. However, children should not be able to see how many or where others voted on, because this could make them feel bad, if they did not get any votes. They should only be able to see where they voted on. CBL can then see an overview of what is voted on and give this back to the participants in a non-judgemental way, for example, in a monthly digest, 'Multiple participants mentioned this ....' (RA6-RA8)

The 'What did others think?' feature operates as a type of 'vriendenboekje' (i.e. friend booklet). It entails all the descriptions of participants' experiences they chose to share from their diaries (as seen below in Figure 23H).

Provide supportive tools for participants to share their experiences while considering privacy and preference. How can we present these perspectives to readers and balance negative and positive experiences to ensure children have a realistic understanding (RA8)? Moderation is necessary to prevent frustrated children or parents from venting (RA9).



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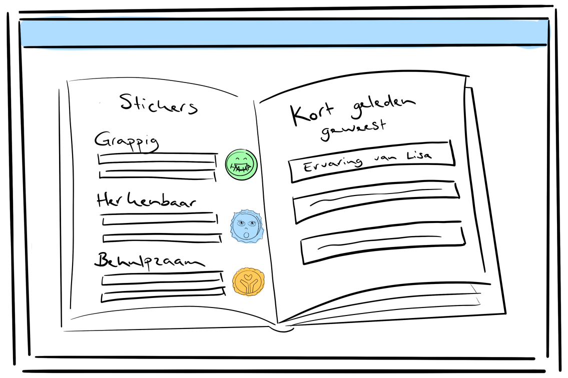
F



G

H

In conclusion, the CBL finds this concept feasible, but an implementation plan was needed to show them how this application could be developed.

Several parts are privacy-sensitive and should be moderated by CBL to limit misinformation and to ensure participants do not frighten each other.

Moreover, the details should cater to younger children without bothering older children or causing them to disengage due to childishness.

By redefining the design vision discussed in the previous chapter, the focus should be on sharing and how participants express and view experiences. Creating a coherent, guided journey throughout the application is recommended instead of having the four separate and loosely connected functions; 'What is going to happen', 'I have a question' 'Friendbook', and 'Diary'.

Using familiar templates such as scrapbooks and mindmaps will aid in making participants feel competent with the app. Next, it is important to conduct a brainstorming session to ensure that the concept is suitable for all participants and to assess its potential for motivating them to share and learn.

5.3 DETAILING

Several CB expressed interest in a peer-sharing tool to see their peers' stories. For example, Isabella (18 years old) mentioned; *"[Sharing experiences with others from the Children's Brain Lab] I would definitely do this! What I mentioned before is that I love helping others! That's how to get further!".* However, they would not all personally share their stories, citing reasons such as *"it is not for me" (Nando)* or Merel said it was not something she was used to, but she could imagine other children wanting to share. (RA7 & RA8). Research has suggested that a lack of confidence is one of the underlying factors behind children's reluctance to express their concerns, opinions and questions about their healthcare (NCB, 2013). This reason could also be seen as demotivating for CB to share their stories. In addition, expressing and sharing is also a reminder of having a condition that hinders their desire for normality. Therefore, this concept's main challenge is the uncertainty of whether enough participants will share their stories to make it a useful platform. In addition, the potential benefits of sharing their perspectives and reflecting on their experiences are many, as named in previous chapters, making it even more desirable to motivate children to contribute to the app actively.

Other considerations not adequately addressed in the concept were:
Details on how the sharing will go and how the users would perceive the stories.
Intellectual and age differences, and specifically, what to do with shared stories that are not useful because they can not express themselves properly.

5.3.1 BRAINSTORMING

Focussing on the previously named challenges, a new brainstorming session has been carried out (Figure 24). This session has included the recurring theme of privacy and moderation. Multiple university students participated in a peer brainstorming session to discuss the app details, as the global overview had already been outlined in the design vision (n=5, industrial design engineering and other studies). Using two how-to's to see all the possibilities in supporting and motivating the children.

- How to - support children in expressing their perspectives. (What tools can we give children to get deeper and more detailed perspectives?)
- How to - motivate children to share their experiences and stories of the CBL?

Key findings that have been incorporated into the design:

- **Support**
  Multimedia means pre-set visual means and drawings to support the stories children want to share

- **Motivate**
  Give rewards for sharing a story
  Spark curiosity, by making the sharing experience mysterious
  Let the children collecting something (clues) in the lab which they can gather in the app, to enhance the consistency between the app and the lab.

- **Age differences & intellectual differences**
  The design should be guiding so the user does not feel lost, but still give them the freedom to be independent and not hinder them in what they want to do.
  Choose a buddy that helps to guide the

user through the app, based on whether the user needs much guidance through the app or not.

- **Other specifics**
  Someone to experience the app with or give a stuffed animal as a companion was mentioned, relating to the previously found idea of having a 'maatje' ('buddy') in the lab.

5.3.2 POSSIBILITIES PRIVACY AND MODERATION

A discussion was held with one of the Grow It! app developers (an app of Erasmus MC gathering answers to surveys about the mental well-being of youth) to determine how to balance privacy and moderation methods in the application. This discussion gave several insights into the risks facing the vulnerable target group in this medical setting. Erasmus MC, like many hospitals, places a strong emphasis on data protection and safety for their patients, recognising the severe consequences that may arise from a privacy breach or enabling cyberbullying by creating a peer-sharing platform. The possible risks were discussed in this conversation, such as where to store data when collecting privacy materials. What if an insurance company discovers an 18-year-old individual has had a brain tumour? Exposing their condition could affect their ability to obtain insurance later in life. This design will be integrated into the Self-Portrait. Therefore, it would use the same data storage and privacy rules. Assuming that the Self-Portrait application has considered all privacy concerns, it will present test results to participants, which is sensitive data. This section and the following chapter mention recommendations and ways to approach moderation and privacy. As this project is a design proposal and the precise information needed to calculate the cost and size of the data storage is not known, these details are not considered necessary for this project.

It was concluded from this conversation that the app should only be accessible to CBL participants and accessed through the link provided in the invitation (while the requirement was in contemplation, it had not yet been formally stated). Also, it was recommended to consider creating multiple versions to explore possibilities within each limitation group (privacy and moderation) without any other limitations influencing the process.

A. No moderation and no privacy risks; No freedom of use, no recognition
A completely anonymous application. The user can only interact through predefined actions. No interaction is possible, and no personal user content (Figure 25).
This version is not considered desirable as the project aims to create recognition and a sense of control and ownership. In this version, the user can not express themselves or see anything that has not been pre-curated.

Figure 24 | Showcase of some results from the brainstorm with fellow students

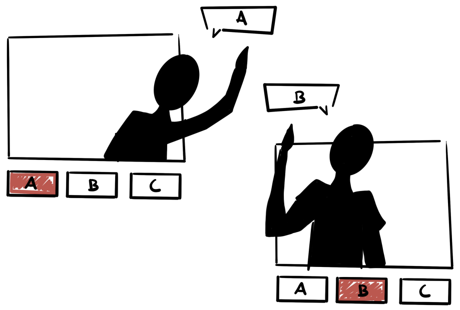


Figure 25 | Version A of moderation and privacy

B. High moderation and high privacy risks; freedom of use, recognition
All users fill in a photo of themselves, with name condition and age. They can freely interact through all means, such as audio, video, drawing and chatting. Everything is possible (Figure 26).
This version is seen as desirable but with high risks, achieving the values set for design, but needs high moderation and set guidelines.

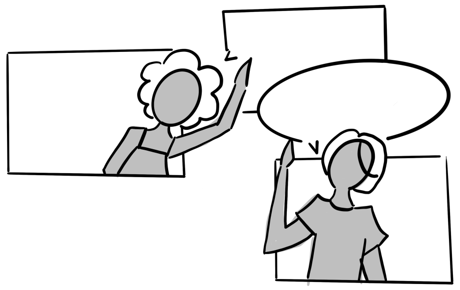


Figure 26 | Version B of moderation and privacy

C. No moderation and high privacy risks; no freedom of use, recognition
All users fill in a photo of themselves, with name condition and age, but can only interact through preset function or cannot interact at all. They can only share their experience by choosing from preset images and words (Figure 27).
This version is not seen as desirable as all personal data is exposed, but the user can not choose what to say or interact within the app.

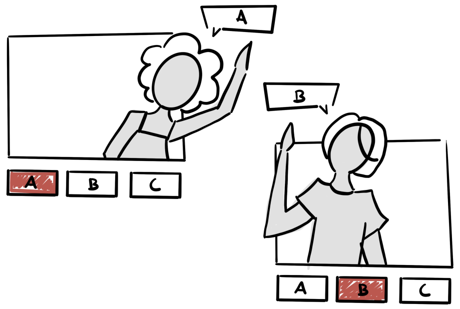


Figure 27 | Version C of moderation and privacy

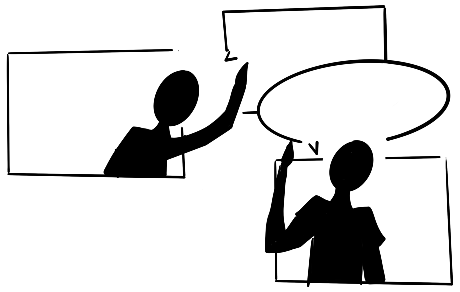


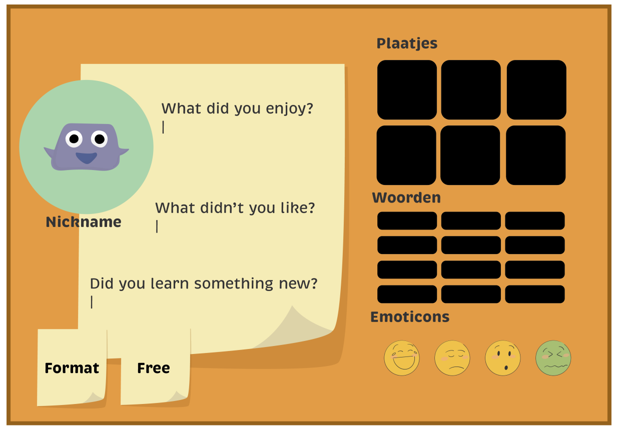
Figure 28 | Version D of moderation and privacy

D High moderation and no privacy risks; freedom of use, no recognition
A completely anonymous app where they can share everything; no names or ages are visible, and they can chat freely (Figure 28).
This version is seen as highly risky as giving freedom to anonymous users is risky, looking at misuse and cyberbullying.

E. Medium freedom of use, medium recognition.
In this version, the app balances freedom of use and recognition.
This version is desirable as it could still enhance the participants' feeling of control and relatedness while remaining conscious of the risks.

The separation of these versions shows that privacy risks are not only related to how secure the app is but also to how much the user wants to keep their personal data private; if they do not want to share their name and photos, they will not use an app that does it automatically. For the final design, how much recognition the participants desire can be tested by showing multiple options. Therefore, the final design considers versions with medium and high moderation and privacy risks (versions B and E). This is because the project focuses on allowing children to express themselves and take ownership. Two outlines of these versions have been sketched in concept ideas to better illustrate the difference, see Figure 29 (on the following page).

Medium moderation
Medium privacy risk

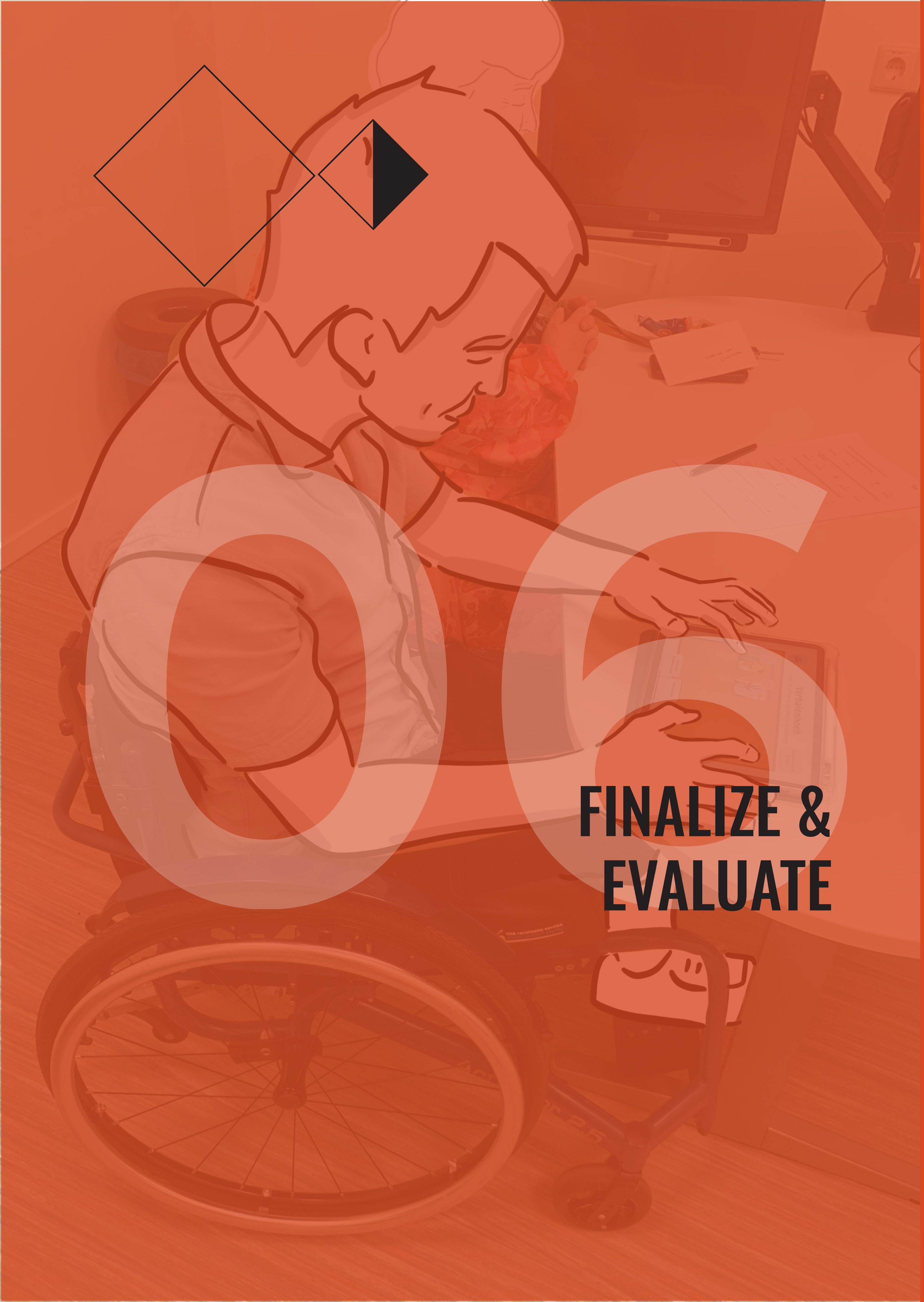


High moderation
High privacy risk

Figure 29 | Versions B and E made into a concept idea

TAKEAWAYS

- Designing the app with adequate support tools for a diverse range of ages and intellectual abilities is essential for accessibility and inclusivity.
- Striking a balance between privacy, safety, and moderation is essential in creating a secure environment for children to share their experiences and engage with others.
- Providing motivation and incentives to encourage active participation in using the app and sharing among participants is necessary.
- Developing methods for presenting the stories and experiences of participants to ensure a balanced and realistic overview, while respecting privacy and sensitivity and not overly restricting the user's freedom.
- Incorporating features to have some sort of direct interaction contributes to a supportive environment in the app and engages the CBL participants.
- Ensuring a consistent and guided user experience throughout the app that connects to the phases of the CBL, creates a coherent and easy-to-understand journey for the participants.
- An implementation plan that outlines the steps required to develop the chosen app concept while addressing privacy concerns and design considerations, enhances the feasibility for the CBL.



6. Final design & evaluation

Chapter 6 showcases the final design and evaluation of the app, providing an overview of the completion of the design process and the assessment of its usability and desirability. The final design Lab Maatjes is presented and evaluated using multiple methods. The goal was to ensure that the app is not only intuitive and user-friendly but also created a positive impact for the target audience (CBL participants). Section 6.1 and 6.2 elaborate on the design choices made and the proposed moderation and privacy measures. Section 6.3 shows all the valuable insights gathered from the test participants. The chapter concludes by outlining the key takeaways and iterations based on this evaluation process.

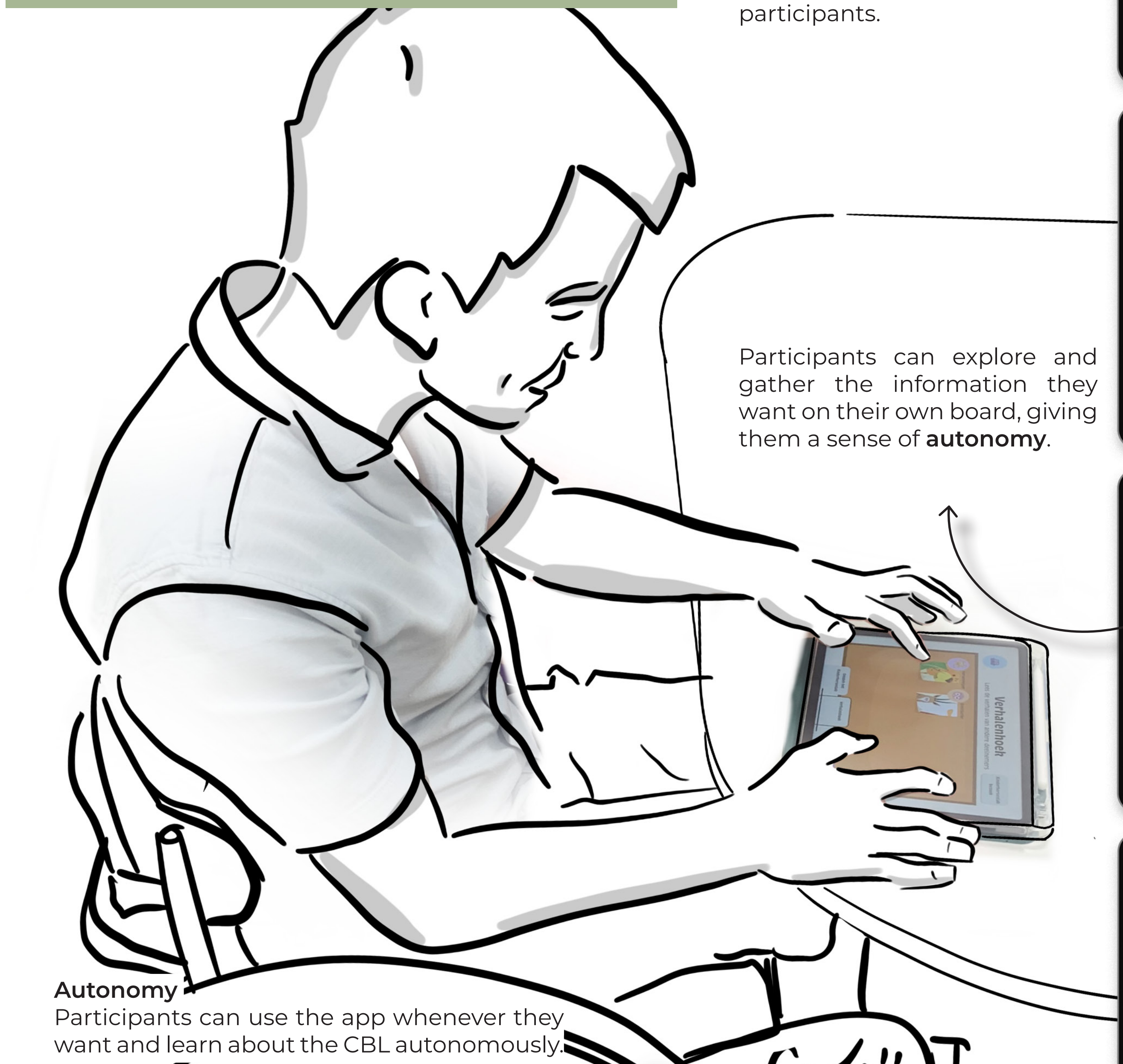
OVERVIEW LAB MAATJES

This overview presents the final design, Lab Maatjes. The images depict the fully iterated app, the storyboard on the following pages shows the app as the first version, which was tested and evaluated to become the app that is seen here.

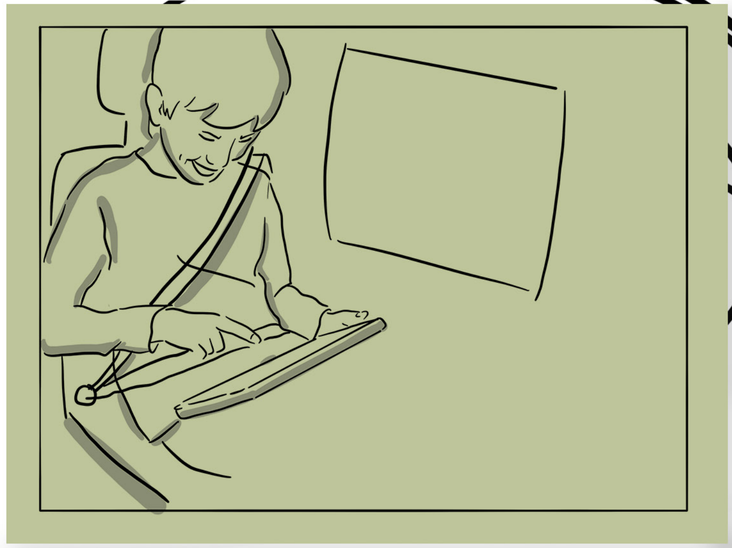
CONNECT

Seeing who else is going and interacting with each other gives them a sense of **relatedness** to the other participants.

Participants can explore and gather the information they want on their own board, giving them a sense of **autonomy**.



Autonomy
Participants can use the app whenever they want and learn about the CBL autonomously.



The CBL avatars take the participant on a journey from home to the lab. They guide the user through the journey, providing support and a **buddy** to accompany them.

Samen op avontuur

Deze deelnemers gaan binnekort ook of zijn al geweest

Ontdek het Kinderhersenlab

Bekijk alvast het lab, lees weetjes en nieuwtjes van het lab

Nieuwtjes

De meeste deelnemers..
- Vonden de beweegkamer het leukste
- En de taaltesten heel saai!

Wist je dat..

Je hersenen wit zijn van binnen en grijs van buiten. Ze bestaan voor driekwart uit water en voor een kwart uit vet.

Hoe ziet het lab eruit?

Mijn avonturenmuur

Mijn avonturen

Opgeslagen verhalen

BreinSurfer

Denkkamer

Moeilijk

Stom

Machinekamer

Eng

Ik hou niet van iets op mijn oren.

Beweegkamer

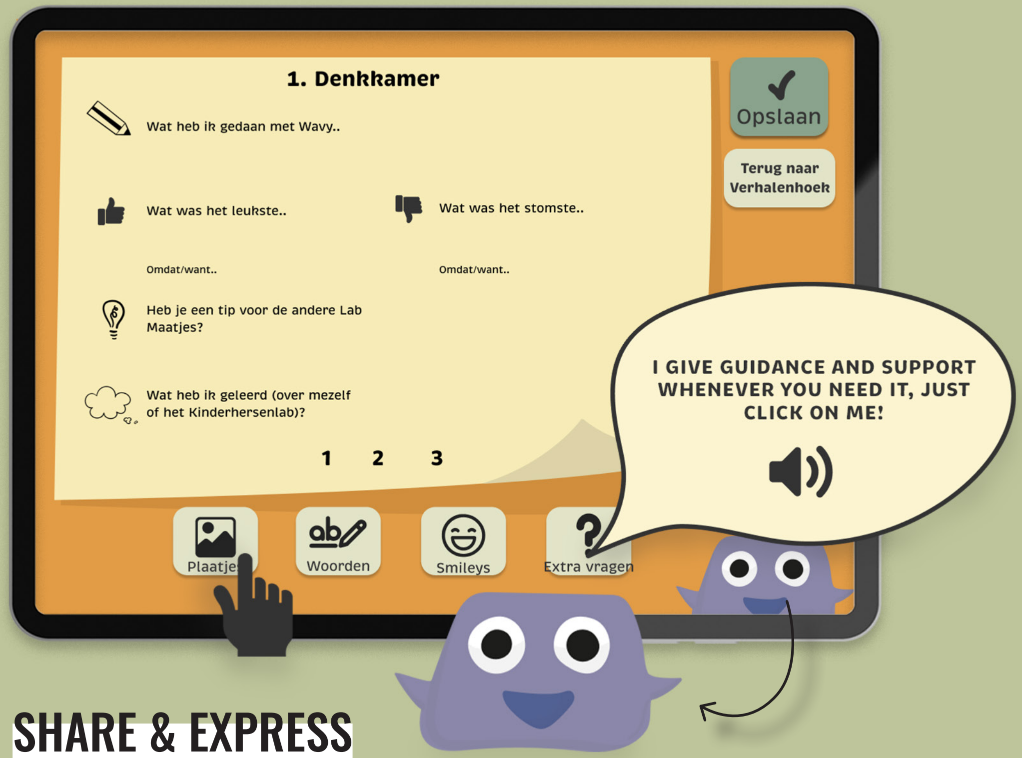
De laatste test was lekker relaxt!

Opluchting

Geef het verhaal een sticker

Met wie wil jij op avontuur?

Als je hulp nodig hebt kun je op je gekozen avatar klikken



1. Denkkamer

Wat heb ik gedaan met Wavy..

Wat was het leukste..

Omdat/want..

Wat was het stomste..

Omdat/want..

Heb je een tip voor de andere Lab Maatjes?

Wat heb ik geleerd (over mezelf of het Kinderhersenlab)?

SHARE & EXPRESS

Expressing and sharing their story in a way that is easy for them gives them a sense of **competence** because they can do it independently. By sharing their story, they can help their peers and feel that their contribution matters.

Creating an artwork together **motivates** participants to share and shows them that they are working together.

Verhalenhoek

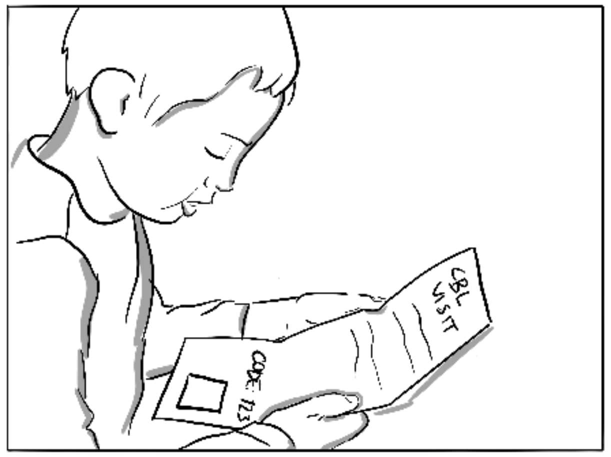
Lees de verhalen van andere deelnemers

CONNECT & DISCOVER

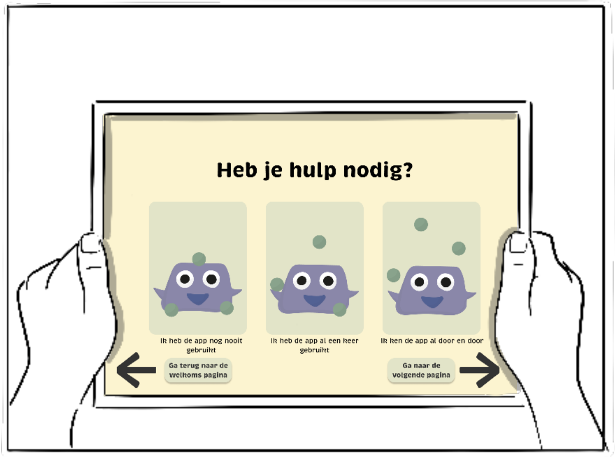
They can discover the CBL before their visit through the eyes of their peers, making the information more **relatable** and engaging to read.

6.1 STORYBOARD FINAL DESIGN

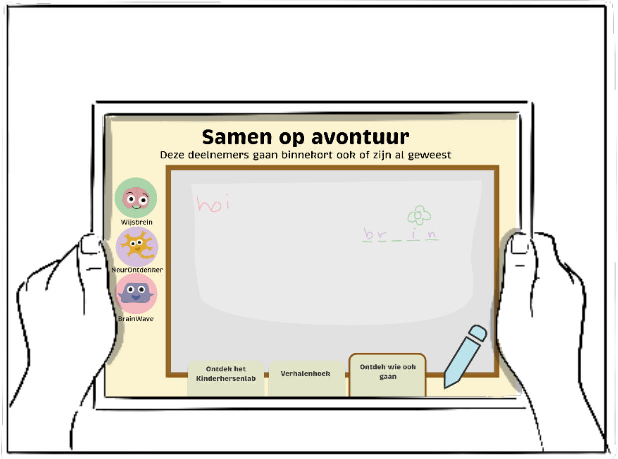
The storyboard depicted in Figure 30 offers a comprehensive overview of the app's functionality and its intended use. Within this storyboard, a distinction arises regarding using a taken picture. It is important to note that while the storyboard showcases the inclusion of a photograph in the prototype, this element was excluded in the final prototype as it is version E of the moderation and privacy risks.



A Invite with code
Alex receives an invitation with a unique code to join the peer-sharing app.

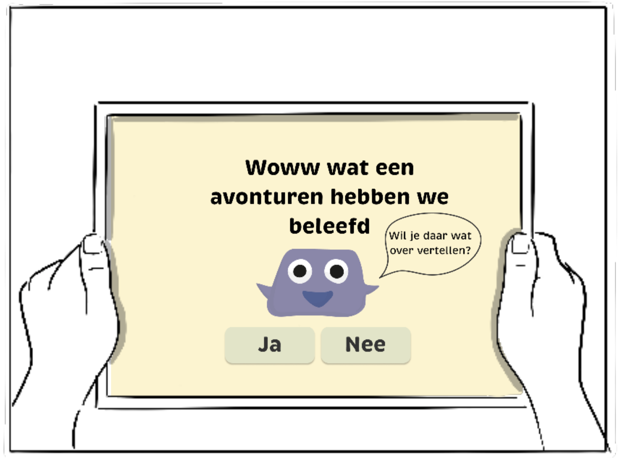


B Initial questions
Alex fills in their initial questions and thoughts about the CBL experience.

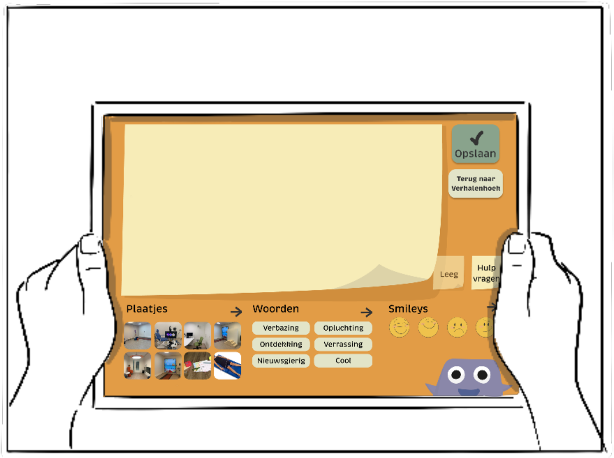


E Connect
Alex can look at what some other participants have written and draw something as well.

F Reminder CBL visit
On the day of their CBL visit, Alex receives a reminder notification.



I Post-visit notification
Alex receives a notification with their CBL visit picture and is prompted to share their adventure with Wavy.



J Easy expressing
Alex shares small details about their experience in an uncomplicated manner.

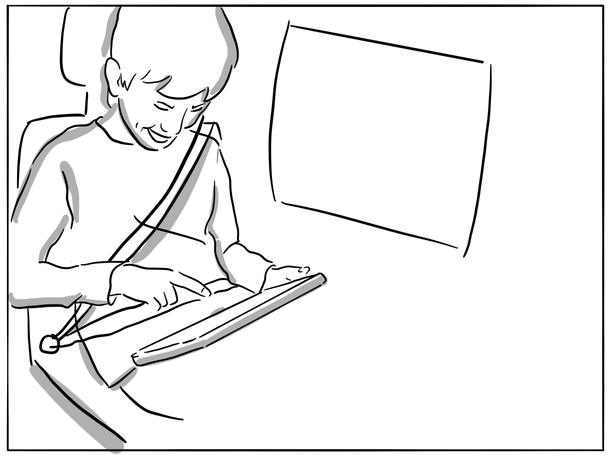
The features of the version B (with photograph) are also evaluated. But only through the presentation of screens rather than a functional prototype. This separation ensures a focused assessment of this particular design aspect.

To see the prototype in action, use this link: https://shorturl.at/mERTV

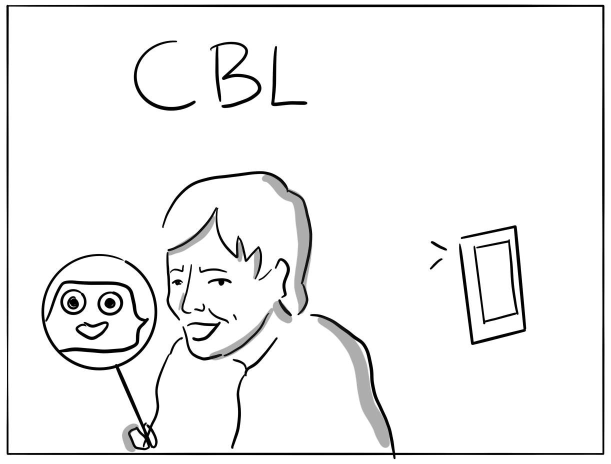
Figure 30 | Storyboard intended use Lab Maatjes

C Discover
Alex can look at stories and experiences shared by peers (other users) on the app.

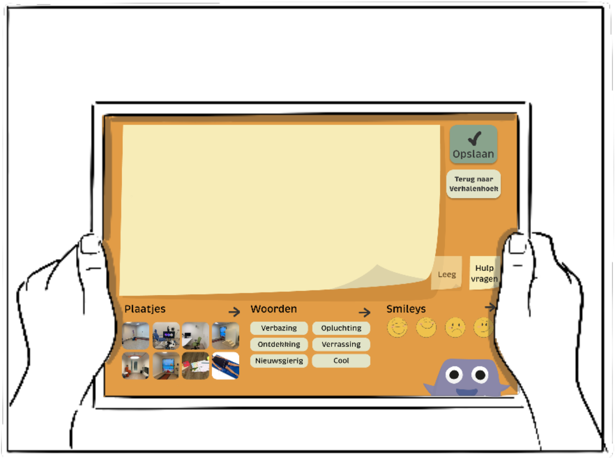
D Discover
Alex explores how the CBL looks and some more fun details of the CBL.



G Having something to do
Alex discovers more stories and experiences shared by others on the app, on the way to the lab.



H CBL visit
Alex visits the CBL, experiencing the testing process firsthand. Alex takes a picture with Wavy .



K Reminder to edit
A later reminder asks if Alex wants to add or change anything to their shared story.

L Sharing with peers
Alex chooses to share their story with others, seeing how the story is another puzzle piece to the participants shared image.

6.2 DESIGN CHOICES

6.2.1 MAIN BOARDS

Sharing board - 'Verhalenhoek' (Story corner)
(Figure 30C)
The main bulletin board showcases children's stories. Here, children can give these stories a sticker to save it on their personal board and remember why by the thought of the sticker. These stickers are only visible to the user who puts them on the story of their peer. As an administrator, the CBL could get useful information from the number of stickers on the stories of the participants. Quantitative and qualitative data from the usage of the stickers is presented on the CBL discover board to give a monthly digest of all the stories shared.

The CBL Board - 'Ontdek het Kinderhersenlab' (Discover the CBL)
(Figure 30D)
On this board, images of the lab rooms are shown, and fun facts about the brain can be found (addressing the trivia facts also available at the CBL wall at the lab entrance). The CBL board was not the design's main focus but is still implemented as it would be hard for a novice participant to understand the experiences of others without visiting the lab and getting a sense of the tests. Lastly, the CBL will be able to address some news about the lab or its participants, for example, 'Did you know most children liked the mobility room?'.

The connecting board - 'Samen op avontuur' (Together on an adventure)
(Figure 30E)
This board is a whiteboard where all the other CBL participants who are about to go to CBL or have gone to CBL can meet. On this whiteboard, users can interact by drawing and writing to each other to have fun and feel connected. A whiteboard ensures freedom to users, decreasing the threshold to connect as they do not have to write messages directly to a person but can write or draw something on their mind without having to address someone, which could be scary. Users can draw and write to each other, promoting a sense of connection and relatedness.

Personal board - 'Mijn avonturenmuur' (My adventure wall)
(Figure 31)
The personal board showcases the user's stories and all the stories they saved. This enables them to explore and sort important information and simultaneously they are able to look back at their previous lab visit experiences.

6.2.2 MAIN ACTIONS

Initial questions
Choose a buddy
(Figure 32)
'To have somebody to go with' (for fun and support)was one of the key takeaways of the sessions with CWB and the brainstorming sessions. Having a buddy increases the participant's motivation and the feeling of support. It is not a given that a participant will encounter another participant during their visit. So, one of the avatars of the CBL can be chosen to guide the user through the process. This choice provides a sense of personalisation and autonomy, allowing users to feel supported and motivated. Also, after the visit, the buddy encourages the user to share what they have experienced. The buddy is similar to Flip the Bear, a tradition in Dutch primary schools where children can take the stuffed classroom animal (Flip) for the weekend and then fill in a scrapbook about the adventures they had together. In the app, the buddy appears on the day of the visit and then asks if the user would like to describe their adventures together.

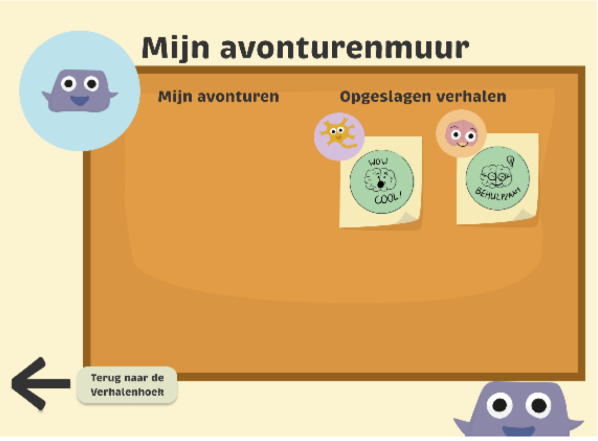


Figure 31 | Personal board

Figure 32 | Choosing a buddy screen

Choose the level of guidance
(Figure 30B)
Based on the brainstorming session, the idea was to create avatars, each indicating the needed level of help and support. Then, based on the children's choices, they get guidance that addresses their intellectual/ age-specific needs. This way, they do not have to ask for external help, which might decrease self-confidence.
Never used the app - Avatar is available everywhere with additional explanations that can be read aloud using the speaker function.
Used the app a lot - The user knows their way around and is a bit older, so no extra explanations are needed. Also, the buddy would guide less than the first time.

Profile creation
Only participants' nicknames and avatars are shown as the prototype addresses version E. For user testing, some screens are also developed to illustrate the idea of version B. That version has real names and photos as user profiles.

Collaborative action
(Figure 30L)
Creating a picture together by sharing the stories makes it all more fun and creates a feeling of togetherness. At the same time, it is an extrinsic motivation to share a story and get another puzzle piece of the image.

Story creation
(Figure 30 J&K)
Children can share their experiences at the lab by creating stories. They can use text, emojis, images, and help words to express themselves. And stick it all together in the way they want, just like a scrapbook. The user has the freedom to choose between an empty format or guiding questions to make expressing their perspectives easier, enhancing their sense of autonomy.
(see Figure 33).
Sharing their experiences and stories with their peers creates opportunities for connection and helping others, further enhancing relatedness.

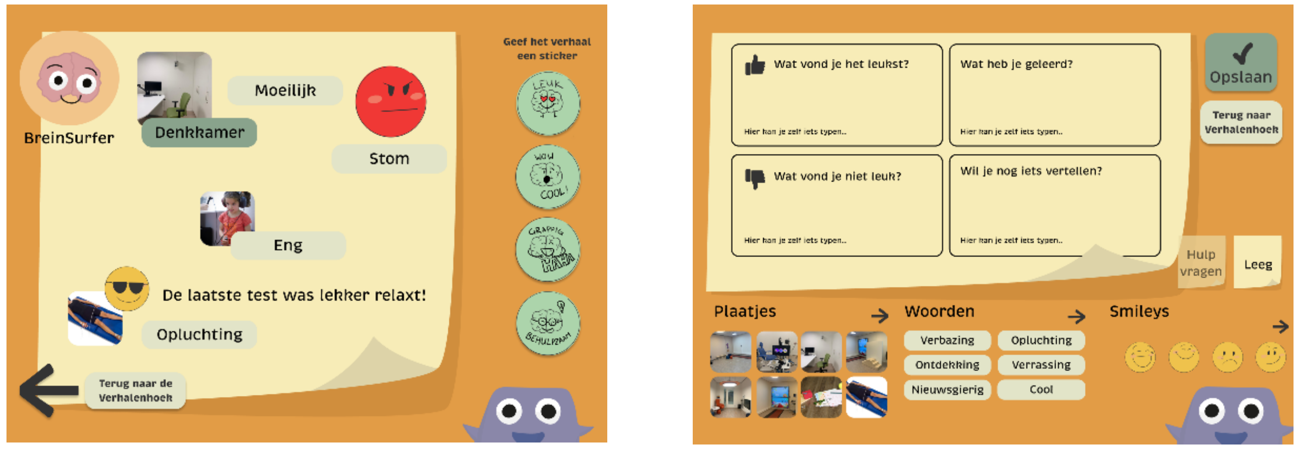
6.2.3 USABILITY

Other usability choices were made based on app design for children (with disabilities) (Nightingale et al., 2017);
- Little text and text read-out-loud function
- Visual elements to enhance comprehension of information
- No busy pop-ups or unexpected animations
- Easy clickable navigation; no drag or swiping
- Big buttons
- It balances simplicity and fun, using avatars and visuals but keeping the screens minimal, with only a title and a bulletin board.
- Every button has an extra description to ensure where the button leads to.

6.2.4 PRIVACY, CONSENT AND MODERATION

Versions B and E were selected for evaluation. Version E only requires motion if a child uses the additional text features. The story is flagged and checked by the CBL before uploading (e.g. for swear words).

The whiteboard is more difficult to moderate as there is more freedom to draw or write inappropriate things. To moderate the board,



De laatste test was lekker relaxt!

Figure 33 | Two formats of story creation an algorithm can be implemented to detect words that are automatically blocked. Or a delay could be placed on drawings so that a parent or CBL clinician has to approve them before they are posted on the whiteboard. In addition, there are no privacy risks in moderation, as no real names or photos are used.

It is a CBL-only application focused on the CBL and the experience. So the expectation is the app will not be misused (cyberbullying or swearing), and clear guidelines and rules of the application at the beginning reduce the possibility of a child breaking them. But children can share things quite bluntly without explanation, which can lead to confusion or stress, so moderation is still necessary.

Parental supervision

Parental supervision and consent are not included in the prototype as children are mainly testing it in a mockup situation, so including this is outside of the scope If the app would be developed and used, these guidelines and parental approval should be in place. Before using the app, parents should approve their children using the app with a clear description of what the app entails and what the children could do on the platform, including possible risks. Also, if a child is under sixteen, a parent should approve if they can share their stories with others outside of their personal board (see Figure 34).

Version B prototype

A more complex app version was made, with higher moderation needs and chances of privacy risks (see Figure 35 and Appendix L). This version allows additional words and images to be added, which also require moderation by a person or an algorithm that checks and flags possible inappropriate photos and words.
The privacy risk is included as the option to share a photo and use the real name is available. As the child has parental consent, it is under control. But for the CBL, it takes up more storage space to ensure that all these photos and names are stored securely.

Focus groups

The design considers both novice participants, who are using CBL for the first time and have limited prior knowledge, and expert participants, who are more experienced and knowledgeable. However, this final design focused primarily on meeting the needs of novice participants.

The design emphasises providing novice participants with clear and accessible information. By including features such as guidance avatars, a user-friendly interface with minimal text, and the ability to choose the level of guidance they need. Novice participants often seek guidance and information to make their CBL experience more comfortable and enjoyable. The design aims to reduce potential anxiety by giving them the knowledge and tools to navigate their first experiences confidently. The app enables them to participate actively in their CBL journey and eventually feel confident in being an expert (Figure 36).

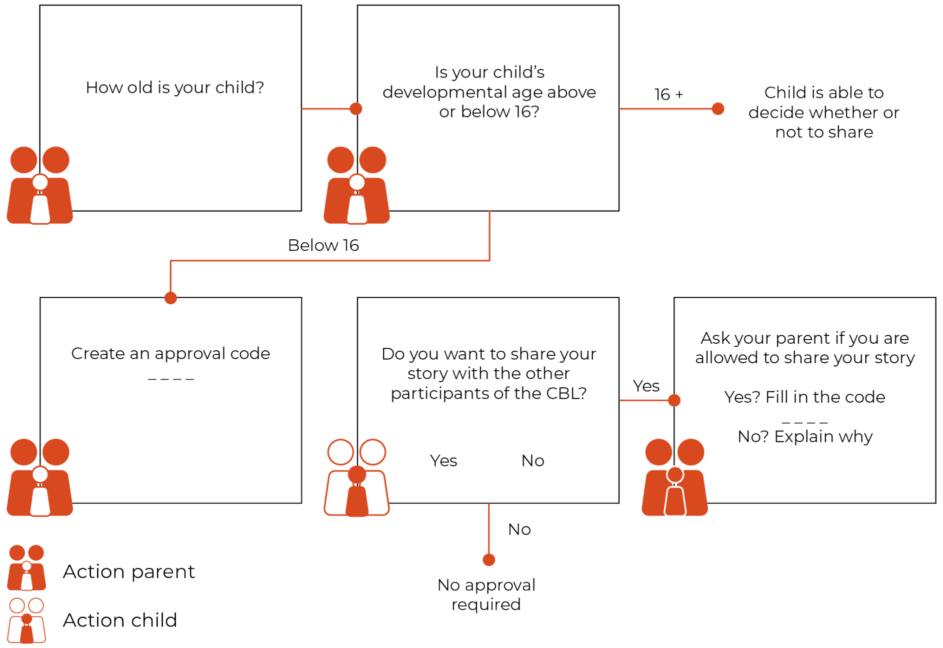


Figure 34 | Parental supervision recommendation

While the design primarily addresses the needs of novice participants, it also accommodates expert-by-experience participants. They have a deeper understanding of their condition and the activities of the CBL, can contribute to the community by sharing their insights and experiences. The design recognises their desire for autonomy and ensures they can access information independently. Lab Maatjes promotes inclusivity and encourages mutual support within the CBL community by creating an environment where both novice and expert participants feel comfortable.

Figure 35 | Version B prototype (with photos)

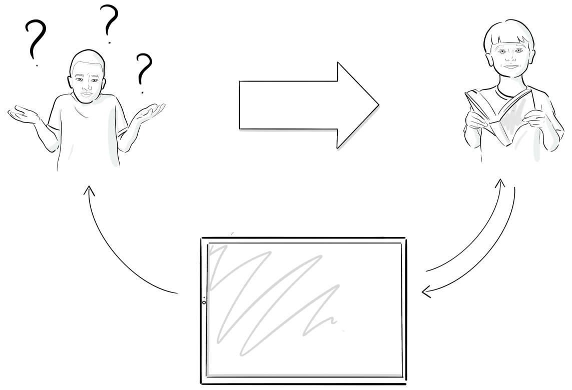


Figure 36 | From novice participant to becoming an expert-by-experience participant

OVERVIEW DESIGN CHOICES

Autonomy

- Choose a buddy
- Profile creation
- Freedom of expression through various forms

Competence

- Choose the level of guidance
- Various support tools for expressing their experience enable them to share independently.
- Creating something together with their stories
- Feeling heard and seen by sharing a story, being able to contribute to the CBL community

Relatedness

- A feeling of recognition and not being alone by seeing the stories of others
- Users are able to interact and go together with CBL participants in the same timeframe.

Usability

- Visual elements
- Little text and text read-out-loud function
- No busy pop-ups
- Easy clickable navigation

6.3 EVALUATION

6.3.1 METHOD

The app prototype was evaluated by several children (2 CWB and 2 CB, who all attended the CBL) to test its usability and desirability. One parent of a CB was present at the session and participated in the evaluation. In addition to this evaluation, a feedback session was held with three CBL clinicians, described in more detail in Section 6.3.4. The goal was to identify potential areas for iteration or recommendations. The think-aloud and active intervention approaches were utilised to stimulate the participants' perspectives during the app interaction (Van Kesteren et al., 2003). The thinking-out-loud method gives insight into the thought process behind participants' behaviour and initial thoughts (Donker & Markopoulos, 2002). As it can be uncomfortable to explain their actions continuously, elaborative questions were asked about what they said while testing the prototype to reduce this discomfort and make it feel more natural.

As prototyping all the possibilities would not be feasible within the given timeframe, a guided scenario was used to ensure that the use of the app was user-friendly and felt natural. The guided plan was also necessary to ensure the participants saw all the functionalities requiring testing through the guided tasks.

Additionally, the laddering method was used to explore desirability factors in depth, as with all previous research activities of this project. This technique using probing questions, asking why something is important to the participant, reveals the deeper thoughts and reasons. This method was also used when participants were asked to complete a survey in which they rated essential qualities of the app (such as feeling in control, freedom and helping others) on a 5-point Likert scale.

The tests were done in SCH or online. The app was used via a tablet, and all tests took around an hour. All the sessions were recorded (audio or video), and this data was analysed by filtering the quotes on negative, positive or neutral experiences, and other interesting insights that were not considered in one of these categories. These were summarised and organised on evaluation topics, such as the three values (competence, relatedness and autonomy), but also usability and general insights into the idea of peer-sharing. These insights are all discussed in the following section and the survey results.

Note. For readability, the participants were given pseudonyms (see Appendix E):
Bart: CB, 13 years old
Jolijn: CB, 9 years old

6.3.2 RESULTS

Overall impressions
Participants liked seeing the CBL before their visit and reading other people's stories (as preparation). Also, one CB mentioned that he wanted to see if people thought the same way he did or if they thought differently afterwards. The parent showed how much she liked the 'Ontdek het kinderhersenlab' and the 'verhalenhoek' and many other small features: *"In conclusion, I like this, and this and this, but everything [the rooms of the CBL and the stories] should have a bit more explanation, otherwise it could frighten the children if it is only this [the word frightening]"*. The two CWB mentioned they liked the app as well naming the following reasons: *"I liked that I had to think back to my experiences at the hospital"* (CWB, 8 years old) and *"I did think it was just special how you can make an app. I don't quite know what it's called but like it's not a game either, But that it's also not a whole so, so. NOS. That you can only read, it's both."* (CWB, 10 years old). Jolijn showed her interest in the app by immediately engaging with the stories in the 'Verhalenhoek': *"No, I want to have a look, I'm only at the first sentence. I thought so too. [haha] [...] [laughing] I already did, because when it said it took too long. That wasn't at all what I had to do in the thinking room. My dad had to come out of the room for a while because otherwise I got a bit distracted. And I sat in the room for two hours and played all sorts of games."* This quote illustrates how she immediately wants to share her own experiences, agreeing with the children's desire to share experiences.

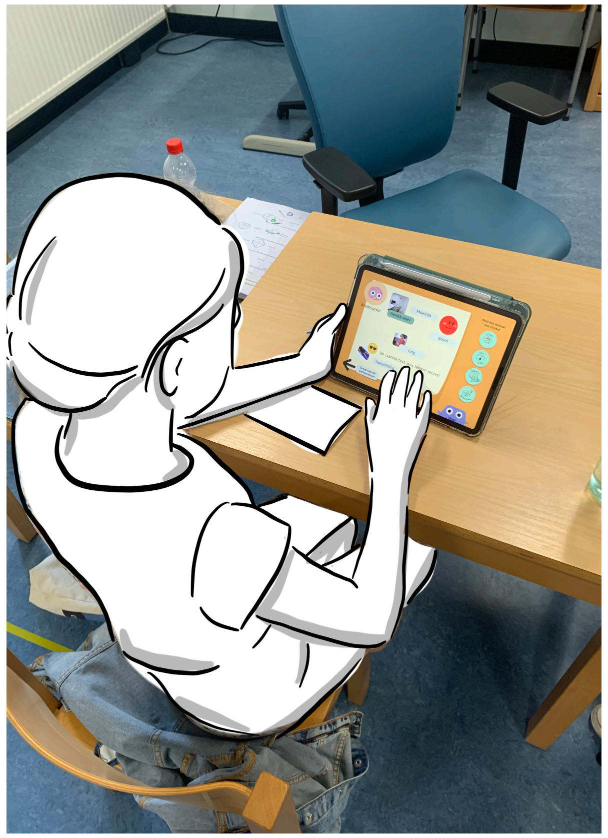


Figure 37 | Example of test set up

It is important to note that all participants were aware that this prototype was not fully functional, so they often looked through the functionality flaws, believing that these would be fixed in the fully functional application. These flaws and confusing points are illustrated in the next part. Some flaws will be iterated, and others will be used as recommendations, shown in Section 6.4 and in Recommendations.

Feedback and improvements on the app

Lay out
- It was unclear whether Wavy, Neuro and Brainy were the avatars of other children as they are also the lab's avatars.
- The layout of the stories could be more structured, making it better readable. It was now confusing which words were linked to which tests and rooms.
- Creating their image by choosing a background and creating an avatar

Age differentiation
- The app should have more visuals or at least less text, or make the text read aloud. Girl (CWB 8 yo) mentioned that younger children find reading harder. The boy (CWB 10 yo) added that children with dyslexia find it difficult because all the text is in different places.
- Give more freedom in options in the 'creating your story' menu (more words, images and emoticons)
- The questions should be more guiding (what did you think of ... explain why..) (parent of Bart)
- As extra feature for younger children, a parent could add some text/explanation to make the story more insightful (recommendation of the parent)
- Bart stated also that adolescents do not need the choice menu of words and images, as they know what they want to say. But they should have limited writing space, so they do not make the stories too long.
- In the phrasing of the participants, the app looks quite childish. Bart mentioned for example that he did not mind this but could imagine older adolescents being hindered by these looks.

Usability
- Navigation could have been better. Sometimes, the participants thought they could click when this was not an option or drag when they could only click on the arrow. Also, the CWB (10 years old) needed to learn how to see the other options in the 'Create your story' menu. In the second session, difficulties were found in thinking they could drag items or how to go further.
- Bart often had an assumption: *"Oh, and then this will probably give more insight about..".* His assumptions were often good tips but not yet integrated.
- When the participant clicks an option in the initial question, it should go directly to the next screen (parent).
- A small explanatory video at the start of the app to show what is possible, just like in games, was recommended by Bart.

Additional
- In the "going together" function (whiteboard), the app could also have some introduction cards explaining a bit about all the participants. So when they meet them in the lab, they know who they are.

Autonomy
If it gives a sense of autonomy that is hard to evaluate on a one-off basis. They could all use the app independently from external help, with small exceptions. An additional instructional video at the beginning would be helpful, as Bart mentioned, to know what each button does and what is possible for extra clarification.
The parent and Bart mentioned that they always chat about the visit after it on the way home (in the car). They mentioned how multiple new insights could pop up after this chat, agreeing with the intended use shown in the storyboard in Figure 30. The parent also stated it would be helpful to let the parent fill in some extra questions to enhance the comprehensiveness of the story. This help from parents would be inconsistent with the value of autonomy and competence, letting the parents override the child's expressions.

However, it would be possible to include an extra reminder to show them that they can talk to their parents about the visit to enhance the reflection and expression of the visit, for example: 'do you want to add something to your story, maybe your parent remembers a funny moment'.

Competence
One observation was that the functionality could easily frustrate a child if they thought it would work a certain way and were repeatedly 'wrong', annoyed or unsure of what to do. This observation is something to bear in mind for the app's usability. Otherwise, the app will reduce their sense of competence.

Relatedness
The reading of the stories of others was positively received. As the quote of Jolijn (earlier mentioned) shows. The other participants found seeing if others would think the same was fun. The whiteboard was received neutral. Often, they did not pay much attention to the feature. The neutral attitude could be because of the limited functioning and the guided scenario. Also, it was unclear to the participants that the feature was about seeing other CBL participants and interacting with them, except for Bart who also gave recommendations to make it more personal.

Version B with pictures and names
Version B (Appendix L) was also shown in the evaluation sessions, and participants' opinions were mixed. Some liked it, and some did not like it at all. One CWB (8 years old) would not like it because others could talk behind her back. All the other participants liked it, the other CWB (10 years old) describing it as; *"a good idea, because then it really is kind of your own"*, implying how it is more their personal account when using real photos. However, it should always be a choice between remaining anonymous or showing their picture.

Table 3 | Overview of survey questions and what they evaluate

Survey	SDT	IV	Design guideline
Q1	Competence	Independent	The design should enable the participants to see what they learn about themselves and what CBL learns from them.
Q2	Competence	-	
Q3	Relatedness	Community	The design should give a feeling of support and companionship.
Q4	-	Inviting	-
Q5	Autonomy	Freedom	The design should enable participants to share what they find meaningful and exciting for others.
Q6	Competence	Support	-
Q7	Competence	-	-
Q8	Autonomy	Independent	The design should provide a sense of control and empowerment.

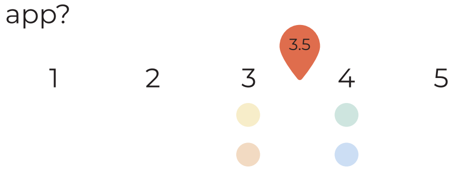
6.3.3 SURVEY RESULTS

This section gives the survey results for each question, explaining what can be concluded from the scores and what this means for the design. The legend below shows which participant is which colour to illustrate how each participant rated each question. The thought behind each question is illustrated in Table 3.

An interesting observation was that one CB (9 years old) was directly cautious when the last step of the interview, the survey, was explained. She mentioned, *'Yeah one time I had to do this [a questionnaire] and it took like an hour..'*, illustrating that a survey can be perceived as tedious.

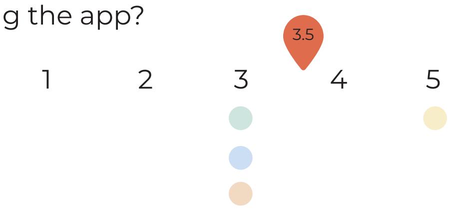
- ● CWB 8 yo
- ● CWB 10 yo
- ● CB 12 yo
- ● CB 9 yo

Self-exploration
Q1 Have you discovered any new things in the app?



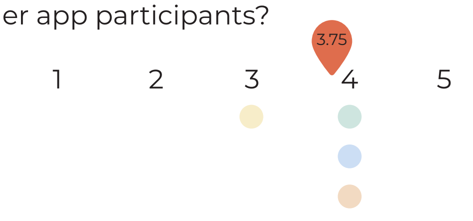
Participants have reported moderate levels of discovery within the app. It has facilitated some new findings, but there may be room for improvement in enhancing the discovery aspect.

Learning
Q2 Do you think you can learn new things about yourself and other participants by using the app?



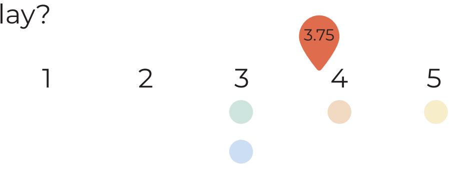
The app appears to provide a platform for self-discovery and learning about fellow participants, but there is potential for further development to enhance this aspect.

Feel of community
Q3 Do you feel that you are together with the other app participants?



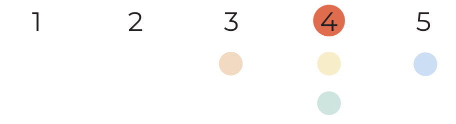
Participants generally feel a sense of relatedness with other app users. This suggests that the app has successfully given a sense of community and connection among participants.

Inviting
Q4 Do you like the app and does it invite you to play?



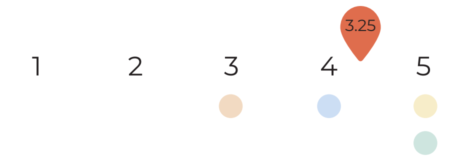
Feedback indicates that participants generally have a positive impression of the app, finding it inviting and engaging. This is a promising sign for user satisfaction.

Feel of freedom
Q5 Can you choose what you want to do in the app?



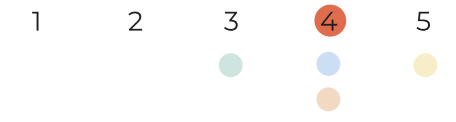
Participants appreciate the ability to make choices within the app. This high score suggests that the app offers a good degree of autonomy and flexibility to participants.

Support
Q6 Do you feel you can get help if you need it?



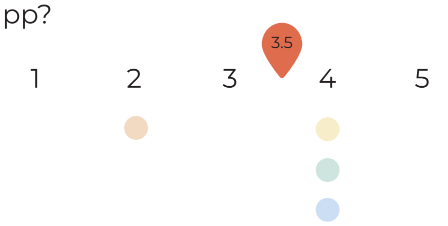
Some participants have expressed a need for improved assistance within the app. This indicates that there may be room for enhancing the app's support and guidance features, although it is not seen from the given score.

Help others
Q7 Do you feel you could help others through this app?



Participants generally feel that the app enables them to provide help and support to others. This is a positive outcome, indicating the app's potential for fostering peer support.

Feel of control
Q8 Can you decide for yourself what you want to do and how you want to do things in the app?



Participants report moderate levels of autonomy in decision-making within the app, also acknowledging the fact that the limited functionality of the app makes it hard to see for them if they can do what they want. There might be opportunities for further customisation and personalisation.

Critical note
Q5 and Q8 are very similar but question a different quality, interestingly enough they are rated quite differently despite their similarity. Q5 received relatively high scores with only minor variations, indicating a consistent positive perception. In contrast, Q8 was predominantly rated four, with the exception of one participant who rated it two, suggesting a more polarised assessment.

All children were also asked to explain why they chose certain answers, with a particular focus on the neutral answers (3). Often they said that they did not know the answer, so they put it in between, or it was just not high and not low.

In conclusion, all questions were rated positively but close to moderate answers, which makes it not possible to draw decisive conclusions on whether the design of the app achieves its values and shows it has room for improvement.

6.3.4 CBL RESULTS

The design should be able to integrate with the Self-Portrait app.
In addition to evaluating the prototype with children, an online feedback session with three CBL clinicians (a paediatric neurologist, an associate professor - rehabilitation medicine and a neurosurgeon) was held (duration: twenty minutes). They clicked through the prototype beforehand, and in the session, improvements were discussed, focusing on feasibility and desirability.

The main concerns and questions were:
- “I liked the questions about what you like and don’t like, but what if they only give negative answers?” (Rehabilitation medicine) - adressed in Section 6.4
- “For what age group do you think this is an appropriate app to give valuable information?” (Neurosurgeon) - see Recommendations
- As there is no control over what children share, the possibility of creating three explanatory videos by CB, managed by CBL, was discussed. Usability concerns about typing in the answers, audio recordings would be better. (Paediatric neurologist) - adressed in Recommedations

It was difficult to establish what the integration with the self-portrait would look like, as the CBL has not chosen one of the MCW concepts, so there is no clarity about the look and feel of the app. It was mentioned that it should not be an app with too many features and that it should be clear to the user where to find which feature in the app (ease of use). The paediatric neurologist recognised the fact that children today interact mainly through stickers and emoticons, so she could imagine how children would use this app.

CONCLUDING REMARKS ON EVALUATION

The app is positively received (not super enthusiastic, one reason for this could be the emphasis on the app being in development and wanting to hear all the flaws), but the main consideration named multiple times was the fact it was not addressing the whole range of the target audience, presented by the following quote by Bart; *“[...] Well, If I take it with the points of improvement that it can be a good app in terms of use for children, but what we said, that it still need the distinction child adolescent here in this case. [..] I think adolescents would less likely think gosh let me use this app, let me put it in this way. In general. The improvement point I listed is actually the only improvement point there are at the moment.Other than that, I think, you just had. Other than that, I think it’s just well. No further points to mention.”*, this illustrates how the adolescents are not addressed in the app. Conversely, there were also suggestions for even more support for younger participants. These observations highlight the importance of tailoring the app to different age groups within the target audience. While the presented version of the app serves as the main design for novice participants, focusing primarily on information consumption and confidence building in sharing experiences, it is important to recognise that expert participants, who tend to be older and more knowledgeable, may require, a different layout and additional tools and features to address their needs effectively.

To address these considerations, future iterations of the app should prioritise the creation of multiple versions, each specifically tailored to the unique requirements of different age groups within the diverse user base. This approach will allow the app to support novice participants on their journey to becoming experts through experience while providing more advanced features and functionality to meet the needs of older participants who are already familiar in the CBL environment. This approach will allow the app to meet the diverse needs of its users better, ensuring a more inclusive and empowering experience for all.

6.4 ITERATIONS

Several iterations of the app prototype were made throughout the evaluation process based on feedback from industrial design students, children and CBL clinicians. Appendix L provides an overview of the different versions of the prototype (1,2,3, and 4), and this section describes the main iterations. To show which prototype version has been tested with whom, a schematic overview is given in Figure 38.

Clarity
The placement of the support tools in the ‘create your own story’ was iterated several times to improve the clarity of the layout (Figure 39A).

Structure of the stories
The information in the stories could have been clearer, as all the words and images were spread around the page in an illogical order. This layout was chosen to make it look playful. The iteration is that the information is now presented in a paragraph style or per room via elaborated questions (Figure 39A & B).

Balance negativity
The negative information given by words alone could be seen as scary, for example, just the words ‘scary’ or ‘painful’ without any explanation. The ‘omdat/want…’ was added to balance the negativity. The additional ‘why’ encourages the user to explain the emotion or perspective (Figure 39A).

After this iteration, there were still concerns, so the user was encouraged to answer what they did not like about the lab. So, another addition was made to allow the participant to give a tip to the other participants; “What would you give as a tip to someone else going to the lab to make it more enjoyable?” (Figure 39A - iteration 2).

Use different avatars as user profiles instead of the CBL avatars.
Neuro, Wavy and Brainy were used as buddies to guide the user through the app and as a user profile. As there are only three characters, it was unclear to participants that the other avatars were those of other app users and not just decoration. The user can now create/choose a more human-like character to clarify who their peers are in the app (Figure 39C).

Elaborated information CBL
As several participants in the ‘Discover the CBL’ function suggested, all rooms would have more pictures and information. Based on the PIS of the CBL, more information was provided for the rooms to illustrate how this could look. For consistency and to make this information more engaging, the buddy chosen by the user reacts to the information given. For example, when the cap of the EEG was explained, Wavy responded as if it were surprised (Figure 39D).

This is the link including all iterations, prototype 4:
https://shorturl.at/zEW03

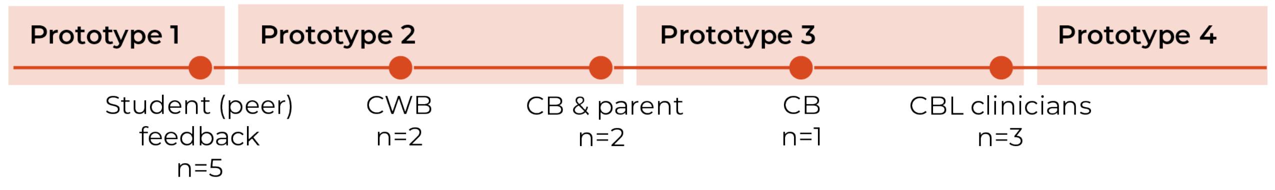


Figure 38 | Order of iterations and evaluation sessions

Old version

Iterated version

Iteration 1

Iteration 2

A

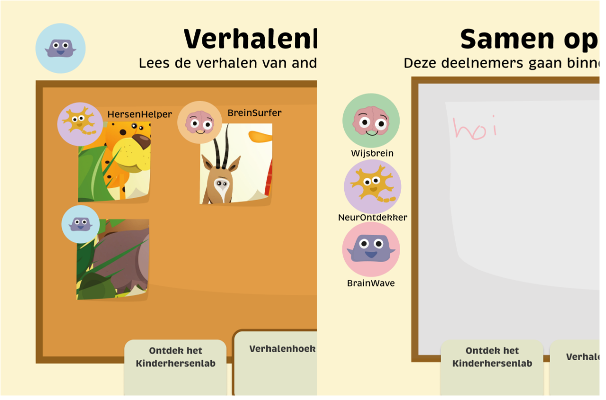
B

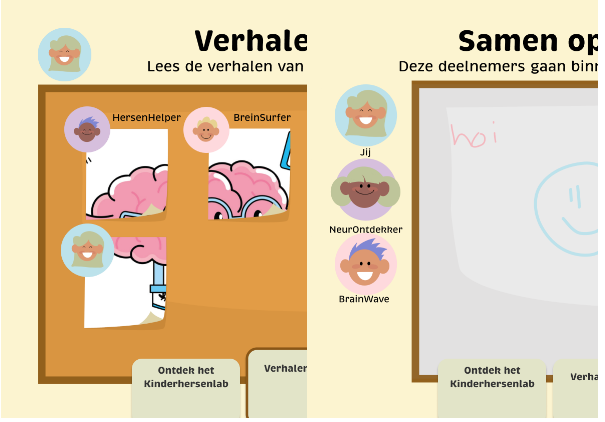
De laatste test was lekker relaxt!

Ik hou niet van iets op mijn oren.

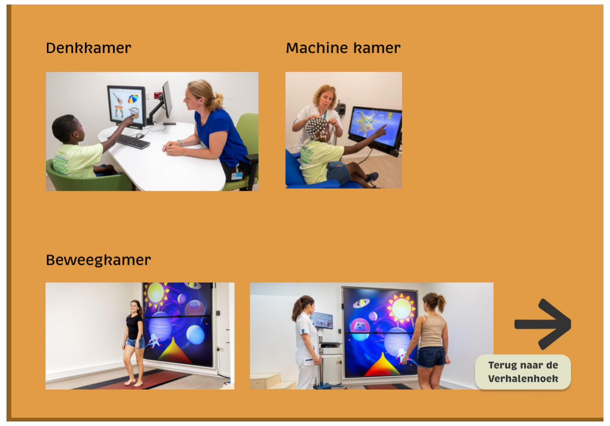
De laatste test was lekker relaxt!

C





D



In de denkkamer ga je aan tafel verschillende opdrachten doen. Zoals met blokken werken en een opdracht samen met je ouder.

Figure 39 | Overview of all the iterated versions of the prototype

CONCLUSION

This thesis addresses the question: ‘How can design empower participants aged six to eighteen in CBL to effectively utilise peer-sharing for preparation and support during their CBL visits?’ The primary objective was to develop a tool that facilitates meaningful peer connections for learning, ultimately fostering participants’ confidence and providing a platform for sharing experiences and knowledge related to their brain conditions. The goal of the tool was to empower participants to feel like experts and contributors in CBL research, nurturing a sense of ownership and curiosity about their brains (and conditions).

The literature together with the various research activities clearly illustrates the need for children, especially CB to have a voice and be listened to (RA4,7 &8; Coyne 2006; Heah et al. 2006; Peeters et al., 2014 ; Van Schelven et al. 2021b). Nicely summarised by Merel (17 years old); *“But I think it [concept idea] is really cool if children can express that [their experiences], and especially if they […] also feel a bit heard and seen, which of course is very important.”*. This study also presented the desire of CB to see and engage with the stories of peers. That is why the design, Lab Maatjes, was generally received positively. But it also raised the question of CB’s competence in expressing their perspectives. The design process actively aimed at creating a supportive app for the CB, and the concern about lack of competence is mainly from the CBL and parents, who are worried about the risks of peer-sharing, and the younger participants who might not be able to create comprehensive stories. The app is aimed to include all CBL participants to let their voices be heard. Still, critically looking at the final design, it should be seen as a prototype, not the final solution, as multiple improvements can be made. These are described in the recommendations section, suggesting how the CB perspective can also give more value to the CBL.

The first is that CBL participants do not find the hospital or the CBL scary, but they like to be prepared and want more information about their visits, what will happen, what they need to do and why. This is included in the app as it is an environment where they can discover the app through the eyes of their peers, together with the global information of the CBL. Second, addressing different age groups is essential, leading to recommendations for two app versions and splitting the age group.

The design is based on self-determination theory and focuses on autonomy, competence and relatedness. It can increase participants’ competence by allowing them to help others by sharing their stories and increasing their confidence by making them feel heard and seen by their peers. As CBL participants can navigate the app independently and gather the information they want, this promotes autonomy, and the freedom to choose features such as an avatar and a buddy also gives a sense of control. Finally, all the app’s features provide a sense of connectedness as it creates a CBL community where they can see each other’s experiences, work together to create collaborative artwork and interact with each other on the whiteboard.

While making decisive conclusions is challenging at this stage, initial responses indicate promising potential, particularly regarding increased autonomy and a sense of relatedness. Participants envision the app as a tool to build community and reduce feelings of isolation.

The desirability of this design is evident in the enthusiastic response from CBL participants, aligning with their desire to connect with peers and see the CBL environment before their visit. The feasibility is underscored by its practicality and adaptability, with potential integration into the Self-Portrait app, and a recommendation for such integration is made. In terms of viability, the design introduces a cost-effective and self-sufficient solution, transforming the CBL experience into an engaging community-driven process, surpassing traditional patient information sheets.

In conclusion, this research demonstrates the potential of design to empower CBL participants, aligning with self-determination theory values. The tool represents a step towards creating a supportive, engaging CBL community where participants contribute to research and connect with peers, fostering a sense of belonging and shared purpose. Ultimately, it offers a more enjoyable alternative to preparing for CBL visits than traditional patient information sheets.

LIMITATIONS

RESEARCH APPROACH

Literature research
The literature examined in this study encompasses not only children with neurological conditions but also individuals with various disabilities (mental and physical) and chronic conditions, as well as literature referencing adults.

Recruitment bias
Recruitment was primarily conducted at two departments within the Sophia Children’s Hospital and, alternatively, through Instagram. It is essential to acknowledge that this limited recruitment strategy has resulted in an incomplete representation of the target group. Not all possible conditions were present, or all ages were interviewed.

Limited sample size
The relatively small number of participants in the research may compromise the study’s ability to draw reliable conclusions.

Flexibility and adaptability
While the study adopted a flexible and adaptable approach, allowing for tailored goals and strategies for each activity, this could present a lack of consistency in the overall research process. The absence of standardised procedures might lead to difficulties in effectively comparing and synthesising the data.

MATERIALS

Testing and validation
The user testing phase was conducted once to assess the suitability of the proposed design solution. However, for significant validation and reliability, further testing is essential. Additional iterations would enhance the credibility of the results and increase the likelihood of producing a more effective and refined final design.

Likert scale
The Likert scale employed in this study is particularly susceptible to interpretation errors. This susceptibility arises because the questions used in the questionnaire were created for this study to assess the attainment of certain values. However, these questions were not rigorously tested for their reliability in accurately gauging the desired information. Additionally, Likert scale questionnaires tend to receive neutral responses when participants do not fully comprehend a question. Certain measures were taken to mitigate these risks, additional questions were asked during the questionnaire, and a ‘thinking-out-loud’ method was employed to assess participants’ comprehension of the questions. Despite these precautions, it’s important to note that the risk of interpretation errors still exists.

Prototype
The prototype was not fully functional, which may have influenced the test results. Participants even mentioned they could not answer a certain question to the truth because of it, namely the question “Can you choose what you want to do in the app?” because the limited functionality of the prototype did not allow it. Frustration with usability flaws can also negatively influence perspectives on the prototype.

RESEARCHER’S SUBJECTIVITY

Data Collection
The researcher’s personal beliefs and perspectives could have influenced the data collection selection of data sources, methods, and questions. This personal influence could result in a skewed or incomplete representation of the research topic.

Interpretation of results
The researcher’s subjective viewpoint may have affected the interpretation of research results, potentially leading to conclusions that align with their preconceived notions or expectations.

Design decisions
The flexible and adaptable research approach allowed the researcher to iterate the design direction as the research progressed. However, this also means that decisions are based on the insights of one to three participants, all interviewed using a different method, making it difficult to state that this was the best design decision objectively.

RECOMMENDATIONS

Accessibility
Make the app available on desktops, mobile phones and tablets to increase accessibility for all participants of the CBL (see Figure 40).

Customisation
More customisation options in the app, for example, creating an image with their avatar (see Figure 41). This customisation gives more control to the user and makes their account feel more autonomous.

Make the profiles more personal
Let the users choose, for example, some additional emoticons to describe their interests. Hence, the other participants also know who someone is and what they like, creating more connection to the other participants (see Figure 42).

Always let it be the participant's choice if they want to share their picture, for example. Making a picture in the lab is recommended as it adds value for the participants to see their visits back more visually.

Privacy & moderation
Implement data security measures to protect user's private information and ensure compliance with data protection regulations. Implement a system for ongoing moderation of language and drawings made in the app. Use algorithms that can detect flagged words (e.g. swear words) in written text and audio and have image recognition to prevent inappropriate imaging.

Usability
An explanation video should be added at the beginning to explain the ins and outs of how the app works.

Guidelines
Set up community guidelines for the app to set rules of what language the participants can not use and what would be inappropriate to share, similar to other sharing platforms (e.g. Instagram). To prevent app misuse such as cyber bullying, swearing or spamming.

Story structuring
To make the app even clearer, it is recommended that when a story is filled in about a room, or when a particular item from a room is used, that this is also displayed in the room on the Discover the CBL page, to give the full package of information in one place (see Figure 43).

Figure 40 | Accessibility

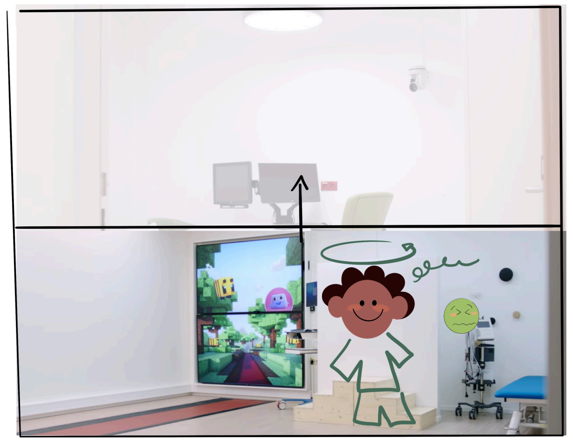


Figure 41 | Customisation

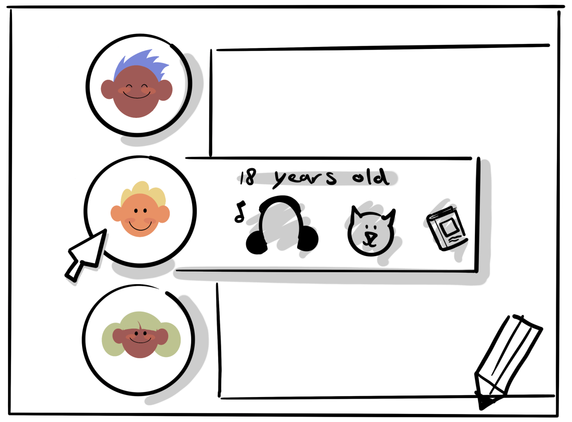


Figure 42 | Personal

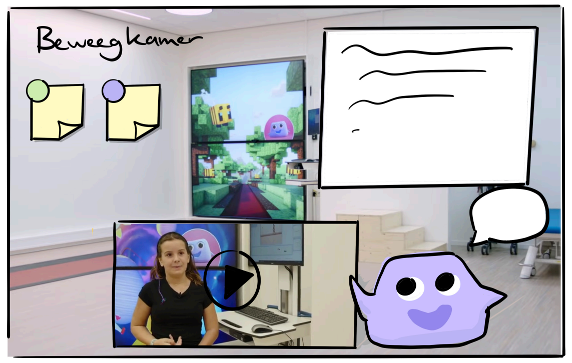


Figure 43 | Story structuring

Age differentiation
It is recommended to split the age group into 6-12 and 13-18 but keep them in the same application so that only different versions need to be switched between. Figure 44 outlines a proposal for what the difference between the two versions would be.

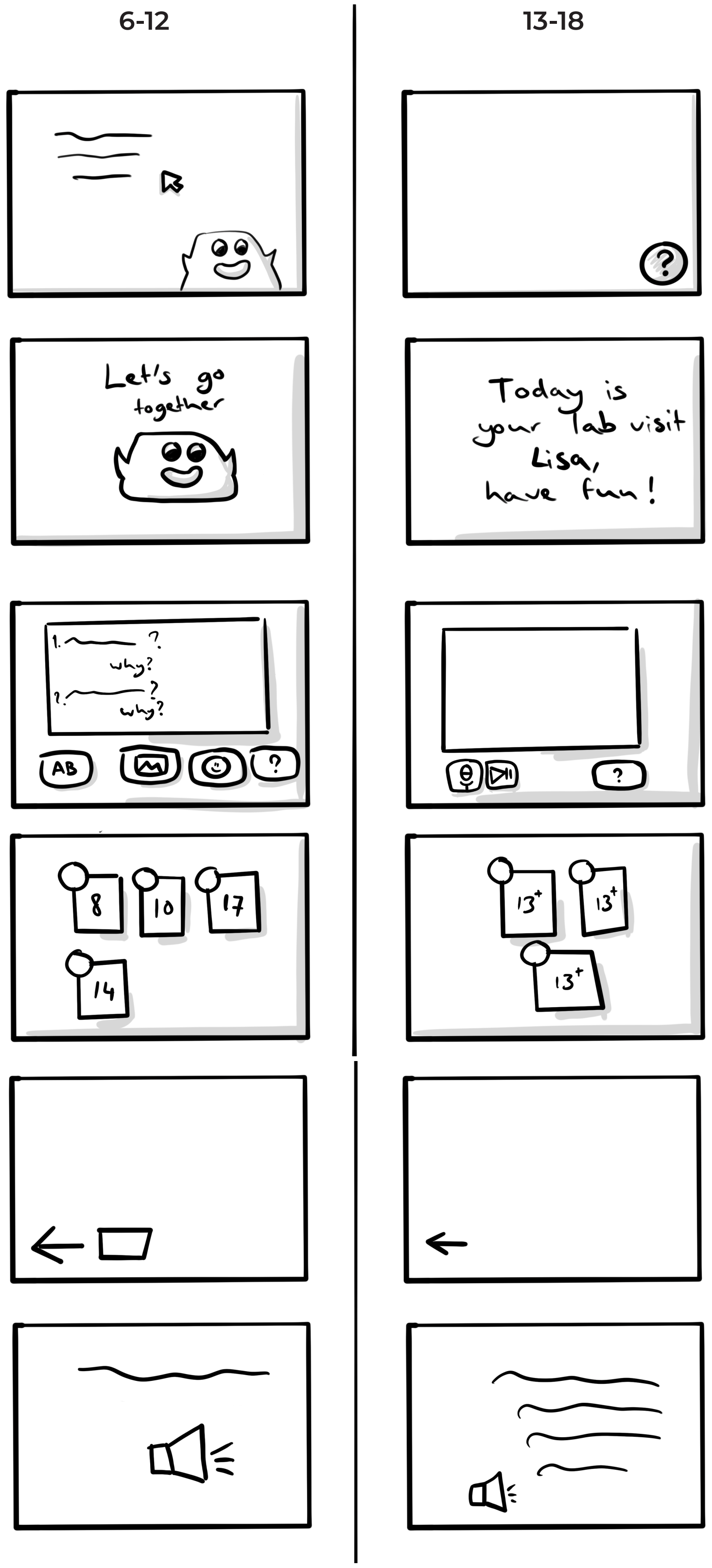


Figure 44 | Overview of all the iterated versions of the prototype

Buddy
In the 13-18 version, the buddy is replaced by normal explanation buttons with a question mark for guidance, as the buddy is seen as childish. They do not need guidance from home to the lab, so the pop-up screens where the buddy shows you support are replaced by a personal and supportive message with a reminder, for example: "Today is your lab visit, have fun!

Layout story creation
The 13-18 version does not need all the extra support tools, giving the user more freedom and more advanced options such as audio and video recording to tell their story. They are more developed in knowing what they want to tell and what is appropriate to share.

Shared stories
The shared stories can be filtered, the user can choose which ones they want to see, the formatted or free shared stories. Younger children will likely want to see both, and older children will only want to see those of their same-aged peers.

Layout
For the 13-18 version, the extra explanations for each button can be omitted, as they have already used the app and are even more used to digital devices. For accessibility reasons, the buttons should remain relatively large to make them easier to click.

Also, in the text, there should be even less in the 6-12 version and more in the 13-18 version. Both versions need a read-aloud function for accessibility, as older children may also have limited vision.

Style
Keep the style the same for both versions for consistency. Use a style that is appropriate for both user groups, such as the flat-character style. If teenagers are addressed in a mature way and the style is neutral and fun, they will engage with the app.

Misinformation

In Chapter 2, the sharing of information between peers was identified as a potential source of shock or misinformation. The parent and CBL also expressed concern that this could unnecessarily frighten children or spread negativity. It is recommended that a type of feedback mechanism is considered. For example, a user feedback system where the participants can state if they think information is wrong, giving them also more control. While it is important to empower children, it is necessary for a CBL clinician to fact-check any flagged misinformation. Not all misinformation is harmful and can actually allow children to articulate their interpretations of tests or results. However, it should not negatively impact other children. Next to this, it should be evident to all users which information is subjective and which information is provided by the CBL and therefore definitive. This can be achieved by introducing a verification label, for instance, to indicate the reliability of information. Although not all misinformation is considered harmful, it is also seen as a strength of the concept. Letting children explain what they think something (e.g. a test or a result) means, but it should not harm other children.

Next to this, it should be clear to all users what information is subjective and what information is provided by the CBL and therefore definitely correct, this could be done by a verification label for example to show what information is true.

FURTHER RESEARCH

Improved evaluation method

- Evaluation in the context of the CBL as the intended use is mainly before and after the visit, and now the participants had to think hard to know what they had done at the lab.
- High fidelity prototype where the user can choose what to share, instead of through a guided scenario, as this was one of the main goals of the design (to empower) and is now hard to evaluate.
- The evaluation should be done with one interviewer and one observer, as it was currently quite hard to evaluate the app's usability, observe objectively, and look at expressions.

Risk assessment

More research into the risks of peer-sharing is recommended, addressing concerns such as misinformation and the sharing of personal data. This evaluation can be achieved by analysing comparable apps, literature, or by conducting a live study of Lab Maatjes (if it is realised).

Usability

Invest in more extensive user research to evaluate the app's usability continuously. To ensure the user feels competent using the app.

Look and feel

Involve CBL participants in co-creation sessions for the app's looks, support features, and layout to see what they think is cool and clear.

Sharing

Conduct long-term testing to assess the app's impact on users and their sharing behaviours over extended periods. And see what kind of information they share and iterate the design features based on their input. An alternative is to do this research before the app is online by conducting creative sessions with multiple multimedia tools and letting the CBL participants (who have been to the lab) describe their experiences. To see what tools they would use and what kind of information they would talk about.

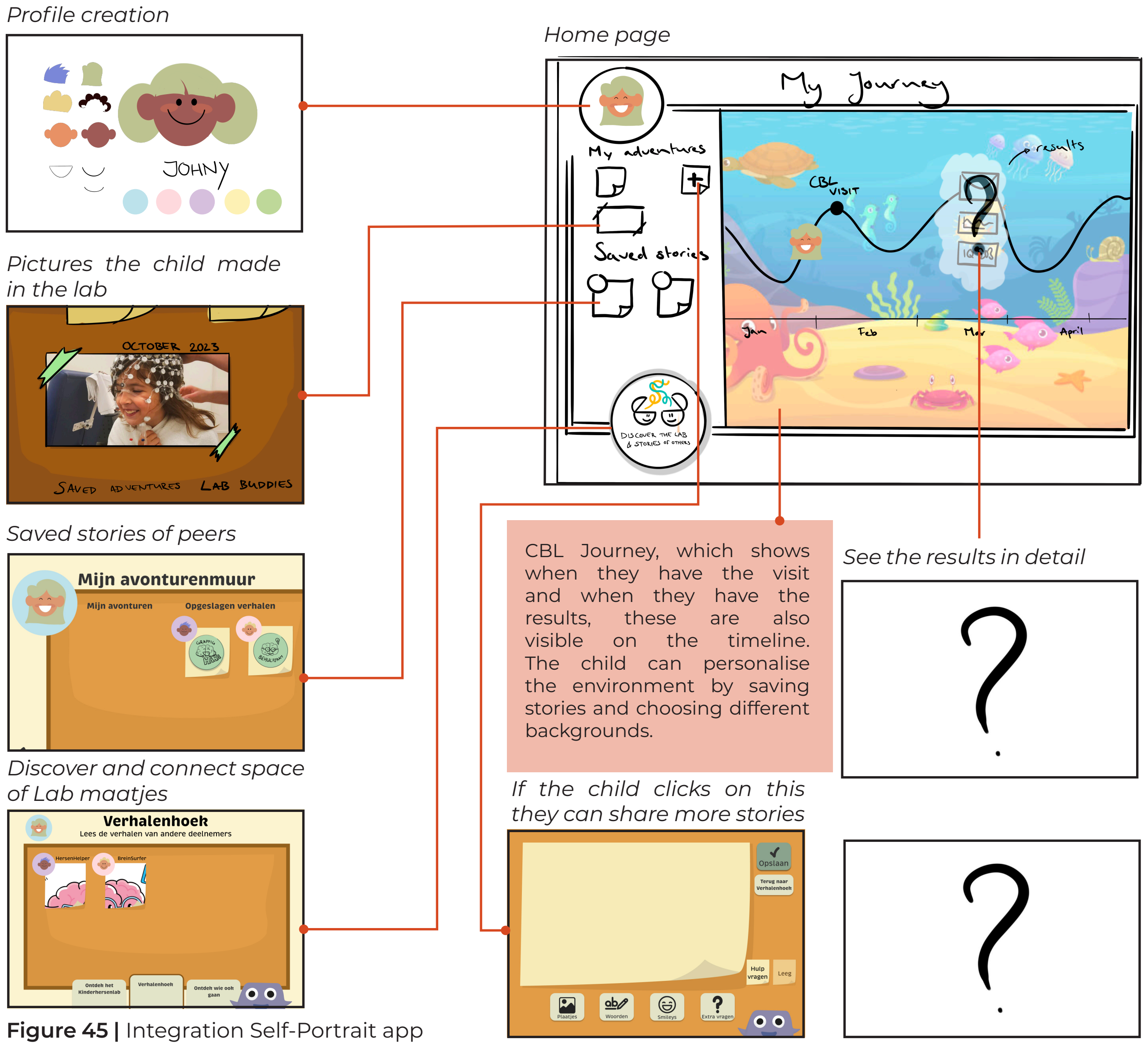
IMPLEMENTATION

INTEGRATION IN SELF-PORTRAIT APP

Lab Maatjes' is recommended for integration into the Self-Portrait. It was designed to be easily adaptable and implementable. It is difficult to conclude how this integration would look like because, so far, only three concepts have been made for the Self-Portrait, all three of which are quite different, and the CBL is deciding between them or making a combination. However, a proposal is made based on MCW's concepts and the prototype shown by MCW's graduate intern, who also made a prototype for the Self-Portrait app. Her prototype was mainly based on the concept of making the CBL experience a travel journey through the lab.

The proposal is outlined in the figure below. For the first use of the app, keep the onboarding the same to make it feel special for the participant receiving the invitation and spark curiosity about the app and the lab.

Choosing a buddy and creating a profile would also be at the beginning, along with some practicalities about parental consent and the app's difficulty level. After this, the personal board will be integrated with a journey map of the CBL, where the results of the self-portrait will be given. Then, to explore the lab and see more stories, the user can click on this page to go to the proposed screens of the Lab Maatjes prototype.



CBL Journey, which shows when they have the visit and when they have the results, these are also visible on the timeline. The child can personalise the environment by saving stories and choosing different backgrounds.

Figure 45 | Integration Self-Portrait app

ICEBERG MODEL

All of the sessions with the children emphasised their obvious enjoyment in sharing their opinions during this study, highlighting the importance of incorporating even more child-centred principles into CBL.

The iceberg model was developed in response to this potential. See Figure 46. This framework illustrates the relationship between how participants' expression of their perspectives can contribute to improving the CBL, which is again beneficial for the participants. The bottom layers demonstrate personal value for participants, such as reflecting on and preserving their experiences for the future, allowing for retrospective engagement as they age. Subsequently, sharing these stories promotes shared value by encouraging collective exploration of commonly held viewpoints. These two layers, 'personal and collective subjective', are already reflected in Lab Maatjes. The CBL can then utilise this collective insight (consensus layer) to refine its information provision and facilitate effective expectation management.

In addition, this approach provides insights into how CBL tests are experienced and if these experiences are as they expect them to be, highlighting areas for potential improvement, thereby enriching the CBL journey overall. This strategic framework is rooted in the foundational concepts outlined in the introductory chapter, which clarified VBHC principles and the use of surveys to capture children's viewpoints. The model is argued to offer a more natural way for children to express their emotions and opinions openly. Nevertheless, it is important to recognise that this approach requires a more complex review process and is less suitable for direct quantitative comparisons. Yet, in this context, the qualitative experiential insights gained from the CBL have significant value that may surpass quantitative metrics requirements.

Also, to make this model ethically appropriate, at the beginning of the app, it should be mentioned that parents and CBL clinicians can read the stories shared in the 'Verhalenhoek' for the platform's safety. Hence, users know that when they share their story, it will not only be read by other CBL participants. In this study, all participants who were asked thought it was okay or even nice for a clinician to read their story. As Isabella mentioned; *"Good, that way they also learn and can adjust care accordingly!"*. Also, the app should give the information that sharing a story could lead to improvements in the lab, but be very specific that it is difficult and the chances of this happening are not high, to manage the user's expectations so that they know it is not always the case.

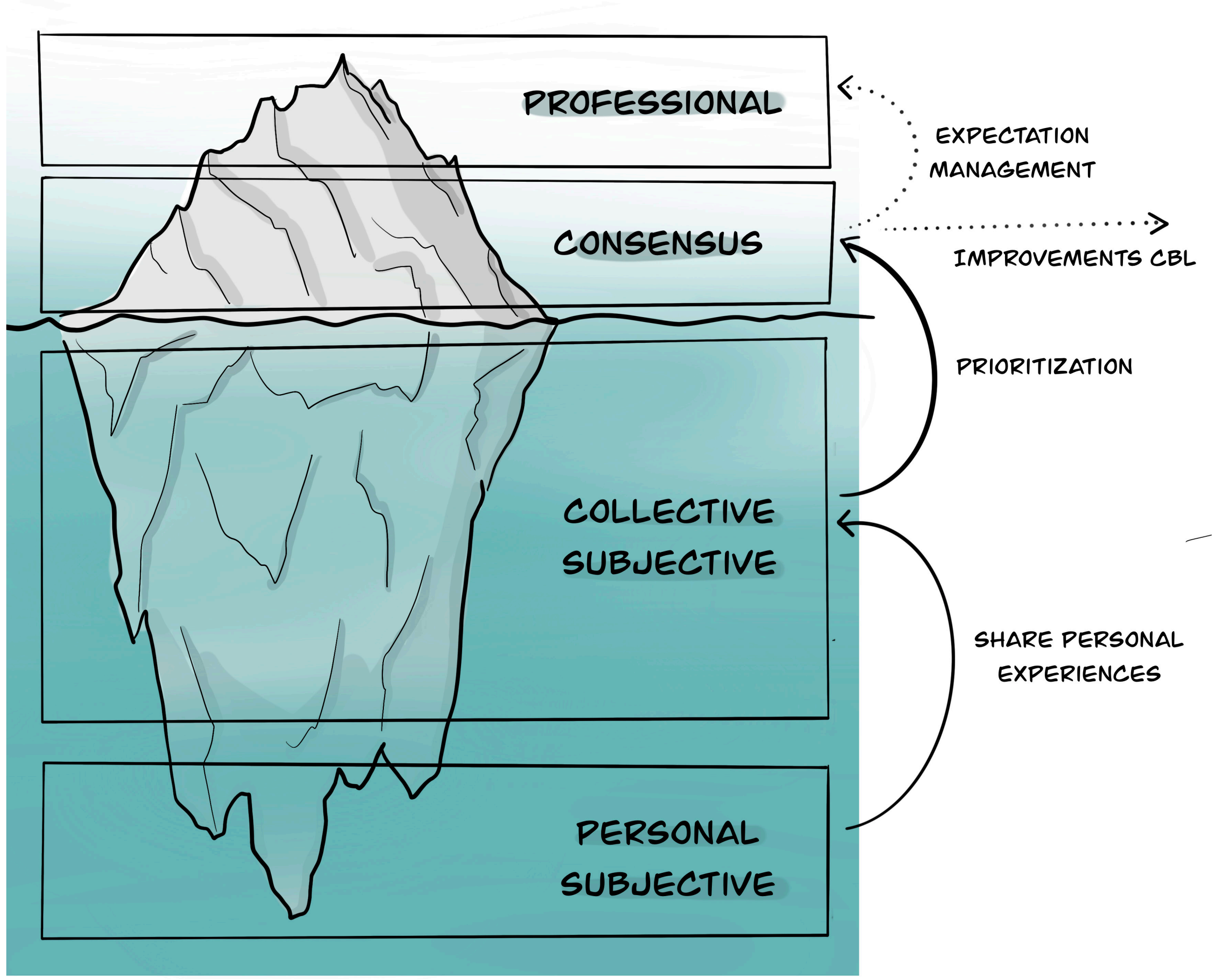


Figure 46 | Iceberg model

Professional layer

This layer can use all the input given by participants in the app to enhance their professional information provision with insights from the children's perspectives. And implement this in expectation management in the 'Discover the lab' function of Lab Maatjes.

Consensus layer

The consensus layer enables participants to prioritise the most important and relevant experiences. These perspectives, originating from the collaborative efforts of CBL participants, can be incorporated into the professional layer or further improved within the CBL environment. This layer aims to make the lab more child-centred and enjoyable.

Subjective collective layer

This layer caters to experienced participants who are already familiar with the proceedings and do not require superficial information. They are primarily interested in discussing, asking questions, and sharing experiences with others. By doing so, they contribute to the collective knowledge and foster a sense of community.

Personal subjective layer

The personal subjective layer serves as a means to support participants in processing information and experiences. It provides them with a space to reflect on their preferences and dislikes.

Descriptive videos of the rooms of the CBL by CB

In the evaluation with CBL clinicians, the question was raised about whether there could be only three videos of each room, as this would be more feasible. This research shows the importance of a sense of control, recognition and the feeling that CB's contributions are valued. The videos would be a good addition to the general information about the room, as this is an engaging way of showing what will happen. However, the value of being able to tell their own story and read those of several others will increase recognition as they will not only see the three children who are likely to have only three different conditions. The sense of control still needs to be improved, as the CB have little say in what the information will be about. Finally, as observed in the evaluation session and the earlier interviews, CB like to help others or see how they are helping to improve the hospital and compare their thoughts with others, which is impossible if not every CB are allowed to express their views.

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During the writing of this thesis the author used Grammarly, DeepL Write and ChatGPT in order to correct grammar and spelling and clarify sentences. For ChatGPT specifically only promts like 'check this sentence for redundancy' or 'smooth out this sentence' are used. After using this tool/service, the author reviewed and edited the content as needed and takes full responsibility for the content of this thesis.

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Appendix

A	Project brief
B	Overview CBL tests
C	Overview development of children
D	Research materials
E	Overview CB (participants)
F	Research analysis
G	Analysis existing tools
H	Peer brainstorm sessions
I	Analysis concept idea
J	First ideas
K	Evaluation plan
L	Prototype versions

APPENDIX A | Project brief

Facilitating Peer Connections and Information Sharing in Child Brain Lab 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 06 - 03 - 2023

09 - 09 - 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, ...).

Hospital visits can be stressful for anyone, but children are especially vulnerable to feeling out of control because of disruptions in their routines and unfamiliar surroundings (Lerwick, 2016). Furthermore, information is not presented in a way that they can understand, leaving them feeling anxious and powerless (Coyne et al., 2014). To promote a positive healthcare experience, it is important to find ways to put children at ease and give them a sense of control.

The Child Brain Lab (CBL) at ErasmusMC, Sophia Children's Hospital, aims to measure brain function and development in children aged 0 to 18. The lab is designed as a playful circuit with three rooms dedicated to testing cognition, senses, motor skills, and more (Figure 1). Children also complete a questionnaire and undergo an MRI scan to create a 3D photo of the brain.

"Our mission is that all children with brain disorders can participate in society at their optimal level," states the CBL. To accomplish this goal, the lab has created two graduation projects together with the Play Well Lab (PWL). The first project, "Zelfportret," is a continuation of previous studies done by Loes Tielen en Paul Meulendijks. It aims to create a specialised children's patient file that will serve as a self-portrait of their brain disorders and include test outcome measures. The second project seeks to connect patients in order for them to share knowledge and learn from one another's experiences. By communicating on an equal level with peers, children are empowered to be their own experts and regain control over their medical conditions. Given how highly children value their peers' opinions, it also stimulates their interest and enjoyment (Meulendijks et al., 2022). This allows participants to develop a sense of community and mutual learning (Figure 2).

Not only do children benefit from the project, but so do various types of doctors and carers, as well as parents or guardians. When a child is calm and prepared for a test, it benefits all parties involved. Parents can also benefit from seeing other children with the same brain disorders as their child to better understand their child's future capabilities.
I am under contract with the PWL, and the CBL is the project's client; they provide knowledge, a network for recruiting participants, and subject-matter experts. The project is a collaboration between both parties, and my contributions are research findings and the final design.

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image / figure 1: Mobility test room in the Child Brain Lab

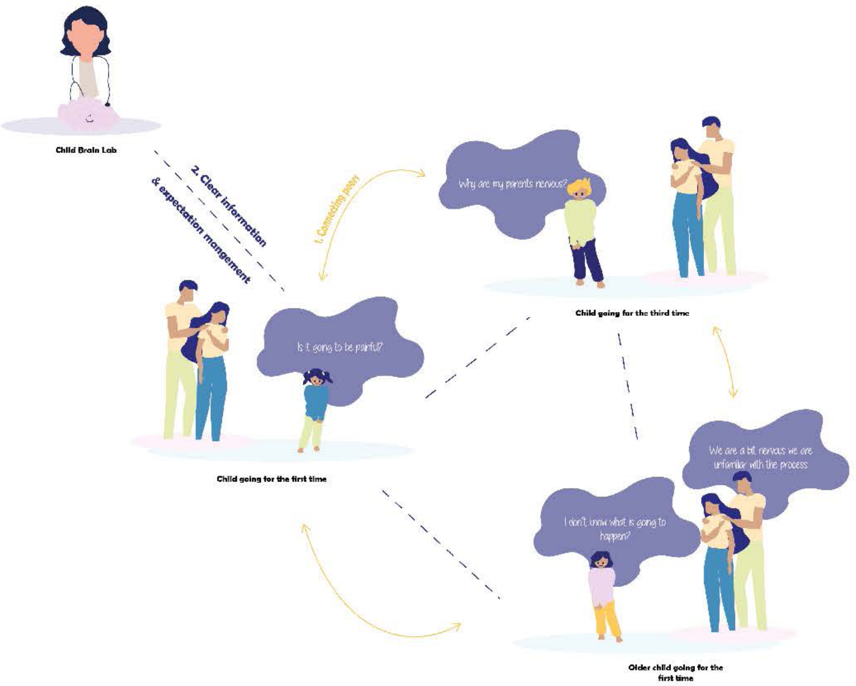


image / figure 2: Context of project including current solution spaces

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.

As mentioned in the introduction, children often feel neglected in their own care, making it important to focus on child-centered care [2]. The Child Brain Lab is aware of this problem and continually seeks to improve the patient experience. The question, "How can we connect participants of the Child Brain Lab to their peers so they can share experiences and learn from one another?" is posed to explore the possibility of peer support. By doing this, it might make it easier for children to cope with their chronic brain disorder and all the tests. Additionally, this initiative may reduce children's feelings of loneliness and isolation, making them more motivated to participate and easier to work with during testing.

There are very few times when children do not interact with their peers, whether at school, in their neighborhoods, or elsewhere. As a result, connecting with their peers is an essential part of their lives. However, in the hospital, they rarely encounter other children. Challenging this project to reinvent these points of contact with peers within medical settings.

Other sub-questions raised by this situation include:
- What do the participants want to get out of peer sharing (e.g. peer bonding, recognition, information)?
- What would they like to share (e.g. experiences, emotions, practical facts)?
- How to ensure that the design is for every child engaging and useful?

To conclude, this project focuses on creating opportunities for peer bonding, recognition, and sharing of practical facts and emotions. Aside from that, it could also explore ways to improve test preparation and make the test experience more enjoyable. By addressing these issues/possibilities, the design could have a meaningful impact on the patient experience and improve child-centered care.

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.

My desired outcome for this project is to develop a design concept that will allow participants aged 6-12 in the Child Brain Lab to form meaningful connections. It also allows children to learn from the experiences of others, increasing their self confidence, and spark curiosity about being a particpant of the Child Brain Lab.

To achieve the desired result, I must consider several important topics:
- The target group is diverse in terms of brain disorders, abilities, age differences, personality traits, and interests, so making the concept customizable or grouping participants based on different characteristics could be helpful. This will give them a sense of ownership and encourage greater participation and curiosity.
- Communication must be adjusted to be sensitive to their medical issues and young age. Paying extra attention to ensure that they understand the goals and benefits of the sessions.
- It is crucial to determine what kinds of information the children find useful to share and to understand the dangers associated with peer-to-peer communication and medical conditions. Nonetheless, meaningful connections can empower children to be curious, become experts on their brain conditions, and reclaim control in uncertain medical environments.
- Creative sessions must be enjoyable and simple to understand to engage the children, and the environment must be safe and fitting to their specific needs.

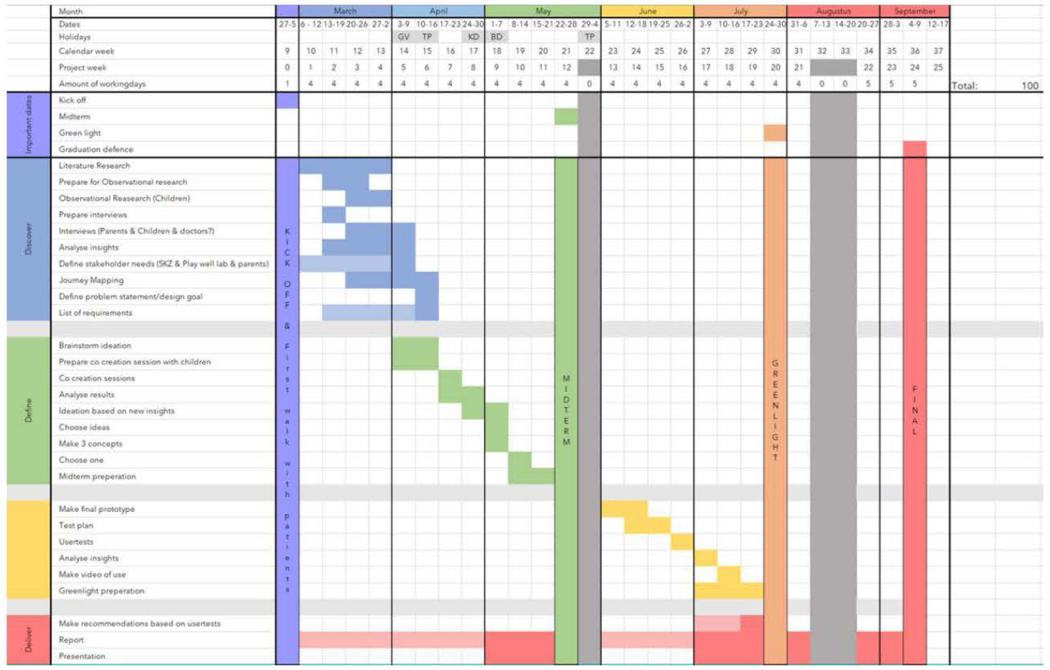
Two opportunities to investigate are; integrating my project with the "Zelfportret". To create an overarching platform that contains all of the tools needed by Child Brain Lab participants. This can improve learning and make the testing process easier to understand and navigate for both children and parents. Secondly, using the waiting period to improve the children's test preparation and make their test journey more enjoyable. As these times are currently spent alone and perceived as anxious and tedious.

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 6 - 3 - 2023

9 - 9 - 2023 end date



My process is split up into four phases, discover, define, develop and deliver.
The discover phase is doing research, by conducting interviews, observations of the tests and desk research. The goal is to find out the needs and wishes of the children and set the context.

The defining stage is about finding the best fitting design by using lo-fi prototypes and doing co-creation sessions to get the input of the target group on how they want the design to look, feel and work. The goal is to come up with one idea/concept.

In the developing stage, I will work out this idea by creating a prototype to test with a few children. So I can see where the improvements lay and create the final product which I will deliver together with the other deliverables.

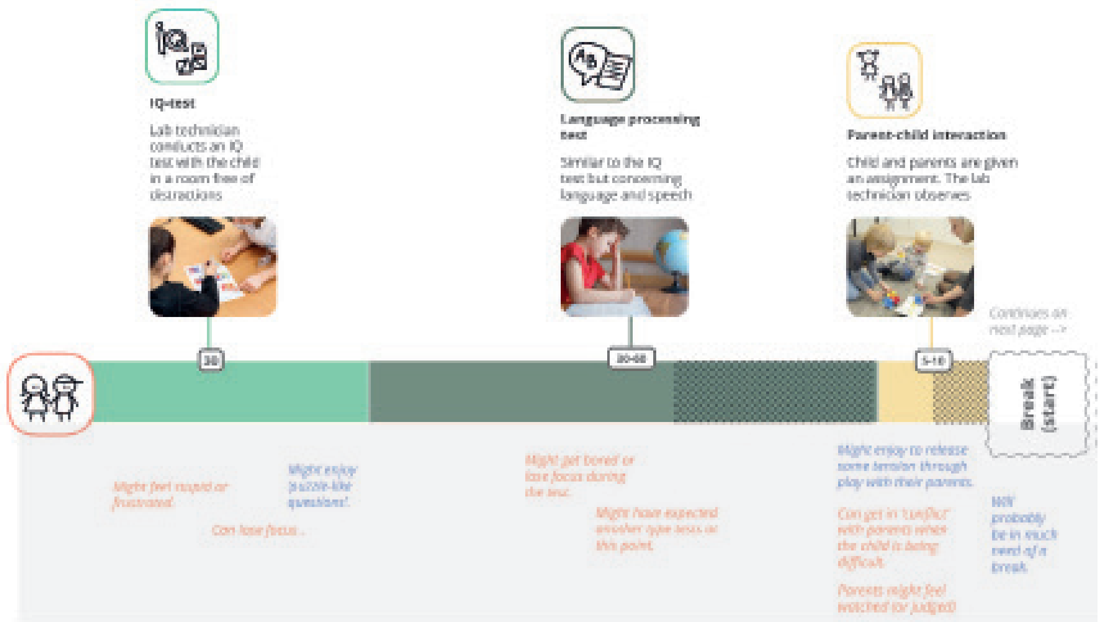
I formed my planning so I can work one day and the other for days to be busy with graduating. My job is at the serious game design studio &ranj and I can work remotely which makes it convenient to combine with graduating. Next to this, I will be three weeks off one week after the Midterm to take a break in between and two weeks in August, due to the summer vacation I already had planned.

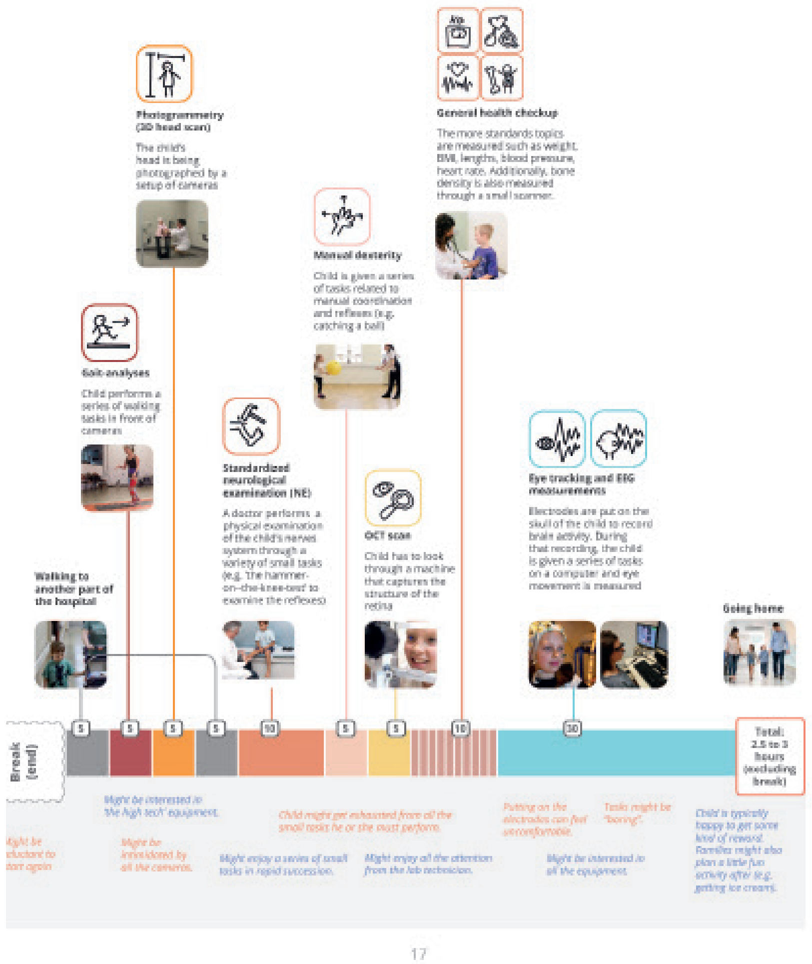
Other points of attention are that the research phase could be delayed. For example, caused of planning issues with both parents and children, the ethics approval is not being signed yet.
Secondly in the summer, my green light is planned which could also have some difficulties in planning with parties that may have a vacation.

APPENDIX B | Overview tests CBL

Meulendijks, 2020, p.16-17

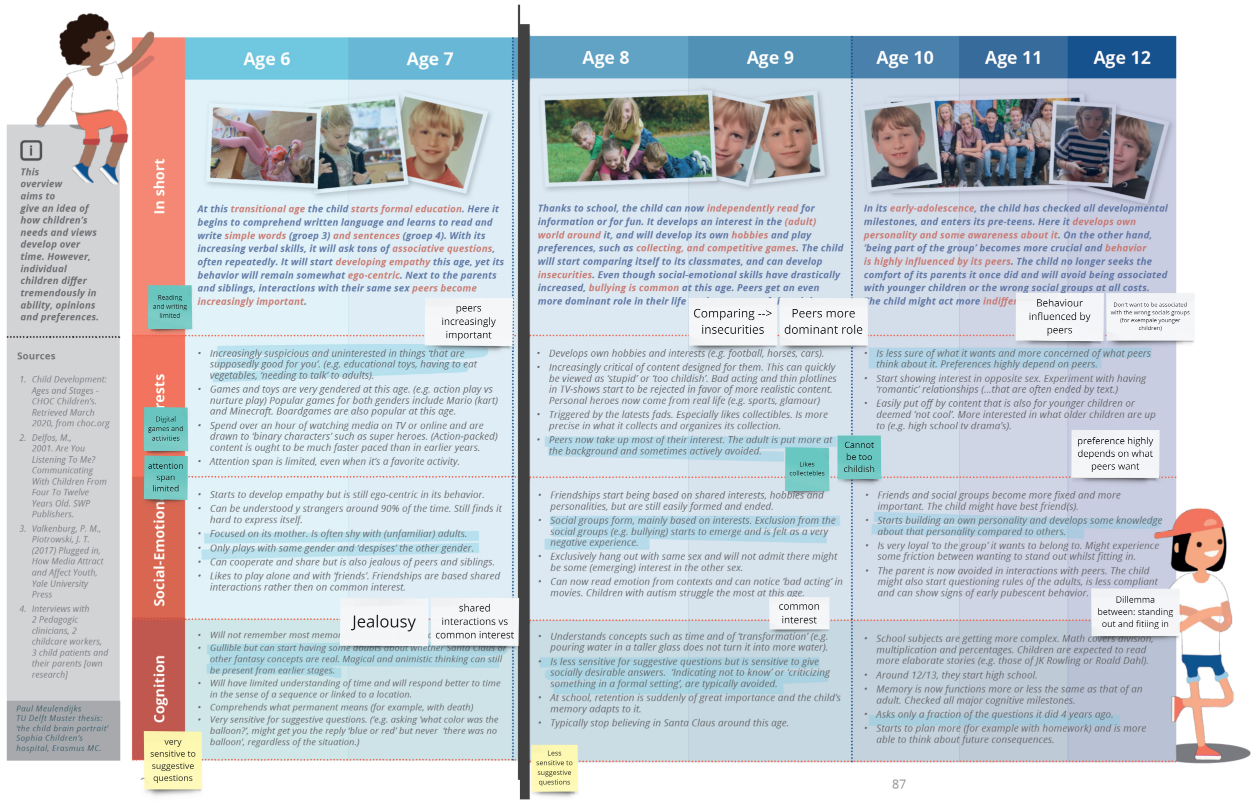
The order and time span is not fitting with the current way of testing anymore as explained in Chapter 2, but the tests are still correct.





APPENDIX C | Development of children

Meulendijks, 2020, p. 86-89
Post its present all relevant points in development for this project



This overview aims to give an idea of how children's needs and views develop over time. However, individual children differ tremendously in ability, opinions and preferences.

Sources

1. Child Development: Ages and Stages - CHOC Children's. Retrieved March 2020, from choc.org
2. Delfos, M., 2001. Are You Listening To Me? Communicating With Children From Four To Twelve Years Old. SWP Publishers.
3. Valkenburg, P. M., Piotrowski, J. T. (2017) Plugged in, How Media Attract and Affect Youth, Yale University Press
4. Interviews with 2 Pedagogic clinicians, 2 childcare workers, 3 child patients and their parents [own research]

Paul Meulendijks
TU Delft Master thesis: 'the child brain portrait'
Sophia Children's hospital, Erasmus MC.

	Age 6 / Age 7	Age 8 / Age 9	Age 10 / Age 11 / Age 12
In short	At this transitional age the child starts formal education. Here it begins to comprehend written language and learns to read and write simple words (groep 3) and sentences (groep 4). With its increasing verbal skills, it will ask tons of associative questions, often repeatedly. It will start developing empathy this age, yet its behavior will remain somewhat ego-centric. Next to the parents and siblings, interactions with their same sex peers become increasingly important.	Thanks to school, the child can now independently read for information or for fun. It develops an interest in the (adult) world around it, and will develop its own hobbies and play preferences, such as collecting, and competitive games. The child will start comparing itself to its classmates, and can develop insecurities. Even though social-emotional skills have drastically increased, bullying is common at this age. Peers get an even more dominant role in their life	In its early-adolescence, the child has checked all developmental milestones, and enters its pre-teens. Here it develops own personality and some awareness about it. On the other hand, 'being part of the group' becomes more crucial and behavior is highly influenced by its peers. The child no longer seeks the comfort of its parents it once did and will avoid being associated with younger children or the wrong social groups at all costs. The child might act more indiffer
Interests	• Increasingly suspicious and uninterested in things 'that are supposedly good for you'. (e.g. educational toys, having to eat vegetables, 'needing to talk' to adults). • Games and toys are very gendered at this age. (e.g. action play vs nurture play) Popular games for both genders include Mario (kart) and Minecraft. Boardgames are also popular at this age. • Spend over an hour of watching media on TV or online and are drawn to 'binary characters' such as super heroes. (Action-packed) content is ought to be much faster paced than in earlier years. • Attention span is limited, even when it's a favorite activity.	• Develops own hobbies and interests (e.g. football, horses, cars). • Increasingly critical of content designed for them. This can quickly be viewed as 'stupid' or 'too childish'. Bad acting and thin plotlines in TV-shows start to be rejected in favor of more realistic content. Personal heroes now come from real life (e.g. sports, glamour) • Triggered by the latests fads. Especially likes collectibles. Is more precise in what it collects and organizes its collection. • Peers now take up most of their interest. The adult is put more at the background and sometimes actively avoided.	• Is less sure of what it wants and more concerned of what peers think about it. Preferences highly depend on peers. • Start showing interest in opposite sex. Experiment with having 'romantic' relationships (...that are often ended by text.) • Easily put off by content that is also for younger children or deemed 'not cool'. More interested in what older children are up to (e.g. high school tv drama's).
Social-Emotion	• Starts to develop empathy but is still ego-centric in its behavior. • Can be understood y strangers around 90% of the time. Still finds it hard to express itself. • Focused on its mother. Is often shy with (unfamiliar) adults. • Only plays with same gender and 'despises' the other gender. • Can cooperate and share but is also jealous of peers and siblings. • Likes to play alone and with 'friends'. Friendships are based shared interactions rather then on common interest.	• Friendships start being based on shared interests, hobbies and personalities, but are still easily formed and ended. • Social groups form, mainly based on interests. Exclusion from the social groups (e.g. bullying) starts to emerge and is felt as a very negative experience. • Exclusively hang out with same sex and will not admit there might be some (emerging) interest in the other sex. • Can now read emotion from contexts and can notice 'bad acting' in movies. Children with autism struggle the most at this age.	• Friends and social groups become more fixed and more important. The child might have best friend(s). • Starts building an own personality and develops some knowledge about that personality compared to others. • Is very loyal 'to the group' it wants to belong to. Might experience some friction between wanting to stand out whilst fitting in. • The parent is now avoided in interactions with peers. The child might also start questioning rules of the adults, is less compliant and can show signs of early pubescent behavior.
Cognition	• Will not remember most memor • Gullible but can start having some doubts about whether Santa Claus or other fantasy concepts are real. Magical and animistic thinking can still be present from earlier stages. • Will have limited understanding of time and will respond better to time in the sense of a sequence or linked to a location. • Comprehends what permanent means (for example, with death) • Very sensitive for suggestive questions. ('e.g. asking 'what color was the balloon?', might get you the reply 'blue or red' but never 'there was no balloon', regardless of the situation.)	• Understands concepts such as time and of 'transformation' (e.g. pouring water in a taller glass does not turn it into more water). • Is less sensitive for suggestive questions but is sensitive to give socially desirable answers. 'Indicating not to know' or 'criticizing something in a formal setting', are typically avoided. • At school, retention is suddenly of great importance and the child's memory adapts to it. • Typically stop believing in Santa Claus around this age.	• School subjects are getting more complex. Math covers division, multiplication and percentages. Children are expected to read more elaborate stories (e.g. those of JK Rowling or Roald Dahl). • Around 12/13, they start high school. • Memory is now functions more or less the same as that of an adult. Checked all major cognitive milestones. • Asks only a fraction of the questions it did 4 years ago. • Starts to plan more (for example with homework) and is more able to think about future consequences.

Reading and writing limited

peers increasingly important

Digital games and activities

attention span limited

Jealousy

shared interactions vs common interest

very sensitive to suggestive questions

Comparing --> insecurities

Peers more dominant role

Likes collectebles

Cannot be too childish

common interest

Less sensitive to suggestive questions

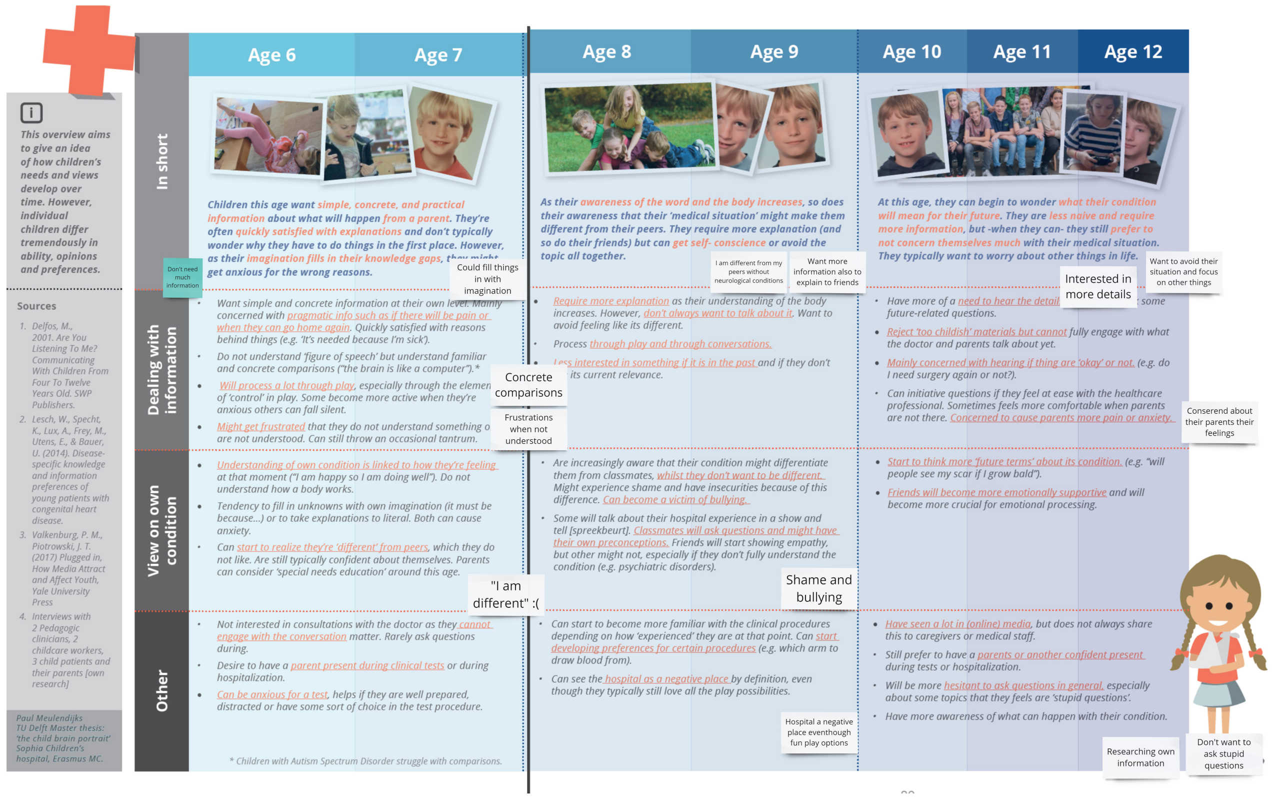
Behaviour influenced by peers

Don't want to be associated with the wrong socials groups (for exempale younger children)

preference highly depends on what peers want

Dillemma between: standing out and fitiing in

87



This overview aims to give an idea of how children's needs and views develop over time. However, individual children differ tremendously in ability, opinions and preferences.

Sources

1. Delfos, M., 2001. Are You Listening To Me? Communicating With Children From Four To Twelve Years Old. SWP Publishers.
2. Lesch, W., Specht, K., Lux, A., Frey, M., Utens, E., & Bauer, U. (2014). Disease-specific knowledge and information preferences of young patients with congenital heart disease.
3. Valkenburg, P. M., Piotrowski, J. T. (2017) Plugged in, How Media Attract and Affect Youth, Yale University Press
4. Interviews with 2 Pedagogic clinicians, 2 childcare workers, 3 child patients and their parents [own research]

Paul Meulendijks
TU Delft Master thesis: 'the child brain portrait'
Sophia Children's hospital, Erasmus MC.

	Age 6 / Age 7	Age 8 / Age 9	Age 10 / Age 11 / Age 12
In short	Children this age want simple, concrete, and practical information about what will happen from a parent. They're often quickly satisfied with explanations and don't typically wonder why they have to do things in the first place. However, as their imagination fills in their knowledge gaps, they might get anxious for the wrong reasons.	As their awareness of the word and the body increases, so does their awareness that their 'medical situation' might make them different from their peers. They require more explanation (and so do their friends) but can get self- conscience or avoid the topic all together.	At this age, they can begin to wonder what their condition will mean for their future. They are less naive and require more information, but -when they can- they still prefer to not concern themselves much with their medical situation. They typically want to worry about other things in life.
Dealing with information	• Want simple and concrete information at their own level. Mainly concerned with pragmatic info such as if there will be pain or when they can go home again. Quickly satisfied with reasons behind things (e.g. 'It's needed because I'm sick'). • Do not understand 'figure of speech' but understand familiar and concrete comparisons ("the brain is like a computer").* • Will process a lot through play, especially through the elemen of 'control' in play. Some become more active when they're anxious others can fall silent. • Might get frustrated that they do not understand something o are not understood. Can still throw an occasional tantrum.	• Require more explanation as their understanding of the body increases. However, don't always want to talk about it. Want to avoid feeling like its different. • Process through play and through conversations. • Less interested in something if it is in the past and if they don't its current relevance.	• Have more of a need to hear the detail some future-related questions. • Reject 'too childish' materials but cannot fully engage with what the doctor and parents talk about yet. • Mainly concerned with hearing if thing are 'okay' or not. (e.g. do I need surgery again or not?). • Can initiative questions if they feel at ease with the healthcare professional. Sometimes feels more comfortable when parents are not there. Concerned to cause parents more pain or anxiety.
View on own condition	• Understanding of own condition is linked to how they're feeling at that moment ("I am happy so I am doing well"). Do not understand how a body works. • Tendency to fill in unknowns with own imagination (it must be because...) or to take explanations to literal. Both can cause anxiety. • Can start to realize they're 'different' from peers, which they do not like. Are still typically confident about themselves. Parents can consider 'special needs education' around this age.	• Are increasingly aware that their condition might differentiate them from classmates, whilst they don't want to be different. Might experience shame and have insecurities because of this difference. Can become a victim of bullying. • Some will talk about their hospital experience in a show and tell [spreekbeurt]. Classmates will ask questions and might have their own preconceptions. Friends will start showing empathy, but other might not, especially if they don't fully understand the condition (e.g. psychiatric disorders).	• Start to think more 'future terms' about its condition. (e.g. "will people see my scar if I grow bald"). • Friends will become more emotionally supportive and will become more crucial for emotional processing.
Other	• Not interested in consultations with the doctor as they cannot engage with the conversation matter. Rarely ask questions during. • Desire to have a parent present during clinical tests or during hospitalization. • Can be anxious for a test, helps if they are well prepared, distracted or have some sort of choice in the test procedure.	• Can start to become more familiar with the clinical procedures depending on how 'experienced' they are at that point. Can start developing preferences for certain procedures (e.g. which arm to draw blood from). • Can see the hospital as a negative place by definition, even though they typically still love all the play possibilities.	• Have seen a lot in (online) media, but does not always share this to caregivers or medical staff. • Still prefer to have a parents or another confident present during tests or hospitalization. • Will be more hesitant to ask questions in general, especially about some topics that they feels are 'stupid questions'. • Have more awareness of what can happen with their condition.

* Children with Autism Spectrum Disorder struggle with comparisons.

Don't need much information

Could fill things in with imagination

Concrete comparisons

Frustrations when not understood

"I am different" :(

I am different from my peers without neurological conditions

Want more information also to explain to friends

Shame and bullying

Hospital a negative place eventhough fun play options

Interested in more details

Want to avoid their situation and focus on other things

Conserend about their parents their feelings

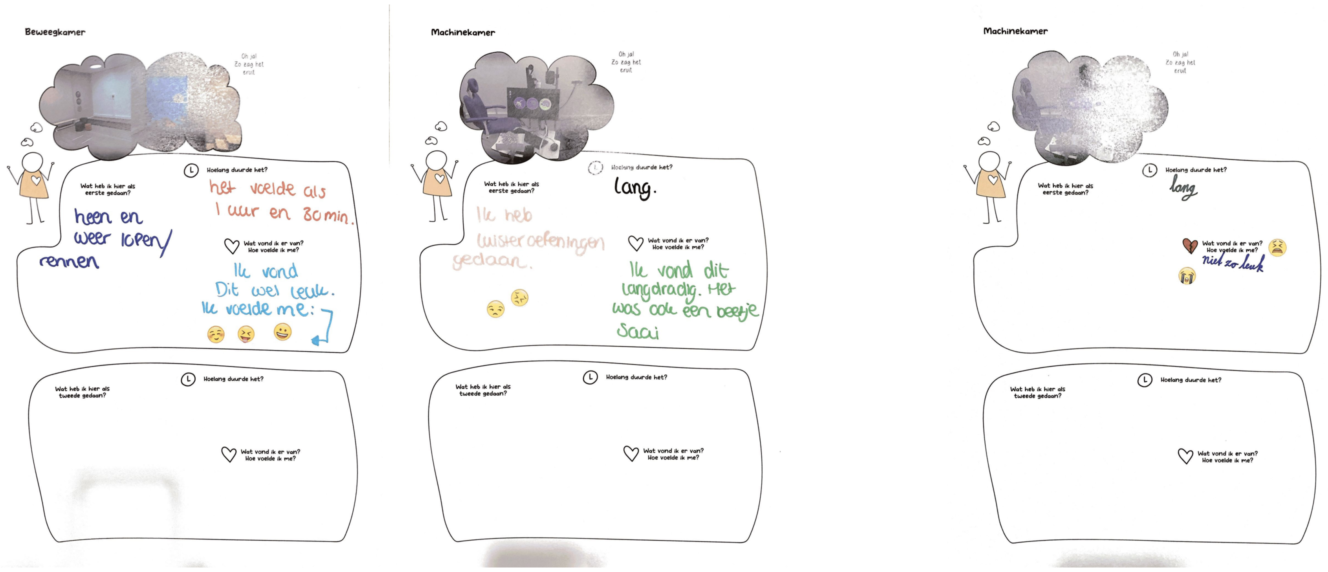
Researching own information

Don't want to ask stupid questions

APPENDIX D | Research activities materials

Make-and-say sessions

In this Appendix on the left is the first session shown and on the right page is the second version of the session shown. Both filled in.



Beweegkamer

Oh ja! Zo zag het eruit

Wat heb ik hier als eerste gedaan? heen en weer lopen/ rennen

Hoelang duurde het? het voelde als 1 uur en 30 min.

Wat vond ik er van? Hoe voelde ik me? Ik vond Dit wel leuk. Ik voelde me: 😊 😝 😀

Wat heb ik hier als tweede gedaan?

Hoelang duurde het?

Wat vond ik er van? Hoe voelde ik me?

Machinekamer

Oh ja! Zo zag het eruit

Wat heb ik hier als eerste gedaan? Ik heb luisteroefeningen gedaan.

Hoelang duurde het? lang.

Wat vond ik er van? Hoe voelde ik me? Ik vond dit langdradig. Het was ook een beetje Saai 😒 😤

Wat heb ik hier als tweede gedaan?

Hoelang duurde het?

Wat vond ik er van? Hoe voelde ik me?

Machinekamer

Oh ja! Zo zag het eruit

Wat heb ik hier als eerste gedaan?

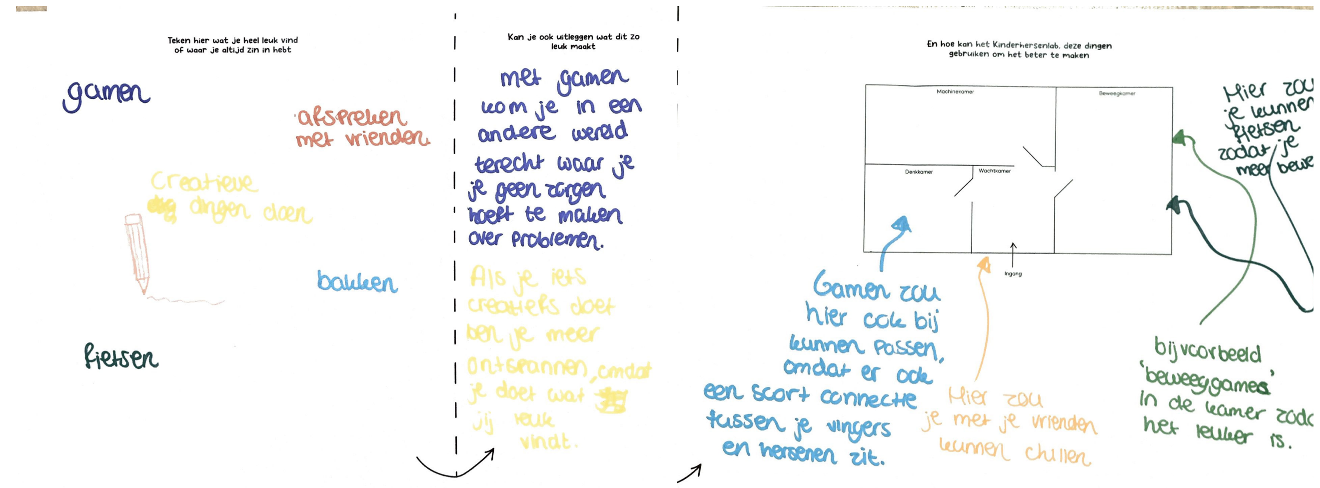
Hoelang duurde het? lang

Wat vond ik er van? Hoe voelde ik me? niet zo leuk 😫 😭

Wat heb ik hier als tweede gedaan?

Hoelang duurde het?

Wat vond ik er van? Hoe voelde ik me?



Teken hier wat je heel leuk vind of waar je altijd zin in hebt

gamen

afspreken met vrienden

Creatieve ~~dig~~ dingen doen

bakken

fietsen

Kan je ook uitleggen wat dit zo leuk maakt

met gamen kom je in een andere wereld terecht waar je je geen zorgen hoeft te maken over problemen.

Als je iets creatiefs doet ben je meer ontspannen, omdat je doet wat jij leuk vindt.

En hoe kan het Kinderhersenlab. deze dingen gebruiken om het beter te maken

Gamen zou hier ook bij kunnen passen, omdat er ook een scort connectie tussen je vingers en hersenen zit.

Hier zou je met je vrienden kunnen chillen

Hier zou je kunnen fietsen zodat je meer bewe

bijvoorbeeld 'beweeggames' in de kamer zodat het leuker is.

Wat zou jij Joris allemaal vertellen of laten zien?

Bijvoorbeeld: Je moet heel lang stilzitten

De beweegruimte is het leukste naar mijn mening.

De testpersoon/arts zijn heel aardig en geven goede uitleg.

aan het einde krijg je meestal een cadeau, dus dan kan je ergens naar uitkijken.

Je kan je eigen 'maatje' kiezen.

Je hoeft niet bang te zijn voor wat er gaat komen.

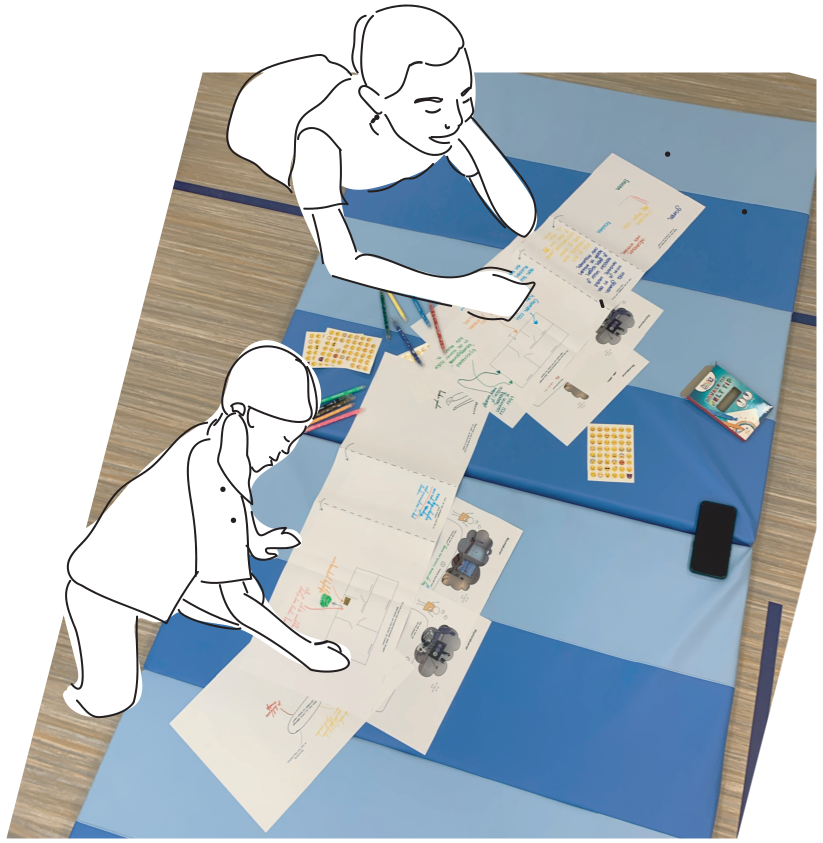
Heyy! Ik ben Joris en ga binnenkort naar het Kinderhersenlab. Jij weet daar alles van hoorde ik...

Wat zou jij Joris allemaal vertellen of laten zien?

Bijvoorbeeld: Je moet heel lang stilzitten

je hebt een maatje

Heyy! Ik ben Joris en ga binnenkort naar het Kinderhersenlab. Jij weet daar alles van hoorde ik...



Hoe kunnen Joris en Saar elkaar helpen?

Teken of schrijf hier al je ideeen

alles mag!

Ze kunnen Samen gaaN

zakken elkaar om helpen

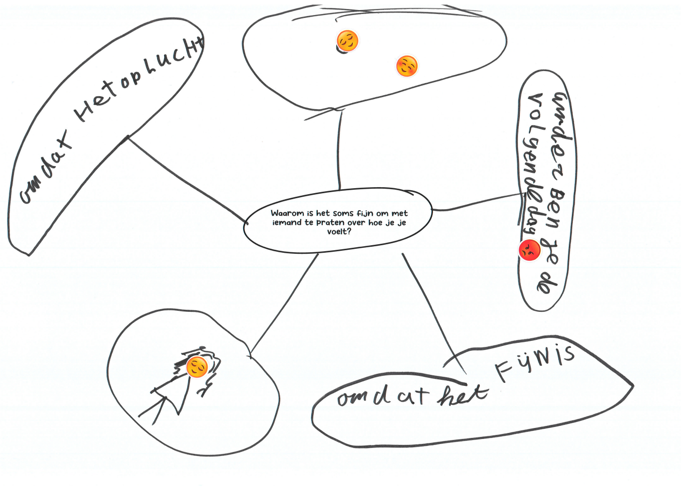
ze kunnen vertellen Hoe Het was

Heyy! Ik ben Joris en ga binnenkort naar het Kinderhersenlab. Jij weet daar alles van hoorde ik...

Heyy! Ik ben Saar en ga ook binnenkort naar het Kinderhersenlab.

was ze eznau

was ze na

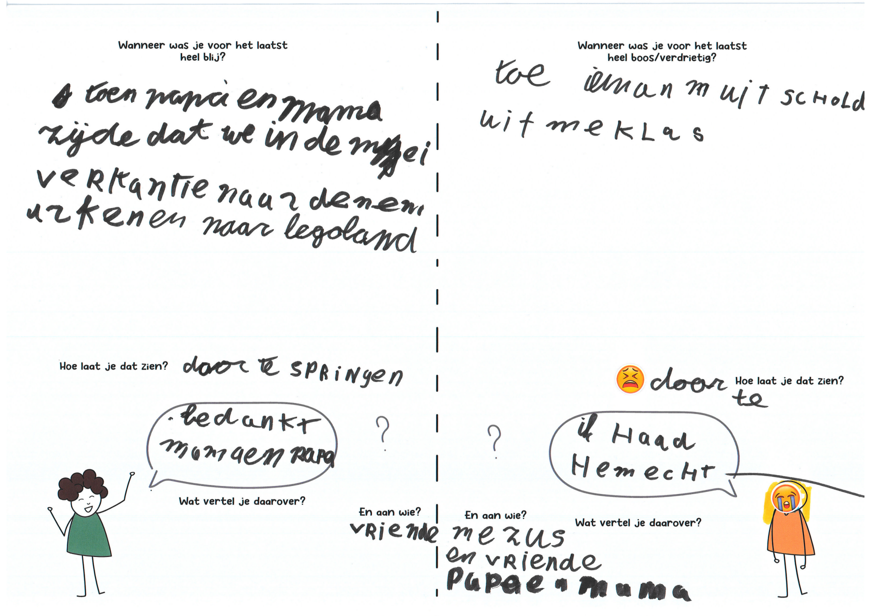


Waarom is het soms fijn om met iemand te praten over hoe je je voelt?

omdat Het oplucht

omdat het Fijn is

omdat ben je de volgende dag



Wanneer was je voor het laatst heel blij?

toen papa en mama zijde dat we in de mei verkantie naar denemarken naar legoland

Hoe laat je dat zien? door te springen

Wat vertel je daarover? bedankt mama en papa

En aan wie? vriende

Wanneer was je voor het laatst heel boos/verdrietig?

toe iemand mij uit schold uit me klas

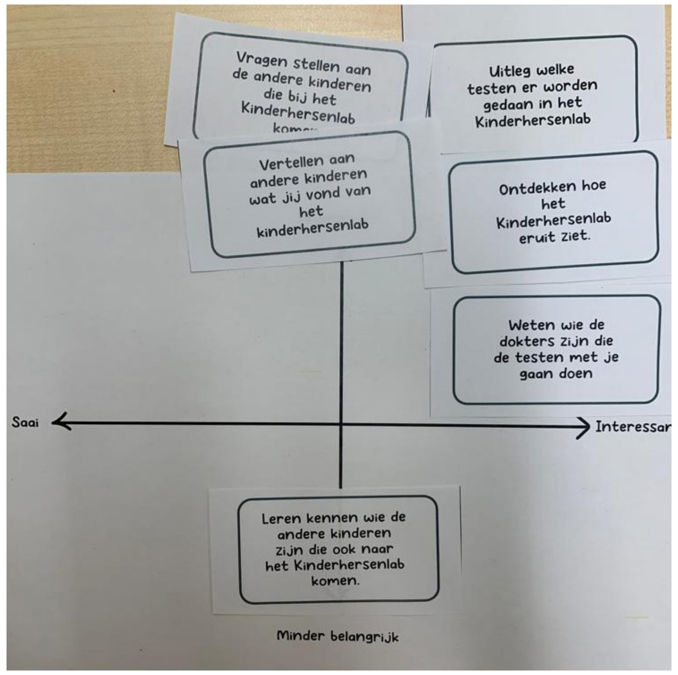
Hoe laat je dat zien? 😫 door te

Wat vertel je daarover? ik Haad Heimecht

En aan wie? me zus en vriende Papa en mama

Short hall-way conversation

In the hall-way of the hospital in between two consultations. Together with CB filled out a matrix on what her preferences were for preparing for a visit to the hospital



Introduction online sessions

Wie ben ik?

Ik ben Charlotte, ik studeer Industrieel ontwerpen en ben nu bezig met mijn afstudeerproject. Verder hou ik van lezen, sporten, films kijken en kleding haken.

Wat is het Kinderhersenlab?

Het Kinderhersenlab

jeugdjournaal.nl

Lauren mag nieuw kinderhersenlab als eerste bezoeken

Bekijk het hele bericht op Jeugdjournaal.nl

Denkkamer

Machinekamer

Beweegkamer

Wie ben jij?

Welke emoji's omschrijven jou het beste?

Sleep ze in het vak

Hoeveel weet jij en hoeveel wil je weten?

Hoeveel wil jij weten voor je naar het ziekenhuis gaat?

Niks — Alles

Hoeveel weet jij al van het ziekenhuis ?

Niks — Alles

Hoeveel weet jij al van jouw eigen ziektebeeld?

Niks — Alles

Hoe bereid je je voor op het ziekenhuisbezoek?

Sleep de plaatjes op de tijdlijn of typ iets nieuws!

Typ hier iets

Typ hier iets

Typ hier iets

Typ hier iets

Erover praten

School

In de auto

Relaxen

Thuis

Fietsen

Videos

Apps

Internet

Slapen

Week ervoor

Dag ervoor

Ziekenhuis bezoek

Wat doe je erna?

Ken jij veel andere leeftijdsgenoten die ook vaker naar het ziekenhuis moeten?

Vertel daar iets over

Vertel daar iets over

Vertel daar iets over

Vertel daar iets over

Er is iemand bij het Kinderhersenlab geweest..

Wat zou je willen dat hij aan jou zou vertellen of laten zien?

Wat hij leuk vond

wat er gebeurt

Wat hij niet leuk vond

Sleep ze in het vak

Foto's

Tekeningen

Filmpjes

Wat hij moeilijk vond

Wat hij makkelijk vond

Wie de dokters zijn

Typ hier iets

Typ hier iets

Typ hier iets

Typ hier iets

Typ hier iets

Typ hier iets

Typ hier iets

Typ hier iets

Nu ben jij bij het Kinderhersenlab geweest...

Wat zou jij willen vertellen of laten zien aan anderen die naar het Kinderhersenlab?

Wat je niet leuk vond

Wat je leuk vond

Wat je allemaal hebt gedaan

Sleep ze in het vak

Foto's

Tekeningen

Filmpjes

Wat je moeilijk vond

Wat je makkelijk vond

Wie de dokters zijn

Typ hier iets

Typ hier iets

Typ hier iets

Typ hier iets

Typ hier iets

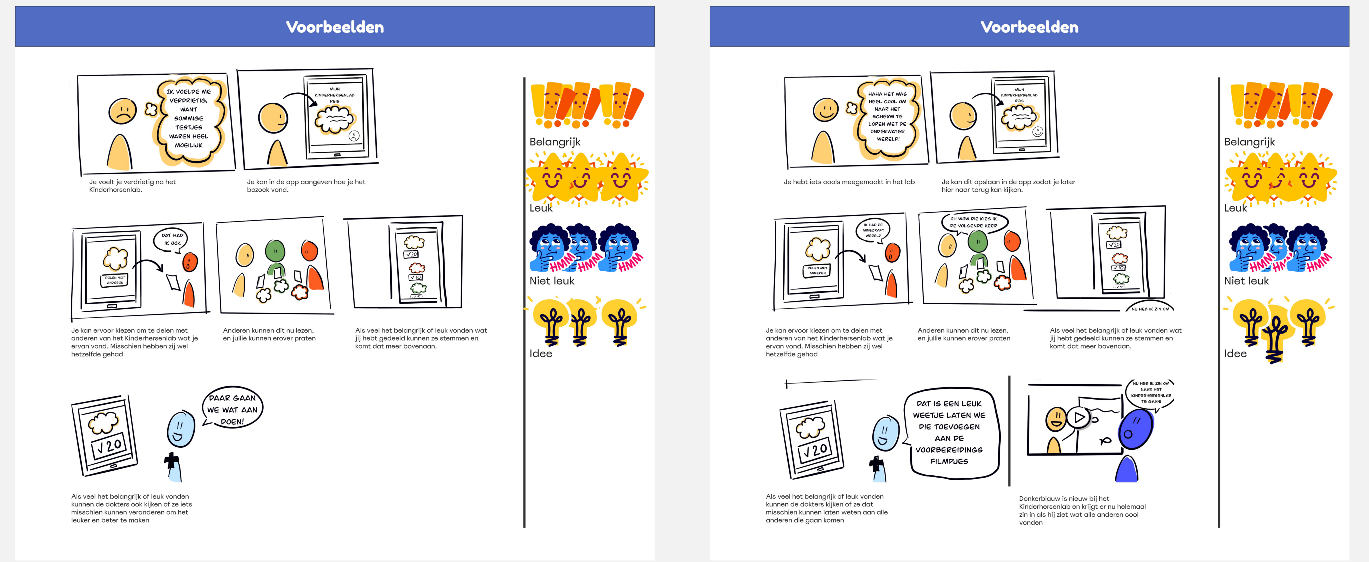
Typ hier iets

Typ hier iets

Typ hier iets

Interview with Nando

Online session via zoom, using storytelling as describe in the Miro board below, cartoons were used to described the idea for a concept. The same introduction for every session was used.



Voorbeelden

Je voelt je verdrietig na het Kinderhersenlab.

Je kan in de app aangeven hoe je het bezoek vond.

Je kan ervoor kiezen om te delen met anderen van het Kinderhersenlab wat je ervan vond. Misschien hebben zij wel hetzelfde gehad

Anderen kunnen dit nu lezen, en jullie kunnen erover praten

Als veel het belangrijk of leuk vonden wat jij hebt gedeeld kunnen ze stemmen en komt dat meer bovenaan.

Als veel het belangrijk of leuk vonden kunnen de dokters ook kijken of ze iets misschien kunnen veranderen om het leuker en beter te maken

Voorbeelden

Je hebt iets cools meegemaakt in het lab

Je kan dit opslaan in de app zodat je later hier naar terug kan kijken.

Je kan ervoor kiezen om te delen met anderen van het Kinderhersenlab wat je ervan vond. Misschien hebben zij wel hetzelfde gehad

Anderen kunnen dit nu lezen, en jullie kunnen erover praten

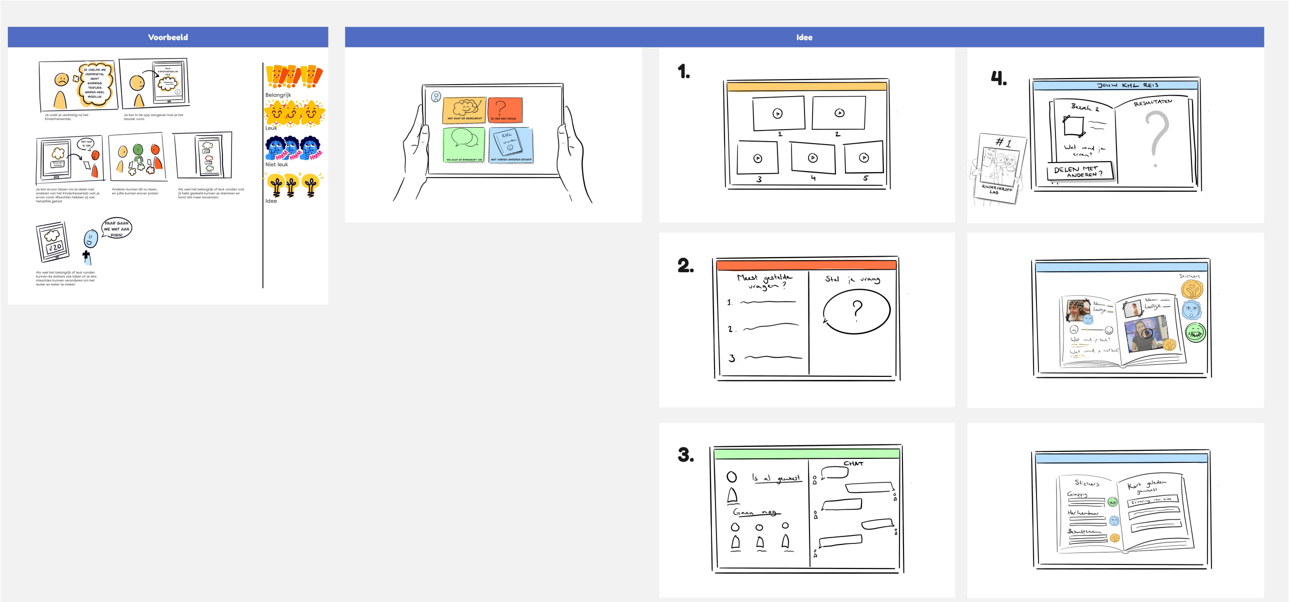
Als veel het belangrijk of leuk vonden wat jij hebt gedeeld kunnen ze stemmen en komt dat meer bovenaan.

Als veel het belangrijk of leuk vonden kunnen de dokters kijken of ze dat misschien kunnen laten weten aan alle anderen die gaan komen

Donkerblauw is nieuw bij het Kinderhersenlab en krijgt er nu helemaal zin in als hij ziet wat alle anderen cool vonden

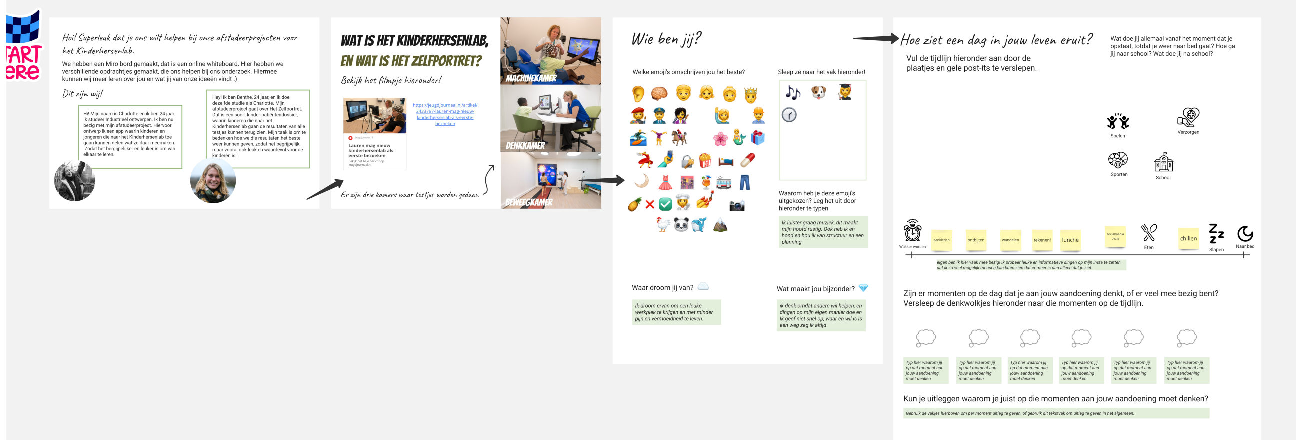
Interview with Merel

In the session with Merel the sketches of the concept idea were shown in parts so she could brainstorm and evaluate per functionality of the app.



Interview with Isabella

This participant was not comfortable with doing an physical or online session. So she filled in a Miro board in her own time, and contacted via Instagram if she had questions. This was done in collaboration with Benthe, below only the part relavant for this project is shown.



Hoi! Superleuk dat je ons wilt helpen bij onze afstudeerprojecten voor het Kinderhersenlab.

We hebben een Miro bord gemaakt, dat is een online whiteboard. Hier hebben we verschillende opdrachtjes gemaakt, die ons helpen bij ons onderzoek. Hiermee kunnen wij meer leren over jou en wat jij van onze ideeën vindt :)

Dit zijn wij!

Hi! Mijn naam is Charlotte en ik ben 24 jaar. Ik studeer Industrieel ontwerpen. Ik ben nu bezig met mijn afstudeerproject. Hiervoor ontwerp ik een app waarin kinderen en jongeren die naar het Kinderhersenlab toe gaan kunnen delen wat ze daar meemaken. Zodat het begrijpelijker en leuker is om van elkaar te leren.

Hey! Ik ben Benthe, 24 jaar, en ik doe dezelfde studie als Charlotte. Mijn afstudeerproject gaat over Het Zelfportret. Dat is een soort kinder-patiëntendossier, waarin kinderen die naar het Kinderhersenlab gaan de resultaten van alle testjes kunnen terug zien. Mijn taak is om te bedenken hoe we die resultaten het beste weer kunnen geven, zodat het begrijpelijk, maar vooral ook leuk en waardevol voor de kinderen is!

WAT IS HET KINDERHERSENLAB, EN WAT IS HET ZELFPORTRET?

Bekijk het filmpje hieronder!

https://jeugdjournaal.nl/artikel/2433797-lauren-mag-nieuw-kinderhersenlab-als-eerste-bezoeken

Lauren mag nieuw kinderhersenlab als eerste bezoeken

Er zijn drie kamers waar testjes worden gedaan

Wie ben jij?

Welke emoji's omschrijven jou het beste?

Sleep ze naar het vak hieronder!

Waarom heb je deze emoji's uitgekozen? Leg het uit door hieronder te typen

Ik luister graag muziek, dit maakt mijn hoofd rustig. Ook heb ik en hond en hou ik van structuur en een planning.

Waar droom jij van?

Ik droom ervan om een leuke werkplek te krijgen en met minder pijn en vermoeidheid te leven.

Wat maakt jou bijzonder?

Ik denk omdat andere wil helpen, en dingen op mijn eigen manier doe en Ik geef niet snel op, waar en wil is is een weg zeg ik altijd

Hoe ziet een dag in jouw leven eruit?

Vul de tijdlijn hieronder aan door de plaatjes en gele post-its te verslepen.

Wat doe jij allemaal vanaf het moment dat je opstaat, totdat je weer naar bed gaat? Hoe ga jij naar school? Wat doe jij na school?

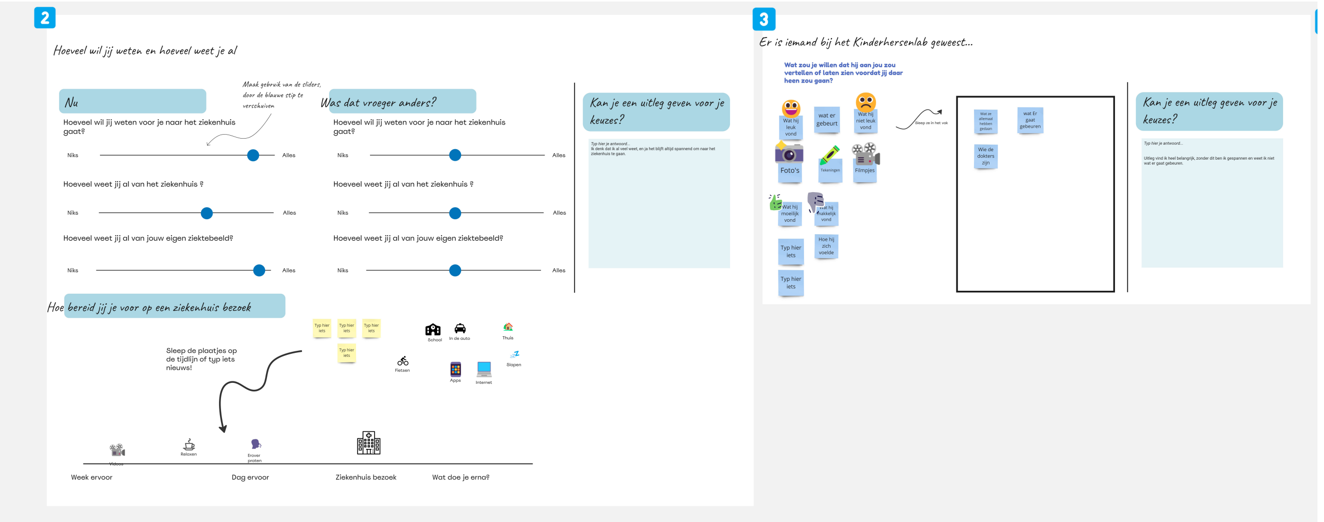
eigen ben ik hier vaak mee bezig! Ik probeer leuke en informatieve dingen op mijn insta te zetten dat ik zo veel mogelijk mensen kan laten zien dat er meer is dan alleen dat je ziet.

Zijn er momenten op de dag dat je aan jouw aandoening denkt, of er veel mee bezig bent? Versleep de denkwolkjes hieronder naar die momenten op de tijdlijn.

Typ hier waarom jij op dat moment aan jouw aandoening moet denken

Kun je uitleggen waarom je juist op die momenten aan jouw aandoening moet denken?

Gebruik de vakjes hierboven om per moment uitleg te geven, of gebruik dit tekstvak om uitleg te geven in het algemeen.



2

Hoeveel wil jij weten en hoeveel weet je al

Maak gebruik van de sliders, door de blauwe stip te verschuiven

Nu

Hoeveel wil jij weten voor je naar het ziekenhuis gaat?

Hoeveel weet jij al van het ziekenhuis ?

Hoeveel weet jij al van jouw eigen ziektebeeld?

Was dat vroeger anders?

Hoeveel wil jij weten voor je naar het ziekenhuis gaat?

Hoeveel weet jij al van het ziekenhuis ?

Hoeveel weet jij al van jouw eigen ziektebeeld?

Kan je een uitleg geven voor je keuzes?

Ik denk dat ik al veel weet, en ja het blijft altijd spannend om naar het ziekenhuis te gaan.

Hoe bereid jij je voor op een ziekenhuis bezoek

Sleep de plaatjes op de tijdlijn of typ iets nieuws!

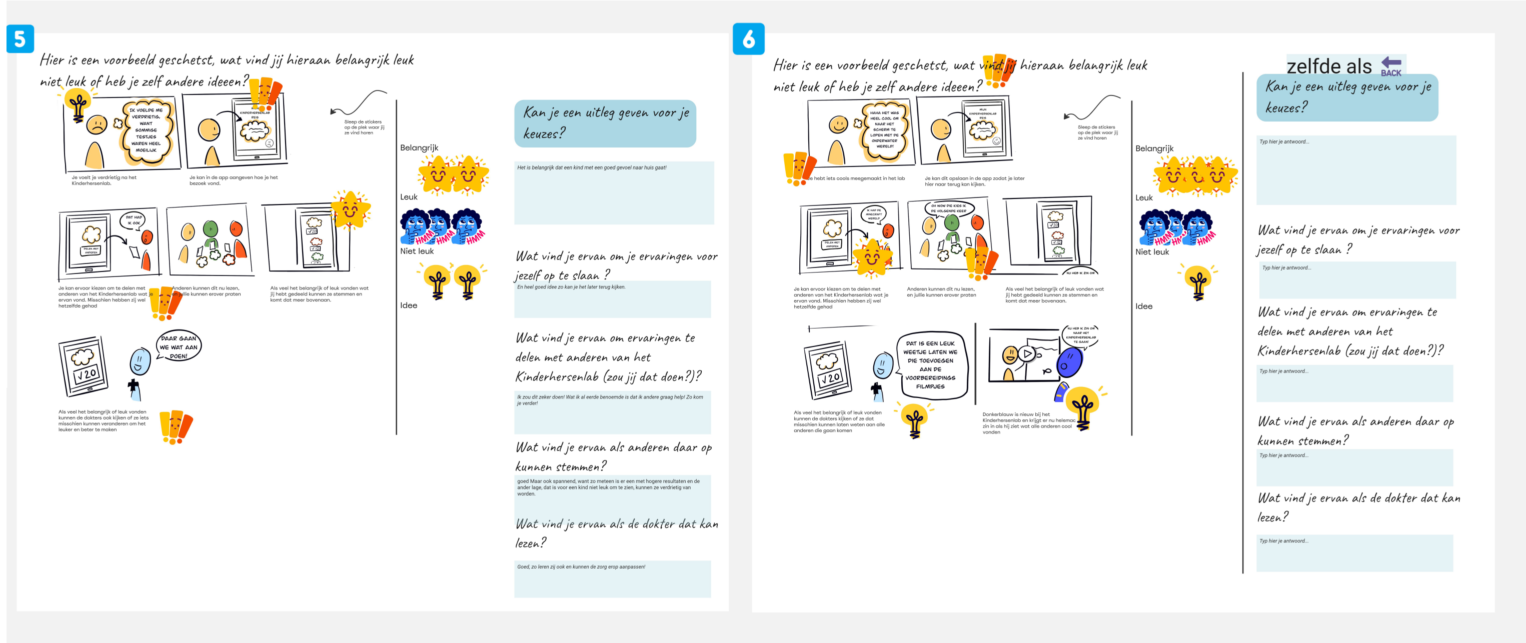
3

Er is iemand bij het Kinderhersenlab geweest...

Wat zou je willen dat hij aan jou zou vertellen of laten zien voordat jij daar heen zou gaan?

Kan je een uitleg geven voor je keuzes?

Uitleg vind ik heel belangrijk, zonder dit ben ik gespannen en weet ik niet wat er gaat gebeuren.



5

Hier is een voorbeeld geschetst, wat vind jij hieraan belangrijk leuk niet leuk of heb je zelf andere ideeen?

Kan je een uitleg geven voor je keuzes?

Het is belangrijk dat een kind met een goed gevoel naar huis gaat!

Wat vind je ervan om je ervaringen voor jezelf op te slaan ?

En heel goed idee zo kan je het later terug kijken.

Wat vind je ervan om ervaringen te delen met anderen van het Kinderhersenlab (zou jij dat doen?)?

Ik zou dit zeker doen! Wat ik al eerde benoemde is dat ik andere graag help! Zo kom je verder!

Wat vind je ervan als anderen daar op kunnen stemmen?

goed Maar ook spannend, want zo meteen is er een met hogere resultaten en de ander lage, dat is voor een kind niet leuk om te zien, kunnen ze verdrietig van worden.

Wat vind je ervan als de dokter dat kan lezen?

Goed, zo leren zij ook en kunnen de zorg erop aanpassen!

6

Hier is een voorbeeld geschetst, wat vind jij hieraan belangrijk leuk niet leuk of heb je zelf andere ideeen?

Kan je een uitleg geven voor je keuzes?

Wat vind je ervan om je ervaringen voor jezelf op te slaan ?

Wat vind je ervan om ervaringen te delen met anderen van het Kinderhersenlab (zou jij dat doen?)?

Wat vind je ervan als anderen daar op kunnen stemmen?

Wat vind je ervan als de dokter dat kan lezen?

Typ hier je antwoord...

Example of interview setup with testers

[INTRODUCTION]
- Children perceive this room as their favorite, why is that?
- Do you notice when participants are done when they arrive at your room?
- Do they want to tell you what they have already done?

THE ROOM
- What tests are conducted in this room?
- What is measured with those tests?
-
- What is the role of the parent?
  Participating
  Providing reassurance when necessary
  Observing
  Not present in the room

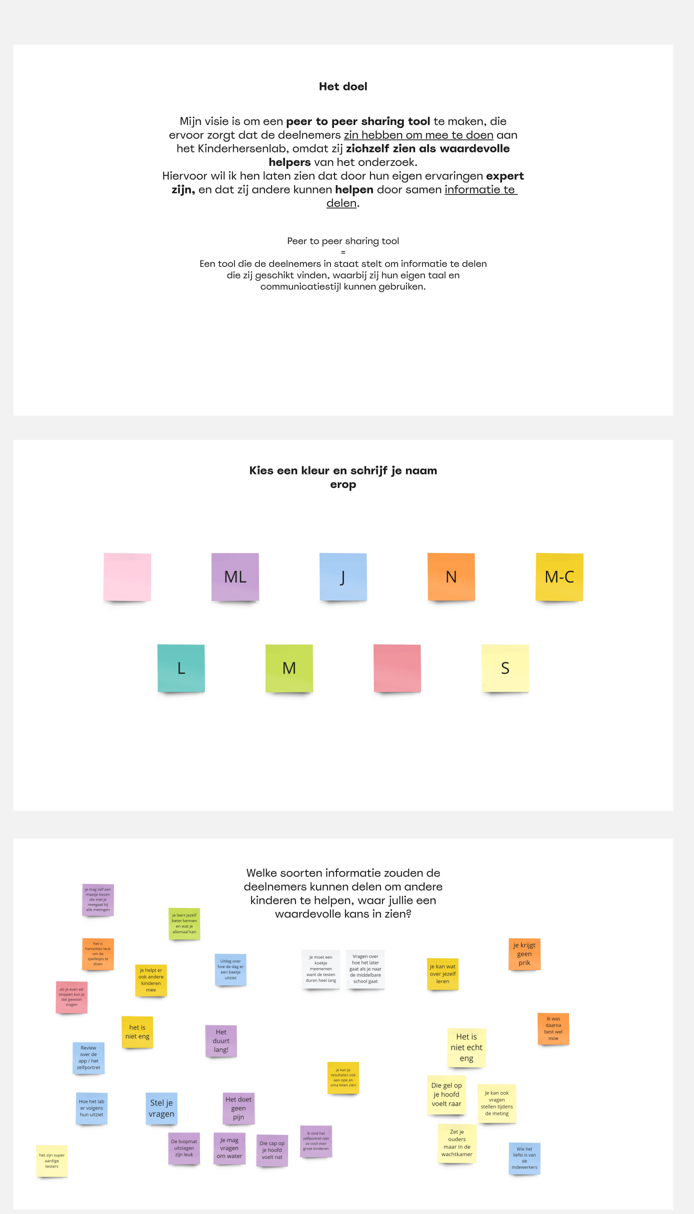
CHILD'S PREPARATION
- Starting to play in the waiting room
- What kind of information does a child receive in advance about...
- the child brain lab?
- the specific cognitive room?
- the tests that will be performed?
- what is expected of them?
- What information do you provide to the participant before the test is conducted?
- In what forms do you explain it (verbal/explaining/demonstrating)?
- Could this preparation be improved to make the measurements more efficient, or would it affect them more?

EXPERIENCE
- How do they react to the space in terms of...
  furniture
  you
  tests
  other
- How do you perceive their attitude towards these tests?
- Do they enjoy it or not?
- Does it require a lot of effort for them?
- Are they a bit worn out or still enthusiastic?
- Do you notice any difference in their attitude because they have already done many tests?

END OF THE TEST
- How is the ending/closure of this room?
  Waiting room
  Proceeding immediately
  Do they get to see their results?
  Do they take something with them?

YOUR PERSPECTIVE
- What do you need from the participants in order to conduct good measurements?
- How do you handle different personalities/attitudes of children?
- Are there any tools you use to calm them down or make them more comfortable, for example?

CBL clinicians brainstorm session



Het doel

Mijn visie is om een **peer to peer sharing tool** te maken, die ervoor zorgt dat de deelnemers zin hebben om mee te doen aan het Kinderhersenlab, omdat zij **zichzelf zien als waardevolle helpers** van het onderzoek.
Hiervoor wil ik hen laten zien dat door hun eigen ervaringen **expert zijn,** en dat zij andere kunnen **helpen** door samen informatie te delen.

Peer to peer sharing tool
=
Een tool die de deelnemers in staat stelt om informatie te delen die zij geschikt vinden, waarbij zij hun eigen taal en communicatiestijl kunnen gebruiken.

Kies een kleur en schrijf je naam erop

Welke soorten informatie zouden de deelnemers kunnen delen om andere kinderen te helpen, waar jullie een waardevolle kans in zien?

Hoe zouden jullie ervoor zorgen dat de deelnemers het gevoel hebben dat ze waardevolle helpers zijn van het Kinderhersenlab?

Welke voordelen en nadelen zien jullie voor het delen van informatie tussen de deelnemers?

Nadelen	Voordelen
Misinformatie	Begrijpelijke taal je beter thuis voelen in het khl

Hebben jullie ontwerpideeën of suggesties voor het creëren van een peer-to-peer sharing tool waarbij de deelnemers zichzelf zien als waardevolle helpers van het Kinderhersenlab?

APPENDIX E | Overview CB

Research phase

ILSE
18 yo
Ceberal palsy
Social media account on CP
Dancing (G-sport)
Social work

NANDO
12 years old
Drain
Basketball
High school

MEREL
17 years old
Brain tumor
Fitness
Going to study medicine (if everything goes alright)

ISABELLA
18 years old
Ceberal palsy
Social media account on CP

Evaluation phase

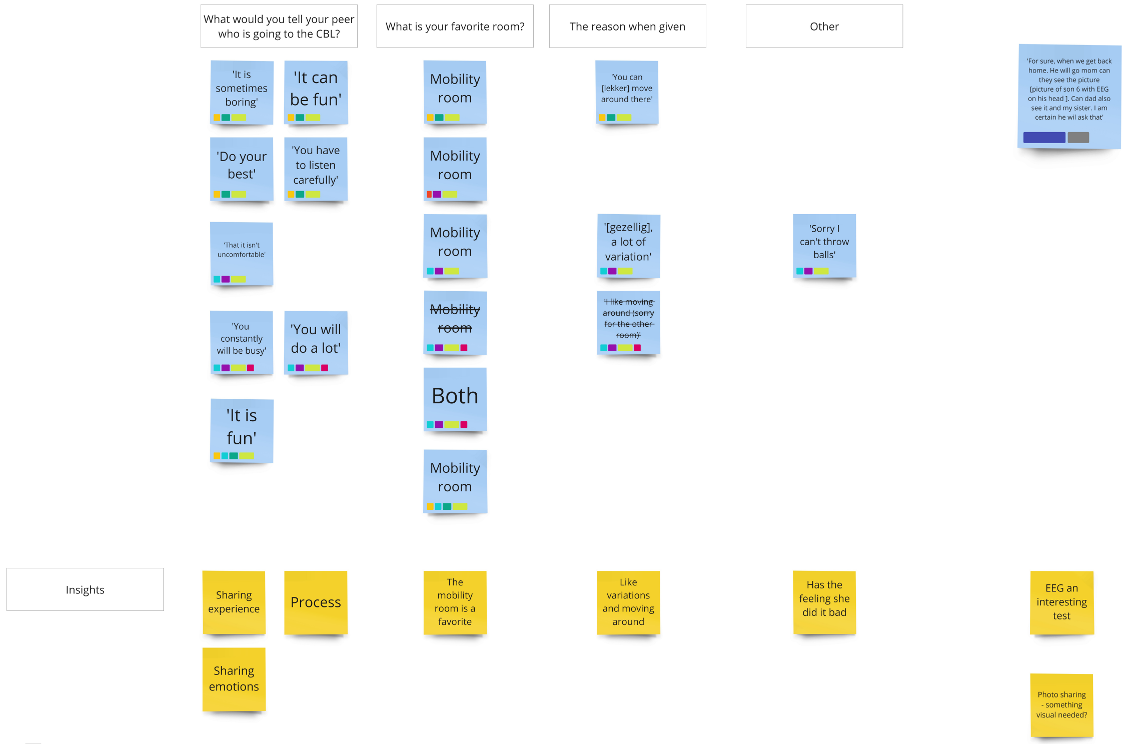
SAM
13 years old
Spina Bifida
Very active in different sports (e.g. shootingsports)
School

JOLIJN
9 years old
Spina Bifida
Arts & crafts
School

APPENDIX F | Analysis research activities

Surveys

These are the relevant of the five surveys conducted by the CBL with the trial participants.



Testers

These are all the points mentioned by the testers about the rooms, and what children thought of it. This is seen from their own perspective and not that of a child.

Rooms	Tests	Duration	Experiences				
Cognition	1. Development/IQ test	1-1.5 hour	This one is the longest so also the hardest and least fun	it gives the feeling of a 'cito toets'	they are much more aware than in other tasks that they are being assessed (older children)	not unpleasant just long and hard	Neutral
	2. Languagetasks (language and speech)	30-40 min	Fun			It is part of it	It just needs to be done
	3. Parent-child interaction	10-15 min	It is fun until 8 years but they like to do something with their parent				
Sensory	1. a. EEG	40 min	Cool is a game and the avatar explains			For the smaller kids it is supposed to be fun so she hopes they will also perceive it that way	
	1. b. EEG	20 min	Overwhelming			They like the games	
	2. Hearing tests	10 min	A bit scary to put something in your ear				
Mobility	1. Weight & height	10 min	They want to know their length				
	2. Lopen en balans	20 min	Super fun				
	3. Gross mobility	30 min	Fun			Most fun	
	4. Fine mobility	30 min	Want to be better than before (quicker)	Competitive		Not so task focused as the other rooms	
	5. BIA	10 min	Boring have to stay still	Scary because of all the wires		freedom	

CBL clinicians

This shows the results of the brainstorm session with CBL clinicians.

APPENDIX G | Analysis of existing support tools

In this appendix is shown how multiple existing tools reflect on the following characteristics:

One-to-One vs Support Groups
Digital vs Physical
Informational - Emotional - Appraisal
Interactive vs Static
Organized by
For whom?

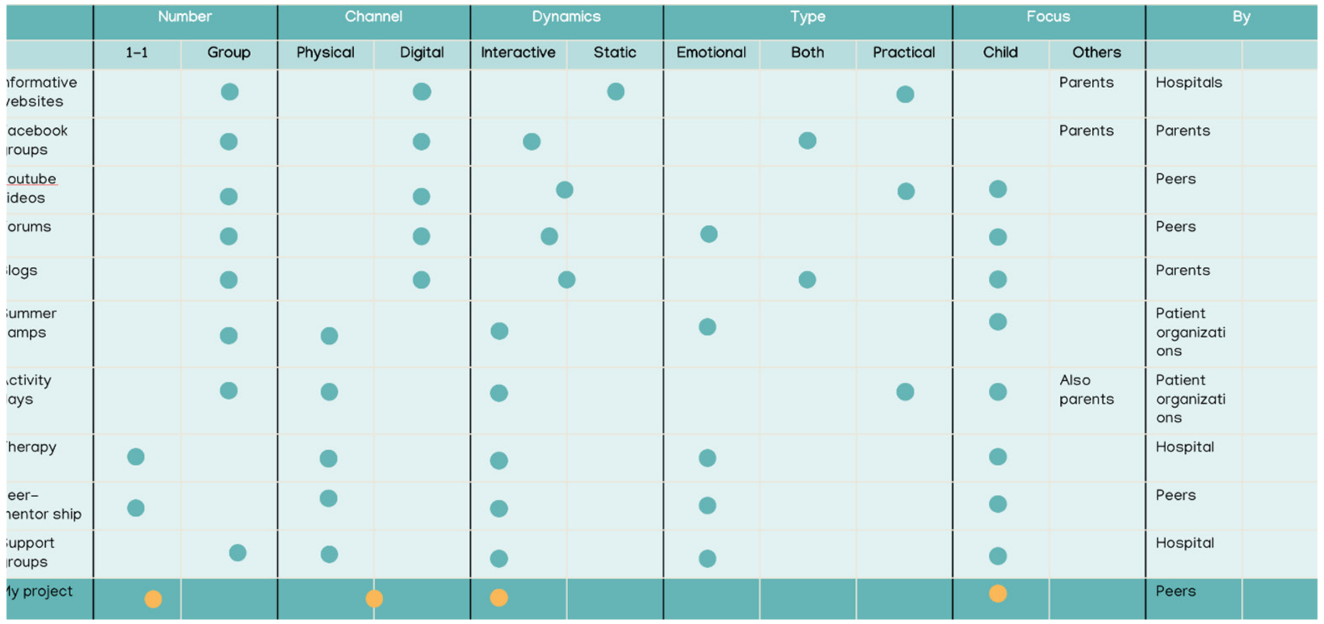
With interactive vs static is meant for example an informative website gives informational support but in a very static way, as the user cannot change anything to it or interact with it. A Facebook group is way more interactive as you can adjust and comment the group in multiple ways.

These variables are based on current (peer) support interventions and their characteristics and how they differ. Most areas of peer support in general are covered with different types of tools or activities. The biggest gap can be seen in the intensity/freedom of the interventions. On the one hand there are summer camps organized which are an intense form of peer support. This has a high threshold to join because you are kind of 'stuck' for a couple of days. It is very interactive but you cannot just take a step back and not participate. On the other side there are more chat platforms where the control is more in the hands of the user in context of when you want to use it and how, but is a more superficial type of platform and support.

There are tools which come close to the tool and used as inspiration and argumentation for how we should take on the designing of this tool. These are;

Breinstraat
Breinstraat is a platform for two groups of people with NAH (non-congenital brain injury): adolescents (12-18) and adults (18+). Here they can find answers and information, as well as connect with others who have gone through similar experiences. Via, they can 'meet' other young people in Breinstraat, as well as find a wealth of information and videos that can assist them. It also enables the users to help others by sharing your own experiences to help others.
The platform is organized by adolescents with NAH with assistance of professionals. They made this platform for the following 4 goals:

- Aknowledgement, recognition and understanding
- In confidence
- Practical and Pleasant
- For now and later



	Number		Channel		Dynamics		Type			Focus		By	
	1-1	Group	Physical	Digital	Interactive	Static	Emotional	Both	Practical	Child	Others		
formative ebsites		●		●		●			●		Parents	Hospitals	
acebook roups		●		●	●			●			Parents	Parents	
outube ideos		●		●	●				●	●		Peers	
orums		●		●	●		●			●		Peers	
logs		●		●	●			●		●		Parents	
ummer amps		●	●		●		●			●		Patient organizati ons	
ctivity ays		●	●		●				●	●	Also parents	Patient organizati ons	
herapy	●		●		●		●			●		Hospital	
eer- entor ship	●		●		●		●			●		Peers	
upport roups		●	●		●		●			●		Hospital	
y project	●		●		●					●		Peers	

Cyberpoli
Cyberpoli is an online platform for educating and informing children and young people (aged 13 to 26) about living with chronic illnesses. Cyberpoli's mission is to provide a safe and interactive environment for children to learn about their condition, ask questions, and connect with peers in similar situations. This is accomplished through the use of engaging animation videos, and resources tailored to the needs and interests of young people. Cyberpoli also has a team of healthcare professionals on hand to offer users expert advice and support, allowing them to better understand and manage their condition. Next to this, they did a lot of interviews with patients to show peer support and they provide chat groups and forums for connecting with peers. Finally, the goal of Cyberpoli is to provide young people with the knowledge and skills they need to live full and active lives, regardless of their circumstances.

Hospital heroes
Hospital Heroes is an app used by four hospitals and counting as a preparation tool for children aged 4 to 10. The children learn about hospital procedures such as weighing and blood sampling by using jungle animals to demonstrate. The app's main function is to prepare the young children before hand to reduce anxiety and stress, and distract the children with AR searching games when they are at the hospital.

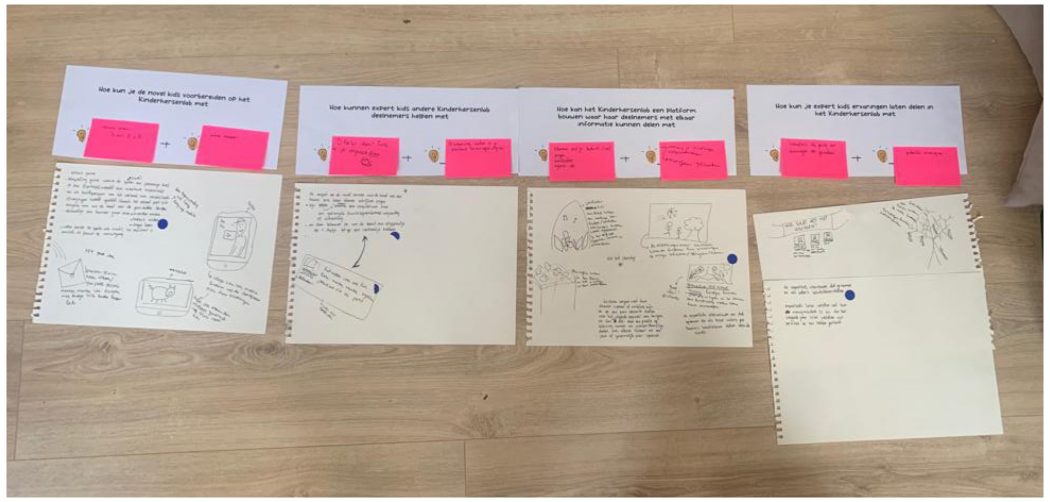
Bodymap tool
The Nivel developed a digital conversation tool that makes young people and healthcare providers aware of this so-called treatment burden and supports them in talking about it: the bodymap tool MyBoT.

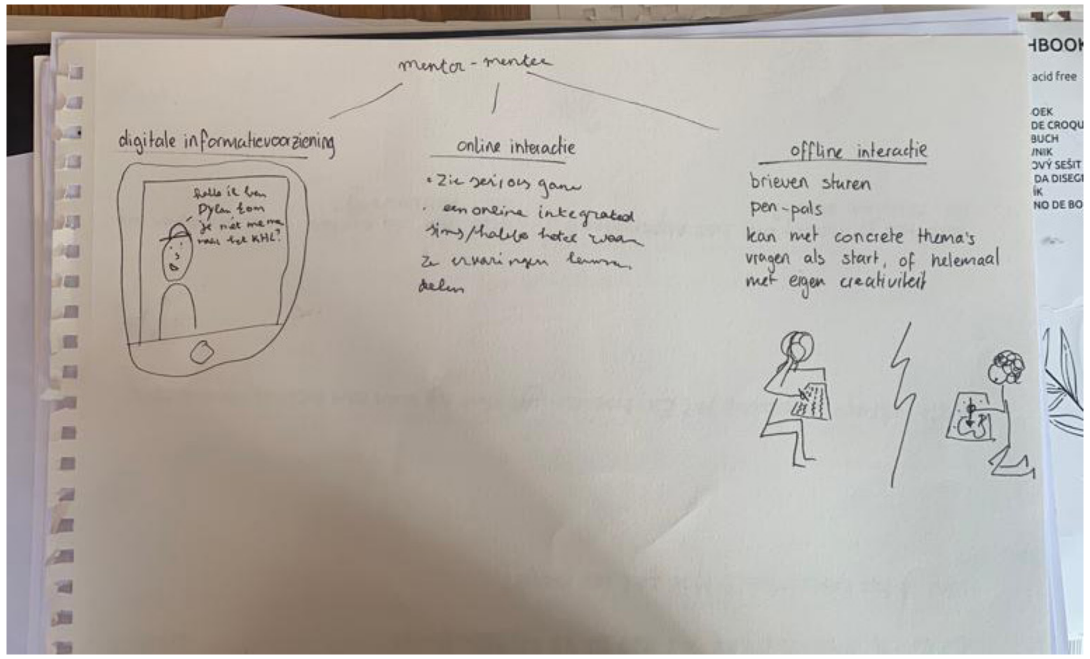
Young people with a chronic condition benefit from - often intensive and long-term - treatment; it reduces complaints and symptoms. However, treatment also affects these young people's daily lives.

APPENDIX H | Peer brainstorm session

Peer brainstorm session with fellow students

Concept idea





APPENDIX I | Analysis concept idea evaluation - quotes

What is going to happen?
"Not too many details otherwise children will maybe practice the tests because they know what to do, this was explained to me by the [testers]" - Merel (17 years old)
Privacy sensitive, could only use nicknames and avatars. Need to protect these children sometimes from themselves, so consent is a difficult topic. - CBL
What if two anxious children are combined - Merel (17 years old)

'What did others think?'

Tricky to stack up frustration from parents or children, which they never could give back and now there is a place where they can relieve this negative feeling and maybe even rant.
Pictures are not necessarily required to make stories recognisable and trustworthy.

Voting with stickers
"What if nobody votes for you" - Parent of Nando
"Should not become like Instagram that the person with the most fun story gets a vote."
"I know enough people who would participate in the voting" - Merel (17 years old)

Diary
"I like it there myself [about the hospital], I would not want to change anything, I like it just fine" [Comes back on his statement.]
"'Yeah actually it's good that you can read back what you liked and did not like yourself" - Nando.
"Yes, perhaps it is also if you fill in all those experiences. We have been completely open about it [medical information], but not everyone [other parents] has. So then again it's nice to show what did you really experience in your childhood too. That it can be used for that too, so to speak. " -P
Some children just suffer a lot from everything that happens. And that they can look back on photos later, when they process them, and also think, oh yes, I actually liked it a lot or something like that, but also just yes, it is part of what happens in your life, so it is nice to look back, I think. - Merel (17 years old)
Yes, It is of course pretty much the first things you do at. Primary school is a scrapbook making. So I think it they do, that wants Everybody it can. But also with fun that you then follow stickers, can put stickers or something with feelings on them. Or like that, you know? Of those emoticons. - Merel (17 years old)

Recognition
"Yes, I would believe the story, so I do not think it's necessary that there are pictures, But I'm more of a picture to a story person myself. So I always like it when I have a face with it."
You yes, then you might also have more of a picture. Otherwise, you quickly think of, oh, people are naturally quick to be like, 'Yes, my child has the same thing', but not because everyone is different. If you know what the person has, then you can compare. Do I really have the same thing? -P

When to use it
"Well, before I would like to read it before I go there before I am going there. So that I know a bit about what to expect." - N
"The first time I definetly want to know. The times then afterwards ... then I'll see."- Nando.

Age differences
Older children may describe better what they have experienced. Yeah, younger children also, maybe. But I think older children are a bit more.
Yes, yes. Actually, older children can describe more, but younger children are, of course, your peers then. That's, then again, also nice.

Reduce stress
Yes, if I look at my youngest [child], Then I think showing a bit of what is going to happen something like that would reduce stress. -P

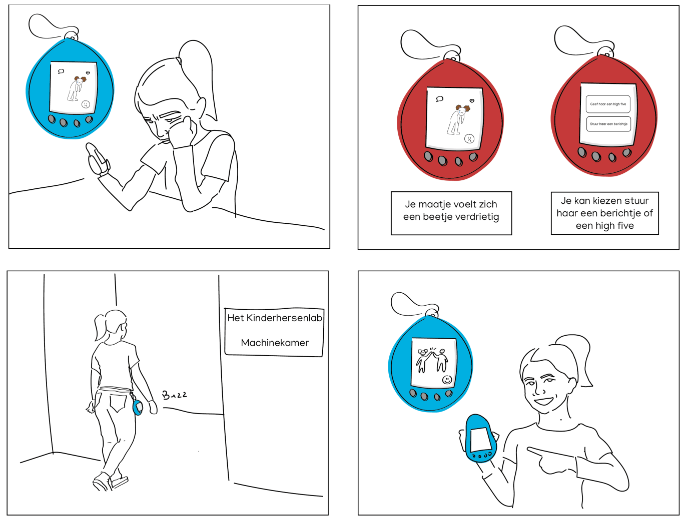
Why relevant
"Ik weet niet dat Ik vind dat niet zo heel erg nodig ofzo Alleen Ik denk wel dat het wel, Omdat het Natuurlijk ook helemaal nieuw, dus je begint ook op een andere manier. Daar moet je denk ik ook moet ik Misschien ook aan wennen,

Maar ik denk dat het wel. Heel tof is om. Als kinderen dat dan kunnen Laten weten, en helemaal als ze dan. Niet echt anders. Ja, dat ze licht dan ook een beetje gehoord en gezien voelen wat? Natuurlijk wel heel belangrijk is. Ja, dus Ik denk wel dat dat het wel gaaf is Als het kan en ook als ze inderdaad heel veel Mensen het zouden kijken. Als één iemand iets vindt, dan is dat een persoonlijke ervaring, maar als heel veel Mensen het vinden. Dat er dan ook daadwerkelijk naar gekeken wordt"

Does it matter if moderated?
This is not the place for the most private situations Yeah, I think it should be possible with something like that because I think if you have things that are just really more private that you'd be better off making a block outside such an app or. So not like that.

"Not convinced doctors will look much into this. I think that it's okay for them to read everything that is said there. But I don't know to what extent they will look at that. But maybe if they're really worried, so that it's okay if they can see it. But I don't think they will. I don't expect that they have time to go and look at that a lot." "Maybe to see, oh, it's going well in the lab."

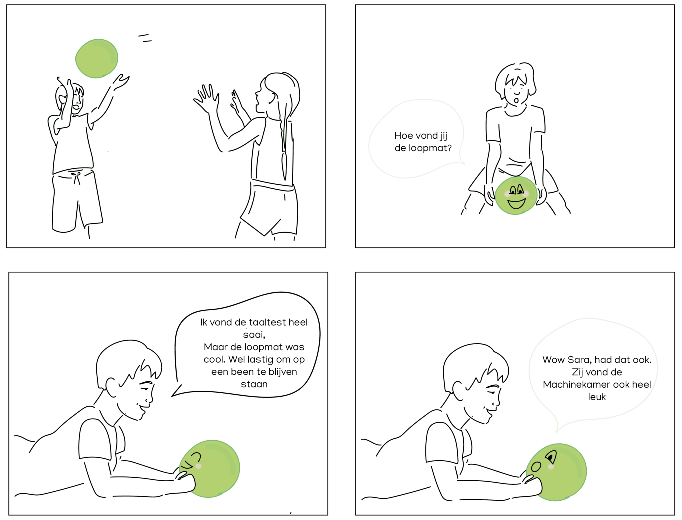
APPENDIX J | Ideation 1 - design to decide



Support Pets **(emotional support)**
Imagine you have to go to hospital. But before you go, you are sent a toy. It is a digital figure of yourself on which you can show how you feel. If you feel a bit scared, you can give your figure a sad smiley face. Then your online friends can help you. For example, they can say “Good for you!” or “It wasn’t scary for me either”. And you can also play games with them in the break between tests.

Competence +
Relatedness +
Autonomy +

Good idea the only limitation of this idea is that the user besides having control over the toy they do not have any freedom further. The interesting point taken was to have someone to go with.



Babbel Ball **(practical support)**
Imagine you are in a lab where they are doing brain research. You have just completed 1.5 hours of tests in the thinking room. Now you get to play with a ball that can ask questions. You can roll, kick or throw it at other children or at your parents. The ball asks questions about how it went and what you thought of it. It also tells stories of other children who have already been in the lab. What do you think of this idea?

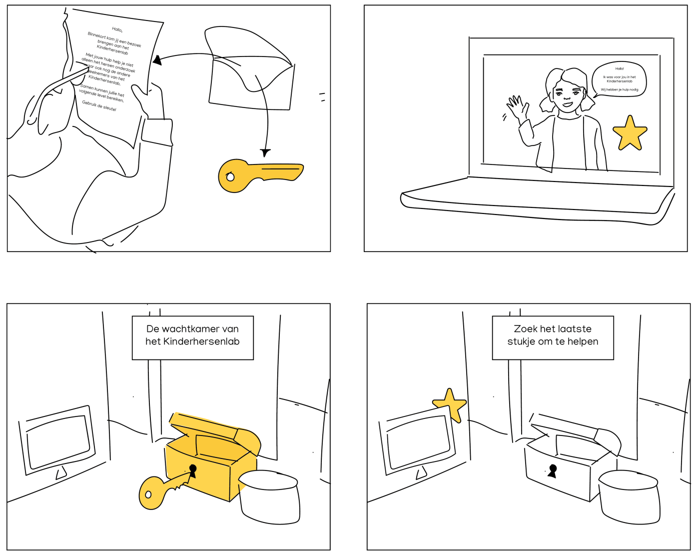
Competence /
Relatedness /
Autonomy +

This idea mainly focuses on a moment of reflection and relaxation what is not the ultimate goal of the design (which is peer-sharing). Also it is a physical activity what could be hard for some CB. The idea of sharing and the ball helping to express is taken to further ideation.

Brain Cafe **(emotional+practical support)**
Imagine an online cafe called “The Brain Cafe” where you can play educational games, both on your own and with others. In the cafe, you can also video call other children who have also been to the Child Brain Lab. This way, you can talk together about problems or fun things you have experienced. It’s just like being in a real cafe, but online!

Competence +
Relatedness +
Autonomy +

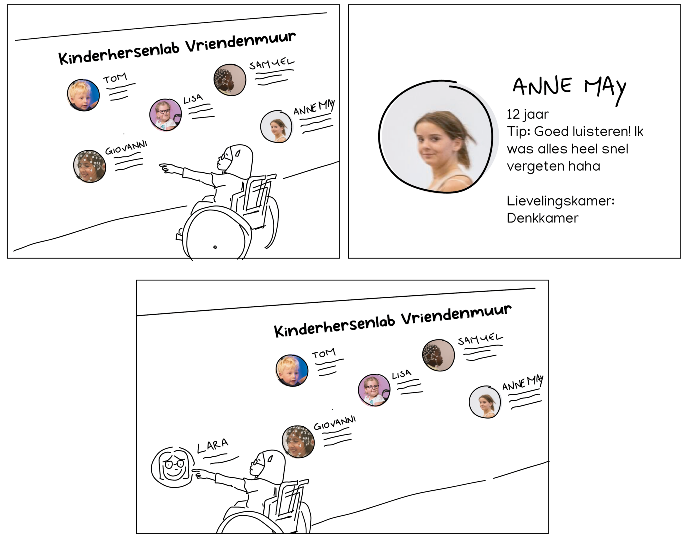
Positive rated idea on the values, but does not fit the context of the CBL and when to use this. Also the threshold of video calling is quite high creating a barrier for peer-sharing. The interesting point is an digital environment gives a lot of freedom to let the user be in control and choose what they want to do within this environment.



Brain Helpers **(practical support)**
Imagine you are going to visit the Child Brain Lab. Before you go, you get a special invitation to an exciting game called “Brain Helpers”. The invitation includes a key and a video explaining how the game works. When you arrive at the lab, you are given a box with toys and other fun things to play with while you wait for the examination. After the investigation, you can use an app to find a special brain part to earn a puzzle piece and move on to the next part of the game with other children.

Competence +
Relatedness -
Autonomy +

Fun idea makes the CBL participants excited to go to the lab. But it could distract from the visit also it does not allow for peer-sharing.



Friendwall **(emotional support)**
Imagine you have been to the Child Brain Lab and you want to show others how much fun it was. On the friends wall, you can see photos of other children who have also been. Each picture is accompanied by a story about what they experienced and learned at the Child Brain Lab. You can also share your own photo and story so that others can see what you have done and learned. This way, the wall of friends gets fuller and fuller and you can look back on a great time at the Child Brain Lab together with other children.

Competence +
Relatedness +
Autonomy -

Fun idea but not a lot of freedom, also you only get the support when in the lab. Privacy wise this would not be allowed in the CBL.

APPENDIX K | Evaluation plan

Planning
- Introduction (of the project and researcher)
- Consent form
- Introduction of the child (and parent)
- Explanation what the guided scenario will do
- Child can go through the app (scenario is read out loud)
- Observe
- Helping where necessary
- Open conversation (when guidance is needed additional questions)
- Survey
- Thank you (give them the thank you present)
- Do they have any questions, if not tell them they can always contact when questions do arise

Guided scenario
I'm going to show you a few things you can do in the app. Please tell me out loud what you are thinking while doing the tasks. If you get stuck or have any questions, let me know. Let's explore the app together!

Task 1:
- Open the app.
- Click that you still need help as it's your first time using the app.
- Choose Wavy to go on an adventure with you

Task 2:
- Look around, and see where you can all go.
- In the story corner, read the story of 'Brain Helper' and give it the cool sticker
- Now read the story of 'BrainSurfer'and give it the helpful sticker

Task 3:
- Find out who is also coming to the lab soon
- Draw something on the board.

[The day has come for you to go to the lab]

Now it's time to share your own experience!
- Click on Wavy for an explanation
- Grab a blank post it
- Indicate that you thought the mat was cool by clicking on the image
- And type in 'that it all took a while' with a sleepy smiley beside it

Closure:
Well done! Now we're going to talk a bit about what you thought of it

Additional questions
- What did you like? (per feature)
- What did not you like? (per feature)
- What would you do differently? (per feature)
- Is there anything missing in this app?
- Does it let you tell your story?
- What do you think of the avatars and nicknames (instead of real names and photos?)?
- What do you think of developing an image together by sharing stories?

Survey
Rating of interaction qualities

1. Have you discovered any new things in the app?

1 Very little
2 A little
3 Normal
4 A lot
5 Very much

2. Do you think you can learn new things about yourself and other participants by using the app?

1 Not at all
2 Somewhat
3 Normal
4 Definitely
5 Very much

3. Do you feel that you are together with the other app participants?

1 Not at all
2 Somewhat
3 Sometimes yes Sometimes no
4 Most of the time
5 Always

4. Do you like the app and does it invite you to play?

1 Not at all fun and inviting
2 Somewhat fun and inviting
3 Sometimes yes Sometimes no
4 Fun and inviting
5 Very fun and inviting

5. Can you choose what you want to do in the app?

1 Almost nothing to choose yourself
2 A few things
3 Quite a few
4 Many things self-select
5 Choose everything yourself

6. Do you feel you can get help if you need it?

1 No help or advice
2 Very little help
3 Sometimes help
4 Quite a lot of help
5 Very much help

7. Do you feel you could help others through this app?

1 No help or advice
2 Very little help
3 Sometimes help
4 Quite a lot of help
5 A lot of help

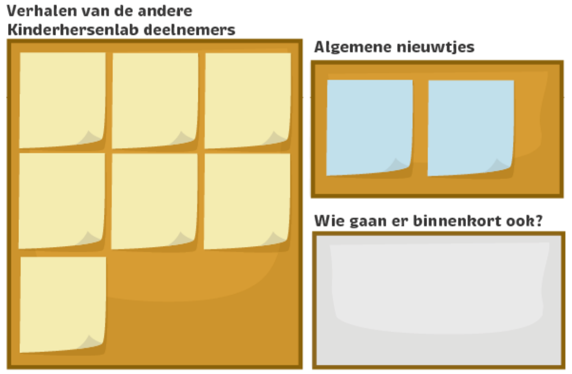
8. Can you decide for yourself what you want to do and how you want to do things in the app?

1 Nothing to decide for yourself
2 Little to decide for yourself
3 Sometimes a little bit
4 Decide a lot yourself
5 A lot to decide for yourself

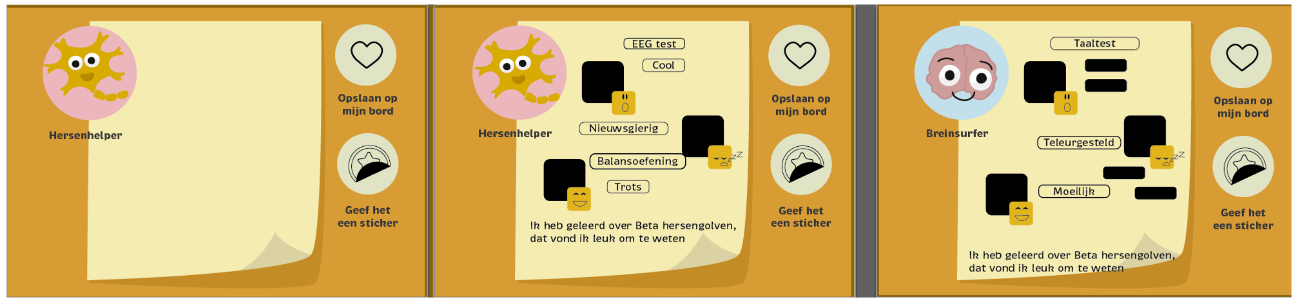
APPENDIX L | Iterated versions prototype

Prototype 1

Peer feedback by fellow students



Wist je dat.. Je hersenen wit zijn van binnen en grijs van buiten. Ze bestaan voor driekwart uit water en voor een kwart uit vet.



Ik heb geleerd over Beta hersengolven, dat vond ik leuk om te weten

Ik heb geleerd over Beta hersengolven, dat vond ik leuk om te weten

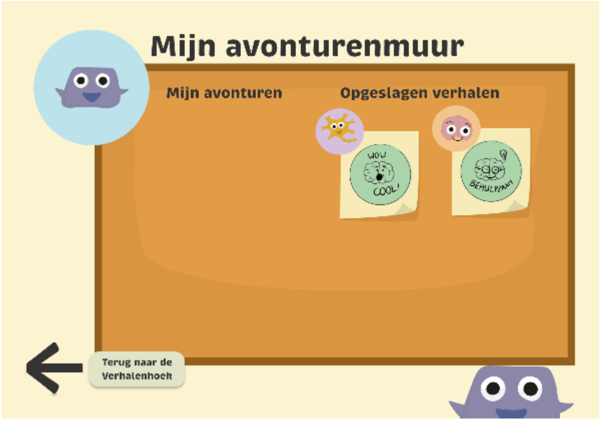
Wat vond ik leuk?

Wat vond ik niet leuk?

Heb je iets nieuws geleerd, zo ja wat?

Prototype 2

Tested with 2 CWB & 1 CB



De meeste deelnemers..
- Vonden de beweegkamer het leukste
- En de taaltesten heel saai

Je hersenen wit zijn van binnen en grijs van buiten. Ze bestaan voor driekwart uit water en voor een kwart uit vet.

Wat heb je geleerd?

Dat er verschillende hersengolven zijn.

Wil je nog iets vertellen?

De dokters waren heel grappig!

De laatste test was lekker relaxt!

Prototype 3

Tested with 1 CB & 3 CBL clincians

1. Denkkamer

In de denkkamer ga je aan tafel verschillende opdrachten doen. Zoals met blokken werken en een opdracht samen met je ouder.

Cool!

Verhalenhoek

Lees de verhalen van andere deelnemers

Samen op avontuur

Deze deelnemers gaan binnenkort ook of zijn al geweest

HersenHelper

Ik vond het Kinderhersenlab heel gezellig, alle mensen waren heel aardig.
Ik vond het op het eind wel lang duren, toen wilde ik eigenlijk liever appen met mijn vrienden.
Het was wel cool dat ik een Minecraft wereld uit kon kiezen.
En ik heb veel geleerd over hersengolven.

BreinSurfer

Denkkamer

Moeilijk

Stom

Machinekamer

Eng

Ik hou niet van iets op mijn oren.

Beweegkamer

De laatste test was lekker relaxt!

Opluchting

2. Machinekamer

Wat heb ik gedaan met Wavy..

Wat was het leukste..

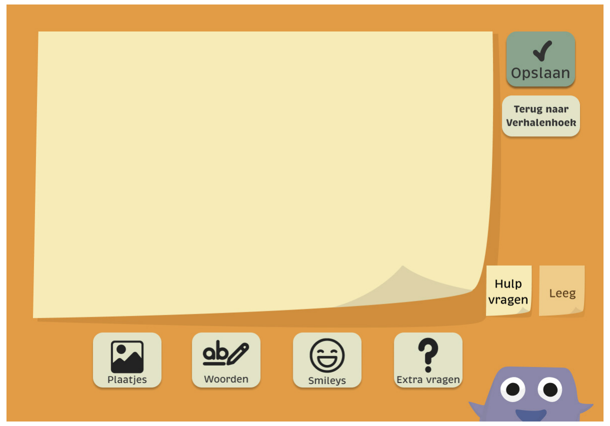
Omdat/want..

Wat was het stomste..

Omdat/want..

Wat heb ik geleerd?

1 2 3



Version B prototype (high risk moderation and privacy)

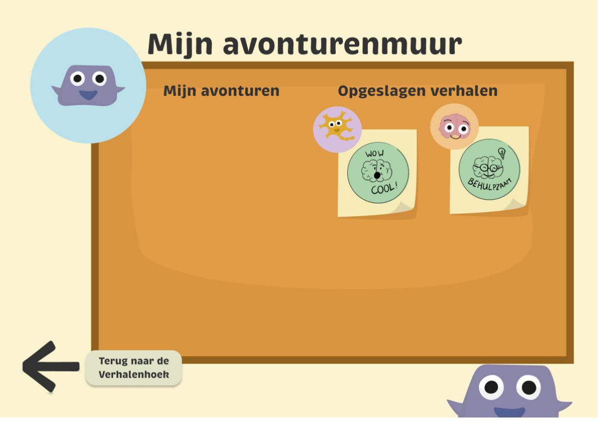
Shown in all evaluation session with 1 CB & 3 CBL clincians

Mijn avonturenmuur

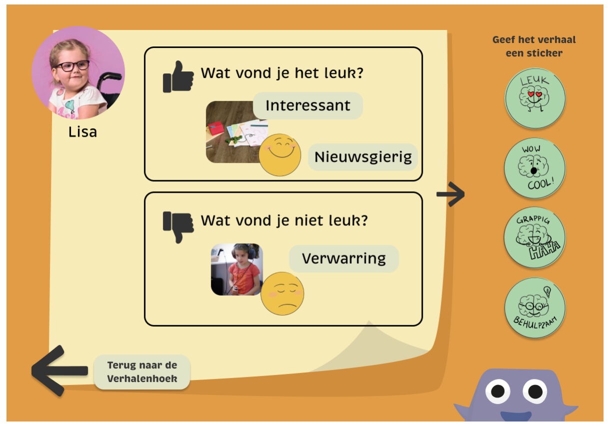
Verhalenhoek

Lees de verhalen van andere deelnemers

Zie jij al wat het wordt? Alle ver halen vormen samen een plaatje



Mijn avonturenmuur



Lisa

Wat vond je het leuk?

Interessant

Nieuwsgierig

Wat vond je het niet leuk?

Verwarring

Stijn

Denkkamer

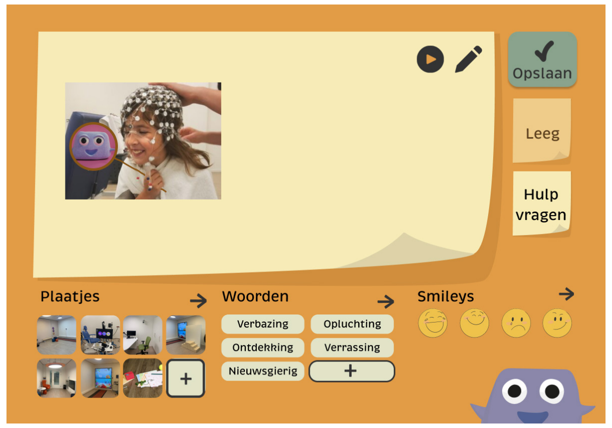
Moeilijk

Stom

Eng

De laatste test was lekker relaxt!

Opluchting



"I was always looking to connect with people like me, so hearing other children's stories would have helped me."

Ilse, 18 years old

October | 2023