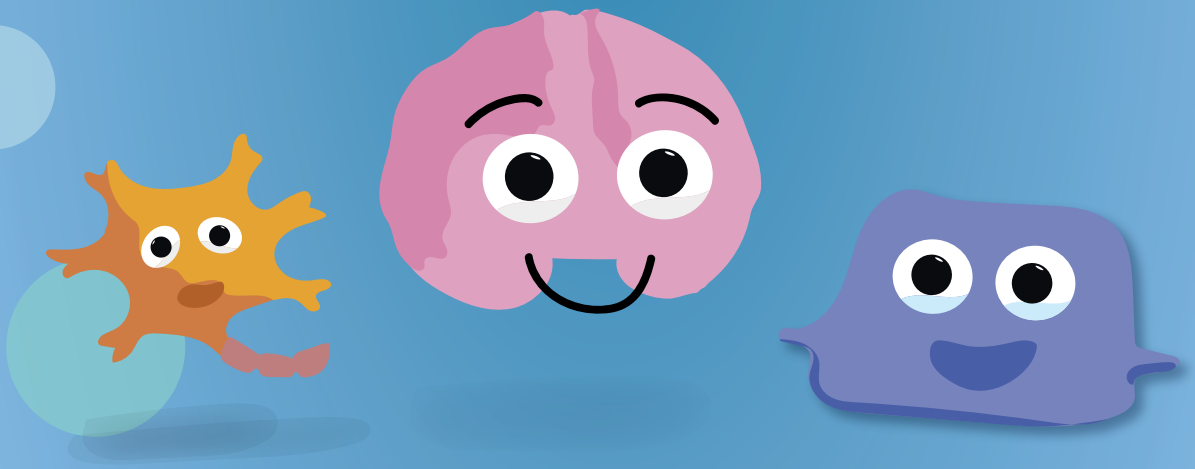
Brainwise with the Self-portrait app

Providing child patients with a meaningful translation of their test-results



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Preface

Dear reader,

The report you are about to read represents eight months of hard work and, more importantly, eight months of hard work filled with joy. Yet, this document signifies much more; it marks the culmination of seven years of study at the Faculty of Industrial Design Engineering at TU Delft. Throughout these seven years, my interest in healthcare design has grown. It is heartening to see the growing connection between healthcare and design, because it's crucial to align products and services with user preferences, especially in the field of healthcare. The Self-Portrait is an excellent example of this, actively seeking to enhance healthcare for children, focusing not only on their physical well-being but also on their participation.

Before you continue reading, I would like to introduce you to the fantastic people without whom this project would not have become what it is today.

First and foremost, I want to express my gratitude to all the children who took the time to assist me with my project. Without you, this project wouldn't have been possible. You not only helped me by sharing your opinions and ideas, but the moments we spent talking always filled me with positive energy, motivating me to continue working on this project. Your contributions have been the driving force behind this effort.

I would also like to extend my thanks to the core team of the Child Brain Lab, along with all the doctors, psychologists, and staff. Thank you for allowing me to 'sit on the kruk' during consultations, for answering all of my about the Child Brain Lab, and for sharing your opinions about the ideas I generated. I felt welcomed and appreciated at Sophia Children's Hospital, thanks to all of you.

Of course I want to thank the four M's: Mathieu, Marijke, Marie-Lise, and Marie-Claire, my supervisory team from both TU Delft and Sophia, who supported, inspired, and assisted me greatly throughout these eight months. Marie-Lise and Marie-Claire, thank you for always finding a spot in your busy schedules and for your dedication to a wonderful project like the Self-Portrait. Mathieu and Marijke, thanks for the excellent guidance, striking a perfect balance between being critical and providing trust, and for showing concern for my well-being. I couldn't have asked for a better supervisory team.

I want to thank my friends for their inspiration, support, and companionship during my graduation. Thanks to all of you, I made it through the long days at the faculty, even while the rest were on summer vacation. I would like to give special thanks to Karlijn, who has always been there for me and provided invaluable assistance when the stress levels began to rise.

Next, I'd like to express my gratitude to my parents and sister, who have been there for me not only during this graduation project but throughout my entire academic journey, always making time for me and offering encouragement when needed.
Lastly, I'd like to thank my dear grandpa, who has always shown interest and amazement in everything I designed in Delft. I would have loved to see you sitting in the audience next week, beaming with pride while I presented the final result. Dear grandpa, I hope you are watching from a distance.

All the best,
Benthe

Abstract

This report delves into the challenging process of translating complex tests from the Child Brain Lab into a design that is both accessible and engaging for children. The Child Brain Lab, part of the Erasmus MC Sophia Children's Hospital, conducts research on brain development to gain a better understanding of the course of brain disorders and improve treatments for children with brain disorders. In return for children's participation in the lab, the hospital aims to provide them with a child-friendly patient dossier: The Self-portrait. The goal of this project is:

To design a digital solution that translates the results from a selection of tests that are performed in the Child Brain Lab, into a meaningful contribution for children (developmental age 6-12 years old) with brain disorders, that will increase their participation in their care path, and positively support their developing self-image.

To design a solution that caters to the needs of the child patients, first the problem space was explored, through literature research and interviews with stakeholders. Within the age range of the target audience, children develop their language skills and transition from imaginative thinking to more logical reasoning. These cognitive abilities influence the formation of their self-image, which led to the framework for contributing to self-image: 'Look what I did' - 'Look how I did it' - 'Look how I did it and what I learned from it.' This framework was used to adapt the app to the needs of the target audience. In addition, the participants' brain disorders present additional challenges, such as poor eyesight and a need for predictability.

The tests for which a translation is being made in the app are the EEG, IQ test, and walking mat. Each of these tests comes with its own set of challenges. For example, the data from the EEG test is complex and elusive for children, and the analysis is quite intricate for physicians. The results of the IQ test are highly valued.
The discovery phase revealed five trade-offs, such as the balance between providing honest information or protecting a child by sharing only positive information. The insights led to the design goal:

Create a personally rewarding visualization of the test-data of the EEG, IQ-test and walking mat for each child that visits the CBL, by highlighting their personal achievements and empowering children to become aware of and accept who they are, in a form that is integrated in the clinical workflow of the Pediatric Brain Centre, and supportive during the full care journey, so that HCPs see the Self-portrait as an enrichment to their work.

The result is an interactive prototype of The Self-portrait, inviting children to explore the world of their own brains. Each test is developed with its own character. For instance in the case of the walking mat, animals are used to give children insights into their walking patterns, envisioning enriched dialogues between children and physiotherapists, potentially leading to improvements.

Throughout the app's development, all stakeholders have been involved multiple times, ensuring the right balance is struck in the design between presenting accurate information aligned with clinical practice while also appealing to children.
Through this endeavor, the project aims to bridge the gap between complex medical data and child-friendly interpretations, fostering a better understanding and engagement with one's health metrics.

Glossary

- **Erasmus MC:** Erasmus Medical Center in Rotterdam
- **EEG:** electro-encefalogram OR electro-encefalography
- **KNF:** klinische neurofysiologie (clinical neurophysiology)
- **PBC:** Pediatric Brain Center
- **CBL:** Child Brain Lab
- **SKZ:** Sophia Kinderziekenhuis (Sophia Children's Hospital)
- **SDM:** Shared Decision Making
- **VBHC:** Value Based Healthcare
- **HCP:** Healthcare provider
- **The Self-portrait:** the app that is the main topic of this thesis – a child-patient-dossier where testresults of the CBL will be communicated.
- **Developmental age:** A child's developmental age is the age they are functioning at on a social, physical, intellectual, cultural and emotional level.
- **EHR:** Electronic Health Record
- **HiX:** the EHR system used in the Erasmus MC
- **GemsTracker:** software for clinical research and quality registrations in healthcare

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Starting off

This report delves into the challenging process of translating complex tests from the Child Brain Lab into a design that is both accessible and engaging for children. This section introduces the project by outlining its focus, context, and approach. Furthermore, it explains the selection of tests for translation and the rationale behind those choices.

Chapter 1 - Introduction

This graduation project aims to make a translation of the results of three tests from the Child Brain Lab into the Self-portrait: an app for children with brain disorders. This introduction contains a short description of the project and its approach. Furthermore, it gives background information about context of this project, introducing the Sophia Children's hospital, the Pediatric Brain Centre and the Child Brain Lab.

1.1 Project introduction

The brain is the most complex organ in your body, yet one of the most vital. Because of your brain, you can move, think, learn, and feel. The first nerve cells are formed in the womb, and from the moment you are born, the brain continues to develop constantly by forming new connections (Hersenstichting, 2023). Sometimes, during pregnancy, at birth, or in early development, something goes awry in the brain. This can result in a child experiencing a brain disorder, which can have a big impact on their lives.

At the Erasmus MC Sophia Children's Hospital (referred to in this report as "the Sophia," abbreviated as SKZ), there is an ongoing commitment to improving the care for children with brain disorders. In 2020, the Pediatric Brain Center was established, where all care for children with conditions affecting the head, face, or brain is centralized. In 2022, the Children's Brain Lab was added, representing a unique collaboration between healthcare professionals and scientists.

In the Child Brain Lab, research is done on brain development, to better understand the course of brain disorders and enhance treatments for children with brain disorders. To achieve this, children with various brain disorders are invited to participate in a series of different tests. Children participate voluntarily in the CBL, and in return for their involvement, the SKZ wants to offer them their own child-friendly patient-dossier: The Self-portrait.

With the Self-Portrait, children can gain insight into the information that is collected about them in the lab, so that they can gain better understanding of themselves and their brain disorder. This will hopefully make it easier for them to understand and speak with the doctors, and empower them to actively participate in their care. As van M.L. van Veelen, head of the Child Brain Lab, suggests: if children feel involved from the beginning, treatments often succeed better (Erasmus MC, n.d.). However, to present the data from the Child Brain Lab in a valuable and child-friendly manner, a translation of the test results is required. To make this translation, the SKZ asked the Play Well Lab from the TU Delft Faculty of Industrial Design Engineering for help, which led to this thesis.

1.2 Project focus

The Self-Portrait will be used by children with various brain disorders, their parents, and the medical professionals of the Child Brain Lab. Each of these stakeholders has their own wishes and needs. Previous projects associated with the Child Brain Lab have analysed these needs and wishes, therefore establishing insights into children's interests, their interaction with the app, and suitable communication methods (Meulendijks, 2020; van Dijk, 2021; Tielen, n.d.). However, these insights

have not yet been linked to specific tests conducted within the lab. Therefore, that will be the primary focus of this project.

Currently, child-focused information is limited in the PBC departments (van Dijk, 2021). Results are primarily communicated in relation to diagnosis or treatment. However, there are opportunities in translating and comparing results to convey richer insights in the self-portrait: insights that are not only related to diagnosis but can also be valuable for a child's self-image.

The target audience where this project will focus on, is children with a developmental age of 6-12 years. From the age of 6, children possess the cognitive abilities necessary for formal 'learning' (Verhulst, 2017). At this age group, children can understand their own results to some extent, but their involvement in their care is often limited. Especially with this target group, the Self-Portrait can therefore make a big impact.

In the CBL, around 25 different tests/questionnaires are conducted, each producing different data. This means that each test may require a different approach when it comes to translation and presentation. To be able to deliver a well-considered design within the scope of this project, the focus will be limited to translating three tests. Some tests may contain more sensitive or challenging information than others. The selection will consist of tests that include various challenges, collectively illustrating the full potential of the Self-Portrait (for the selection, see Chapter 2).

The solution that this project aims to deliver is a high fidelity interactive prototype of the Self-portrait app, focussing on the translation and communication of test results of three tests. By combining literature research with user research, the knowledge, preferences, and needs of all stakeholders will be investigated in relation to the test selection. These insights will serve as the foundation for designing the app. During the design process, all stakeholders will frequently be involved to ultimately arrive at a final design proposal that is desirable, feasible, and viable.

1.2.1 Project goal

The goal of this project is design a digital solution that translates the results from a selection of tests that are performed in the Child Brain Lab, into a meaningful contribution for children (developmental age 6-12 years old) with brain disorders, that will increase their participation in their care path, and positively support their developing self-image.

1.3 Project context

1.3.1 The Sophia Children's Hospital and Pediatric Brain Centre

The Sophia Children's Hospital is the pediatrics partner of the Erasmus Medical Center in Rotterdam, the Netherlands. Every year, the Sophia treats approximately 5000 children with various conditions affecting the brain, the head, or the senses (Erasmus MC, 2019). These often involve complex disorders, requiring children to get involved with multiple medical specialists. To centralize all expertise related to the brain, scalp or face, the Sophia established the Pediatric Brain Centre.

The Pediatric Brain Centre (abbreviated as PBC) is a unique collaboration among scientists, brain- and behavioural specialists: the first of its kind in Europe (Erasmus MC, n.d.) The ultimate goal of the PBC is to ensure that every child with a brain disorder or developmental delay reaches their optimal level of functioning and participation in society. What sets the Pediatric Brain Centre apart is its close partnership between healthcare professionals and scientists. By involving science more directly in healthcare, an important step is taken towards achieving better health outcomes for children with brain disorders. This direct collaboration is reflected in a special section of the PBC: the Child Brain Lab.

1.3.2 The Child Brain Lab

The Child Brain Lab opened in June 2022. This research lab consists of three departments, where IQ and speech, neurophysiology and sensory function, and motor function tests are conducted. By collecting and analysing data from all visitors, researchers gain a deeper understanding of the brain, enabling better assessment of the effectiveness of treatment or therapy, ultimately leading to improvements in treatments (Erasmus MC, n.d.).

The CBL operates with two levels of participation. Level 1 participants don't physically visit the lab but complete validated questionnaires on aspects like their quality of life, emotions, and general health. On the other hand, level 2 participants both fill out the questionnaires and come to the lab to complete the tests in all departments. These tests have been selected based on research by Heydenrijk-Kikkert et al (2023). Figure 3 shows a map of the lab, showing the three departments and specifying which tests are conducted in each room. A list of all questionnaires is shown in appendix B.

Figure 1: *The Sophia Children's Hospital and Pediatric Brain Centre (Erasmus MC, n.d.) (Vrienden van Sophia, n.d.)*

Figure 2: *Illustration at the entrance of the Child Brain Lab (Erasmus MC, n.d.)*

The idea of the lab is that children make several visits to it as they grow up. To structure this research, the CBL uses different age groups. Starting from the point when children begin participating in the lab, the intention is for them to visit once within each age trajectory. These groups are designed to align with significant developmental milestones in a child's life (N. Kool, CBL psychologist). You can find a table summarizing these age groups in table 1. Consequently, children might end up visiting the CBL up to five times in total.

TABLE 1: *Age trajectories in the Child Brain Lab (source: Child Brain Lab)*

Trajectory	Age of participants
1	0-12 months
2	30-42 months
3	5-8 years
4	9-14 years
5	15-18 years

Take-aways Introduction

- In the CBL, caregivers work together with scientists. The Self-portrait therefore is situated between the fields of care & science.
- The CBL will be visited by children between the ages of 0-18 with different brain disorders, and therefore with a wide variety of capabilities and needs.
- Children will visit the CBL several times during their youth, with a maximum of 5 times.
- The Selfportrait should help the PBC to achieve that every child with a brain disorder can achieve his/her optimal level of functioning and participating in society, starting with participating in their carepath.

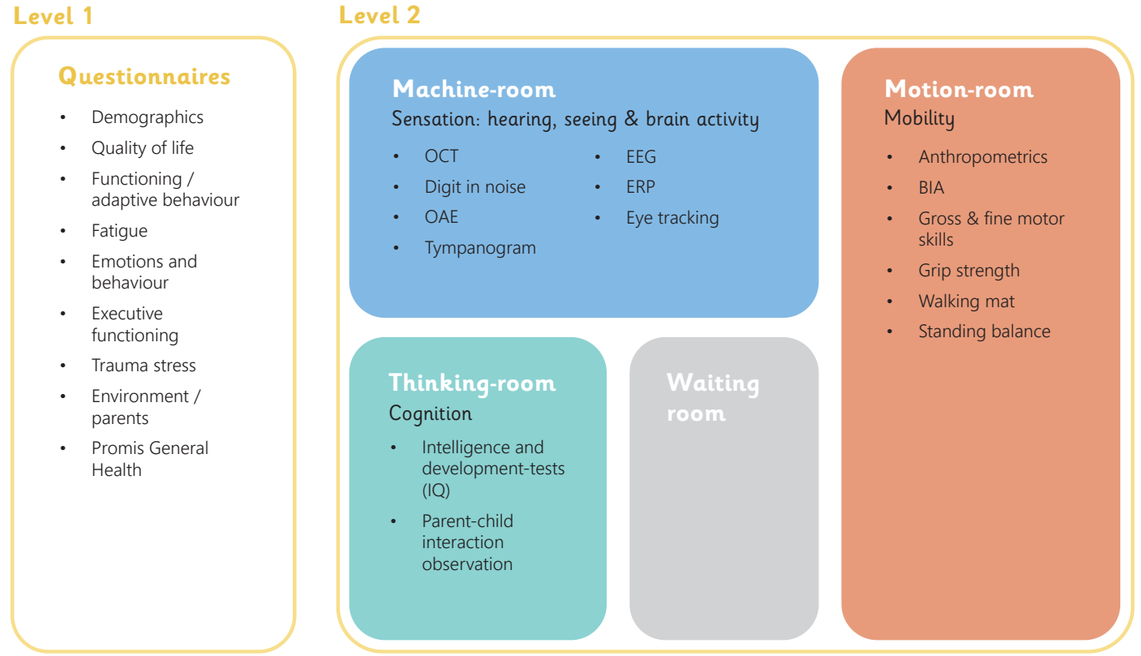


Figure 3: *Overview of the Child Brain Lab*

1.4 Project approach

The design process is an iterative one with various divergent and convergent phases. The primary overarching approach employed for this project is the Double Diamond Method, which was originally designed by the Design Council in 2004 (Design Council, 2023). This method begins with exploring the problem through research, following which the insights gathered from the discovery phase are utilized to redefine the problem in a new and clear manner. In the second diamond, attempts are made to solve the problem by initially diverging and exploring numerous potential solutions. The final phase, 'deliver,' involves evaluating and refining solutions to come a final solution.

1.4.1 Discover

In the discover phase, research was conducted through literature research, semi-structured interviews, generative sessions, and observations. The goal of the discover phase was to understand the target group, comprehend the tests, determine how to share test data with the target group, and gain insights into the data structures within the CBL

Generative research with children

A crucial component of the discover phase focused on investigating the desires and needs of children for the Self-portrait app. However, young children can have a difficult time abstractly describing what their technology needs and wants may be (Druin, 1999) . To assist children in expressing their thoughts, generative tools such as a trigger set, which includes a selection of images and words to trigger associations and memories (Sanders & Stappers, 2013), were utilized.

In addition to this, efforts were made to reduce the power imbalance that children can experience. The 'idiot adult' approach was implemented (MacDougall & Darbyshire, 2018), in which the researcher emphasizes that he/she knows nothing about the subject and requires the child's assistance.

1.4.2 Define

In the define phase, the insights obtained from the discovery phase were used to articulate challenges and opportunities for the design. To provide direction in how to overcome the challenges while making use of the opportunities, a design goal was formulated, and an analogy was used to establish an interaction vision (van Boeijen et al., 2013). Additionally, based on the insights, a list of requirements and preferences was compiled to create a comprehensive overview of the design's specifications.

1.4.3 Design

During the design phase of this project, ideation was somewhat intertwined with user research. The insights gained from the discover phase served as a foundation for ideation, during which various ideas were generated through brainstorming. These ideas were then translated into approximately six different idea directions for each test, serving as conversation starters in discussions with stakeholders, to determine the desired elements in the Self-portrait. This approach is referred to as research by design.

1.4.4 Deliver

In the final stage of the Double Diamond method, one main idea direction was selected for each test based on the research conducted in the design phase. These directions were further developed through in-depth literature research, additional ideation, and multiple user evaluations. This process enabled the creation of a final design that is feasible, viable, and desirable. A final evaluation round involving all stakeholders resulted in recommendations for further development.

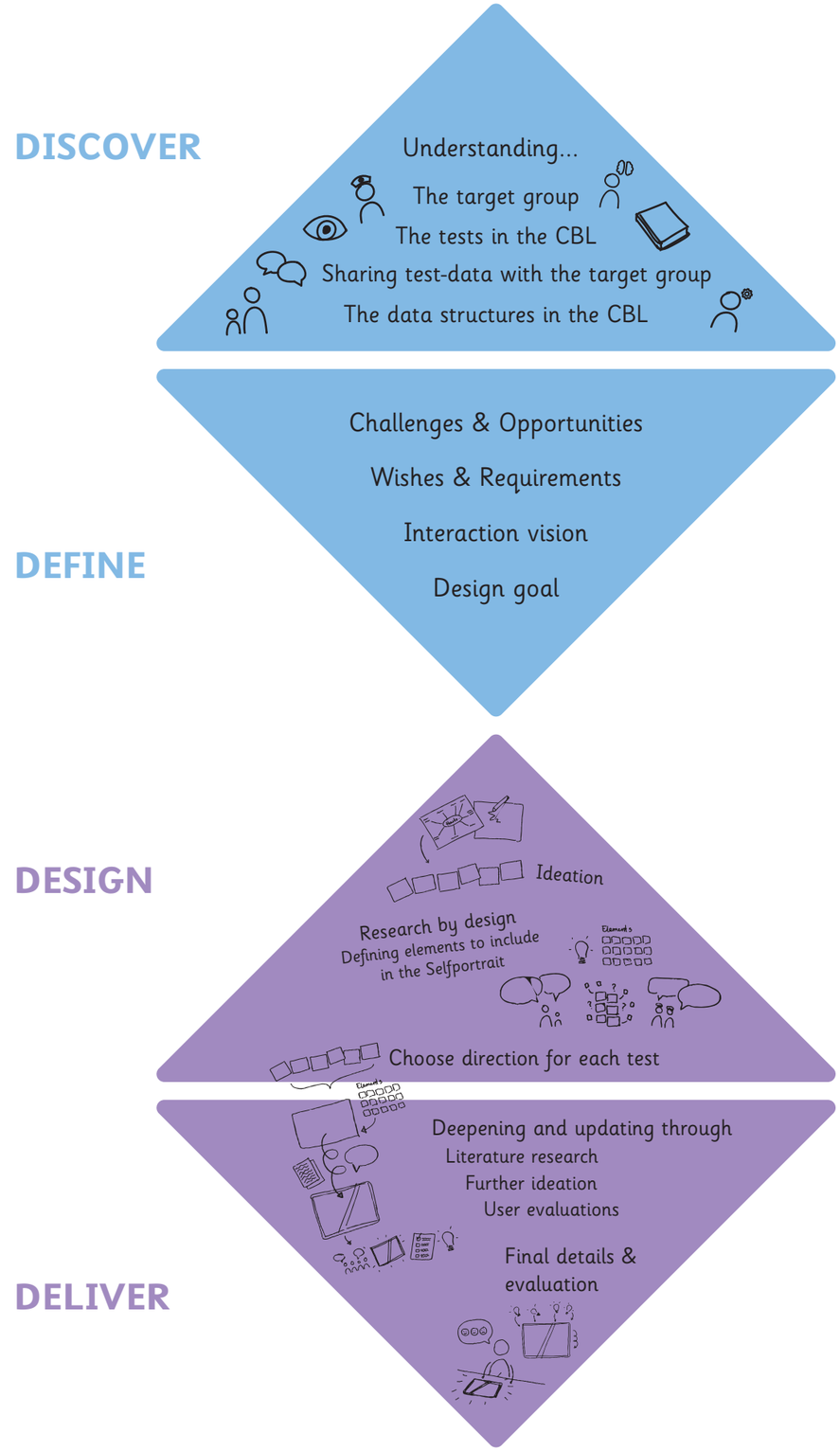


Figure 4: Double diamond approach

Chapter 2 - Selecting the tests

Within the project's timeframe, there is room to translate three tests. In order to make the greatest possible contribution, an effort has been made to select tests that showcase the full potential of the Self-Portrait. This section explains the choices made in this regard. By delving into the various tests in the lab, criteria were established for the test selection. This section explains the selection based on these different criteria.

2.1 Delving into the CBL tests

The first step in making a selection was to get an idea of which tests are conducted in the CBL. To understand the content of the tests, web-based research was conducted on all tests mentioned in Figure 3: Overview of the Child Brain Lab. This knowledge was supplemented with experiences from the CBL-staff and responses to a questionnaire filled out by healthy children who had tested the CBL test procedures (appendix C).

2.2 Criteria for the test selection

Upon analysing the acquired knowledge of each test, tests could be classified into several categories, on which the criteria for test selection were based. An overview of the research into the tests can be found in appendix D. The criteria that have been established to make the most comprehensive test selection are as follows:

1. The selection should contain one test from each room of the CBL, so all focus areas are covered.
2. The selection should contain tests with a focus on the functioning of the brain and body.
3. The selection should contain tests of different levels of difficulty for children to understand
4. The selection should contain test with higher and lower stakes for different kind of brain disorders
5. The selection should contain tests that differ in how children experience them

2.3 The test selection

The tests selected based on these criteria are the EEG, the walking mat, and the IQ test. Table 2 displays the characteristics of each test. These tests are discussed in detail in chapter 5.

TABLE 2: *Characteristics of the chosen tests*

	EEG	Walking Mat	IQ-Test
1 **CBL Room**	Sensory	Motor	Cognition
2 **Focus on functioning of...**	Brain	Body	Brain
3 **Difficulty for children**	Difficult	Understandable	Medium
4 **High stakes for children with...**	Epilepsy	MS or Cerebral Palsy	All kinds of brain disorders, but especially with intellectual delay
5 **Experienced by children as...**	Unknown, a bit annoying	Fun	Nervous, a bit boring

Discover

The discovery phase aims to acquire the knowledge necessary to enable a valuable way of communicating CBL-test-results to CBL-patients. This chapter first delves into the patients - the developments in cognitive capabilities and self-image of children with a brain disorder, then into the subject matter to be communicated - the diagnostics performed by the physician in the CBL, and finally, into the communication itself. Insights in this chapter have been generated through literature research, hospital observations, and interviews with physicians, patients and their parents.

Chapter 3 - Research approach

In short the design goal for this project is:

Design a digital solution that translates the results from three tests that are performed in the Child Brain Lab (the EEG-test, the IQ-test and the walking mat), into a meaningful contribution for children of 6-12 years old (developmental age) with brain conditions, that will increase their participation in their care path, and positively supports their developing self-image."

Several research questions are connected to the design goal.

Translate the results from 3 tests...

What data do the tests provide, and what does it mean? (chapter 5)

...that are performed in the Child Brain Lab...

How is the Child Brain Lab organized and how can the Self-portrait fit in this? (chapter 7)

...into a meaningful contribution...

What is the current understanding and attitude of children towards the EEG, IQ-test & walking mat? (paragraph 6.5)

... for children of 6-12 years old (developmental age) with brain conditions...

What are the capabilities and needs of children with a developmental age of 6-12? (paragraph 4.1)

What are the challenges associated with having a brain condition? (paragraph 4.3)

...that will increase their participation in their care path...

What are the influences on child participation? (paragraph 6.1-6.5)

...,and positively supports their developing self-image.

What is a self-image, what are the influences on it, and how does it develop for children? (paragraph 4.2)

These research questions have been answered by literature research, observations and interviews with HCPs, children with and without brain disorders, and parents. The research activities are shown in the figure 5 below.

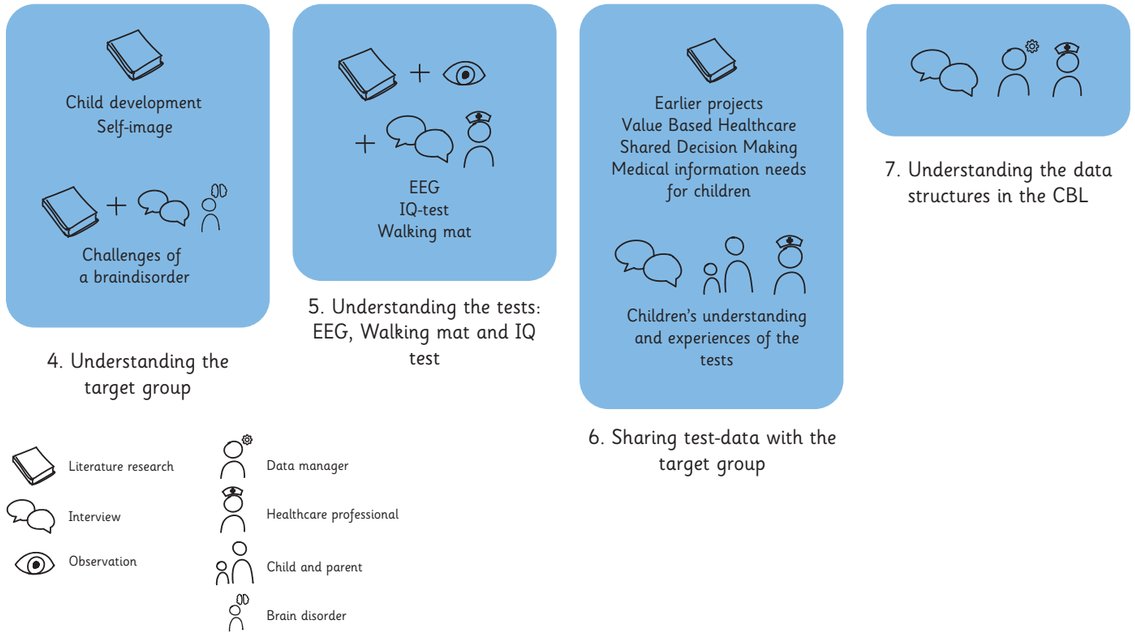


Figure 5: Research activities discovery phase

Chapter 4 - Understanding the targetgroup

This graduation project is designing The Self-portrait for the participants of the Child Brain Lab with a developmental age between 6-12 years old, with a variety of brain disorders. That brings a broad target group with varying capabilities, wishes and needs. This paragraph aims to create an overview of these capabilities and needs of the target group. Therefore research is done into typical child development between 6-12 years old, including the development of their self-image. In addition to this, the chapter takes into account the special needs that come with a brain disorder.

4.1 Cognitive development

It is evident that children between the ages of six and twelve have the required fine motor skills needed for the use of touch screen technologies (Souto et. al., 2019). However, research into cognitive development aims to gain insight into what cognitive capabilities children have (to understand information), and what their needs are (regarding receiving information).

The period between 6-12 year old, is known in the Netherlands as the 'school age'. It is a period where cognitive abilities of children develop to meet new milestones (Feldman, 2016). This means that children's thoughts, behaviours, emotions and relationships change. Figure 6 provides a summary of the primary developments between the ages of six and twelve, that influence or provide inspiration for the Self-portrait's design. This overview is based on the work of Acuff & Reiher (1997), Apperly & Robinson (2002), Bee & Boyd (2004), Feldman (2016), Kail (2003), Sharman et al. (1995), and Stein et al. (2019).

Looking at the intellectual developments, four important factors that improve as children grow older are language, selective attention, abstract thinking and information processing. Regarding social-emotional developments, children progress from egocentrism to understanding diverse perspectives and eventually embracing social group norms. Children's interests become a bit more serious and realistic when they get older. In general, most children share interest in helping others and collecting. What stands out from the timeline is that most theories describe major changes in the development around the age of seven or eight years old. Here, children move from imaginative thinking to more logical thinking, which influences their social-emotional development, and interests.

As the project's target audience consists of children with a developmental age ranging from 6 to 12 years old, this overview serves as a foundation for the design. Nonetheless, it's essential to recognize that children with brain disorders may have specific requirements, which will be addressed in paragraph 4.3.

Take-aways

- The shift from imaginative thinking to more logical reasoning that takes place around the age of 7/8 can influence children's needs for the Self-portrait
- For younger children take into account their limited abilities in language, selective attention, abstract thinking and information processing
- Younger children like random exploring, while older children prefer games with more structure and complexity.
- Children of all ages love collecting and always want to help others.

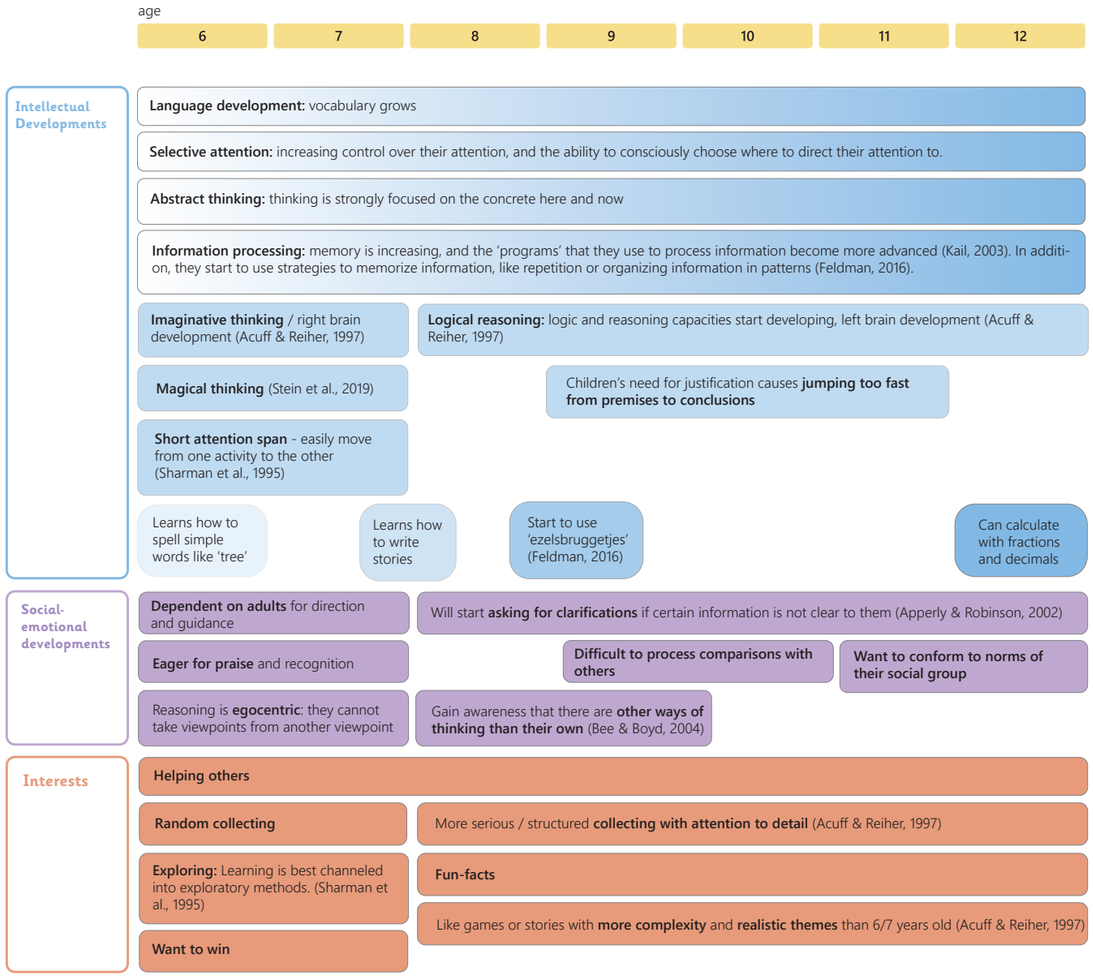


Figure 6: Typical child development between 6-12 years old

4.2 The development of a self-image

As was stated in the project goal (paragraph 1.2.1), one goal of the Self-portrait is to support the developing self-image of the CBL participants. Therefore, research was conducted to understand what a self-image is, its developmental process, and the factors that impact it.

A self-image or self-concept can be defined as children's representations and evaluations of themselves as individuals. These self-images differ for every child. Some children like themselves, whereas others feel negatively about themselves. Some children believe they can grow and build their abilities, whereas others believe their abilities are fixed and unchangeable. (Brummelman & Thomaes, 2017)

4.2.1 How a self-image develops

Just as cognitive abilities of children develop (see paragraph 4.1), the self-image develops and changes over time as well. It is not a static property but rather a dynamic cognitive construction that the child makes (Epstein, 1973). According to Harter (1999), the self-image is dependent on the cognitive abilities of a child. She stated: "because the self is a cognitive construction, the particular cognitive abilities and limitations of each developmental period will represent the template that dictates the features of the self-portrait to be crafted". Such a template that Harter speaks about, can help in dictating features of the Self-portrait that this project designs. Therefore this chapter aimed to use the cognitive abilities described in figure 6, combined with literature about self-image, to create a template of the development of the self-image. This template, shown in figure 7, was the inspiration for the framework for contributing to self-image that is described in paragraph 9.2.

The construction of a self-image also seems to be impacted by the shift from imaginative thinking to more logical reasoning that was discussed in paragraph 4.1. For the youngest children, egocentric reasoning is seen again, since children are not aware of implications of the skill levels of peers in social comparison, which results in their self-image being unrealistically positive. As children grow older, their self-image becomes more realistic and includes more complex qualities. We see that the

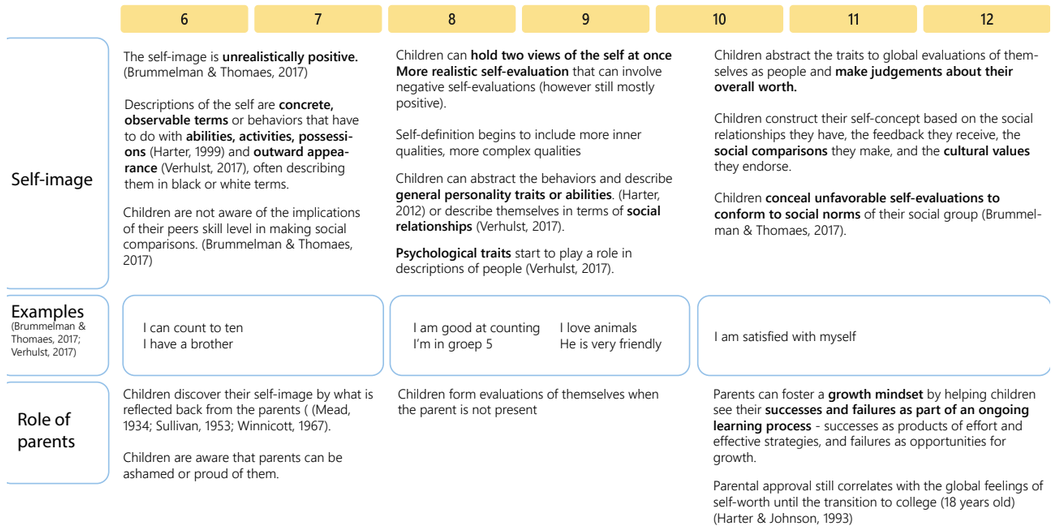


***Figure 7**: Development of the self-image*

self-image of the oldest children, who are further social-emotionally developed, is most impacted by their social group.

4.2.2 Influences on a self-image

Figure 6 shows how the cognitive capacities influence the form and shape of a child's thoughts about him/herself. But what influences the content of those thoughts? Scholars agree that at the heart of this self-development, are social relationships. Not only do children develop their self-concept through their interactions with others (Brummelman & Thomaes, 2017), more specifically children come to see themselves as they believe they are seen by significant others (Cooley, 1902; Mead, 1934).

Parents play the most crucial role here. From a very early age children discover their self-concept by what is reflected back from the parents (Mead, 1934; Sullivan, 1953; Winnicott, 1967). This has to do with parents beliefs. The parents' perception of the child's traits is in part based on the real properties of the child and in part read through the personalized lenses of the parents (Wachtel, 2001). Not only are children influenced by their parents projections, children also value what their parents think of them. When children fail on a task, they may conclude that they are unworthy, if they believe the task is important to adults. Considering parents' beliefs is therefore essential when aiming to contribute to a positive development of the self-image.

Does a self-image change? Children do believe that self-images can change over time (Co-research & Design with Children). However, individuals do not always revise their self-image in the face of new data (Greenwald, 1980; Sedikides, Green, Saunders, Skowronski, & Zengel, 2016; Swann, 2012). Possible explanations for this could be that they may not be interested in the data, they may lack the cognitive capacities to incorporate the data, they may dismiss the data as invalid, or they may be motivated to maintain their self-concept despite the data. (Brummelman & Thomaes, 2017). If the Self-portrait wants to influence a self-image, it should therefore make sure that the data in the app is easy to incorporate and interesting for children.

Take-aways

- Between 6 and 8, children's self-image is mostly based on abilities or activities, and is unrealistically positive
- From 8 years old, children get a more realistic self-image, which can also include negative self-evaluations
- From 10 years old, children make judgements of their overall worth.
- From 10 years old, social comparisons influence self-evaluations, meaning that sometimes children conceal unfavourable self-evaluations to conform to social norms
- Until around 18 years old, but especially at a young age, parents have a big influence on the formation of a child's self-concept, and therefore should be taken into account when designing the Self-portrait app
- For children to revise their self-image in face of new data, this data needs to be interesting, important and understandable to them

4.3 Children with brain disorders

In this section, the challenges associated with having a brain condition are explored, with the aim of complementing the insights gained from children without brain conditions. This research focuses specifically on the brain conditions within the start groups of the CBL (see table 3).

TABLE 3: *Start groups of the Child Brain Lab*

Start groups Child Brain Lab
Autism
Spina Bifida
MS
GRIN/GRIA
Crouzon
Cerebral Palsy
Sturge-Weber syndrome
Cerebral/Brain Overgrowth
Persistent Stuttering

The start groups are the groups of disorders that are the first to be invited to participate in the CBL. Firstly, an exploration is made into the impact of a brain disorder on one's self-image. Secondly, an overview of shared challenges is compiled, and these challenges are linked to the implications for app design qualities and app content. In this overview of challenges, special attention is directed towards children with autism. Autism is a developmental disorder that is prevalent within the CBL, often occurring in combination with other disorders within the initial groups.

4.3.1 The impact of a brain disorder on one's self-image

Paragraph 4.1 posed the question if children with brain disorders see themselves differently than healthy children, and in what way? This has been researched by combining interviews with children with a brain disorder with insights from literature. Table 4 shows the participants of the interviews. The interview activities can be found in appendix E.

TABLE 4: *Child participants with a brain disorder*

Participant	Age	Gender	Disorder(s)	CBL experience
C1	12	Female	Brain tumor	None
C2	18	Female	Cerebral Palsy (CP)	None
C3	7	Female	Problem with brain control of stools, used to have a hip deviation	None
C4	16	Male	MS-related syndrome, behaviour disorders including ADHD & PDD-NOS	First visit planned
C5	7	Male	Cerebral overgrowth, behaviour disorders	Invited
C6	6	Male	Cerebral overgrowth, behaviour disorders	Invited

Impact on self-image

Mejstad et al. (2008) researched the self-image of deaf and hard-hearing children, and found that self-image, as reported by the whole group of deaf and hard of hearing children who participated in the study, did not differ from self-image among the general population of children of the same age.

Based on interviews with the child participants from this project, their condition also seems to have little impact on their self-image. Their self-descriptions primarily revolved around their personality (I'm a good listener, I'm a cheerful person) and their interests (I'm crazy about the fire department, I love dancing and music). Additionally, there was no apparent connection to their condition in the drawings of young children (see Figure 8). Only C2 mentioned her condition in her self-description.

"I like everything because I can do everything" – C3

In response to the question "what is your dream," it appeared that for each child, their condition did not hinder their dreams. Three participants expressed a desire to help other people as their dream, and for one of them, this was related to her condition.

"What I would also like to do is become a doctor so that I can help other children with the diseases they have, like me." - C1

Self-awareness of brain disorder

Davies & Jenkins researched whether children with learning disabilities 'understand' what is meant by their condition, whether they apply such a label to themselves, and if this is mostly because of discourse or experiences (Davies & Jenkins, 1997). From their research, it was concluded that most participants incorporated the categorical identity of someone with learning difficulties into their self-image based on their experiences. Discourse did not have a big effect, since the vast majority of the participants did not understand the various terms and meanings used to refer to people with learning difficulties. When describing their specific disability, most young people focused on the physical impairment (Davies & Jenkins, 1997).

Looking at the interviews from this project, C1 t/m C4 did understand what was meant by their condition, and could explain it well. What stood out was that most of them described mostly physical impairment, which supports the insight from Davies & Jenkins (1997). For C5 and C6, who are both young children with learning disabilities, it was unclear how aware they were of their brain disorder.

4.3.2 Shared problems of children with brain disorders

Children with brain disorders often experience limitations in daily functioning that involve their mental and sensory functions, mobility, communication, self-care, and their community and social life. Despite the different underlying conditions, they share similar problems (Heydenrijk-Kikkert, 2023). A comprehensive overview of the disabilities associated with each of the start groups can be found in Appendix F.

Designing for children with autism

Designing for children with autism demands special consideration. It is is a complex disorder with varying degrees and different symptoms for each child. When designing for children on the spectrum, there are a few things to take into account:

Predictability: A prominent characteristic of people with autism is their need for predictability. They can become quite upset if their routine is disrupted (Gaines, 2016). In a predictable environment, it is easy to navigate throughout spaces. Designers can bring order to spaces by being consistent in layout

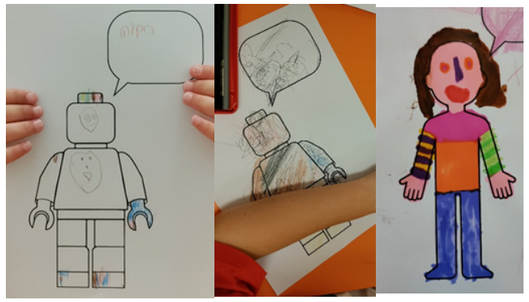


***Figure 8**: Three 'self-portraits' where children were asked to draw themselves.*

(Gaines, 2016), and by clearly identifying paths, making clear what their starting point and their end point is (Lynch, 1960).

Sensory input: Generally, children with ASD are either hypo-sensitive or hyper-sensitive to certain information pertaining to smell, sight, taste, sound or touch (Gaines, 2016). Children with hypersensitivity can be easily overwhelmed by incoming sensory information. In addition, people with ASD have difficulties with processing information from several senses at once. Rapid switching of attention between two stimuli is difficult for them (Gaines, 2016). Therefore, when designing for people with ASD, the amount of sensory input should be tailored to the level of sensitivity of a child. Sensory information should guide the attention and not distract.

Coherence: The weak central coherence theory explains that people with ASD can have troubles with integrating details into a meaningful whole (Sánchez et al., 2011). They look at individual pieces, and focus on extraneous details rather than thinking about things cohesively. For children on the spectrum to understand things well, information should be presented in a coherent way: including features that help in organizing and understanding the information (Herzog & Leverich, 2003), like patterns of brightness, size, texture, line, shape, and colour (Kaplan & Kaplan, 1989).

Language: Weak central coherence could also explain why some people with ASD understand meanings of individual words but struggle to understand the meaning of complete sentences (Brock et all, 2002). The focus on extraneous details could mean that any language mistake can distract them. In addition, some individuals with ASD have issues discerning irony, metaphors or jokes (Frith, 1989). Therefore, for people with ASD it is best to use simple and straightforward language.

Personalization & control: Most individuals with ASD, especially children, like to be in spaces that include personal items. Personalizing spaces provides them with a feeling of choice and control. When people have the opportunity to make choices and control their daily lives, they experience greater wellbeing (Gaines, 2016).

Implications for app design qualities

The list below presents the most important limitations that children from the start groups can experience that affect their interaction with the app, and the corresponding design qualities that need special attention.

- **Bad sight**: font size and colour contrasts
- Hearing loss: sound qualities of the audio feedback, like volume & pitch
- **Less sense of touch or power in hands**: delicacy of interaction elements, like haptic feedback and the size of buttons
- **Epilepsy**: animations
- **Low attention span**: length of tasks or stories
- **Autism & Intellectual disability**: predictability, sensory input, coherence, language and personalization

Implications for app content

In each brain condition, children experience various motor or cognitive limitations. On top of that, even within a single condition, it can vary which limitations a child faces. These differences not only impact the design qualities of the app but also influence the significance of the app's content for a child. This impact is particularly evident in the following three aspects:

1. What children can learn from the tests (about their disorder):
2. Which test results will have the biggest impact on a child
3. What the consequences of the test results are for the children's lives.

For these reasons, it is important to identify nuances in the extensiveness of information presented, and the degree of directness and sensitivity used when presenting results. The delineation of these nuances is explored during the Research by Design phase (paragraph 14.2), during which these topics are discussed with HCP's and children from the target audience.

Chapter 5 - Understanding the tests: EEG, IQ test and Walking Mat

In this chapter, a deeper understanding is gained of the three chosen tests. For each test, literature research is combined with interviews with experts from the PBC, to learn about the procedures, the results and their meaning. This was done to find out what potential data could be presented in the Self-portrait.

5.1 Study set-up

Eleven test experts from the PBC were interviewed to learn about the procedures and data collection of the EEG, Walking mat and IQ-test.

5.1.1 Research question

- What is the procedure of each the three tests in the CBL?
- Which data is collected?
- What do the results signify?

5.1.2 Participants

All interview participants are shown in Table 5.

5.1.3 Method

Semi-structured interviews

Healthcare professionals were interviewed using a semi-structured interview. A script was made for each interview, touching upon the topics of test procedure and data collection, and presenting data in the Self-portrait. For each interview, the script was adjusted to the expertise of the HCP.

TABLE 5: *expert interview participants*

Participant	Profession	Expertise	Interview date
E1	KNF lab technician (child neurology department)	EEG	6th March
E2	KNF lab technician (child neurology department)	EEG	10th March
E3	KNF lab technician (child neurology department)	EEG	10th March
E4	Research worker & tester sensory room CBL	EEG	15th March
E5	Pediatric neurologist	EEG	19th May
E6	Biomedical Engineering Intern CBL	Walking mat	5th April
E7	Pediatric physiotherapist & tester motion room CBL	Walking mat	22nd May
E8	Pediatric psychologist & tester cognition room CBL	IQ-test	21st March
E9	Pediatric psychiatrist	IQ-test	10th May
E10	Pediatric psychiatrist	IQ-test	25th May
E11	Pediatric psychiatrist	IQ-test	25th May

Figure 9*: EEG in the CBL with the electrode-cap and interactive game (Dijkstra, n.d.)*

5.2 Results

With the collected information, research questions from section 5.1.1 can be addressed. The sections below provide the answers to the research questions for each test. Additionally, for each test, it is indicated which potential data can be presented in the Self-portrait.

5.2.1 The EEG in the Child Brain Lab

Procedure

EEG stands for electroencephalography. It is defined as an electrical activity recorded from the surface of the scalp with the help of metal electrodes and a conducting medium (Abhang et al., 2016).

At the CBL, this is measured by wetting a cap with electrodes and placing it on the child's scalp (see Figure 9). The child sits in front of a screen on which various tasks appear, like recognizing facial expressions, a memory game, and challenging pattern-puzzles. The complete list of tasks can be found in Appendix G. During the EEG measurement, it is essential for the child to remain as still as possible, as muscle electrical activity can interfere with the results. During the measurement, the CBL-tester writes down observations that may potentially affect the test outcome, such as touching the EEG-cap a lot. These observations make it easier to filter the results later. The complete EEG procedure takes approximately 30 minutes.

Data from the test

The result of the recording is shown in figure 11 and is called an electroencephalogram (also abbreviated as EEG). Each line shows the differences of electrical potentials between two electrodes (E5). This EEG is manually analysed by a neurologist, who looks for patterns and deviations.
In addition to this, a scalp topography map can be made, which shows the presence of certain wavelengths in certain parts of the brain (Hairston, 2018).

Data significance

An EEG signal between two electrodes consists of many waves with different characteristics. However, there are five widely recognized brain waves, who are shown in figure 10. EEG has applications in various domains, like locating areas of damage, monitoring cognitive engagement, investigating epilepsy, testing epilepsy drug effects, investigating sleep disorders, and monitoring brain development. (Abhang et al., 2016)

The most important applications of EEG in the Child Brain Lab are:

Monitoring brain development: Analysing an EEG can show whether overall brain activity is within the normal range, or lagging behind. This can be determined by examining the EEG's speed and assessing whether the quantity of each type is within the expected range. Deviations from the average EEG patterns may indicate a delay in the development of the child (E4).

Investigating epilepsy: In EEG, epileptic activity can be recognised. This could occur even when a child is not experiencing epileptic seizures. An epileptic seizure is also clearly visible in an EEG. In the case of epilepsy, another application of EEG is to examine the effects of medication.

Locating areas of damage (for example following a tumor): if deviations occur in the EEG, this could indicate that certain areas of the brain are damaged.

ERP: Next to the typical brainwaves, reactions to stimuli like flashlights or beep-sounds can be recognized (E4), which is used to measure event-

related-potentials (ERP).

In typical brain development, the frequency of brainwaves increases when children get older. That means that some slower brainwaves, like delta and theta waves, will typically disappear during child development (E5), and other typical brainwaves will become more apparent. The alpha waves are a very good indicator of brain development (E5). This background rhythm, that occurs when eyes are closed, will start with a frequency of 2 or 3 Herz for infants, and speed up till around 10 or 12 Herz at around 10 years old. From this age, the frequency usually stays the same.

In general, brain development means that the network of braincells is expanding and strengthening (E5). In other words, the collaboration of all the brain cells within the brain becomes better and better.

Children usually believe that an EEG can read their thoughts (E2). This is not true, it can only be recognized that children are thinking hard, not what they are thinking about. Similarly, and EEG reveals if a child is dreaming, but does not reveal what the dreams are (E5).

Potential data to present in the Self-portrait

Based on the knowledge of this paragraph, the following data could possibly be presented in the Self-portrait:

- Procedure
  - Observations that can influence the test (nerves, tiredness)
  - How well the child has remained still
  - The experience of wearing the cap
- Results
  - Raw data Matlab file (screenshot, animation, or simplified version)
  - Presence of alpha, beta, theta, delta, and gamma waves
    - How frequently each type occurs
    - Where in the brain each type occurs
  - Brain responses to various tasks performed
    - Eyes closed
    - Flashing lights or clapping hands
    - Typical brain activity when a child is asleep
    - Typical rain activity when a child is dreaming
    - Typical brain activity during deep thought
  - Presence of epileptic activity
  - Changes in the frequency of typical brainwaves over the years
  - Disruptions in the EEG, caused by blinking or other muscle movement
- Interpretation
  - How 'busy' the brain is
  - How well their braincells can work
  - together (how strong is the network)
  - How nervous or relaxed a child was
- Explanation
  - What brain waves are and how they are generated
  - How the brainwaves typically develop over the years
  - What happens in the brain during epileptic activity

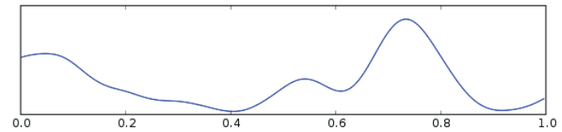
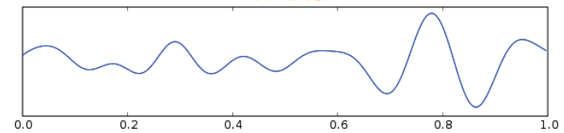
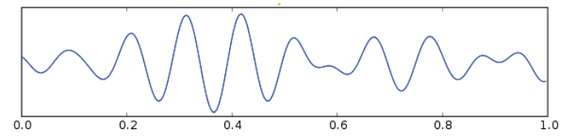
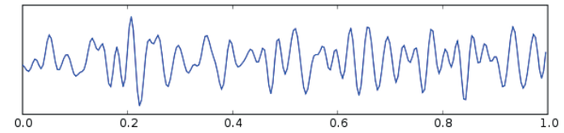
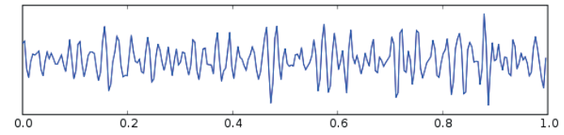
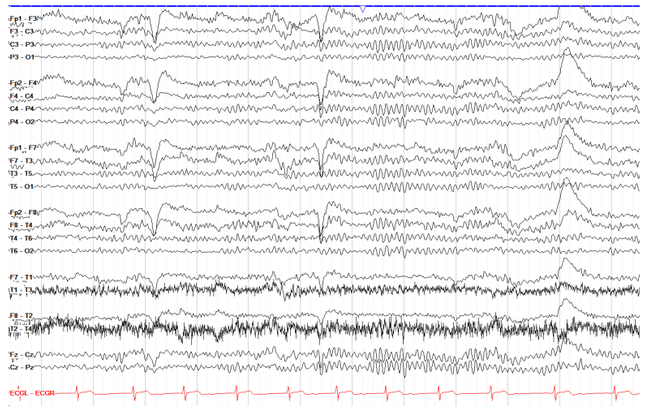
Wave	Description	Image
Delta	Appear when someone is sleeping	
Theta	Appear when someone is drowsy or deeply relaxed	
Alpha	Appear if someone is calm or has their eyes closed	
Beta	Appear when someone has an active mind, is anxious or busy	
Gamma	Appear during problem solving or concentration	

***Figure 10**: Five typical background waves (based on Abhang et al., 2016)*



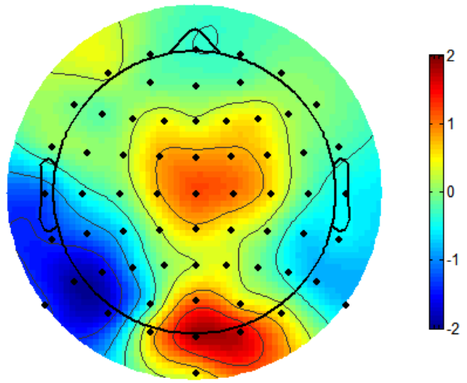


*Figure 11: Example of electroencephalogram (LearningEEG, n.d.) & **Figure 12**: typical EEG scalp topography (Slayback et al., 2018)*

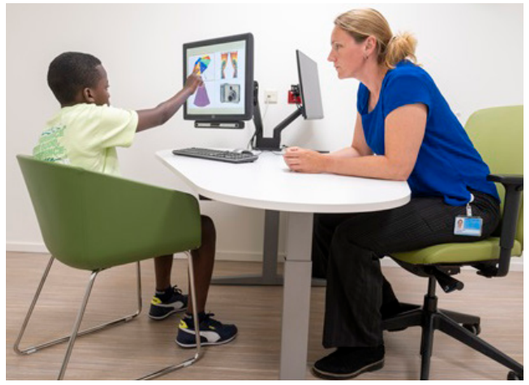


***Figure 13**: The IQ-test in the CBL (Willemse, n.d.-a)*

5.2.2 The IQ-test in the CBL

Procedure

IQ stands for Intelligence Quotient. An IQ test is conducted to measure intelligence. The term intelligence is used to assess a child's level of cognitive abilities in comparison to their peers (Verhulst, 2017).

There are various types of IQ tests designed for different target groups. At the CBL, children of different ages with varying disabilities participate, which means that different types of IQ tests are used. The most commonly used IQ test at CBL is the WISC-V. This test is designed for children aged 6 to 16 (E8). The WISC-V used at the CBL consists of ten subtests divided into five domains. Table 7 shows the domains together with how they are usually explained to children in the SKZ* . For each subtest, the child receives a series of tasks that progressively become more challenging. The psychologist records how many tasks the child can complete without errors for each subtest. Some tasks are also timed. In total, the IQ test takes approximately one and a half to two hours (E8).

An IQ test is always administered by a psychologist or psychiatrist. When IQ tests are conducted clinically at the SKZ, it is usually the same psychologist or psychiatrist who provides medical feedback. Normally, the results of an IQ test for children under the age of 12 are shared only with parents, and the child is not present during this feedback session. When delivering the IQ test results, the scores are discussed, compared with those of other children, and parents are always consulted to ensure they identify with the outcome. If the results imply that support services are recommended, it is discussed with the parents to determine if they require such assistance. Consequently, it will be a novel practice to communicate the results of an IQ test to children under the age of 12.

* The specific tasks that children need to perform are confidential and should not be shared publicly to prevent potential practice, which could affect the outcome of the IQ test.

Data from the test

The raw data that comes from an IQ test includes how many tasks a child has completed for each subtest and how quickly they did so. From this, five index scores are calculated. These are the Verbal Comprehension Index (VCI), Visual Spatial Index (VSI), Fluid Reasoning Index (FRI), Working Memory Index (WMI), and Processing Speed Index (PSI).

Ultimately, a comprehensive IQ score is derived from the WISC-V. An IQ score can range from 0 to 150 and reflects how someone's intelligence compares to individuals of the same age and gender. Table 6 shows the interpretation of IQ scores from 50 onwards.

***TABLE 6:** Interpretation of IQ scores (SKZ, n.d.)*

IQ	Interpretation
>130	Very gifted
121-130	Gifted
111-120	Above average intelligence
90-110	Average intelligence
80-89	Below average intelligence
70-79	Borderline Intellectual functioning
50-69	Moderate intellectual disability

Data significance

A total IQ is the ratio of mental age to chronological age, multiplied by 100. So, for example, a six-year-old child with a score similar to most five-year-olds would have an IQ of 5/6 x 100 = 83 (Verhulst, 2017). This tells a child how well they can learn and think compared to their peers.

In addition to the total IQ, several index scores are obtained. These scores provide insights into a child's strengths and weaknesses related to learning and thinking. Table 7 provides explanations for each index score according to the 'WISC V explanation to a child' guidelines from SKZ. Usually, it is only one domain that is significantly stronger or weaker than the other four domains (E8), while the differences between the other domains are not significant.

Furthermore, the reliability of the index scores can vary per child. For instance, if a child scores notably differently on the two subtests within the Working Memory domain, one cannot say with certainty how good that child's working memory is.

Potential data to present in the Self-portrait

- Raw scores:
  - Results per task (time of completion, or '7/15 tasks are completed')
- General IQ score
  - Explanation, comparison with children of the same age
  - Comparison with other visitors to the CBL
  - General IQ scores over time
- Scores per domain
  - Comparison with domain scores of other children
  - Comparison with the child itself: identifying strengths and weaknesses
  - Variability within each domain – how reliable is the score

o Explanation
- What is IQ and intelligence
- Link the domains to brain areas
- Daily life examples related to the domains

o Procedure
- Observations that can influence the test (bad concentration, nerves)
- Tasks that the child completed

o Results

***TABLE 7:** WISC-V domain scores – explanation to children (source: SKZ)*

Verbal Comprehension Index (VCI)	This is about how well you can explain your thoughts using words. It's about how good you are at explaining the meanings of different words and how well you can describe the most important similarities between words. So, it's all about how skilled you are with words.
Visual Spatial Index (VSI)	In these tasks, it's not about language at all. It's about how well and how quickly you see things. It's also about looking at shapes and how well you can manipulate them in your mind. It's about how good and how fast you can use your hands to recreate them. For example, the task where you had to recreate patterns with blocks belongs here.
Fluid Reasoning Index (FRI)	Here, it's all about whether you can quickly understand new information and come up with solutions. Finding cause-and-effect relationships and thinking logically is important. For instance, the task where you had to balance a scale belongs here.
Working Memory Index (WMI)	In these activities, you need to remember information, like numbers and letters. Sometimes, you even had to change their order. This is important for learning at school and for remembering and applying rules in subjects like grammar and math.
Processing Speed Index (PSI)	These are two tasks where you have to work very quickly, and you're also under pressure because of the time. Paying attention and staying focused are important here. How well and how fast you can write or draw figures is important too.

** The specific tasks that children need to perform are confidential and should not be shared publicly to prevent potential practice, which could affect the outcome of the IQ test.*

***Figure 13**: Walking mat procedure in the CBL (Willemse, n.d.-b)*

5.2.3 The walking mat in the CBL

Procedure

The walking mat is a long mat on the floor (see figure 13), that participants are required to walk on. Integrated into the mat are pressure sensors that can measure how children place their feet (E7). Additionally, two video cameras are positioned around the mat to capture the child's walking pattern. One camera records the child from the front, while the other is perpendicular to the walking direction. Two tests are conducted on the walking mat: the walking test and the balance test.

Walking Test

Children are asked to walk four times back and forth on the mat while barefoot. The objective is for children to walk as naturally as possible at a normal pace. In some cases, a child may walk with assistance, such as wearing shoes for extra support, holding an adult's hand/tester's hand, using a tripod, or a walker.

At the end of the walkway, there is a large TV screen. Before starting to walk, children can choose an environment they want to walk towards, such as a forest, an underwater world, or in space. Additionally, they can select one of the characters from the CBL, which will appear on the screen.

Balance Test

During the balance test, coloured footprints are placed on the mat. The participant is then given various tasks to perform. The specific tasks assigned to a child depend on their abilities. While performing the tasks, the mat measures the pressure distribution of the feet and assesses how long a child can maintain each task (E7). The tasks are:

1. Stand with both feet together.
2. Place both feet right in front of each other.
3. Stand on one foot.

Data from the test

The outcome of the walking test is a dataset with an extensive list of values. An example of such a spreadsheet can be found in Appendix H. Additionally, various diagrams are generated, as illustrated in Figure 14. These diagrams provide information about the pressure distribution on the feet, as well as the speed, length, and width of the strides (E6). Furthermore, videos from both cameras are saved. These serve as reference material, for instance, when notable deviations are observed (E7).

Data significance

The data obtained from the measurements can be compared to a database of walking patterns of healthy children, to determine if the walking pattern is within the normal range. If the walking pattern deviates from the norm, the data can reveal in what ways it differs (E6).

When a walking pattern deviates, it may indicate that a child has an increased risk of stumbling or falling. Therefore, the results can provide insights into a child's stability and safety while walking (E7). Additionally, the walking mat can show if there are differences between the left and right sides of the body. This can be linked to brain functioning (the left hemisphere controls the right leg and vice versa) (E7).

In some cases, a plan can be developed to help a child improve their walking pattern based on the results from the walking mat.

Potential data to present in the Self-portrait

- Procedure
  - Number of steps taken
  - Choice of background and buddy
  - Utilized walking-aids
  - Observations that may affect the test
- Results
  - (Anonymized) video
  - Animation of footsteps
  - Pressure distribution in the feet (image or animation)
  - Walking speed
  - Length and width of steps
  - Variation between different steps
  - Position of the feet: turned inward or outward
  - Differences between left and right
  - Standing balance
- Interpretations
  - How safely or stable a child walks
- Explanation
  - How the brain controls movements
  - Explaining different walking abnormalities like a clubfoot

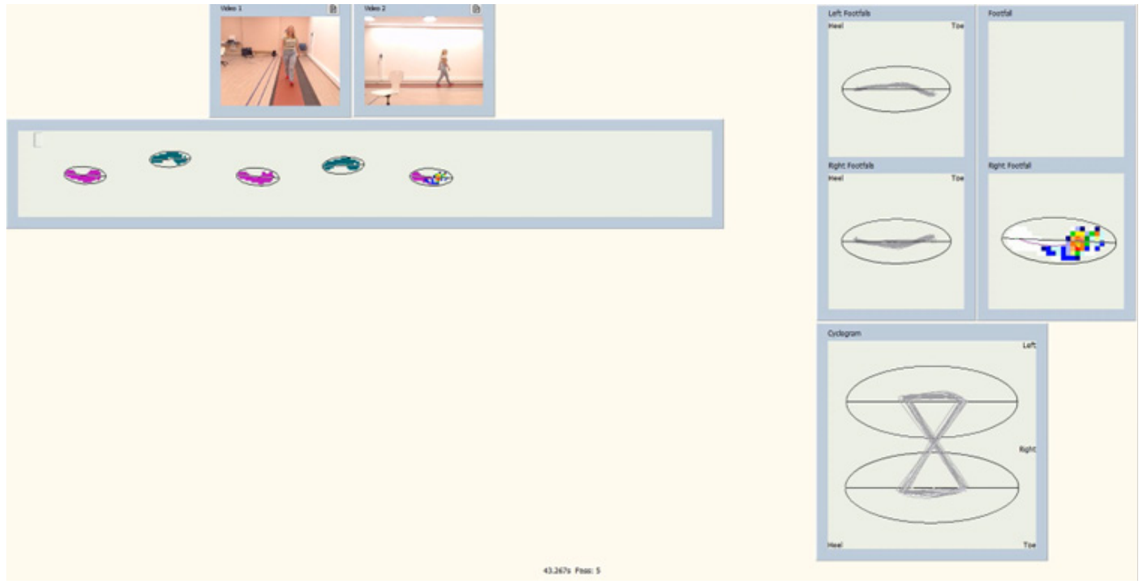


***Figure 14**: Screenshot from the walking test results*

Chapter 6 - Sharing test-data with the target group

Now that we have gained insight into the target group and the tests, the question remains of how best to share the obtained information with the participants. This part of the research phase therefore looks into insights from earlier projects, two developments that play a significant role in the medical world and within the Erasmus MC, and looks into literature about the communication of medical data to children. Lastly, a small-scale qualitative research study was done to discover what children's current understanding and attitude towards the tests from the CBL is.

6.1 Insights from earlier projects

Prior to this project, three previous projects have collected valuable insights into communicating results with children. This section explains the key findings from these projects. The projects are listed in table 8.

Meulendijks' project (2020) focused on the question, "How can we involve patients in their clinical tests and test results in a child-centered way?" He mapped out the context of the CBL, providing various insights into how children can be more engaged. His design proposal gave rise to the idea for the Self-portrait app. Thielen (n.b.) used co-design with children in her research to discover the requirements for the Self-portrait app and proposed a general design concept for the app. Additionally, Van Dijk (2021) examined the current state of child participation in the PBC and the ongoing developments in promoting child participation. She translated her findings into design interventions to enhance child participation in the PBC.

All projects yielded valuable insights. These insights were compared to each other to provide an overview of the main findings. An overview of all clustered insights is presented in appendix I.

The main design requirements that were found by both Meulendijks (2020) and Thielen (n.d.) are as follows:

- Use layering in information (to cover the diversity of the target group)
- Make it relatable, create links to daily life
- Use metaphors
- Use easy and clear language
- Make it personalizable
- Create an overview of results over time

TABLE 8: *Former projects related to the Self-portrait*

Title	Author	Year
The Brain Self Portrait - *A project on involving child patients in their clinical tests and their test results*	Meulendijks, P.	2020
Dancing through the paediatric consultation: 'it takes three to tango' - *Evaluating child participation and (re)designing interventions on participationin the Child Brain Centre*	Van Dijk, T.	2021
Het Zelfportet - *Ontworpen voor het Kinder Hersen Lab*	Thielen, L.	n.b. (>2021)

These design requirements will, therefore, be incorporated into the elaboration of the tests and further evaluated with the stakeholders.

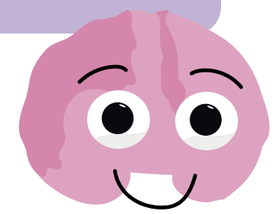
However, among the insights from the various projects, some discrepancies have been identified as well, namely:

- Conveying a truthful image (Thielen, n.d.) vs. children not wanting to be confronted with their disorder too much (Meulendijks, 2020).
- Children wanting to compare results with others (Thielen, n.d.) vs. not wanting to be different (Meulendijks, 2020)
- Control of parents (Van Dijk, 2021) vs. control of the child (Meulendijks, 2020)

These will be taken into account during the analysis in the define phase (chapter 9-12).

Take-aways

- The main design requirements that have emerged from previous projects are:
  - Use layering in information (to cover the diversity of the target group)
  - Make it relatable, create links to daily life
  - Use metaphors
  - Use easy and clear language
  - Make it personalizable
  - Create an overview of results over time
- Identified discrepancies that need to be taken into consideration are:
  - Conveying a truthful image vs. children not wanting to be confronted with their disorder too much
  - Children wanting to compare results with others vs. not wanting to be different
  - Control of parents vs. control of the child



6.2 Value Based Healthcare

In light of their ambition to be a pioneer in innovative care, the Erasmus MC introduced Value-Based-Healthcare (VBHC) as the quality standard (Hazelzet, 2017). The PBC also embraces VBHC as the quality standard in its activities, including the practice of sharing medical data with patients (through the Self-portrait). This section therefore outlines the key characteristics of VBHC and discusses their implications for the Self-portrait.

Value based healthcare is a global reform movement, in response to an increasingly challenging healthcare environment, with increasing healthcare costs, raising chronic diseases, ageing populations and increasing community expectations. According to Porter (2009), the focus of healthcare systems at that time was on minimizing the cost of each intervention rather than on maximizing value over the entire care cycle. He proposed a system where care is organized in the way that it maximises value for the patients. The definition of value in this case, is as follows:

$$\text{Patient value} = \frac{\text{Patient relevant outcomes}}{\text{costs per patient to achieve these values}}$$

***Figure 15**: Patient value (Porter, 2006)*

Patient relevant outcomes include not only survival, but also the degree of health or recovery achieved, the time needed for recovery, the (dis) comfort of care, and the sustainability of recovery (Porter, 2008). This means that care does not stop with a successful brain surgery. The full cycle of care needs to be considered, including the experience of the patient before, during and after the surgery.

The costs per patient do not only refer to the direct costs: those of the medical procedures, or de resources used in treatment, but also to indirect costs like travel associated with appointments or lost income because of missed work (Australian Healthcare & Hospitals Association, 2022).
To maximise value for the patient, both outcomes and costs must be considered across the full cycle of care, recognizing that a cycle of care can be provided by multiple providers over time, which is illustrated in the following example:

A child has a brain condition that is caused by an excess of fluid in the brain. This can be addressed by surgically inserting a shunt into the brain (performed by a neurosurgeon). The brain condition may lead to this child having autism or ADHD (assessed by a psychologist), for which they receive medication (prescribed by a psychiatrist). The child may also experience epileptic seizures (diagnosed by a neurologist), have reduced muscle tone and thus requires assistance with movement (from a physiotherapist), or encounter difficulties with urination (examined by a urologist).

In this scenario, the patient interacts with several HCPs. This calls for multidisciplinary care teams, with the PBC serving as a good example. In the CBL, these multidisciplinary teams are further augmented with scientists, who work together with HCP's to improve care. Within the PBC, the Self-portrait has the specific role of keeping the child informed, motivated, and engaged. These are the 'patient relevant outcomes' (see figure 15). To align with the value-based healthcare philosophy, this requires consideration of the entire care path and supporting collaboration among various healthcare professionals.

Simultaneously, the costs per patient to achieve these values can be viewed as the risks associated with presenting test results to children. The primary risk involved is that if communication is not handled properly, it can have a significant emotional impact on a child. To maximize value, it is essential to minimize these risks. Therefore, attention must be paid to children's sensitivity in receiving information.

Take-aways Value Based Healthcare
- The Selfportrait can deliver the most value if it considers relevant patient outcomes over the full cycle of care.
- Patients interact with several HCP's during their carepath. The Selfportrait should therefore support the collaboration of these multi-disciplinary care professionals.
- The (emotional) costs for children should be minimized by paying attention to a child's sensitivity in receiving information.

6.3 Shared Decision Making

Erasmus MC employs the Shared Decision Making (SDM) approach in physician-patient communication, which means that the patient is actively involved in decision making. Within the PBC, there is also a commitment to using SDM and increasing children's level of participation in their care. The self-portrait can play a significant role in this regard. Therefore, this section summarizes the key information about SDM and child participation.

Shared decision making (SDM) is an evidenced-based approach that promotes collaboration between patients, family members, and healthcare providers when making health decisions. By exchanging information about the evidence (options, risks, and benefits) and the patient and family's preferences and values, HCPs, patients, and family members can deliberate to determine the best treatment plan (Légaré et al., 2011). This approach to decision-making is recommended as a key feature of good clinical care (WHO, 1994), has garnered increasing international support among policy makers, and is recommended by pediatric regulatory organizations (Boland et al., 2019). According to Vaknin and Zisk-Rony (2010), children and healthcare providers both benefit when children are encouraged to offer their own input on matters that directly affect them.

Nonetheless, implementation of SDM in paediatric healthcare remains limited (Boland et al., 2019). Firstly because pediatric decision-making includes multiple stakeholders (i.e., child, family members, and HCPs), each with their own preferences and values. Parents act as surrogate decision makers, having to make decisions on their child's behalf. Secondly, it is hard to determine the extent that children should be involved, since children's evolving developmental context impacts their participation in health decisions.

This second limitation was addressed in the graduation project of Van Dijk (2021), who researched what the current and desired levels of child participation at the PBC are. To determine the level of involvement of the child in decision making, Shier's pathway of participation can be used (figure 16). According to the HCP's of the PBC, the desired level of participation is always up to level 3 (taking account of the child's opinion). However, most professionals are reluctant to move toward level 5, because they see the risk of 'too much participation'. They do find it important to ask what the child prefers, but only if there is genuine freedom of choice or when the child has the cognitive capabilities to understand the situation (Van Dijk, 2021).

Van Dijk concludes that optimisation of child participation is not per se about pushing decision-making-involvement to a higher level of the Shier-pathway, but about creating meaningful

***TABLE 9:** Micro-level interventions on child participation – simplified (Van Dijk, 2021)*

Target	Type of intervention	Explanation
Child	Information provions	Information on condition, treatment and procedures
	Skill development and skill support	Targeting communication and assertiveness skills. May include preparation tools or tools that can be used during interaction.
	Child-friendly hospital design	Stress-reducing hospital environment
Parent	Information provision	Information on condition, treatment and medical procedures
	Skill development and motivation enhancing	Explanation on the relevance of child participation and on developmental changes in the child's ability to participate
HCP	Information provision and motivation enhancing	Explanation on the relevance of participation, education on legislation and children's rights
	Skill development	Addressing the following skills: communication, organisational and/or pedagogical competence

participation. For example, if one wants to reach level 3, interventions could help the child in expressing its opinion. Van Dijk summarized the current suggestions for interventions on optimizing child participation. Table 9 shows a simplified version of her summary, the full table can be found Appendix J.

Inviting and supporting children to participate is one of the facilitators of SDM that were found by Boland et al. (2019). All findings from Boland et al. have been summarized and are shown in table 10. Knowledge of the identified barriers and facilitators influencing SDM is required for successful implementation of the Self-portrait (Baker et al., 2010). Among all the barriers and facilitators of SDM defined by Boland et al. (2019) and existing interventions that have been proven to improve SDM (van Dijk, 2021), the elements where the Self-portrait is most likely to make a contribution are:

1. **Providing high-quality information about the condition or options:** tailored to a child's developmental needs and the child/ parent literacy needs.
2. **Inviting and supporting children & parents to participate**: skill development and creating a positive relationship / open and respectful atmosphere.
3. **Integration into the clinic workflow**: fitting the solution with the heavy workload of HCP's and in the care pathway of patients.
4. **Consider the stakes**: involvement of children does not always have to be aimed for at the same level. HCPs and parents reported being more willing to involve children in decisions when the potential outcomes were considered less risky. Similarly, children reportedly preferred to be involved in lower stake decisions. (Boland et al., 2019).

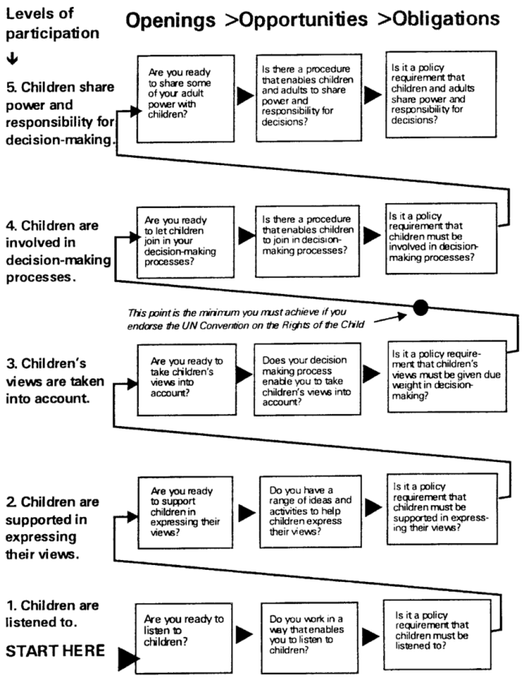


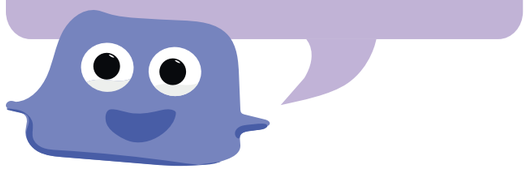
***Figure 16**: Shier's pathway of participation (Shier, 2001)*

***TABLE 10:** Summary of the barriers and facilitators from the study of Boland et al. (2019)*

Level	Facilitators	Barriers
Decision level	Lower stake decisions –decisions where potential outcomes are considered less risky	Features of the options (a perceived lack of options, unacceptable alternatives, affordability)
		Lack of research evidence for the various options
Innovation level (i.e., SDM)	High quality information	Poor quality information about the condition
	Information that is appropriately tailored to the child's developmental needs and child/parent literacy needs	Options that were inappropriately tailored to the child and family's health literacy needs
		Engaging in the SDM process requires too much time
Adopter level (i.e., HCP's, parents, children)	Children being older and perceived to have adequate decision-making-consequence	Parent's and child's emotional state (overwhelmed, anxious, in denial, or defensive)
	Parents and/or children being in good health	Perceptions of poorer health status of the parent and/or child
	Agreement with and desire for a SDM approach	Lacking agreement with SDM in principe
		HCP's lack of SDM skills
Relational level	Trust and respect in relationships between adopters	Power imbalance – systematic exclusion of children from the decision-making conversation
	Respectful communication, appreciation for each adoppter's expertise	Power imbalance – child feeling too disempowered or intimidated in SDM discussions
	Inviting and supporting the child and family throughout the SDM proces	HCP providing only one option, or his/her preferred options only
Environment level (i.e., pediatric clinical practice)	Access to SDM tools (e.g. patient decision aids), resources, and/or training	Insufficient time due to heavy workloads
		Clinic workflow and poor continuity of care hindering SDM
		Practice norms (e.g. expectation that the HCP's duty is to make the decision)

Take-aways Shared Decision Making

- Shared Decision Making is an evidence-based approach that is recommended by pediatric regulatory organizations, and proven to fit both children and healthcare providers
- Optimizing child participation should be focused on creating meaningful participation in the level that suits a child's cognitive abilities
- The Selfportrait should aim for:
    - Providing high quality information tailored to a child's developmental and literacy needs
    - Inviting and supporting children & parents to participate
    - Integration into the clinic workflow
    - Considering the stakes of decisions when aiming for a certain level of involvement



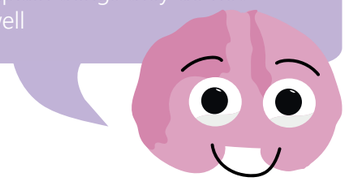
6.4 Medical information needs for children

Existing literature on the medical information needs of children, parents and clinicians, mostly focused on information about procedures: how to prepare, who to talk to, how does the environment look (Aufegger et al., 2020). Other findings are the need for information about sensory aspects of the procedure (what will they touch, taste, smell, hear), and what emotions a child might feel before, during and after a procedure (Bray et al., 2019).

However, the main focus of the self-portrait will not be on providing information of the procedures, but on communicating results. General insights can be found about medical information provision for children. For children, knowledge is gained optimally by actively accessing information and constructing their own understandings through engaging with multiple elements (gamification, augmented reality, a chatbot), to influence multiple aspects of a procedure (Bray et al, 2020). Parents expressed the need for medical information that is easily understandable for parents, and conveyable to their children (Aufegger et al., 2020). Language is important when talking about sensitive topics such as illness. Language should be concrete and specific, to avoid misunderstanding (Stein et al., 2019). It should be direct, and as simple as possible, but there should be a balance between being understandable but not "baby-ish". Language should be tailored to a child's particular age group. Technical jargon should be avoided: this is experienced by adolescents as an attempt to keep them powerless (Stein et al. 2019). In addition, it should be avoided that children misinterpret medical information because of magical thinking. For children between the ages of 4 years and 7 years, what causes illness (and death) is substantially influenced by what is known as magical thinking. Magical thinking is used to describe children's belief that thoughts, events, or wishes can cause external events (eg, that illness can be caused by a particular thought or behaviour) (Stein et al., 2019).

Take-aways

- Most research into medical information needs focused on the need for information about the procedure
- Including multiple elements that children can actively engage with, will help children to gain knowledge
- Language should be concrete, specific, easily understandable but not "baby-ish"
- Young children are influenced by magical thinking to explain things they do not understand well



6.5 Children's understanding and experiences of the EEG, Loopmat and IQ test

To ensure that the information in the Self-portrait is a meaningful contribution for the CBL participants, it is important that the information aligns with children's current understanding and their expectations for the Self-portrait. To gain a good understanding, a generative session was conducted with children and their parents, and HCPs were interviewed about this. All the insights were collectively analysed to identify key themes.

6.5.1 Research questions

1. How do children experience the test and receiving of results?
2. What is children's understanding of the test?
    a. What do they think the test measures?
3. What would children like to learn from the test results?
4. How would children like to see the test results being presented?

6.5.2 Participants

Children

The children that participated in this study are healthy children that have 'tested' the tests from the CBL. That means they have experienced the test procedures, but did not receive their results. In total, six different children participated, divided over three sessions. All participants were children from healthcare workers from the SKZ. In every session, the children that participated were siblings of each other. In table 11, the child participants and their characteristics are shown.

Parents

Two mothers of the participants from table 12 participated in the study. Important to mention is that both women were employees of the Erasmus MC and therefore are familiar with hospital procedures.

Healthcare professionals

The HCP's that participated in this study are E1, E2, E3, E4, E7 and E8 from table 5.

TABLE 11: *Child participants generative session test experience*

Participant	Age	Gender	Session	Period between tests/research session estimate
C7	8	Female	1	2 weeks
C8	14	Female		
C9	8	Female	2	2 months
C10	10	Male		
C11	13	Female		
C12	6	Male	3	3 months
(C13)	3	Female		

TABLE 12: *Parent participants generative session test experience*

Participant	Gender	Parent of	Profession
P1	Female	C9, C10, C11	Pediatric physiotherapist
E1	Female	C12, C13	KNF lab technician

6.5.3 Method

Generative research sessions (children & parents)

To find answers to the research questions, a generative session was prepared. For this session, make tools were used to reveal tacit knowledge (Sanders & Stappers, 2013). The set-up consisted of two templates for every test. These templates are shown in figure 17 and 19. Children were asked to fill in the templates and express their thoughts using a trigger set: a selection of images and words, to trigger associations and/or memories (Sanders & Stappers, 2013). In addition, coloured pencils were available to add their own images and words. Children were given a couple of minutes to fill in their template (individually or in pairs), whereafter they were asked to explain what they made. All session materials are shown in Appendix K. During the session an audio-recording was made, and photographs were taken of finished templates.

***Figure 17**: This template was used to answer research questions 1 and 2.*

***Figure 18**: Example of study set-up of the generative research session*

Semi-structured interviews (HCPs)

A semi-structured interview was conducted to determine how communication with children about the tests is currently handled by HCPs and how they would like this communication to be. Additionally, HCPs were asked about their perceptions of how children experience the different tests. The interview guide can be found in appendix L.

EEG observations + short interview

During three observations of the EEG procedure, short interviews were conducted with the patients and their parents. The insights from these interviews are also considered during the analysis.

***Figure 19**: This template was used to answer research questions 3 and 4. From this template, different versions were made for different ages.*

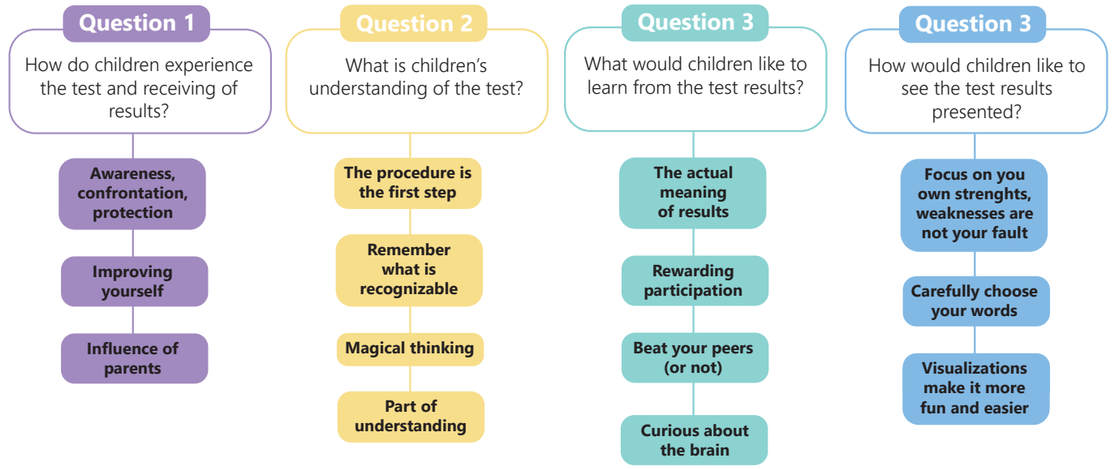


***Figure 20**: Results of the thematic analysis of the generative session & interview data*

6.5.4 Analysis

All generative sessions and interviews were audio-recorded and transcribed. In the transcripts, important quotes are highlighted. These quotes are placed on digital post-its on a Miro board. Data about all tests from all three sessions was analysed using a thematic analysis (Vaismoradi et al., 2013), where there was no distinction between tests. From this, overall themes appeared regarding each research question.

In addition, the data from each test was analysed separately, with the goal to gain insights in the understanding of that test.

6.5.5 Results

The analysis revealed several themes corresponding to each research question. These themes are depicted in Figure 20 and are further explained below. The thematic analysis can be found in Appendix M.

1. How do children experience the test and receiving of results?

Awareness, confrontation and protection

The test results will not always bring good news, and receiving them can be confronting for a child, causing stress (parents, HCP's). Parents seek to protect their children from this by monitoring the results (parents). Particularly when a child is unaware of a limitation, the balance between confrontation and protection becomes crucial.

"For very confronting results, I would like to check it before we show it to my son" – mother of a six year old (during EEG observation)

Improving yourself

Children see the test as a means to find areas for self-improvement (children). It's a good thing to emphasize personal progress rather than comparing oneself to others, but this approach can also carry risks. In certain conditions, despite their efforts, children may still score lower the next time (HCP's).

"I can clearly see how I performed, and think of what I can improve" – P4

"Often, you see that these children actually regress, so the next time they score worse, or can't even walk anymore." – E7

Influence of parents (parents, HCP's)

In the case of young children, parents play a significant role in the experience of the test and the test results. Parents are often present during

the procedure and when the results are given, which can impact a child's experience (parents, HCP's). This influence can be positive, as parents can provide reassurance (parents), but it can also have a negative impact if parents themselves are disappointed with the results (HCP's).

"How the child feels, would depend on how her parents handle the situation." – E3

2. What is children's understanding of the test?

The procedure is the first step
Children perceive the procedure and the steps involved, as an integral part of the test. Memories of the test are dominated by the actions children had to perform, rather than what was being measured during the test (children). Sometimes, children even considered their performance during the procedure as part of what was being measured (children), as illustrated in the quote and figure below.

"What was being measured? 'I think they were checking if I had the courage to do it." – P6

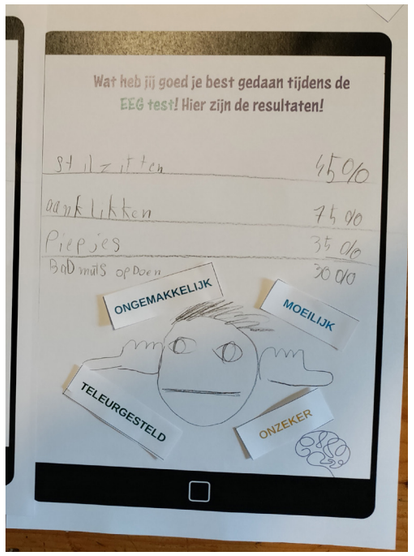


***Figure 21**: Filled template with results about procedure (P4)*

Remember what is recognizable
The elements that participants remembered from the test were primarily things that were recognizable and easily linked to daily life (children), such as footprints and the size of their steps. In addition, the recognizable characters (Wavy, Breeny, & Neuro) were mentioned by almost all participants as their first recall.

"That red mat looked a bit like a running track" – P1

Magical thinking
When HCPs introduce the test to children, they choose their words carefully. Incorrect wording can potentially trigger incorrect associations in children due to magical thinking (mentioned in paragraph 4.1) (HCP's). This is illustrated by the quotes below:

"Then electricity is sent through, but I don't mention that because they might think they're being electrocuted." – C7
"I once had a girl who said, 'Oh, but now I shouldn't think about my secrets.' So I said, 'It's okay to think about them! Because I can't see those.'" – E2

Timeline of understanding
As children grow older, they tend to understand the tests better. From the descriptions provided by children regarding the walking mat and EEG, as well as the ways in which HCP's would explain the test to children of different ages, a sort of 'understanding timeline' could be deduced. This timeline illustrates which concepts are often understood first and which follow, and is displayed in Figure 22.

4. How would children like to see the test results presented? (Design insights)

Focus on your own strengths – weaknesses are not your fault
Children, parents, and HCPs emphasized that each child has their own strengths, and lower-than-average scores are often beyond one's control. Therefore, it is important to encourage children to compare themselves with their own progress and pay attention to their strengths (parents, HCP's). Everyone is unique, and achieving a high score

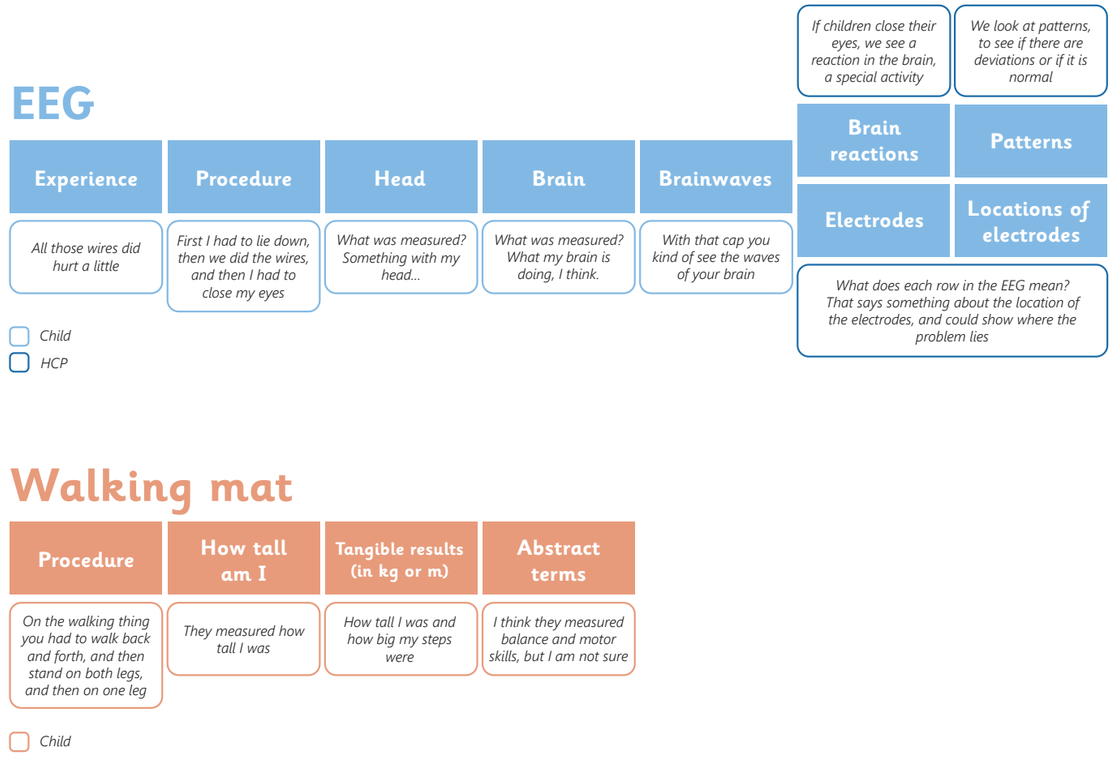


***Figure 22**: Understanding of the EEG and walking mat*

does not necessarily make someone better than others.

"Imagine you're not as good at walking, and it's a bit of a struggle. In that case, that is not your fault, because it's just the way you are." – P5

Carefully choose your words
When communicating the results, it is key to use the right wording. Firstly, positive language is preferred to avoid causing unnecessary anxiety in children (children, parents, HCP's). Additionally, HCPs tailor their language to the child's age. For the Self-Portrait, it should be carefully considered which information is communicated, because results may raise questions for children and parents that the doctor cannot address at that moment (HCP's). Unnecessary worry should be avoided in this case.

"You ALWAYS need a positive quote, regardless from what you achieved, because you should always stay positive" – P5

"I try to avoid the word 'pijn' (hurt), because when you say 'het doet geen pijn' (it doesn't hurt), they only remember the word 'pijn' (hurt), and forget the word 'geen' (doesn't). – E2

Visualizations make it more fun and easier
Children prefer to see images, videos, or animations, and they remember these well (children). Visualizations not only make the experience more engaging for children but can also make it more comprehensible (children). In practice, HCP's often use visual examples or demonstrations to explain things to children (HCP's).

"For young children, I always explain everything step by step, and demonstrate it" - E3

"I think, having animations would make everything more fun. Visual things help you to notice, understand and remember things better." – P2

Take-aways

- The path of understanding can form a guideline for tailoring explanations about testresults to the level of understanding of children

- Theme's regarding test(result) experience are:
  - o Awareness, confrontation and protection
  - o Improving yourself
  - o The influence of parents

- Theme's regarding test(result) understanding are:
  - o The procedure is the first step
  - o Remember what is recognizable
  - o Magical thinking

- Theme's regarding what content to present in the Selfportrait are:
  - o The actual meaning of results
  - o Rewarding participation
  - o Beat your peers (or not)
  - o Curious about the brain

- Themes regarding how to show content in the Selfportrait are:
  - o Every child has their own strenghts
  - o Carefully choose your words
  - o Visualizations make things more fun and easier

Chapter 7 - Understanding the data- and workflow in the CBL

A successful product not only meets the wishes and needs of the user but must also be feasible. For this project, this means that the Self-Portrait should align with the current operational processes of the PBC. This chapter delves into the workflow and data structure within the CBL to address the question of how test data transition from the lab to the Self-Portrait and ultimately return to the patient.

7.1 Approach

The insights in this chapter are based on interviews with various HCP's from the CBL. First, a data structure was established together with the data manager of the CBL. This structure was then reviewed with the testers and involved doctors from the CBL, and finally modified based on their feedback.

TABLE 13: *Interview participant Data journey*

Participant	Profession	Interview date
E12	Data manager CBL	4th May

7.2 The full CBL journey

The first step in gaining an overview of the data journey is to examine the journey from the patient's perspective. The Self-Portrait is an app that is used over multiple years. At which points during that CBL journey is data collected and returned? In Figure 23, the age trajectories are depicted, indicating the moments when testing occurs and when children receive results in the Self-Portrait. Figure 24 delves a bit deeper into the patient journey and describes the phases a patient goes through during the CBL journey.

There are five testing moments that can be communicated in the Self-Portrait. Assuming a child will start using the Self-Portrait from the age of 6, they can view the results of two or three tests at that time.

As shown in Figure 24, there are several weeks between scheduling a test appointment, taking the test, receiving the results, and the next consultation. This period, between scheduling a test and the next consultation, will likely be the period in which the Self-Portrait is most frequently used by the child. Therefore, potential interactions with the Self-Portrait are described at each step here. Between the results consultation and the next CBL testing moment, there may be a few years during which the child is probably not actively engaged with the CBL. During these years, the child may have other hospital appointments where they could access the Self-Portrait.

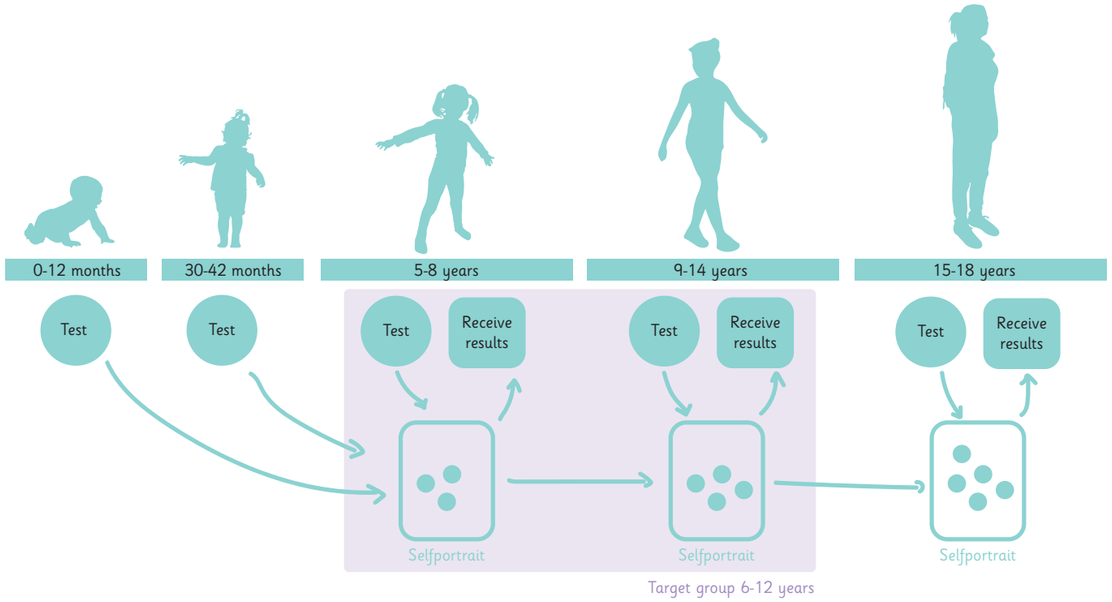


Figure 23: *The full CBL journey*

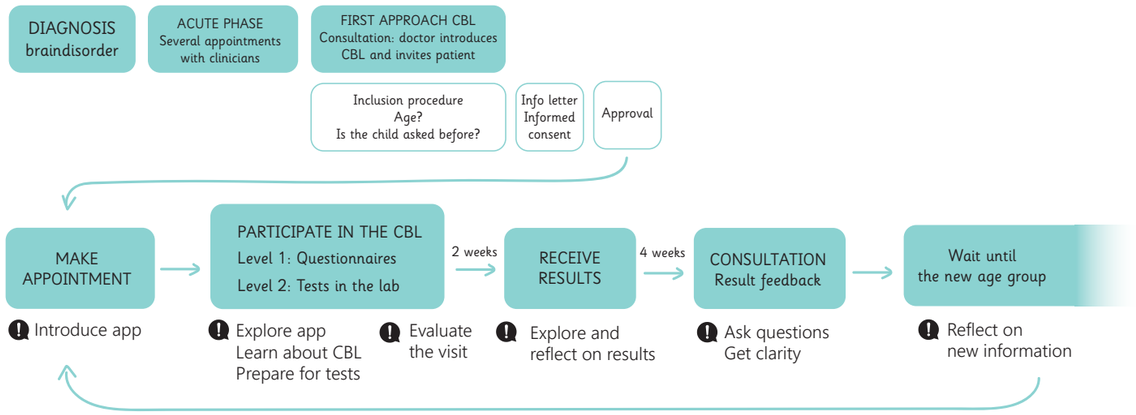


Figure 24: *The full CBL journey - detail*

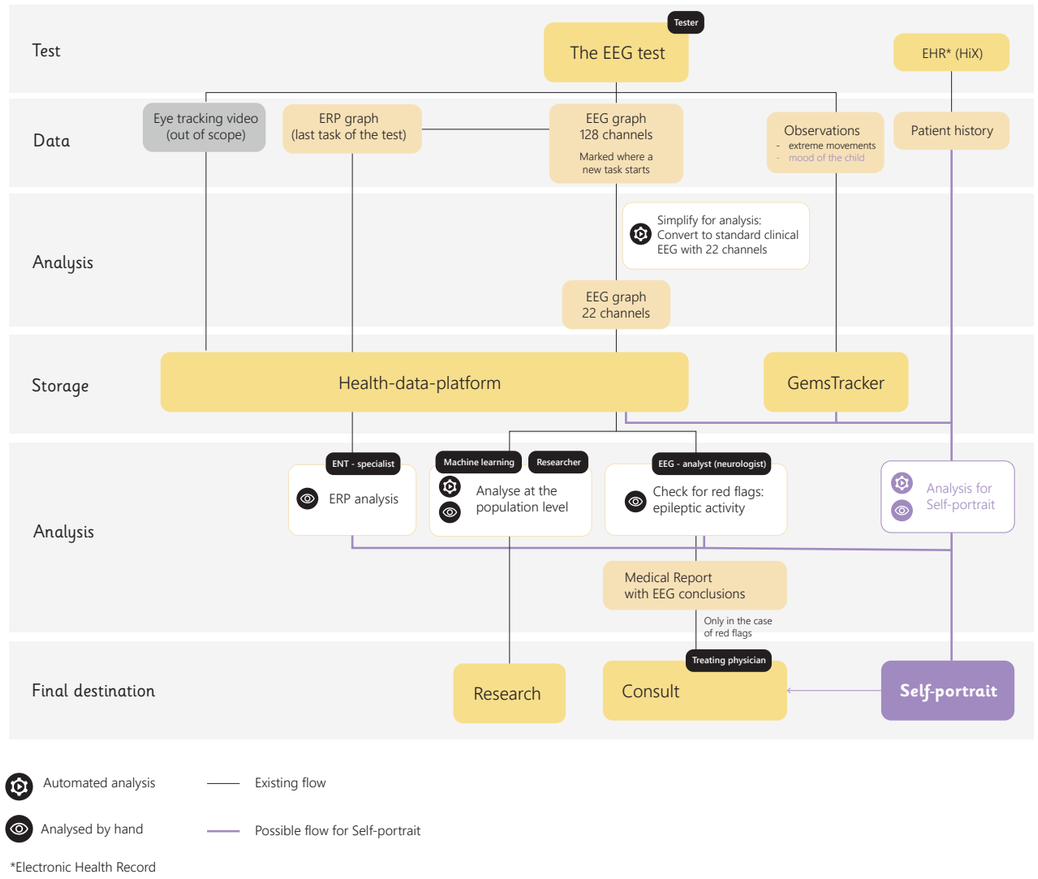


Figure 25: *The EEG data journey*

7.3 The CBL data journey

Now, we zoom in on the section between 'participate in CBL' and 'consultation.' This is where the data processing occurs. This data processing is being mapped out so that the design of the Self-Portrait can take into account the existing clinical processes. The black lines represent the existing processes, while the purple lines indicate possible additional steps required for the Self-portrait, and how they relate to the other steps in the data journey.

The data journey of the EEG shows that the EEG graph that is derived directly from the test, should first be simplified before it can be analysed. After that, it is stored in the health data platform. This is the platform where all data is stored and derived from when needed for research. The EEG graph is currently checked for red flags by hand. Further analysis is only done at population level.

IQ-test

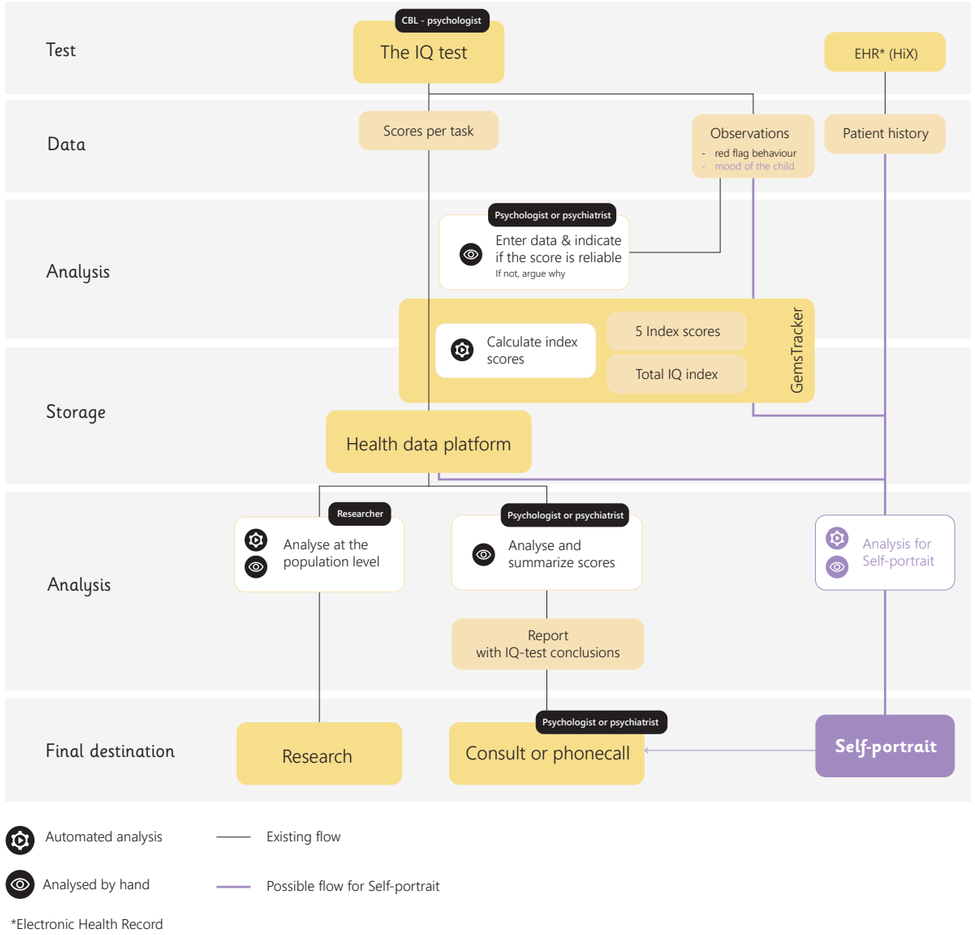


Figure 26: *The IQ-test data journey*

In the data journey of the IQ test, it can be observed that the raw scores are initially recorded by hand. Subsequently, the psychologist enters them into the Gemstracker, where the index scores and total IQ score are automatically calculated. Following this, a report is written, and the results are always conveyed to the patient through a consultation or a phone call.•

Walking mat

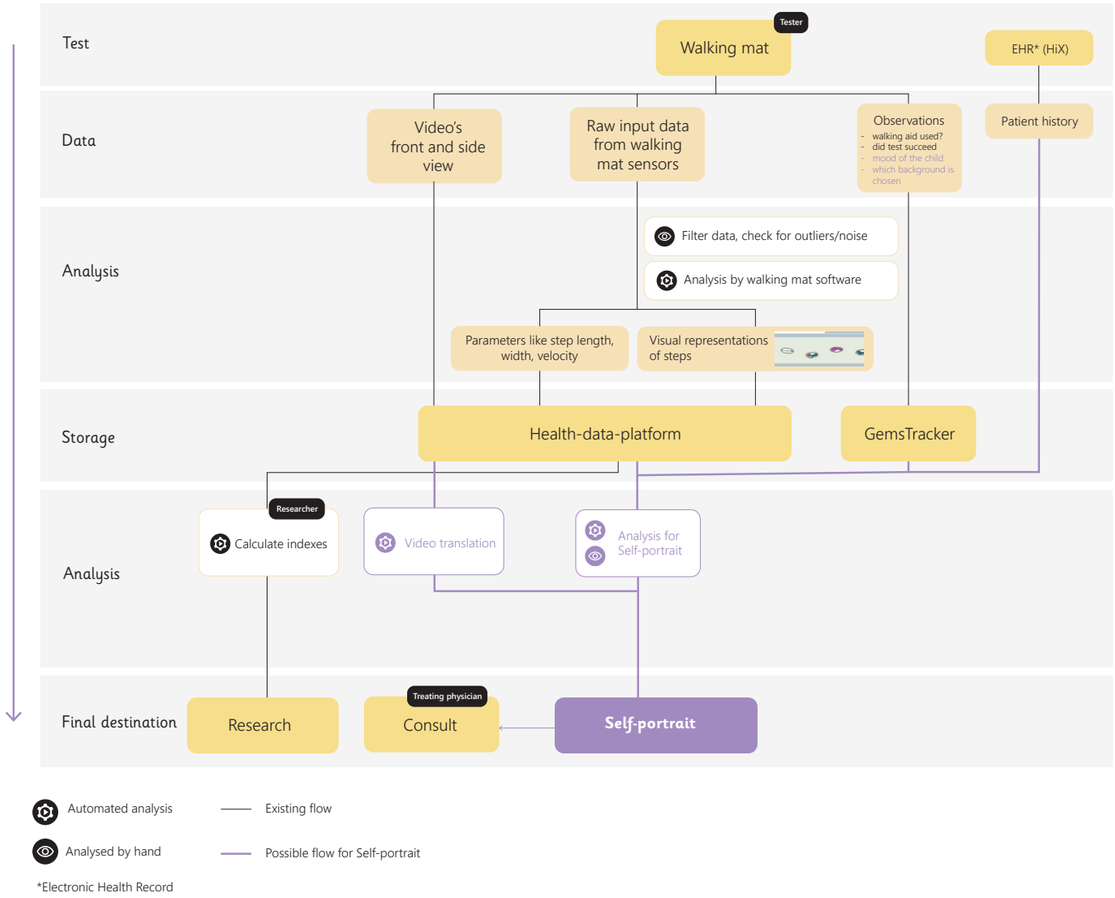


Figure 26: *The Walking mat data journey*

The walking mat provides a video and a file containing the raw input data from the walking mat sensors. The walking mat tester manually filters the data, after which it is automatically analysed by the walking mat software. What stands out in this graph is that, currently, the walking mat data is not provided as feedback to the patient but is only used for research purposes.

Comparing these data flows, there are a few points of consideration:

- Observations
- Analysis
- Stakeholders
- Medical disclosure

7.3.1 Observations

In interviews with HCP's (Chapter 5), it became clear that test results may be influenced by a child's emotional state, posture, and medical background. In the clinical setting, observations are made and included in the clinical report. These observations are not currently a standard practice in the CBL. In the figure, the black text under observations indicates which observations are currently recorded. If observations are required for the Self-portrait analysis, there are options for recording them in Gemstracker. This would be an addition to the current practices in the CBL. These options are indicated with purple text.

7.3.2 Analysis

In the current clinical practice of the CBL, there are three main moments on which data is analysed or processed:

1. Automatic processing of raw data before it enters the Health data platform.
2. An analysis that involves writing a brief report that is shared with the attending physician or placed in the patient's electronic health record (EHR).
3. Analysis performed for scientific research.

These analyses are partially automated and partially manual. The analysis for the Self-Portrait would be an additional step. To minimize costs and processing time, it is desirable to make as much use as possible of the analyses that are already taking place. If an extra analysis is required, it is preferable for it to be automated and utilize the already collected data. Section 16.6 explains the necessary analysis and processing steps for the Self-Portrait.

7.3.3 Stakeholders

The data journey involves various individuals. In the case of the EEG, a different person is responsible at each step. Data is collected by one person, analysed by another who writes a report, and ultimately, the data is fed back by yet another doctor. This doctor is not always an expert in the field and often has access only to the patient's EHR, not the raw data. For the Self-Portrait, this means that the data must be communicated clearly so that even a non-expert doctor can answer children's questions.

7.3.4 Medical disclosure

During conversations with HCP's, it became evident that there are varying ideas regarding the medical disclosure for each of the tests. In principle, no medical report is written for the walking mat, and thus, no feedback is provided. In the case of the EEG, feedback is given only when epilepsy or other red flags are detected in the EEG. For IQ test results, medical disclosure is a regular practice, typically done by a psychologist or psychiatrist. Currently, this is done via a phone call or in a consultation. An important detail is that in current practices, IQ results for children under the age of twelve are only given to parents.

The SKZ plans to provide patients aged six and above with their test results through the app, after which these results would be discussed in their next consultation with the primary healthcare provider. The question is how the Self-portrait and the consultation can complement each other. Particularly with the IQ test, there are doubts about whether all information should be communicated before the consultation, as one would want to prevent children from worrying unnecessarily about the results. Another option is that children only gain access to their results during the consultation and can review them afterward. A third option is a middle ground, where children can view a (secure) portion of the results in the Self-portrait, which is then supplemented during the consultation. These options are visualized in Figure 27. In the above scenarios, an additional step in the data journey should be included in which a doctor (or parents) indicates when the consultation has taken place, allowing new information to be added to the Self-Portrait

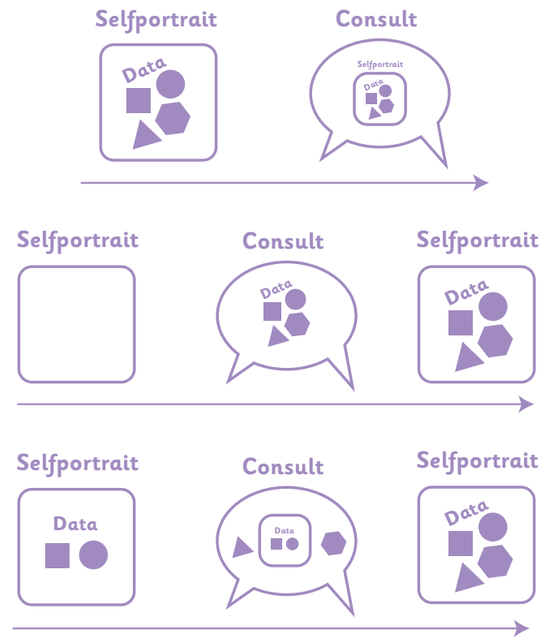
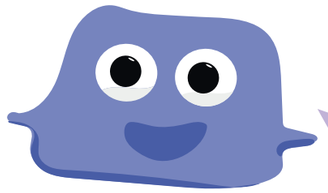


Figure 27: *Options in which the Self-Portrait and consult can complement each other*



Take-aways

- There are five testing moments that can be included in the Self-portrait, from which two testing moments take place before the age of six
- The Selfportrait app will probably be used between scheduling a CBL appointment and discussing the results during a consultation, so it can help in preparing for tests, evaluating the visit, exploring test results, preparing for consultations, and during consultations.
- In the CBL, some data is analysed automatically and some data is analysed by hand.
- Observations are only noted in the CBL if they are heavily affecting the test outcomes
- To minimize costs and processing time, it is desirable to make as much use as possible of the analyses that are already taking place.
- The results will typically be communicated by the attending physician, which means that they may not always be an expert in the area of the tests.
- Consider the app as a collaboration with the consultation: information that is not suitable for communication in the app can be provided during the consultation.

Chapter 8 - Summary of the Discover phase

During the discovery phase, insights were gained concerning the patient, the subject matter to be conveyed, and the communication process itself. Children undergo significant developmental changes between the ages of 6 and 12. Their selective attention improves, as does their ability to think abstractly and store information. Moreover, around the age of 8, a shift in thinking occurs, as children transition from imaginative thinking to logical thinking. These cognitive developments also impact their self-image. Their self-image becomes progressively more realistic and detailed. While it was primarily based on abilities and possessions before, a twelve-year-old child can now make comprehensive self-evaluations and comment on their overall self-worth. Having a brain disorder doesn't significantly affect a child's self-perception, but most children are aware of their condition, especially its physical limitations. Additionally, there are several shared issues among children with disorders from the starter groups that affect the design of the app, with autism deserving particular attention.

A comprehensive understanding has been established regarding the three tests conducted at the CBL: the EEG, the IQ test, and the walking mat. The procedures, data generated from the tests, data interpretation, and potential data for communication in the self-portrait are clear for all tests. Lastly, insights have been gained into communicating test data with children. VBHC and SDM are two important developments in healthcare that the Self-portrait must consider. The Self-portrait should contribute to the full cycle of care and can facilitate SDM by inviting and supporting children to participate. When communicating medical information, it's crucial to use appropriate language that is concrete and understandable, while avoiding magical thinking. Moreover, children absorb information better when actively accessing information and engaging with multiple elements.

Research into children's current understanding of the tests and their expectations revealed various themes. Children perceive the test procedure as an integral part of the result and would like children to be rewarded for their participation in the CBL. They view tests as a means to identify areas for improvement but also emphasize the importance of maintaining a positive outlook. They recognize that everyone is different, and a low score is usually not their fault; they can't do anything about it. Lastly, a timeline of understanding the tests has been formed for the EEG and the walking mat, typically beginning with a child's experience and becoming progressively more factual and detailed.

Define

In this phase, the take-aways from the Discover phase are used to guide the Design phase. Initially, all takeaways were analysed to identify challenges and opportunities. Based on this, a design goal and interaction vision were formulated, serving as the foundation for the design process. This chapter concludes with a list of requirements and wishes, that includes all the elements to be used as criteria for evaluating different ideas.

Chapter 9 - Challenges & opportunities

Clustering the take-aways from the discover-phase, revealed several challenges and opportunities regarding the app design.

9.1 Challenges

Challenge 1: Trade-offs for every decision

During the interviews with HCPs, children, and parents, it became evident that several considerations need to be made when communicating medical information to young children, especially as this is not yet a common practice. Most of the challenges can be categorized into the following four trade-offs:

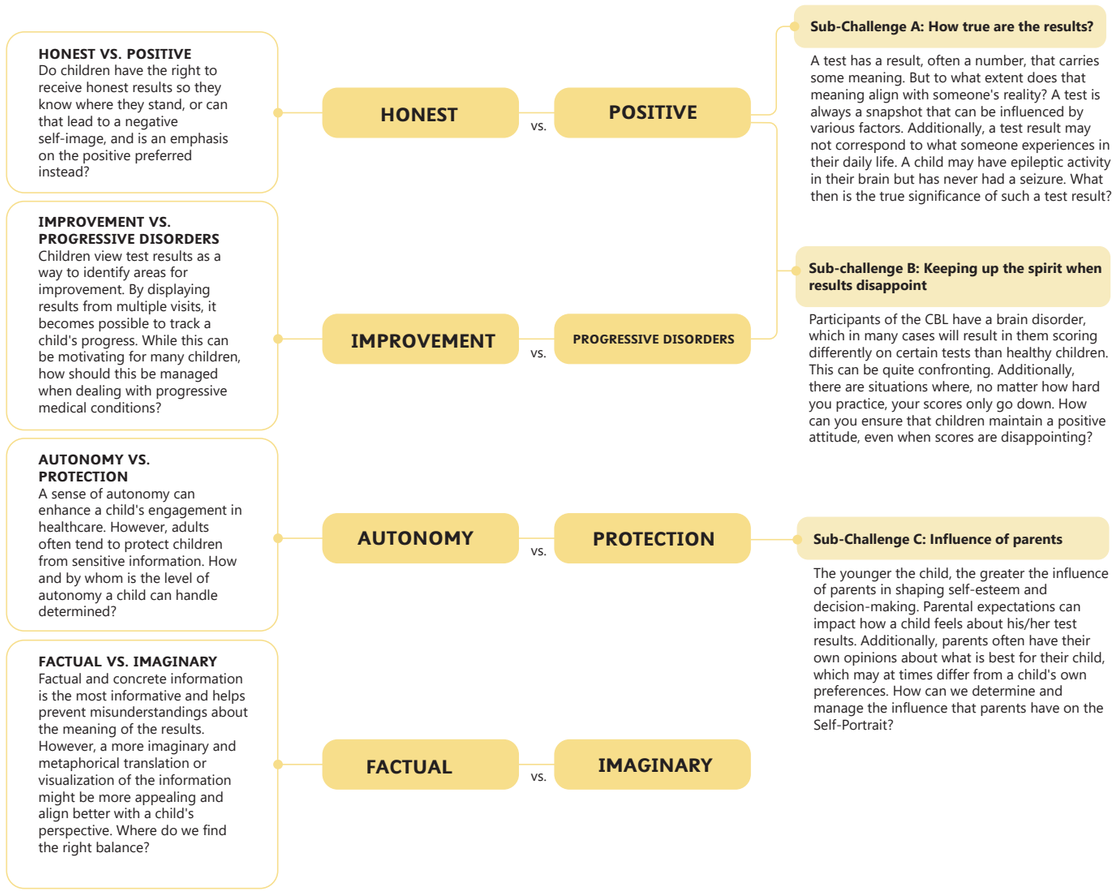


Figure 28: *Challenge 1: Trade-offs*

Challenge 2: Adding value for each child

As The Self-Portrait will be used by children of various ages and with different conditions, catering to each child's needs will be a challenge. There are differences in what children can comprehend, what their interests are and which potential impact the Self-portrait may have on a child's self-image. Additionally, each condition creates a unique filter through which results are perceived, with certain results being more valuable or confronting for a child.

Challenge 3: Fitting in the clinical practice

The Self-Portrait is an addition to the current duties of the physicians at the PBC. To ensure that this becomes a valuable addition, two challenges need to be addressed. Firstly, the Self-portrait should add value to clinical practice: it should assist physicians during their consultations, even when the physician is not an expert in interpreting the results. Secondly, providing input for the Self-portrait (processing and entering the data) should fit within the working hours and tasks of the various HCPs.

Challenge 4: Me vs. the rest – comparing to others

A test result typically reflects a child's performance in comparison to an average. In this way, you are essentially comparing a child to their peers. However, discussing this is a sensitive subject. On one hand, children often want to know how they stack up against their friends, but on the other hand, a child may not want to feel different from their peers. So, to what extent do you make this comparison?

9.2 Opportunities

In addition to the challenges, several opportunities emerged from the Discover phase that can contribute to overcoming the challenges.

Opportunity 1: Reward children for more than their test results

- **Praise the process**

The generative sessions revealed that children perceive the test procedure as an integral part of the testing experience. Furthermore, providing process praise – praise for the process that led to the child's success – lets children believe in their ability to grow and develop (Brummelman & Thomaes, 2017). Thus, this offers opportunities to 'keep up the spirit' (see challenge 1a).

- **Contribute to science**

What makes the CBL unique is the collaboration between healthcare professionals and scientists. Children, particularly from the age of 7, are eager to help other children. While a child may not always be proud of their test results if they are disappointing, the focus can still be placed on empowering the child and maintaining a positive outlook by highlighting their contribution to science, through which they help to improve the care for their peers.

- **Look at what you've learned**

By relating the test results to facts about the brain, children can feel proud of what they have learned about themselves and the brain. Furthermore, linking the results to how the brain functions can help a child better comprehend and remember the results.

Opportunity 2: Having fun with the results

Various ways have been identified to make it more enjoyable for children to receive information. This can be achieved through the use of visualizations, relatable examples, interactivity, or incorporating collectible items. In addition, children best acquire knowledge by actively accessing information and by engaging with multiple elements.

- **A world to explore**

Many of the subjects and activities within the CBL are unfamiliar to children. This can be both nerve-wracking and exciting for them. Moreover, receiving an invitation to participate in the CBL is a unique opportunity, as not every child is receiving this. To emphasize the positive side, there is an opportunity to present the CBL as an exciting world full of discoveries.

- **Animals**

Animals are commonly used in children's books, games or series. They have been proven to enrich a child's developing sense of self and interactive skills. Therefore, using animals in the explanations of the results can be a way to make the Self-portrait interesting and enjoyable for children.

- **The creative room**

In addition to the thinking-, motion-, and machine-room of the CBL, the Self-portrait could be interpreted as the 'creative room.' In the context of actively assessing and interacting with information, the test results can serve as tools to create something meaningful. In this way, receiving the test results also feels like a reward.

Opportunity 3: Join the CBL team and collaborate with the doctors

The idea of the Self-portrait app is that it can assist doctors during a consultation, which aligns well with children's willingness to help others. Therefore, an opportunity is to make children feel like they are part of the CBL team. Give children the idea that they are truly part of the team and emphasize that, by participating, they contribute to the lab. Motivate them to actively think about their results in order to work effectively with the doctor during discussions. Extend this approach throughout the full cycle of care, from preparing for a visit to reflecting on progress.

Opportunity 4: A framework for contributing to self-image

The variations among children of different ages mean that self-image may not look the same in every age group. By comparing insights about a child's cognitive development and the evolution of a self-image, three levels were distinguished at which the Self-portrait can contribute to a positive self-image. This is illustrated in figure 29.

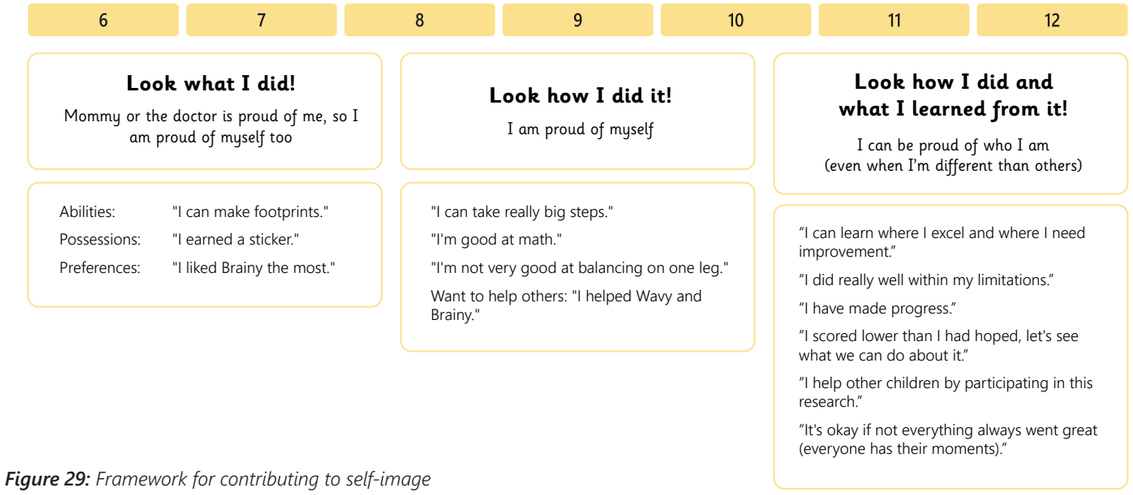


Figure 29: *Framework for contributing to self-image*

Chapter 10 - Design goal

In the ideal outcome of the Self-Portrait, the identified challenges are overcome, and the opportunities are used. To provide direction in this regard, a design goal has been formulated, resulting in the following outcome:

The goal is to create a personally rewarding visualization of the test-data of the EEG, IQ-test and walking mat for each child that visits the CBL,

by highlighting their personal achievements and empowering children to become aware of and accept who they are,

in a form that is integrated in the clinical workflow of the Pediatric Brain Centre, and supportive during the full care journey, so that HCPs see the Self-portrait as an enrichment to their work.

Chapter 11 - Interaction Vision

The goal is to facilitate the two modes of thinking that emerged from the research phase with the Self-portrait: first, the imaginative mind of a six-year-old, in which self-image is still unrealistically positive, and second, the child aged 8+ where logical thinking develops, the child wants to learn, and self-image becomes more realistic. This provided direction for the two consecutive interactions: first discover, then deepen. These are two desired interactions for the Self-portrait.

To establish a vision of what interaction with the Self-portrait looks like, an analogy is used (van Boeijen et al., 2014). Interaction qualities are derived from this analogy, which provide inspiration for designing the app.

The interaction vision is shown below.

Interacting with the Self-portrait should feel like...

It's like walking in the forest, filled with chirping birds. Gradually, you start to distinguish various sounds and learn which birds are singing. Then, you also understand what they have to tell you.

11.1 Interaction qualities

- It feels like a special place that not everyone has access to
- The product allows the user to wander around in the way that he or she likes
- Paths and signs help users to guide the way if they don't know where to go
- There is a lot to see, and all elements look interesting and inviting
- Users are motivated to take a closer look and learn about what they see
- After learning about what they see, users are encouraged to reflect on what the information means to them

11.2 Setting the mood for every test

The metaphor of a forest with birds helps to get an idea of the interaction with the app in general. However, within the app, three different tests are developed, each with its own characteristics. In the forest atmosphere, a metaphor has been chosen for each test that illustrates the attributes of the test. This metaphor can be used as inspiration for design choices for each test.

The EEG

The EEG is like a forest at dusk: mysterious, unique, and it sparks curiosity

Results from the EEG test can be hard to grasp, but children are highly interested in it. The EEG is like the evening setting in the forest, with various nocturnal creatures emerging that you haven't seen before.

Figure 30: *Forest at dusk (Creative fabrica, n.d.)*

The IQ-test

The IQ test is like a hidden pond: calm, awe-inspiring, reflective.

Children and their parents are eager yet anxious to learn the results of their IQ tests. The results offer a reflection of oneself, which can be confronting at times. A pond is a calm and awe-inspiring place where one can take the time and find privacy to view their results.

Figure 31: *Hidden Pond (Staatsbosbeheer, n.d.)*

The walking mat

The walking mat is like a climbing tree: inviting, recognizable, and fun

Children enjoy the walking mat test and can easily relate the results to their daily life. The results of the walking mat can serve as motivation to continue practicing, maybe adjust strategy, and keep trying to climb higher in that tree.

Figure 32: *Climbing Tree (Pixabay, n.d.)*

Chapter 12 - Wishes and Requirements

To gain a clear understanding of the app's necessary features, a list of requirements was compiled based on the research phase and subsequently validated with stakeholders. In addition, ten wishes are formulated, that function as evaluation criteria during decision-making.

12.1 List of Requirements

General

1. The app should be suitable for tablets and mobile phones

Users

2. The app can be used independently by children with a developmental age from 6 years old
3. The app must be usable by children with
   - Bad sight
   - Hearing loss
   - Speaking difficulties
   - Less sense of touch or power in hands
   - Epilepsy
   - Colourblindness
4. The app must be usable by children with autism:
   - Low-stimulus
   - Clear structure
   - Straight forward language

Use children / parents

5. Children should be able to save questons and reactions on results in the app
6. The Self-portrait should pose questions about the topic
7. Children should be able to actively interact with results / Children should be able to actively assess and engage with information
   - Each test should include at least one interactive element
8. A child must have control over what he/she does (not) want to see
9. Parents should be able to monitor what their children can see / do in the app.
10. The app should be personalizable
11. The app should allow for exploration and deepening of knowledge

Use HCP's / Data

12. The data presented in the app must be
    - Retrievable from the Health Data Platform, including data from:
      - Test-software
      - A simple observation form
    - Data that children themselves input into the app
13. Data from the Self-portrait should be understandable without expertise

Content

14. The content of the Self-portrait should cover the full cycle of care of the Child Brain Lab.
    - Understanding the tests:
      - Explanations about test procedures
      - Information about the brain
    - Receiving the results at home:
      - Personal testresults

- During a consultation:
    - A clear overview of personal results (in one screen)
    - Space for personal notes from child, parent and HCP
- Preparing for the next visit
    - Explanations about the CBL
- Reflection over the long term
    - Overview of the results from earlier visits

1. The app cannot make value-judgements about children
2. The app should reward the child's participation
3. The app should emphasize the fact that tests are a "snapshot"
4. The app should make a child aware of their contribution to (neuro)science.
5. The content fits with how children construct a self-image at different ages.

Design

6. The solution should make use of physical explanation aids: visualisations, not only words.

Language

7. Content of the app should be available in Dutch and English
8. Information should be tailored to a child's developmental needs and the child/parent literacy needs.
9. Technical jargon needs to be avoided or otherwise properly explained
10. Language should be concrete and specific

Ethical

11. Information in the app should be approved by medical professionals
12. The app cannot give children a diagnosis
13. The app cannot force children to make a medical decision or purposely steer children into a direction
14. Content of the app should not be harmful for children

Privacy

15. Personal information cannot be shared with third parties
16. The Self-portrait should be in line with the privacy regulations of the Sophia Children's Hospital

EEG

The design should....

17. Show a visualisation of personal brainwaves
18. Explain what the typical brainwaves mean in relation to the child
19. Emphasize the building of the network in the brain

IQ-test

The design should....

20. Refer to the 10 exercises of the WISC-V
21. Give an indication of the general IQ-score
22. Explain a child's strengths and weaknesses based on the domain-scores

Walking mat

The design should....

23. Show a visualization of the walking pattern
24. Have a link to the chosen background during the test
25. Include walking aid (if used)
26. Give information about:
    - Standing balance
    - Pace (snelheid)
    - Step width / height
    - Pressure distribution
    - Angle of feet
27. Compare left & right foot
28. Have a link to brain functioning

12.1 List of Wishes

In addition to the list of requirements, a list of wishes has been established. These wishes will be used to evaluate ideas and concepts.

1. Children feel empowered to think about and react on their results
2. The Self-portrait supports the HCP in their explanations during consultation
3. The visualisation is easy for children to link to the test-experience
4. The time and effort to edit the Self-portrait should be minimized / It is easy to process for HCP's
5. Children can actively assess and engage with information in a fun way
6. The visualisations of the results are recognizeable / easy to link to daily life
7. The app has a positive influence on the self-image of a child
    - The app focusses mainly on the strenghts of the child
8. The app invites parents to discuss results with their children
9. The Self-portrait stays interesting over multiple years of use
10. The app allows caregivers of multiple disciplines to collaborate efficiently

DESIGN

This chapter showcases the Design phase, where all insights are translated into an app design for communicating test-results to the patients of the CBL. The design process is an iterative process in which insights are translated into ideas, these ideas are transformed into concepts, and these concepts are updated to form a final design.

Chapter 13 - The iterative process

This chapter presents the Self-portrait ideation, and the iterative process that has been followed to shape the structure and content for the final concept, where the design goal, research insights and list of requirements and wishes are integrated. This process consists of three parts.

Part 1: Defining the elements to include in the Self-portrait

Goal:
Translate the outcomes of the research phase into various idea directions that serve as conversation starters to discuss the trade-offs and opportunities with stakeholders and derive insights from them.

Outcome:
Additional insights into key themes, a better understanding of the perspectives of doctors, parents, and children regarding the trade-offs. Promising directions for each test. Overview of elements to present for each age group.

Part 2: Deepening and updating potential concepts

Goals:

- Consolidate the promising elements and develop an idea direction into a conceptual direction, leading to a functional prototype, for each test.
- Gain insights into whether the method of presenting information aligns with the target audience through various iterations and user evaluations, and obtain insights into cognitive ergonomics.
- Deepen content with the help of literature and involvement of physicians.

Outcome:
Functional prototype with a list of improvement points.

Part 3: The final details and evaluation (chapter 16 + 17)

Goal:
Incorporate the improvement points into a final app design and evaluate to what extent the design goal has been achieved.

Outcome:
Final design with an evaluation of the design goal and recommendations for further development.

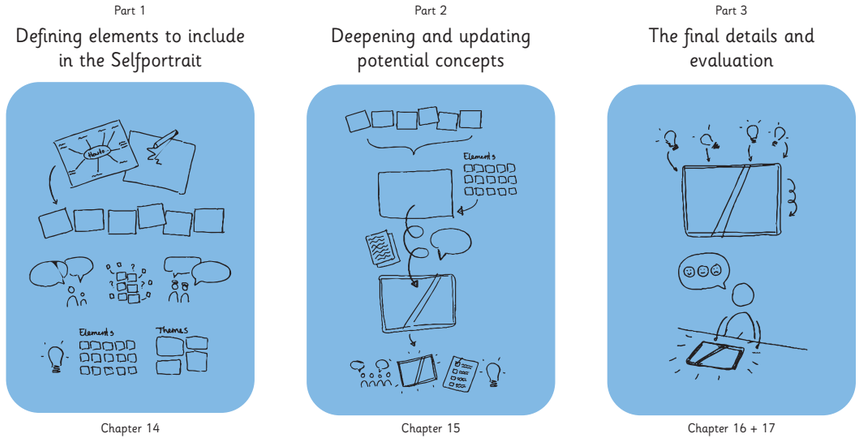
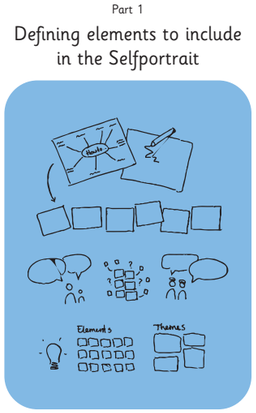


Figure 33: The iterative process

Chapter 14 - Part 1: Defining elements to include in the Self-portrait

In the first part of the design process, the insights from the Define phase were translated into various design directions for each test. These design directions were discussed with the HCPs from the CBL, children with a brain disorder and their parents, to ultimately create an overview of which of all the potential elements will be included in the Self-portrait and which communication methods are most promising.



14.1 The idea directions

To shape the idea directions, individual ideation was carried out using brainstorming techniques like How-tos (van Boeijen, 2014). This was conducted separately for each test, with key characteristics of the test serving as starting points for ideation, such as *"How to visualize brainwaves?"* for the EEG. Additionally, the formulated opportunities of paragraph 9.2 served as the starting point for a brainstorming session that was not specific to any particular test, asking questions like *"How to reward someone?"*.

Ultimately, this process yielded six idea directions. These were elaborated upon separately for each test, resulting in six to eight idea sketches per test.

The idea directions are listed below.

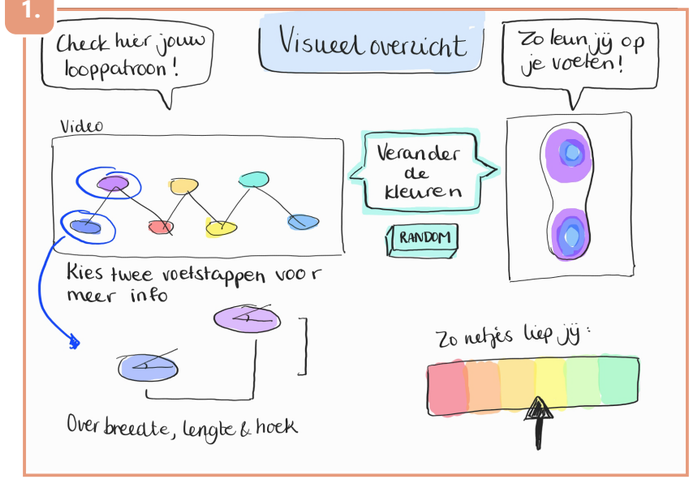
1. A factual representation of the results
2. A representation where the results are translated into a visual example
3. A translation of the results that incorporates animals
4. A direction focused on personalization and creativity with the results
5. A direction centered around competition
6. An imaginary version of the results that provides a visual impression of the outcomes

Additionally, various elements that emerged as promising from the research phase have been incorporated into the different ideas. These elements include:

- The characters from the CBL (Wavy, Breeny & Neuro)
- Rewarding children for their participation
- Providing information about (the child's performance during) the procedure
- Showing the contribution to scientific research
- Displaying results over time to see development
- Providing information about the brain
- Connecting the information to daily life with examples
- Layering in information

To illustrate, examples of the idea directions from all three tests are presented on the following pages. In Appendix N, the idea directions for all tests can be found.

1.

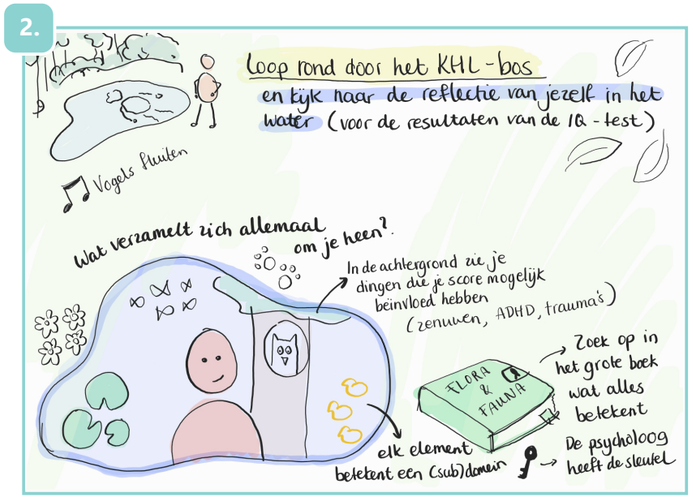


Layering information

Contribution to scientific research

Layering information

2.



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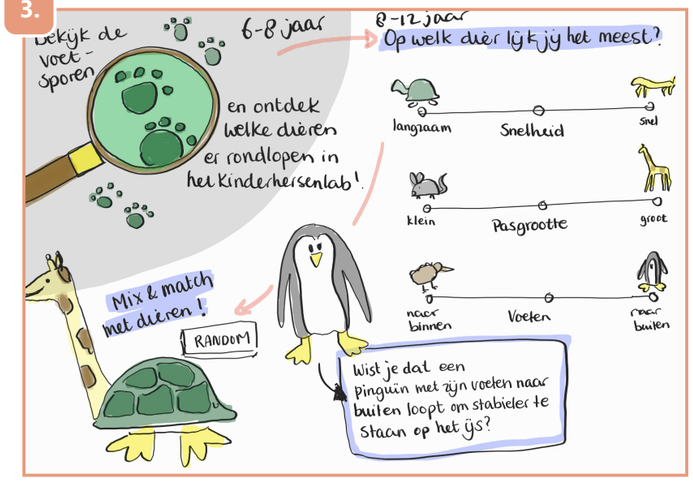
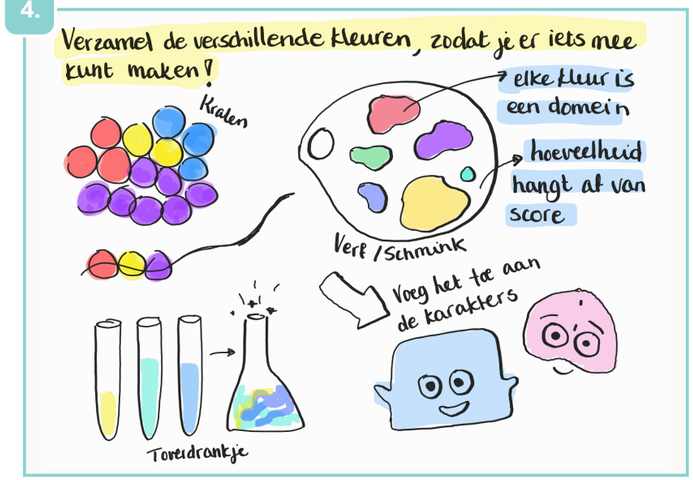


Layering information

Examples from daily life



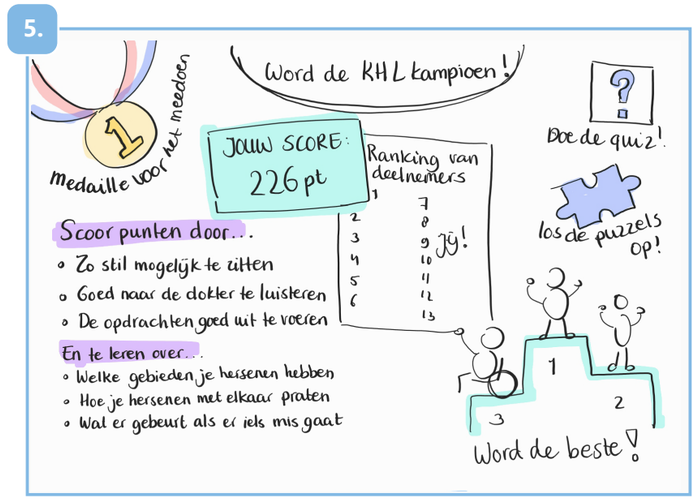
Characters

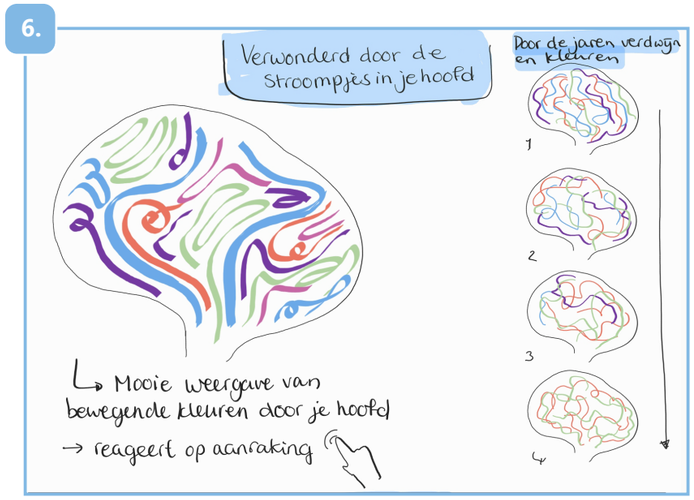
Rewards

Performance during procdure

Compare with others

Providing information about the brain





Results over time

= EEG
= IQ-test
= Walking mat

14.2 Discussing the ideas

These idea directions were discussed with children, their parents, and HCP's, to find answers to the research questions below. The first step involved discussions with various HCPs, where a group of experts came together for each test. This process provided new insights from an HCP's perspective, but there remained speculation about what a child would or would not want to know. To address this question, the ideas were subsequently discussed with children and their parents.

14.2.1 Research questions

- What ways of presenting information are preferred (with special attention to the trade-offs)?
- Which of the elements that are listed in 14.1 are desired in the Self-portrait?

During the session with children, special attention was given to the following questions, which arose during the session with HCP's:

- Does a more abstract translation make the app more enjoyable/interesting for a child?
- Is a factual representation of information more confronting for a child?
- Does a child have a need for honest scores or more positive scores?
- Does a child want to know how their results compare to other children?
- Does a child want to know if there is epileptic activity in their brain? (and what do parents think of this?)

14.2.2 Participants

The participants of both evaluation rounds are listed in table 14, 15 and 16.

14.2.3 Approach

HCPs:
In the first part, the ideas were laid on the table and explained one by one. After that, HCPs were invited for an open discussion. Within this discussion, the researcher raised all the trade-offs, to ensure that all of them were addressed.

Children & their parents:
In the second part, the idea sketches were broken down into individual elements. The elements were presented by test category, and children were asked to categorize the ideas into three boxes: *I want to know...; I don't want to know...; I'm unsure* (see Figure 35). Afterward, they were asked to explain their choices, and specific questions were posed regarding the trade-offs.

The same steps were taken with parents, with the potential addition of the extra question:
"Your son/daughter wanted to know (element X), how do you feel about that?"

Figure 34: Discussing walking mat ideas with HCPs in the motor room

Table 14: HCP participants idea direction evaluation

Participant	Profession	Session
E4	Research worker & tester sensory room CBL Pediatric neurologist	EEG
E5	Pediatric Neurologist	
E13	Neurologist specialized in EEG	
E8	Pediatric psychologist & tester cognition room CBL	IQ-test
E10	Pediatric psychologist	
E11	Pediatric psychologist	
E7	Pediatric physiotherapist & tester motion room CBL	Walking mat
E14	Ass. Prof. Rehabilitation Medicine	
E15	Child physiotherapist	
E16	Pediatric rehabilitation physician	

Table 15: Child participants idea direction evaluation

Participant	Age	Gender	Disorder(s)	CBL experience
C1	12	Female	Brain tumor	None
C2	18	Female	Cerebral Palsy (CP)	None
C5	7	Male	Cerebral overgrowth, behaviour disorders	Invited
C6	6	Male	Cerebral overgrowth, behaviour disorders	Invited
C14	18	Female	Cerebral Palsy (CP)	None

Table 16: Parent participants idea direction evaluation

Participant	Gender	Parent of
P2	Female	C1
P3	Female	Boy, age 15 (developmental age +- 3), GRIN-disease, autism, ADHD, non-speaking

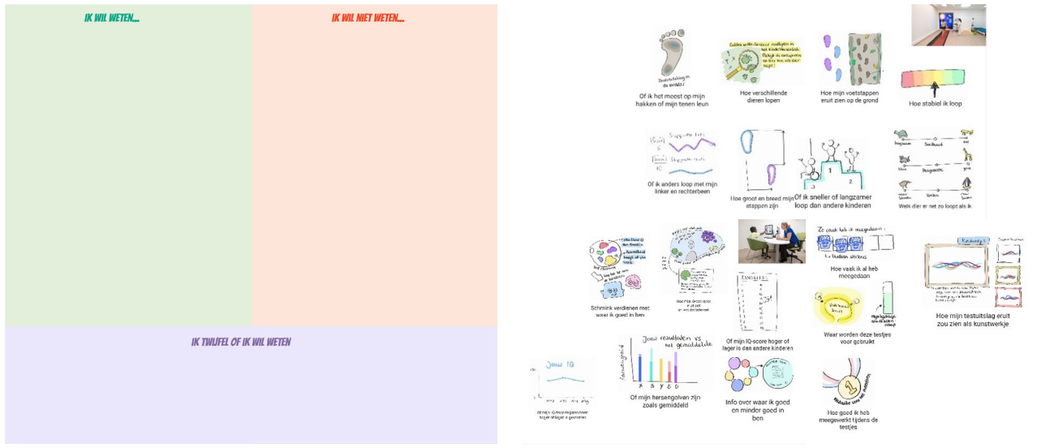


Figure 35: Study set-up evaluation with children & parents

14.3 Results

From the discussions with HCPs, children, and their parents, themes emerged that confirmed the previously generated insights. Additionally, new insights and a new trade-off were found. The key themes are elaborated below, with, in some cases, a reference to implications for the walking mat, EEG, or IQ test.

14.3.1 New trade-off: medical responsibility vs. providing examples

A test result often becomes meaningful to a child when it undergoes an interpretive process and when an example from daily life is given. However, from conversations with doctors, it became clear that one must be very cautious about the claims made based on the test results. Certain examples or interpretations may not be entirely medically justifiable based solely on the test data.

MEDICAL RESPONSIBILITY vs. **PROVIDING EXAMPLES**

EEG

For instance, the presence of epileptic activity in the EEG does not necessarily mean someone has epilepsy, and therefore, nothing can be stated about this in the Self-portrait. In any case, a medical diagnosis must not be made in the Self-portrait. On the other hand, alpha waves are suitable for representation in the Self-portrait because there is more certainty about them.

Walking mat

In the case of the walking mat, the results in the idea-sketch were linked as an example to a reason for wearing orthopedic insoles, but professionals advise against mentioning this because it is not a conclusion that can be drawn based solely on the presented walking mat results.

IQ test

To explain a score of an IQ domain, it can be enlightening to link it to what can be noticed at school. However, this must be done in a general sense and cannot be made personal because it does not depend solely on an IQ test score.

14.3.2 Clear link between test-experience, app-content and consultation

It is essential for the presentation of results in the Self-portrait that a child can effectively link the results to what he or she has done during the test, but also to what the doctor can and will explain during a consultation. In this regard, it should be considered if the information really means something for a child's treatment or life.

EEG

During the consultation regarding the EEG results, various types of brainwaves that have been measured will be discussed. Therefore, it is helpful to clearly visualize these waves in the Self-portrait. One example that may not need to be represented is asymmetry in brainwaves on the EEG since it is currently not addressed in practice.

Walking mat

The walking mat is an experience that children remember, so in this case it is especially valuable to have a clear link to the experience in the results. For this reason, it is worthwhile to include the standing balance test as well. Children remember this well and associate it with the walking mat. Additionally, some children may use walking aids while walking on the mat. It is valuable to indi-cate this because a child can then link it to the testing experience, and it also affects the test re-sults.

14.3.3 Comparing and value-judgements (challenge)

A question that was frequently discussed is whether to compare children with others or not. From the parents' perspective, this doesn't benefit a child much. It mainly creates insecurity and can make a child a target for bullying, which is prevalent during the school years. Both parents and HCPs believe it's more important for a child to see their own progress, understand their strengths and weaknesses. The focus should be on a child's own milestones.

From the children's perspective, there is a desire for comparison, but not necessarily with other children. One of the participants mentioned wanting to know how her IQ score or walking pattern compares to other children, so she knows what to work on. If hers is lower than others, it's not a problem if she knows it's due to her condition; then, there's nothing she can do about it. Generally, children do want some form of comparison to better understand their results, but comparing to other children makes it too personal. The quote below illustrates this: apparently, 'an average' isn't necessarily linked to other children. Children are also curious about their progress, so the compar-ison is with themselves.

"I don't want to know if I walk faster/slower than other children, but I would like to know the aver-age." – Girl, 18 years, CP

IQ-test and walking mat

The most important thing is that the presented information should not carry a value judge-ment. This means that the results should not be labeled as good or bad. The test results should not be performance-oriented, although participating in a test can be seen as an achievement.

14.3.4 Factual vs. imaginary – reasoning for using metaphors

There are various reasons to choose a more factual or more imaginary representation of the results within the Self-portrait. Conversations revealed that the reasons for this vary depending on the test.

Older children usually preferred a more factual representation over an imaginary one, as they found it more informative. Additionally, it was mentioned that at a younger age, they can appreciate an approach with animals or a forest. Younger children talk about "fun," while older children talk about "interesting." This seems to confirm that the approach of exploring and deepening aligns with a child's preferences.

EEG

Representing the EEG in the Self-portrait consists of two parts: explaining what the EEG is and how the brain works, and displaying personal information from the EEG. Neurologists suggested that for explaining the brain and the EEG, using a metaphor could be a good way to make it understandable for children.

However, for presenting personal information, it is more suitable to provide somewhat more factual information. This way, the child can better relate it to what happened during the procedure and what the doctor can explain during the conversation.

IQ-test

For IQ-test results, a more imaginary and abstract representation is desired because it can prevent the child from feeling confronted with a high or low score when viewing the results. An abstract representation also aligns well with the abstract world of the psyche.

Walking mat

For the walking mat, using comparisons with animals can work as a striking example or explanation. In practice, physiotherapists also use animals to provide examples of how children walk.

"For example, try walking like a mouse." – E7

14.3.5 Honest vs positive – it is what it is

While doctors question whether information directly related to a condition could be too confronting, it turns out that the child participants are actually most interested in such information. Therefore, it is important to present this information. Children do not necessarily mind if their test results are lower than average due to a condition; they cannot change it. However, this does not mean it cannot still be confronting, so care must be taken in how it is presented.

According to the parents who participated in the evaluation, honest information can also help in understanding what's happening and, consequently, in accepting it. It is what it is; the brain condition exists, but now we'll see how to deal with it best.

"(What if you score lower than others?) I can understand it because you know the reason why it is. That's the tumour in your head." – Girl, 12 years, brain-tumour

14.3.6 Protection vs autonomy

Parents in a supportive role

Parents in this evaluation primarily viewed their role as supportive. Their aim is not to determine what a child sees or doesn't see but to be informed so they can engage in conversations and provide support when necessary.

EEG – Epilepsy

Representing epileptic activity in the Self-portrait raised discussions. Firstly, because it can be confronting for a child to see; if a child is unaware, it can induce fear. If a child is already aware, it can emphasize the situation and lead to negative feelings. On the other hand, for a child who is aware of their epilepsy, it can also be interesting and contribute to understanding.

14.3.7 Performance during the test procedure

Regarding the opportunity (section 9.2) to provide feedback on a child's performance during the

procedure, two things came up. Children expressed that they don't want to feel like they are being tested on how well they cooperate, especially if the feedback is negative. However, they found the reward for participating very important. Additionally, HCP's expressed that providing feedback on the procedure results should not encourage undesirable behaviour during the tests.

Walking mat

Speed is something that is easy to measure and children are curious about, but the goal during the test is not to walk as fast as possible. So, the focus should not be on speed to prevent children from running next time.

14.3.8 Patients with a developmental age below six years old

Participants C5 and C6, both at a young developmental age, had difficulty indicating their preferences and reasons when discussing the ideas. This could mean that they didn't fully understand what was being presented. One possible connection between the elements chosen by participant C5 is the presence of a character (Breeny, Wavy, or Neuro). For participant C6, a possible connection is the use of bright, cheerful colours. P3, the mother of a boy with a developmental age of approximately 3 years old, mentioned that a personal photo would provide recognition.

14.3.9 Which elements to show and not to show (test and non-test specific)

The discussions provided more clarity on which elements are desired and which are not to be displayed in the Self-portrait. You can find this information in the overview in section 14.4.1.

Walking mat

Regarding the walking mat, there was some uncertainty among doctors about whether individual parameters such as step size or speed are what children want to know, or if a child would benefit more from an indication of "how safely do you walk." This was tested with children, and it was found that they are interested in both aspects.

14.4 Conclusions

Discussing the ideas with the stakeholders has provided a lot of clarification regarding the app's design. By comparing the new insights with those from the Define phase (chapter 9), a general list of do's and don'ts was compiled, and the framework for contributing to self-image from paragraph 9.2 was supplemented with an indication of which elements should be displayed in the app for each group.

14.4.1 General list of do's and don'ts

Do's

- o Use layering of information
- o Make a clear link to a child's memory of the test-experience
- o The app should clearly show differences over time
- o Link results from every test to the functioning of the brain
- o Show contribution to scientific research
- o Reward participation
- o Remind that the test is a snapshot
- o Use facts & figures to positively trigger children
- o Pay attention to (performance during) procedure
- o The app should only contain information that doctors are 100% sure of

Don'ts

- o Value judgements
- o Performance-oriented focus
- o Ranking or comparing to other children
- o The information in the app should not cause troubles for the test participation

Keep in mind

- o Providing personal information is the main goal
- o A child knows a lot about him/herself already
- o Avoid information overload - don't forget that the Self-portrait shows information from a lot of tests

14.4.2 Guidelines for each age group

By incorporating input from doctors, children, and their parents and aligning it with the categorization outlined in paragraph 9.2, a new categorization emerged with guidelines for the information to be provided to children in each age group. This categorization is presented in table 17.

Table 17 Elements to include in the Self-portrait

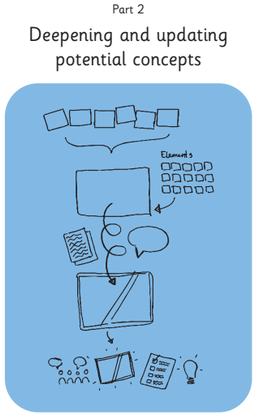
	EEG	IQ-test	Walking mat
Easy 6-8 years	• You have completed the test! • What does the hat do? • What are brainwaves? • Which waves has my head made? (visually) • Explanation that there are different types of waves.	• You have completed the test! • Get to know the five domains: - What tasks have you done for each domain? • Do I have a special domain?	• You have completed the test! • What do my footprints look like? • How do animals walk? • Which animals do my footsteps resemble?
Medium 8 - 10 years	**Elements of easy, plus:** • Which waves can be recognized? • Which waves were visible in my head at the following moments? - Eyes closed - Deep thinking - Reacting to stimuli - When I am tired	• You have completed the test! • Which domains did I score higher or lower in? • Do I have a special domain, and what does that mean? • How does my IQ change over time?	• You have completed the test! • What do my footprints look like? • What variables are there, and how do I score on those variables? - Standing balance - Pace (velocity) - Step width / height - Pressure distribution - Angle of feet • How do my brains make me move? (simple) • Which animals do my footsteps resemble?
Hard 10 - 12 years	**Elements of medium, plus:** • What do the waves say about me? • How many waves are there in my head and in which areas of the brain? • How has my network grown in recent years? • Option: What does my epilepsy look like in my head?	**Elements of medium, plus:** • How do my IQ-scores differ from the average?	• You have completed the test! • What do my footprints look like? • What variables are there, and how do I score on those variables? • How do my brains make me move? (more comprehensive) • Which animals do my footsteps resemble? • What is the average walking pattern?

DELIVER

In this section, the initial step involves selecting an idea direction for each test that will serve as the foundation for the final design. Essentially, this represents the intermediate phase between design and delivery. During the delivery phase, each test's idea direction is further developed through additional literature research, ideation, and user evaluations. This ultimately yields a final design that is both feasible, viable, and desirable. A final evaluation round involving all stakeholders resulted in recommendations for further development.

Chapter 15 Part 2: Gradually deepening & updating potential concepts with close user involvement

In this section, insights from all discussions about the ideas are considered to make a choice for the most promising idea direction for each test. For each test, this direction will be developed into a functional prototype by further exploring the literature and conducting various evaluations with children. Ultimately, the prototype will be tested in the classroom. The primary focus of this section is whether the visualization of the results aligns with the children's perspective.



15.1 Choosing the leading idea directions

To make an informed decision on which idea direction serves as the basis for further development, the various idea directions have been evaluated against the wishes using the weighted objectives method (Roozenburg & Eekels, 1998).

This method was chosen because the wishes established for the app are general wishes. However, each test has a distinct procedure and character. This means that different wishes carry varying degrees of importance for different tests. In addition to using the weighted objectives method, the insights from the idea discussions were also taken into account when making the choices.

Below, for each test, it is explained which direction has been chosen, which wishes from paragraph 12.2 weighed most heavily in this decision, and which elements from other idea directions will be incorporated. The full weighted objective decision matrices can be found in Appendix O.

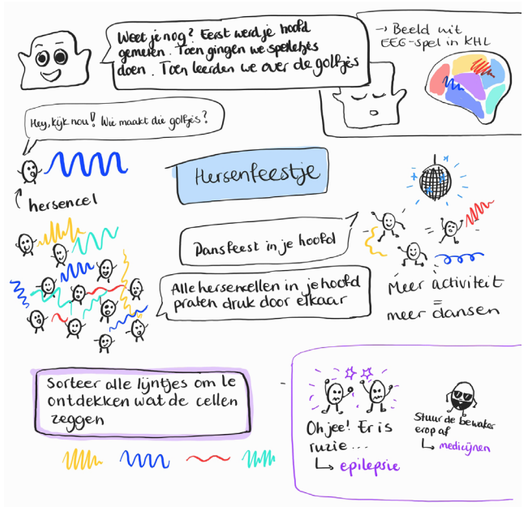


Figure 36: *Brain party*

15.1.1 EEG

The leading idea direction that has been selected for the EEG was the imaginative metaphor The Brain Party.

Reasoning

The EEG is an abstract concept that is difficult for children to understand, and brainwaves are also intangible. Therefore, the wishes that help make an abstract concept tangible are extra important. These wishes include 6) Recognizable / easy to link to daily life and 2) supports HCPs in their explanations during consultation.

Key considerations for development

What needs to be added to this idea direction is a focus on a child's personal results. An important wish associated with this is 3) Linkable to test experience. Therefore, when developing The Brain Party, consideration should be given to:

- Clarifying that the waves on the screen come from your own head
- Clarifying which waves occurred at which moments during the test
- Visualizing the brainwaves in a way that makes them easy to link to the EEG graph

Figure 37: *Thought pond*

15.1.2 IQ-test

The chosen idea direction for further development is The Thought Pond.

Reasoning

The result of an IQ test is considered as the most sensitive subject, yet it can also tell a child a lot about themselves. Therefore, the desires 7) Positive influence on self-image and 1) children feel empowered to think about and react to their results are especially important. Additionally, the metaphor of the pond (also used in Chapter 11 Interaction Vision) aligns well with the world of the psyche.

Key considerations for development

When elaborating on this idea, several important factors must be taken into account. Firstly, for the IQ test, it is crucial to focus on self-comparison; gaining insight into one's own strengths and weaknesses. Furthermore, for the IQ test, it is vital to avoid value judgements.

The IQ test result is not about precise scores but about raising awareness of the different domains that can influence your intelligence. An IQ test result can tell a child a lot about themselves, so explaining the meaning is important. Therefore, for communicating the results, it is essential that:

- It is instantly clear what the (significant) differences are between the domains
- Use concrete examples to explain the meaning of the domains

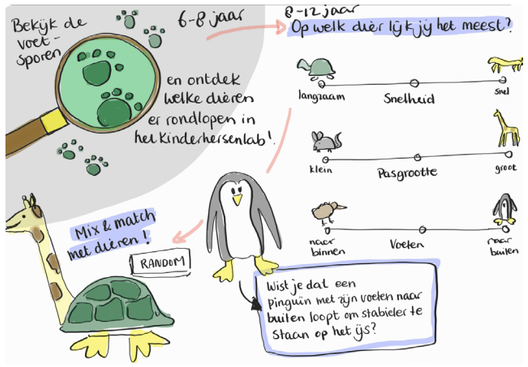


Figure 38: *Animals of the CBL*

15.1.3 The walking mat

The idea direction chosen as the foundation to proceed with is The Animals of the CBL.

Reasoning

The walking mat is the most relatable test for children. Additionally, unlike the IQ test and EEG, in some cases improvement can be achieved through practice with the walking mat. Therefore, the most important for the walking mat are 3) the visualisation is easy to link to the test-experience, 6) the visualisations of the results are recognizable/ easy to link to daily life and 2) support HCPs in their explanations during consultation – explaining what you will practice and what you can achieve with it.

In addition, the use of animals has been proven to be very appealing to children. It is also easy to relate to the CBL, as animals are often used as examples in the CBL practice. The value judgment that comparing to animals can bring plays a smaller role in this case than with the IQ test, as the outcome of the walking mat is considered a less sensitive subject than the IQ test results.

Key considerations for development

The following considerations should be taken into account when working on this idea direction:

- Children love to see their footprints. Linking these footprints to the chosen background during the test is the optimal way for children to connect the outcome to the test experience. Therefore, this should be included in the final result.
- When choosing animals, potential value judgments should be avoided.

It is important to strike a good balance between making it appealing to children by using animals while still keeping it clearly relatable to the child's performance or characteristics.

15.1.4 Overarching concept

The three tests are integrated into a single app. During the ideation phase, it was considered to adopt an overarching theme for each test, such as animals or nature. However, because crafting an engaging translation for each test is already a challenging task, the primary focus is to ensure that each test stands on its own. An exploration of children's books on the topic of the brain reaffirmed this decision. Many of the children's books that were reviewed did not adhere to a single theme. Instead, they used consistent visual language and recurring characters to create a cohesive narrative, as exemplified in the book (Walliman & Newman, 2018) shown in Figure 39.

The concept for the Self-Portrait also involves assigning leading roles to the characters from the Children's Brain Lab and integrating them throughout the app. To create a cohesive experience and establish connections between the different components, the metaphor of 'a journey through the brain' was chosen. This metaphor symbolizes the journey children will experience as they discover new information about their brains, and provides opportunities to link various themes together.

15.2 User-involvement

During the conceptualization phase, the selected idea directions were further developed. To gain a clear understanding of whether the created concept directions resonate with the target audience, children were involved several times during the conceptualization phase to evaluate the generated concepts. Three evaluations were conducted with patients from the PBC, followed by an additional evaluation held at a school in which four 8th-grade classes participated.

15.2.1 Evaluations with children with brain disorders

During the conceptualization phase, three evaluations with children were conducted. The participants can be seen in table 18. During the evaluations, the concepts were presented using screen drawings or an interactive prototype, and discussed using a semi-structured interview (see figure 40). The main goal of the interviews was to determine if the design, language used, and interactions resonated with different age groups and to identify areas for improvement. The research setup can be found in appendix P.

Figure 39: Pages of 'Professor Astrokat – Reis door je lijf' (Walliman & Newman, 2018)

The evaluation with C3, who was 7 years old, gave more insights into the world of experience of a child of this age. In general, this participant was less interested in detailed information than anticipated. However, it was confirmed that the visualisations of the results elicited a reaction from the child, as is illustrated in the quote below.

There was doubt beforehand whether the visualization would be too childish for twelve-year-old children, but the evaluation with C1 gave the indication that the level of providing information was suitable for her age.

The main takeaway from the evaluation with C4 was that this app can be suitable for children on the autism spectrum. Besides some incorrect phrasing in the text, he found the app valuable, interesting, and enjoyable.

Figure 40: Concept evaluation with screen drawings

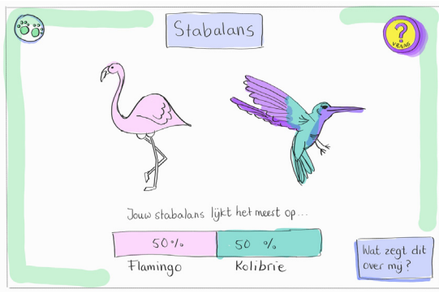


Figure 41: Concept screen drawing walking mat

If you see this result, what do you think of it?
Well, then I would say that I am more like a flamingo.
So you do not agree with what you see?
No... that bird... that is not my thing, nah-ah.
-C3

Table 18: Participants concept evaluation

Participant	Age	Gender	Disorder(s)	CBL experience	Tested with...
C1	12	Female	Brain tumor	C1	Screen drawings
C3	7	Female	Problem with brain control of stools, used to have a hip deviation	None	Screen drawings
C4	16	Male	MS-related syndrome, behaviour disorders including ADHD & PDD-NOS	First visit planned	Interactive prototype

15.2.2 Evaluating usability & defining areas for improvement

The final evaluation round took place in the 8th grade of an elementary school. The purpose of this evaluation was to assess the usability of the app, determine how well the concept aligned with the design goal, and identify areas where further improvement was needed.

Figure 42: Classroom introduction to the project

Research questions

1. What are the current usability issues?
2. Does the design align with the world of experience of an 11/12-year-old child?
3. Does the design have the effect that was aimed for (does it achieve the design goal)?

Table 19: Examples of questionnaire statements

Questionnaire statements (selection)
I think the app is logically organized
Why do you think the app is (not) logically organized? Please explain.
I find the information in the app to be interesting
Viewing results in the app has provoked thought
If the results made you think about something, what were you thinking about?
Receiving the test result in the app gives me a sense of accomplishment

Participants

The participants in this study are the students of four 8th-grade classes from an elementary school in Haarlem, the Netherlands. The ages of the students in the classes range from 10 to 12 years old. In total, 95 children completed the survey, with the gender ratio being approximately equal, and 12 children participated in an in-depth interview (2 boys and 2 girls for each test).

Method

A combination of qualitative and quantitative research was conducted. The quantitative research was carried out with all four classes. Children received a classroom introduction to the project and were then asked to try out a prototype of the app (figure 43). Each child received a prototype of one of the three tests, along with a series of tasks to perform independently. After exploring the app, each child filled out a questionnaire. One part of this questionnaire included a child-friendly adaptation of the System Usability Scale (Putnam et al, 2020) (Appendix Q). In addition, children were asked to choose on a five-point scale if they agreed with several statements. These statements were derived from components of the design goal. For two statements, an explanation was asked. Table 19 shows some example questions from the questionnaire. For further explanation of the questionnaire questions, please refer to appendix R.

Following the quantitative research, four children from each test group participated in the qualitative part. In three ten-minute semi-structured interviews, children from each test group were asked to explain their choices from the questionnaire. Various topics from the survey were selected based on notable results from the quantitative part. For the complete research setup of the classroom evaluation, please see appendix R.

Analysis

The analysis of the questionnaire was conducted both as a whole and separately for each test, enabling a comparison of the tests by question. For each question, a pie chart was generated to illustrate the frequency of each multiple-choice response. Additionally, two open-ended questions were examined to identify recurring themes in the responses. Furthermore, the interview was recorded, transcribed, and significant quotes were highlighted.

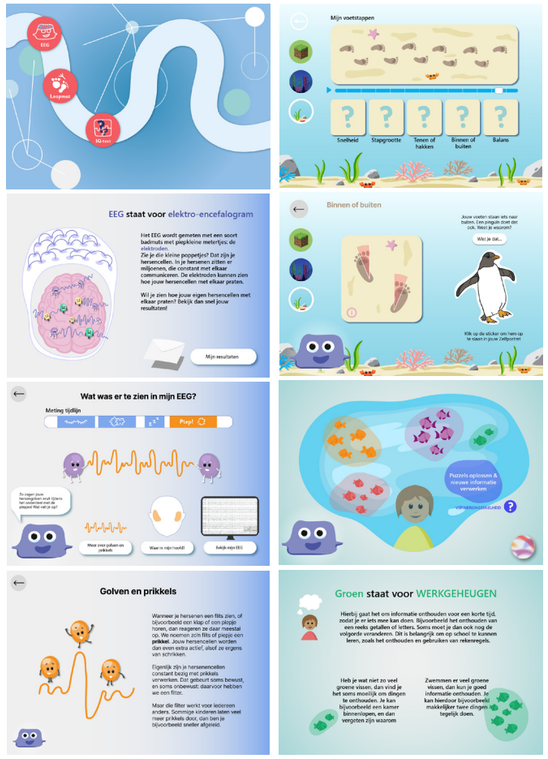


Figure 43: Screenshots from the prototype that was tested in class

Figure 44: Language use (EEG & Walking mat)

Results

The IQ test questionnaire received 32 responses. The Walking mat questionnaire received 36 responses, and the EEG questionnaire received 27 responses. From the responses, it was evident that images and texts were clearly readable for all tests. The language level used was generally perceived as 'just right' (70%). However, for EEG, 19% found it 'too difficult.' Regarding the walking mat, 23% considered it 'too easy,' and 11% 'way too easy.' For the IQ test, a large portion of the responses were neutral regarding the statement 'I find the information in the app interesting.' Children found the EEG test the most interesting.

Children found the walking mat the most enjoyable part to use, and the IQ test the least enjoyable. Only 4% reported that they found it unpleasant to view the results. Surprisingly, for the IQ test, this was 0%. 40% answered neutrally. The rest responded 'disagree' or 'strongly disagree.'

For the statement 'viewing the results made me think,' less than half of the children responded with 'agree' or 'strongly agree.' The majority of responses were neutral. The IQ test results made children think the most, while those of the EEG made them think the least. Among the children who mentioned being prompted to think, most gave answers related to themselves (14 times), such as 'About how my brain is structured.' Additionally, children thought about the provided information (7 times), like 'About the animal facts, because they were very interesting,' or about their peers with a brain disorder (7 times) 'Because some children have a brain disorder, and that makes me think.'

Children mainly stated that they learned about the brain (36.5%). Following that, they mentioned learning about themselves (23.5%), learning about their brain disorder (18.7%), learning about Kinderhersenlab (13.9%), and 7.4% indicated that they didn't really learn anything from the app. An overview of all pie charts is shown in appendix S.

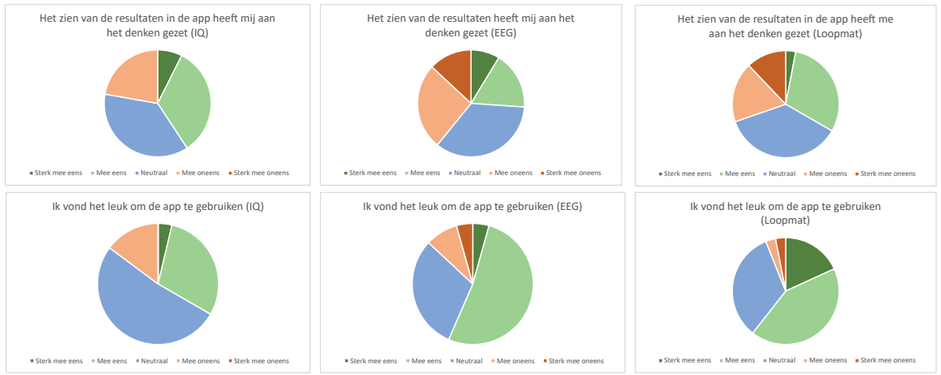


Figure 45: Results of concept evaluation questionnaire

System Usability Scale

The SUS questions were answered 91 times. The average SUS score was calculated according to (Brooke, 1996). The resulting SUS score was 53 on a scale of 1-100. According to Sauro (2010), a score of 66 is considered average. A score of 53 means that 75% of apps score higher in usability. This score implies that there is still much room for improvement in terms of usability.

Discussion

The app prototype did not function like the final app would. Not all buttons were clickable, and the prototype did not fit precisely on the iPad screen used by the children. Despite emphasizing in the test instructions that it was a prototype and not everything worked, children indicated multiple times that they found this confusing. Therefore, the usability score may not be entirely reliable. Nevertheless, the user test provided valuable feedback from the children, offering a clear understanding of the strengths and weaknesses of each test implementation. This is further elaborated on in the following paragraph.

15.3 Conclusions and improvement areas

15.3.1 What are the current usability issues?

The outcome of the SUS revealed that there is significant room for improvement in usability. The interviews made it evident that children sometimes found it unclear what they needed to do or what their next steps should be. Therefore, more guidance needs to be added. Additionally, navigation lacked consistency, so this area also requires attention. However, the texts and images were easily readable.

The EEG section was perceived by children as the least logically structured, thus necessitating an improvement in the screen layout for the EEG.

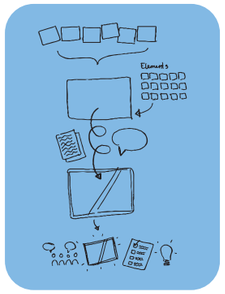
15.3.2 Does the design align with the world of experience of an 11/12-year-old child?

In general, the classroom evaluation highlighted that the display method aligns well with children's experiential world. Particularly, the vibrant colors and animals were appreciated, and not considered overly childish. Based on the questionnaire results, it came forward that the information provided for the walking mat should be more comprehensive. This was also indicated in the interviews, as children expressed a desire for more extensive result information than currently provided.

15.3.3 Does the design have the effect that was aimed for (does it achieve the design goal)?

The primary insight is that with this app design, children do not find it bothersome to view their test results. As for whether the visualization feels rewarding or prompts reflection on one's identity, children expressed a relatively neutral sentiment. However, most children did indicate that the app provides opportunities to learn about the brain and about themselves.

In particular, there is room for improvement in making the EEG section feel more personalized. Interviews revealed that EEG information was often perceived as general rather than personal information. Nevertheless, the screen image was seen as representing their personal EEG.



Chapter 16 Final Design

The points raised in the evaluations in Chapter 15 have been incorporated and have resulted in the final design of the Self-portrait app, which is presented in this chapter. Here, the main design choices made are explained, with references to the previously established challenges, opportunities, and insights.

16.1 Introducing the Self-portrait: Travel through and discover the world of your brain!

The final design of the Self-portrait app invites children into the world of their own brain. The app guides children along a path where they encounter various icons, each leading to one of the CBL tests. Each test is elaborated with its own character, designed to showcase the test results optimally. By exploring all the tests, children can discover a wealth of information about their own knowledge, abilities, and brains.

The Self-portrait embodies a cheerful and personal character through the use of vibrant colours and distinct characters. Additionally, the colours aid in comprehending and retaining information, making different elements easier to distinguish from one another. The Self-portrait is designed with numerous interactive elements, allowing children to click around and discover new information. This layered approach empowers children to take control of what they want to see or not.

The primary focus of the Self-portrait is to inform children about their achievements, with an emphasis on minimizing value judgments and comparisons with others. The app combines personal test results with standardized explanations accompanied by concrete examples. This way, the results provide children with a link to their daily lives while ensuring that all information remains medically justifiable.

Participation in the CBL and using the app is rewarded through stickers. Children can collect stickers by exploring various sections within the app, and these stickers are stored in their own collection. Later, they can use these stickers to create their own brain self-portrait. Furthermore, children are offered the opportunity to react during result viewing through question/response stickers and smileys. The "my questions" page provides a clear overview of what a child wishes to discuss, both for the child and the doctor.

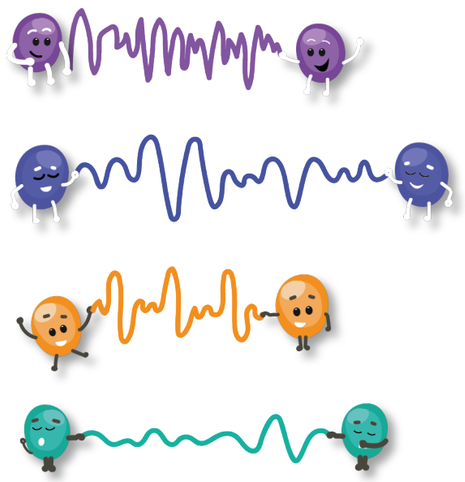
The app includes three difficulty categories, containing information as described in Table 17. This way, each child receives information tailored to their own interests and abilities. In the following paragraphs, the design choices for the third category are explained in detail, followed by an explanation of how the display has been adapted for the other difficulty levels.

Figure 46: Final Design

16.2 EEG

The EEG section displays the results of the EEG test. As mentioned in paragraph 5.2.1, the two main functions of EEG in the CBL are monitoring brain development and investigating epilepsy. However, if solely measured by one EEG, those brain waves do not provide much information about a child's brain functioning. Conclusions are usually drawn in combination with the results of other tests. What a child can learn from the EEG is primarily an understanding of the different types of brainwaves that can occur in their head.

Therefore, the primary purpose of this component is to clarify to the patients, which various types of waves were observed in their brain and what these waves signify, enabling them to become more aware of the complex processes in their brains.



Trade-off
Medical responsibility

16.2.1 Choices explained

Wish
The visualisation is easy for children to link to the test-experience

A In the design, an effort has been made to establish a logical link between the test experience and the most significant information that can be derived from an EEG. Therefore, the decision was made to communicate the results of the EEG based on the tasks performed in the Child Brain Lab. In most cases, the various tasks correspond to specific brainwave patterns.

The components of the test are presented in a timeline that children can click on to see which brainwave was observed at that time. This was done with the aim of making children feel that the brainwaves were genuinely measured during their test, rather than just receiving general information about different brainwaves.

Interaction quality
Elements look interesting and inviting

B To make brainwaves tangible for children, they are depicted using small figurines representing the brain cells that communicate with each other. The posture of these brain cells also conveys the meaning of the waves.

In the descriptive text, reference is made to the personal experience of the test. The shape of the wave displayed is the same for every child for feasibility reasons.
The waves that will be displayed in the app (if they show up in the child's EEG) are:

Eyes closed - Alpha waves
Difficult puzzle task - Beta waves
Video with beeps - Wave responsive to beeps
Child is tired / drowsy - Theta waves
Child has epilepsy - Epileptic activity

Challenge
Adding value for each child - layering in information

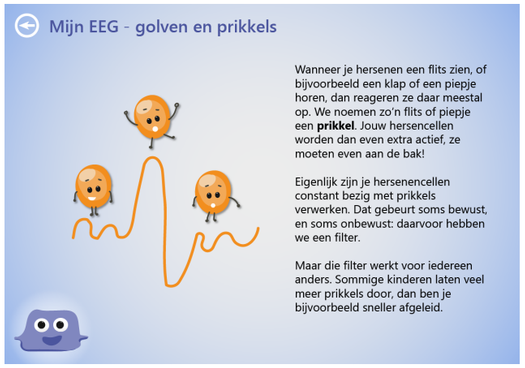
C To facilitate deeper understanding, children can find more information here about the meaning of the wave and the location of waves in the head.

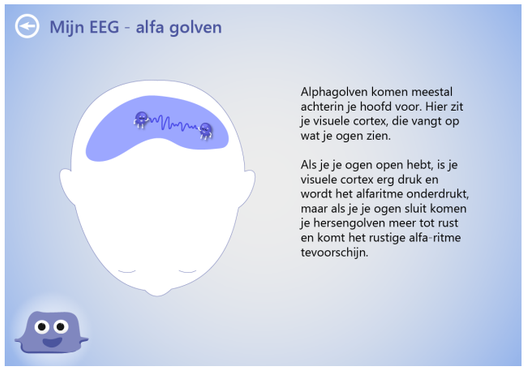
Opportunity
Look at what you've learned

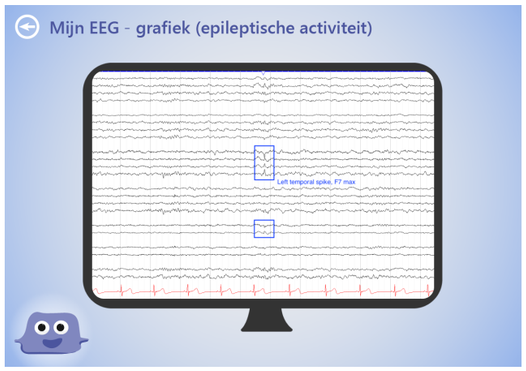
In the section "Where in My Head," a visualization is provided to show where in the head the wave was measured (based on which electrodes were used). Additionally, an explanation is given about where these waves are typically measured in the head and why. Many waves tend to occur in the same areas of the head, with a logical explanation.

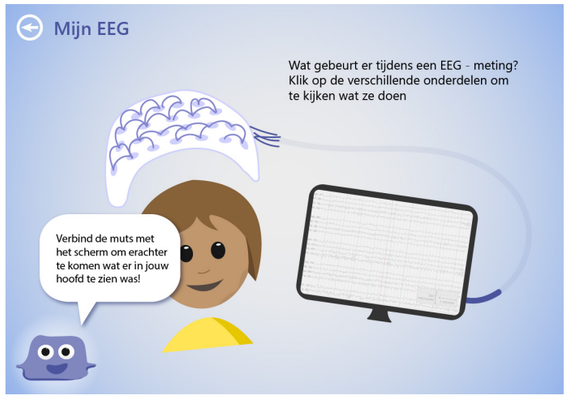
Wish
The visualisation is easy for children to link to the test-experience

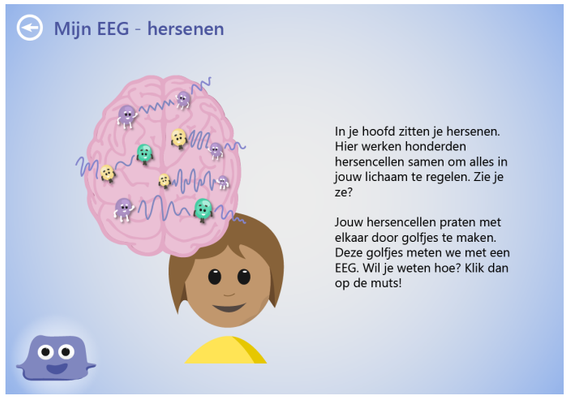
D The option to view raw data fulfills the children's desire to "see what the doctor sees" and enhances the sense of personal information. This chart uses squares to indicate where the specific wave is recognizable.

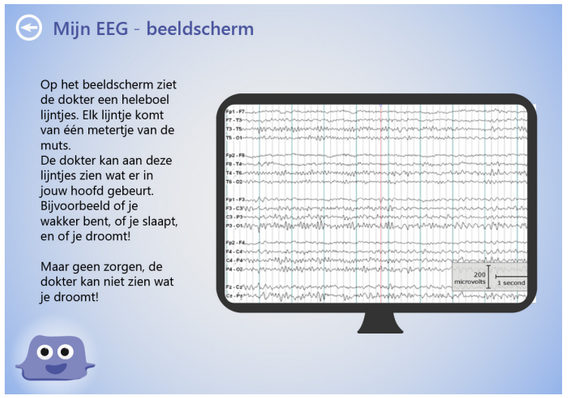












E Children can click on the various components to get an explanation about the EEG, which they should recognize from their test experience. Here, they will learn about what brain waves are, how the cap measures them, and what the doctor can see on the screen. The language of this explanation has been tailored for each age group.

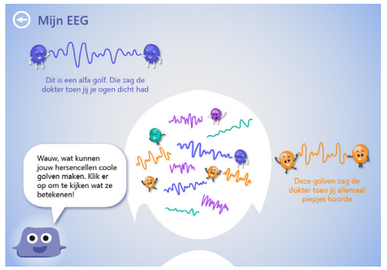
Take-away
Pay attention to the procedures

Opportunity
Framework for contributing to self-image

16.2.2 Variations per age group

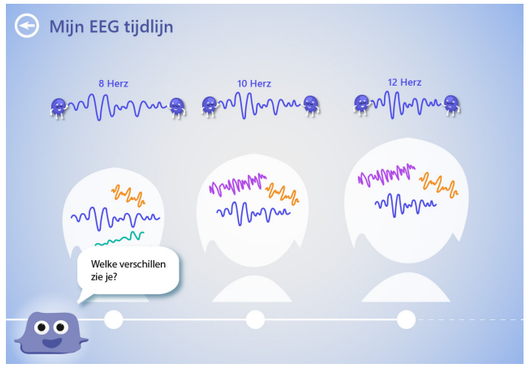
For young children, the emphasis is on making it clear that various waves pass through a head: 'See what kinds of waves are in my head!'. With older children, the focus shifts more towards learning about the meaning of the waves. The visualization for the two oldest groups is the same, but the oldest group receives more information than the middle group (see Table 17). For instance, the presence of epilepsy is only indicated in the oldest group.

16.2.3 Overview over time



Challenge
How true are the results

The most significant change to expect in an EEG over the years is the increase in the frequency of brainwaves. As mentioned in paragraph 5.2.1, it is a reliable assumption that the frequency of alpha waves increases as one grows older. Therefore, My EEG timeline is presented with the various waves measured in the head, highlighting the frequency of the alpha wave. This provides the child with the most meaningful information about their brain development and visually displays the differences at a glance in an engaging manner.



16.3 IQ-test

The IQ test section displays a translation of the five index scores and the total score from the IQ test in the CBL. The goal of the IQ section is to make a child aware of their own strengths and weaknesses in a lighthearted manner, so they can better understand why they face certain challenges in daily life. The child looks into the pond and sees a "reflection of themselves," where cheerful fish visualize the five domains. The visualization is based on the balance between the different domains, emphasizing the comparison of a child with themselves.

16.3.1 Choices explained

A The fish initially swim mixed together to illustrate that the different IQ domains are related to processes in your head that intermingle and influence each other.

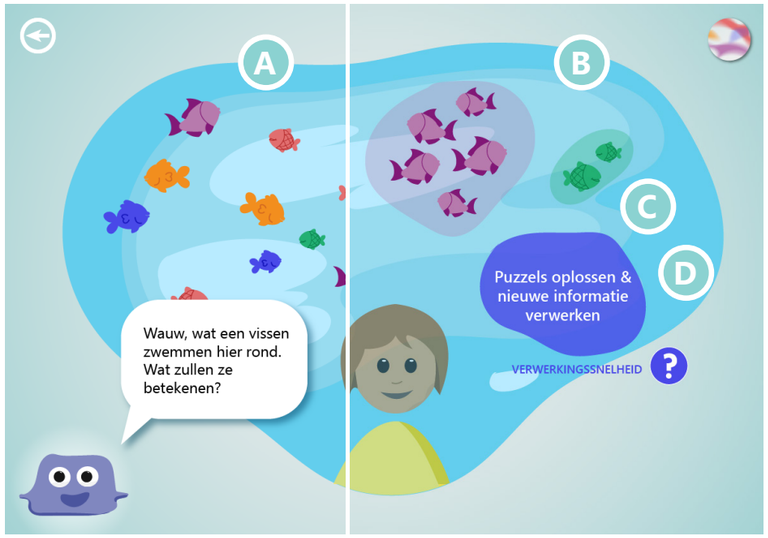
Challenge
Comparing to others

B The pond provides an at-a-glance overview of the proportions between the various domains. The number of fish is not influenced by the total IQ score. Every child is rewarded with a pond full of cheerful fish, regardless of their total IQ.

Wish
Children can actively assess and engage with information in a fun way

C The app is interactive since children click on the different colored fish to reveal deeper layers of information.

D A brief, child-friendly description of each domain is emphasized. Additionally, the official name is mentioned to create a clear link to the test and to engage children seriously.



E When a child desires it, they can receive more information about a domain by clicking on the question mark.

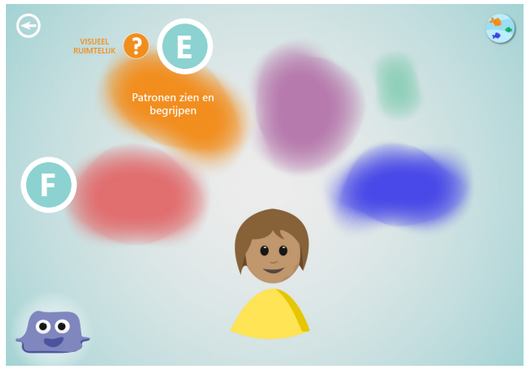
F The child can also opt for a sensory-friendly display with color clouds representing the five domains.

G Explanation of domains in simple language with concrete examples

H Each domain is associated with a distinct color that is prominently featured in the explanation. This use of color helps children remember it more easily and allows for easy reference by a doctor, parent, or child during a consultation.

I Description without value judgment

J Mentioning concrete examples from everyday life



Wish
The visualisations of the results are recognizeable

16.3.2 Variations per age group

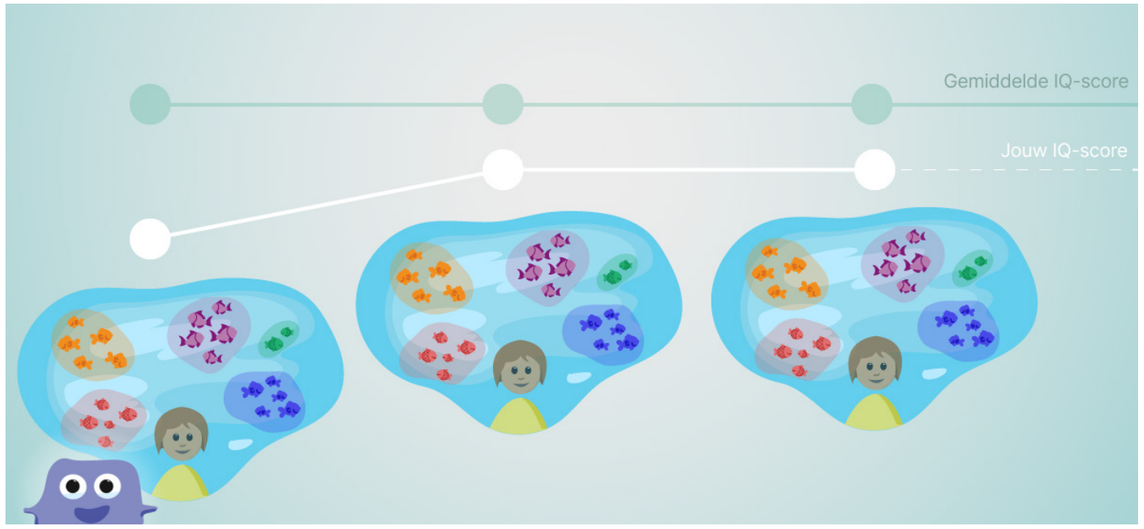
The layout with the pond is the same for all age groups, but for the first age group, the official domain name has been replaced by a single simple word that implies the meaning of the domain. In the detailed explanation of the domain, the emphasis for young children is on the tests a child has performed, which is in line with Figure 29 (“Look at what I did!”).

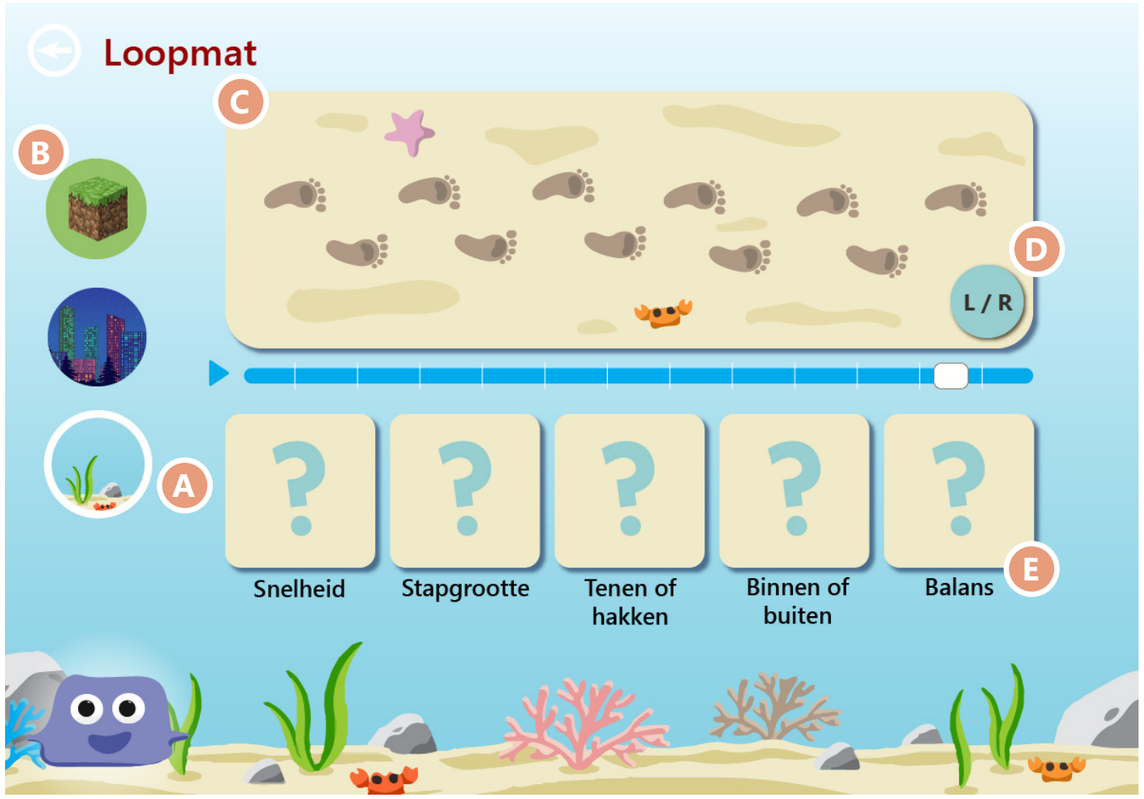
Opportunity
Framework for contributing to self-image

16.3.3 Overview over time

In the overview over time, the ponds are compared to each other so that you can instantly see if the proportions within your domains have changed. Additionally, the timeline provides an indication of the total IQ, represented without a number, to emphasize the comparison of different years rather than the specific IQ value.
For the oldest children, a line is included to indicate the average IQ. As mentioned in section 14.3.3, children apparently experienced comparing with ‘an average’ different from comparing with other children.

Wish
Children feel empowered to think about and react on their results





16.4 Walking mat

The walking mat section displays the results of the walking test and the balance test. The goal of the walking mat section is to provide children with recognizable information about their walking pattern and, in a playful manner, to give them an idea of how their walking pattern compares to the average. Expectations are that this insight will benefit to their conversation with the physiotherapist about what children can practice and what they could improve in their walking pattern.

16.4.1 Choices explained

Wish
The visualisations of the results are recognizeable

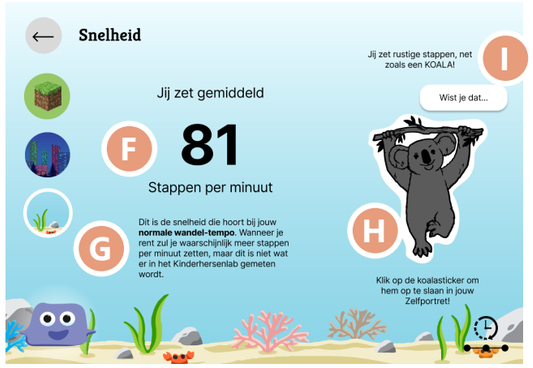
A For the feedback, five variables recognizable to children and frequently practiced by physiotherapists with children have been selected.

Wish
The app should be personalizable

B Children can choose from the backgrounds that are available in the CBL, providing a clear link to the test experience.

C An animation displays children's footprints related to the chosen theme.

D Children can access more information about the difference between their left and right foot, where explanations are also provided regarding how the brain controls movement.



Wish
The visualisation is easy for children to link to the test-experience

E Stability is a separate test, that is performed right before or after the walking test. For the stability test, children stand still on the mat in various ways (for example on one foot).

F Displaying in steps per minute is easier for children to grasp than m/s or km/h.

G The explanation emphasizes that it's about walking pace to prevent children from running during the next test.

Opportunity
Having fun with the results - Animals

Challenge
Comparing to others

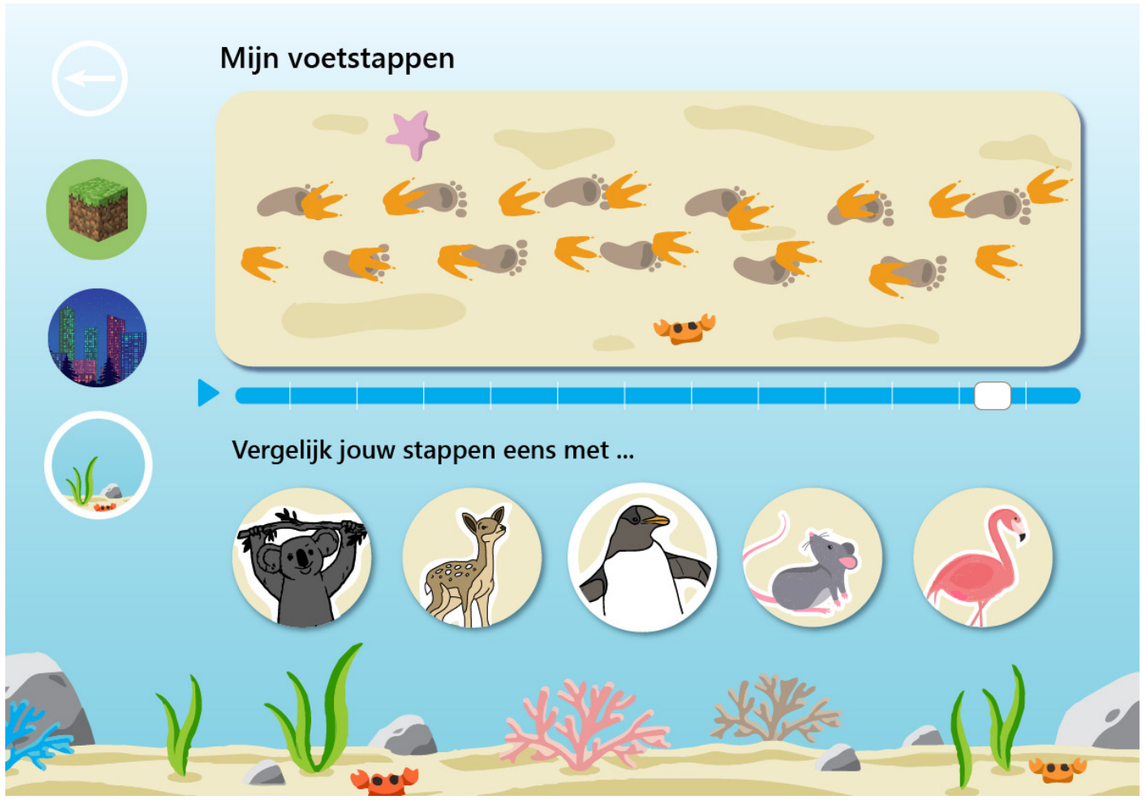
H Based on their walking pace, the child earns an animal sticker. In this context, animals with judgmental connotations (e.g., slow snail) are avoided. In practice, animals are also used by physiotherapists to explain movement.

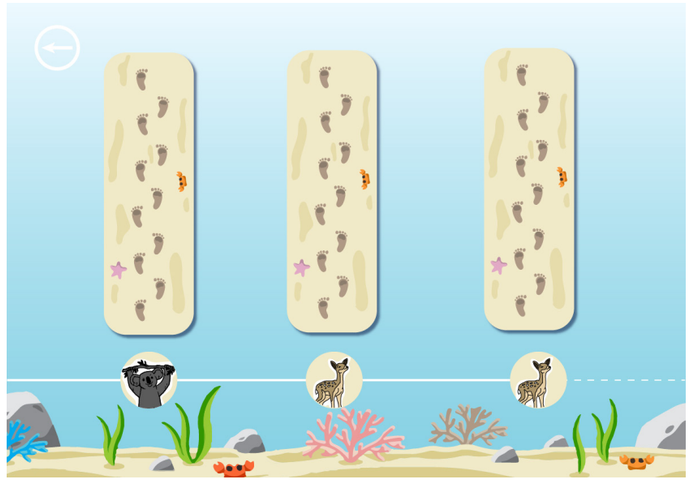
Challenge
Honest vs. Positive

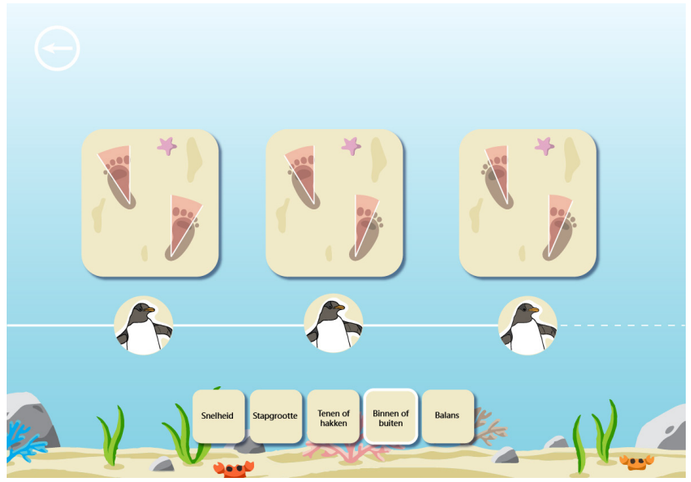
I Avoid phrasing that could be negatively interpreted, such as 'you are slow.'

Opportunity
Look at what you have learned

J Children love fun facts. That's why fun facts about the animal they've earned are provided. These fun facts also explain why the animal suits the specific walking pattern.







16.4.2 Variations per age group

For young children, the emphasis is placed on "look at the footsteps I can make," and only the walking pattern is depicted. Children (unconsciously) gain insight into the variables by comparing their steps to animal footsteps. A physiotherapist can explain these examples when necessary.
For older children, more emphasis is placed on the various variables, and they are displayed separately and in greater detail. For the oldest children, the footsteps of the average walking pattern for their age group can be loaded.

Opportunity
Framework for contributing to self-image

16.4.3 Overview over time

For young children, the timeline displays footsteps along with the most characteristic animal. For older children, it also provides the variables over time, allowing them to analyse in more detail.

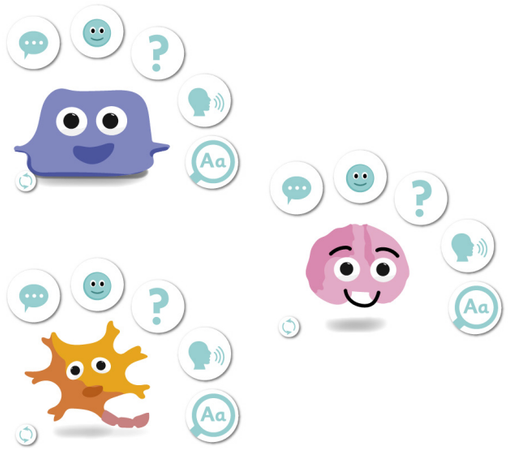
Wish
Children feel empowered to think about and react on their results

16.5 Supporting features

16.5.1 Wavy, Breeny and Neuro

In the Child Brain Lab, the characters Wavy, Breeny, and Neuro are there for participants to "help them." This is exactly what they also do in the app. The character is like a buddy for the children, who takes them on a journey and is always positioned in the lower-left corner of the screen to encourage, support, or guide them. The character will provide tips to a child through text bubbles on what to do and also includes various functions, as indicated below:

- Apply response stickers.
- Apply emotion stickers.
- Provide visual cues for screen interactions (where to click or drag).
- Read aloud.
- Magnifying glass to enlarge text (for those with poor vision).

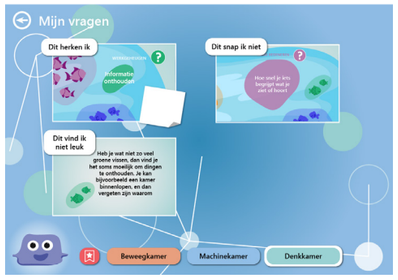


16.5.2 Reactions & questions

To ensure that the Self-Portrait also contributes to children's participation in their care, the option has been added for children to post questions and/or response stickers in the app. To keep the threshold low, there are pre-made statements. These statements encompass the various reactions children may have when viewing information that could prompt them to ask a question and are partially inspired by the evaluations with children during the project (see quote).

"This pond doesn't look right at all (Deze vijver klopt echt niet). Why not? Everything should be as big as that one because I can do everything."
- C3

All posted question stickers are displayed in a list under "My questions," making it easily accessible during a doctor's consultation. In the same overview, children or parents can make a note once the doctor has answered the question.



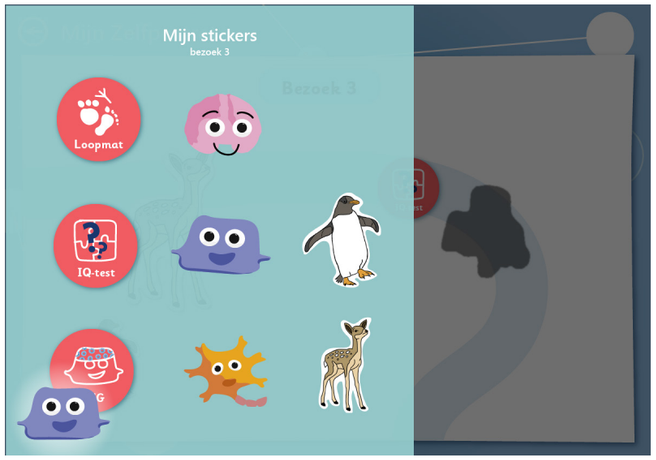
Take away
The Selfportrait should aim for inviting and supporting children & parents to participate

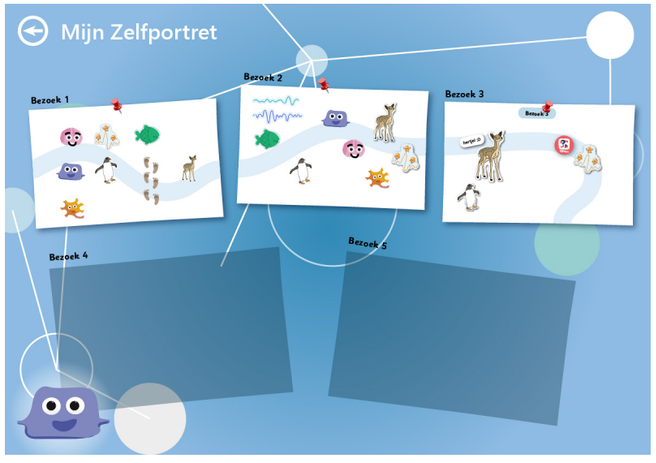
16.5.3 Earning stickers and My Self-portrait

Because children enjoy collecting items, they can earn stickers in various places within the Self-Portrait. These stickers serve as rewards for participating in the CBL and aim to motivate and reward them for exploring as much information as possible in the app. The stickers include a set of standard stickers related to the Child Brain Lab. More importantly, there are stickers that convey information about a child's own test results. For each test, the stickers that can be earned represent the test outcomes.

My Self-portrait
In the context of "becoming aware of and accepting who you are (design goal)," children are encouraged to view their results from a broader perspective. For each visit, children receive a card representing a segment of the path through the world of the brain. On this card, they can glue all stickers they have earned, customized to their liking. In an overview, children can eventually see all their visits displayed side by side as one continuous path.

Opportunity
The Creative Room





16.5.4 CBL knowledge

The CBL knowledge page raises children's awareness of their contribution to science. The visualization links to brain development and the "strengthening of the network." This "brain network of the CBL" is visualized, with more points and connections being added as more children participate in testing. A child's own contribution is highlighted by making those points a different colour from the rest.

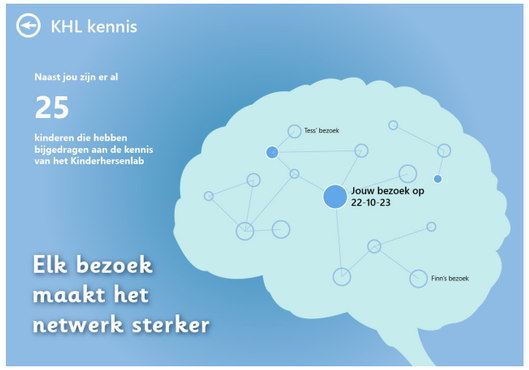
Opportunity
Reward contribution to science

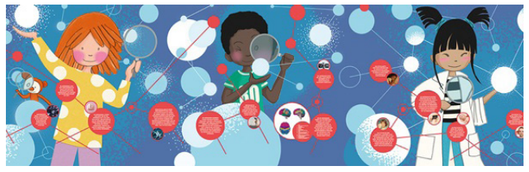
16.5.5 Design choices

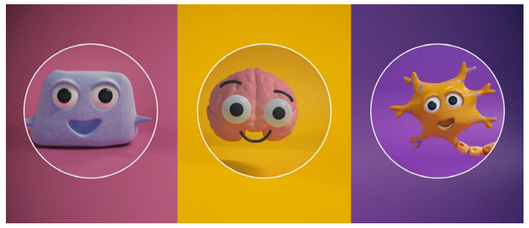
In the design language, an attempt was made to incorporate elements from the physical Child Brain Lab. An effort was made to strike a balance between the design language of the image at the entrance of the CBL and the modern characters of the CBL.

Furthermore, the colours of the rooms from the CBL have been integrated into the app's design to make it recognizable for children which test was conducted in which room: Motion room = red, thinking room = green, machine room = blue.

The font used for headings and titles is Sassoon Primary Infant. This font was designed through research with children and is commonly used in screen fonts for interactive educational software (Sassoon & Williams, 2015). A sans-serif font was used for the basic text because it is generally preferred by people with autism (Northern Ireland Assembly, n.d.).







16.6 Feasibility of the design: data processing

In the final design, consideration was given to the feasibility of obtaining the necessary data, utilizing insights from Chapter 7. To illustrate the feasibility of the final design, an overview was created, outlining the required data and the steps needed to translate it into the Self-portrait. This overview was validated and discussed with two experts: the data manager of the CBL (E12) and the neurologist responsible for EEG analysis at the CBL (E5). The data processing for each component of the app is explained in figures 47-50 on the next pages.

16.6.1 EEG

The key information to be presented in the Self-portrait consists of the brainwaves commonly recognizable in an EEG, which are frequently expected in the EEGs of the CBL participants. Therefore, the EEG graph needs to be analysed to detect these waves. This can be done automatically in many cases, but due to numerous disturbances in the EEG, errors in the analysis may occur. As depicted in the diagram, a manual check is required. Analysing an EEG is no easy task. During the evaluation with the EEG analyst at the Child Brain Lab, several issues emerged:

1. Epileptic Activity:
Detecting epileptic activity in the EEG is a standard action that is performed in the CBL and is, therefore, easily achievable. Concerns related to representing epileptic activity primarily revolve around displaying details such as the heatmap and proportions. One significant reason for these concerns is that the amount of epileptic activity detected in the brain does not necessarily correlate with the severity of a child's epilepsy. Visualizing this impression through a heatmap can be misleading. Furthermore, reliable automatic detection of such epileptic abnormalities is currently not feasible (C5). These epileptiform abnormalities are highly variable and can frequently change even within the duration of an EEG measurement. Therefore, the recommendation is to display only the standard epileptic wave, with a segment of the EEG showing the deviations.

2. Detecting Frequency:
It is easily achievable to calculate the frequency of alpha, beta, and theta waves. Nevertheless, the initial concept of adjusting the wave's representation in the Self-portrait based on these frequencies seems to be a significant effort for a relatively insignificant outcome, given that children are unlikely to notice or derive meaning from such modifications. What adds value is mentioning the alpha wave's frequency since it typically demonstrates consistent changes over time. Consequently, the Self-portrait will exclusively present the alpha wave's frequency in textual form.

3. Displaying Proportions:
It is technically possible to automatically analyse the proportions of how often each wave occurs relative to the others. Nevertheless, there are risks that disturbances in the EEG may influence the outcome of this analysis, potentially leading to inaccurate information in the timeline overview. For example, muscle activity related to blinking is a slow activity that can resemble theta waves. If a child blinks frequently during a visit, it may falsely appear as though the EEG has become slower. Therefore, it has been decided not to display these proportions in the Self-portrait.

4. ERP - Beep Test:
During the discussion, it became clear that ERP provides a separate EEG chart that is not examined by the neurologist. The ERP chart is analysed by the ENT (Ear, Nose, and Throat) specialist. Since no evaluation has been conducted on this, the feasibility

Analysis - EEG

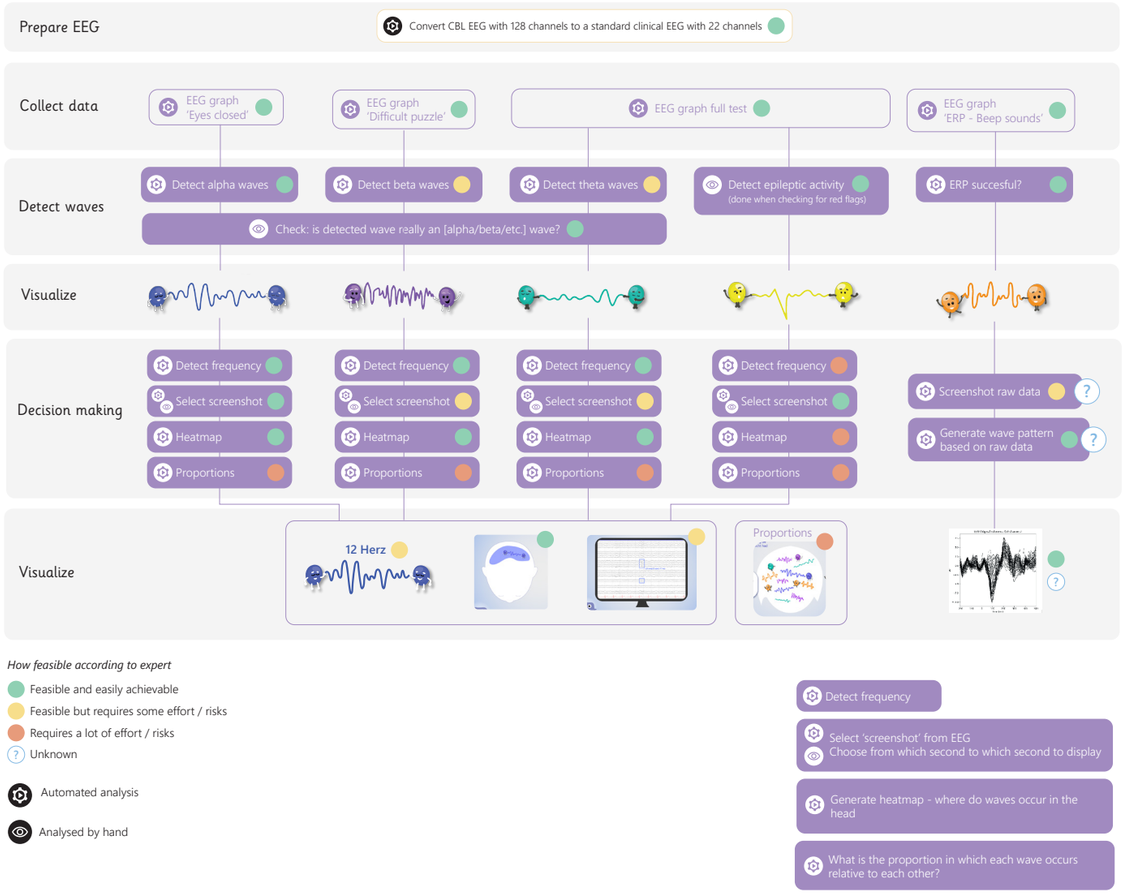


Figure 47: Data processing that is needed for the EEG-part

Analysis - IQ test

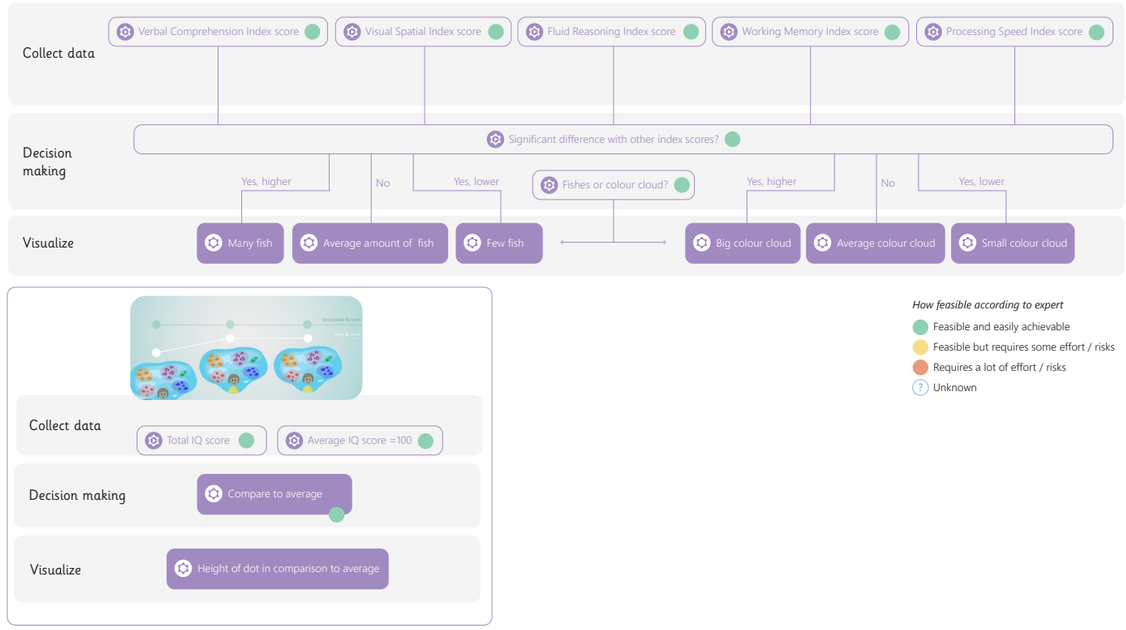


Figure 48: Data processing that is needed for the IQ-test-part

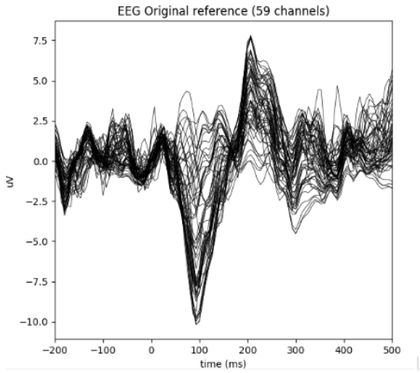


Figure 49: Event related potentials (Neurotech EDU, n.d.)

of this component could not be ascertained with certainty. An insight from the evaluation is that the 'response wave' becomes clearly visible when overlaying the waves of all beeps. For displaying on the computer screen, the recommendation is to present a graph like the one shown in Figure 49, instead of a segment of the EEG.

16.6.2 IQ-test

As the figure illustrates, the IQ test data required to display the "thinking pond" consists of the total IQ score, the five index scores, and a parameter indicating the significance of these index scores. This data can be entirely extracted from the measurements and calculations already conducted in the Child Brain Lab, without requiring additional process steps for HCP's.

16.6.3 Walking Mat

As described in section 5.2.3, the walking mat provides a dataset with an extensive list of parameters (see Appendix H). The data required for the walking mat component, such as the average step length or foot angle, can be extracted from this dataset. For the translation into the Self-portrait, simple calculations are needed, such as determining whether the number is below, equal to, or higher than the average. Therefore, the data processing steps required for the final design of the walking mat are feasible. However, some additional processing steps are necessary for certain aspects, which will demand more time from a HCP. These steps are highlighted in yellow and one of them elaborated upon below.

Center of pressure

An additional step by an HCP is required to determine how the center of pressure deviates from the average. For this, the tester needs to perform extra post-processing. In practice, it needs to be tested how much time this post-processing takes to make an informed decision about whether it should be excluded from the Self-portrait.

16.6.4 App in general

The design of this app requires that data from the Health data platform can be combined with data from Gemstracker, HiX, and data entered by the child in the app. According to the data manager, this is feasible because the Self-portrait is likely to become a part of an Erasmus-wide app. This facilitates communication between all the different platforms at Erasmus. Logging into the app will be done via DigiD, ensuring privacy and displaying the correct patient data.

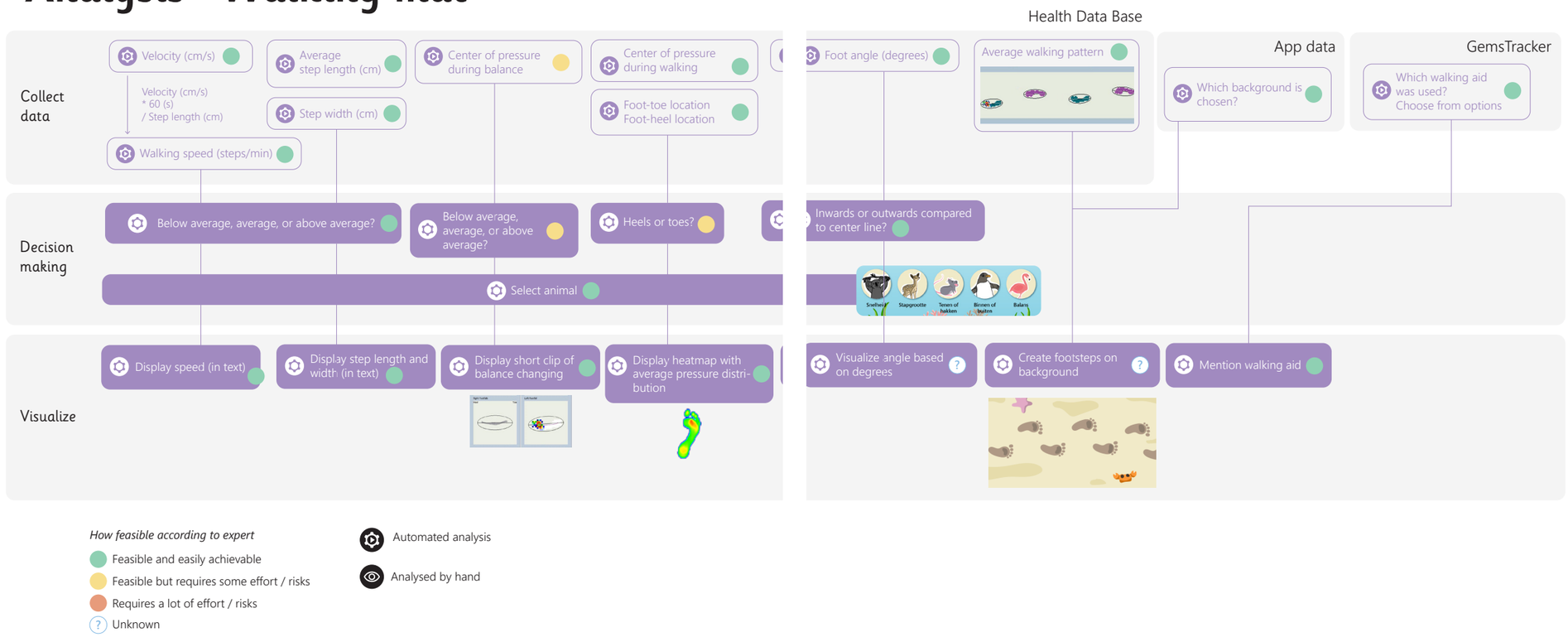


Figure 50: Data processing that is needed for the Walking mat-part

Chapter 17 Final evaluation

During the process, many stakeholders were involved, contributing to various iterations of the design. The final evaluation assesses the final design with the aim of determining whether it fulfills the design goal and meets the desired criteria. This evaluation included input from healthcare professionals (HCPs), children with brain disorders, and their parents. Insights into how well the design goal has been achieved and identified areas for potential improvement have been provided. Some of these improvements have already been incorporated into the final design described in Chapter 16. They will be discussed alongside other possible areas for future enhancement.

17.1 Research goals

The final evaluation had three main objectives:

1. Assess the extent to which the design goal and the wishes have been met.
2. Identify necessary improvements to better align with the design goal or the wishes.
3. Evaluate usability, including navigation and comprehension.

Two types of evaluations were conducted, one involving children (and their parents) and another involving healthcare professionals.

17.1.1 Evaluation with children (and parents)

This evaluation had two main objectives. First, it aimed to determine if the app met the design goal from the perspective of children, specifically whether it would assist them in participating in their healthcare. Additionally, the evaluation focused on usability, including the clarity of navigation (whether children can easily identify the buttons to switch between different screens) and understandability (whether the images are clear and comprehensible to children, effectively conveying the intended meaning).

17.1.2 Evaluation with HCP's (and involved designers)

The evaluation with HCP's primarily focused on the challenge of "fitting in the medical practice," specifically emphasizing the last part of the design goal:

"in a form that is integrated in the clinical workflow of the Pediatric Brain Centre, and supportive during the full care journey, so that HCP's view the Self-portrait as an enrichment to their work."

The questions asked revolved around the accuracy of the presented information, the alignment of the design with the clinical workflow, and whether the HCP's expected the design to make a positive contribution to children and healthcare.

17.2 Approach

For the evaluation with children, two individual sessions were conducted. For the evaluation with HCP's, a group session was organized.

17.2.1 Evaluation with children (and parents)

One evaluation session was conducted in person with participant C1 and her mother, who were already familiar with the project. The other session was held online with a 17-year-old patient who recently participated in the tests at the CBL. The evaluation combined observation with semi-structured interviewing. To assess the app, an interactive prototype was presented on a tablet, and children were guided through the app using a list of tasks. By using this list of tasks, it ensured that participants were exposed to all relevant components without being distracted by non-functional elements.
During the execution of the tasks, observations were made regarding which buttons children attempted to press to achieve their objectives, in order to evaluate the clarity of the app's navigation. After the task execution, a semi-structured interview was conducted, with questions related to the design goal and wishes. The interview guide can be found in Appendix T.

Table 20 Participants of final evaluation (children)

Participant	Age	Gender	Disorder(s)	CBL experience
C1	12	Female	Brain tumor	None (PBC patient)
C15	17	Female	MS	Motor & sensory room, earlier IQ-test experience

17.2.2 Evaluation with HCP's (and involved designers)

The evaluation with HCP's was conducted in a hybrid meeting with the presence of ten participants (5 in person, 5 online). Their characteristics are detailed in table 21; notice that not all participants in this session were HCP's. During the meeting, the final design was presented to the group by collectively navigating through the prototype. Subsequently, HCPs had the opportunity to offer their feedback, and a discussion took place on the following topics:

- Initial Impressions
- Content
- Do you find the information provided to children appropriate for the target audience?
- Integration into Practice
- To what extent can this design be beneficial for a physician during consultations?

The evaluation concluded with the completion of a questionnaire (see Appendix U). In this brief questionnaire, HCP's were asked to indicate, on a 5-point scale, the extent to which they agreed with the statements below, with 1 = strongly disagree, 2 = disagree, 3 = neutral, 4 = agree, and 5 = strongly agree.

- The presented design is a valuable addition during a consultation.
- The presented design fits well within the current clinical practices of the Pediatric Brain Center (consider data collection/processing needed for filling out the Self-portrait, for example).
- The design presents results in a way that positively contributes to a child's self-image.
- This design encourages children to participate more in their healthcare.

When responding to the statements, a distinction could be made between the app in general, the EEG part, the IQ test part, and the walking mat part. Additionally, after each statement, HCP's were asked to explain their answers.

Table 21 Participants of final evaluation (HCP's)

Participant	Profession	Expertise
E4	Research worker & tester sensory room CBL	EEG
E5	Pediatric neurologist	EEG
E7	Pediatric physiotherapist & tester motion room CBL	Walking mat
E8	Pediatric psychologist & tester cognition room CBL	IQ-test
E12	Data Manager CBL	CBL
E13	Pediatric rehabilitation physician	Walking mat
E17	Coordinator CBL	CBL
E18	Pediatric neurosurgeon & head of PBC	PBC
E19	Professor Design for Children	Design
E20	Product Designer MCW	Design

Table 22 Questionnaire results – average scores (1 = strongly disagree, 5 = strongly agree)

	General	EEG	IQ	Walking mat
Valuable addition consultation	4,5	4	4,5	4,2
Fits with clinical practices*	3,9	3,7	3,9	3,9
Positively contributes to self-image	4,3	4	4,4	4,2
Encourages child participation	4,5	4,5	4,5	4,5

**Answered by 7 participants instead of 10 due to a lack of expertise.*

17.3 Results

From the evaluations, the following insights emerged:

17.3.1 Results children

Usability - navigation

The basic navigation between the various test results and the main menu was clear for both participants, as they immediately used the correct buttons. However, within the pages of each test result, it was not always evident what was expected from the participants. For one participant, for example, it was not immediately clear that she could click on the coloured fish in the IQ-test. When a task was assigned by the designer or when there was a speech bubble from Wavy (the character in the app) providing guidance, it became immediately clear for the participants what to do, and both participants understood where to click to delve further into the information. Therefore, when a user lands on a page for the first time, the chosen character (Wavy, Breeny or Neuro) should provide explanations and hints regarding the steps that can be taken.

When performing the task "You don't recognize yourself in this test result and want to leave a comment," both participants instinctively clicked on Wavy, expecting to find the option to leave a comment there. However, the icons that appeared around Wavy were not self-explanatory, and both participants clicked on a button other than the correct one.

Usability – understandability

Participant C1 expressed that she found the information on all pages easy to understand and had no need for more or less information. The accompanying images were clear and aided in better comprehension of the information.

> ***"It's just right; the amount of information and content shouldn't be too much for children, or else they won't understand. I think this is a good amount of information." - C1***

For participant C15, the app appeared a bit too childish, which aligns with expectations as she is older than the target audience.

CBL Knowledge page

For both participants, it was not immediately clear what the purpose of the CBL Knowledge page was and what the images on the page represented. It was understood that the blue circles represented your own visits, but the intended message "you contributed to science - your visit contributes, together with all other children, to the knowledge of the CBL" did not come across. When the message was explained, the page was appreciated. Therefore, the design of this page will need to be adjusted to better convey the message, which will hopefully enhance the feeling of being rewarded.

17.3.2 Results HCP's

In general, all attendees expressed a highly positive reception of the presented design. Table 22 displays the average scores for each statement in the questionnaire, both for the overall concept and for each individual test. The table illustrates that participants mostly agreed or strongly agreed with three out of the four statements.

The statement 'fits within clinical practice' scored slightly lower than the others. Regarding this, HCP's mentioned that they believe the Self-portrait is feasible, but they expect that a significant amount of work will be required to process the data for the Self-portrait (they had not seen the data processing charts from paragraph 16.6 at this point). What played a role as well, was the lack of consensus within the CBL on how the Self-portrait will be integrated into clinical practice. For example, during the evaluation, an internal discussion arose about the feedback of the walking mat results.

> ***"Aligning with clinical practice, we need to carefully consider the balance of information: what if the measurement is still primarily for research, how to present it." – E12***

Another thing that can be noticed is that the EEG component scored slightly lower than the other tests. This is likely because there is uncertainty about how meaningful the different waves are for children. One of the HCP's described it as follows:

> ***"I think the EEG information is especially rewarding as a result of effort (and that the IQ tells children more about themselves)." – E5***

Tips and tops

Some positive aspects that were highlighted during the evaluation are:

- Cheerful design
- No value judgment
- The IQ Pond remains full, even if a child scores low
- Question stickers that provide simple prompts
- Displaying raw data
- The quick reminder of the test before showing the results

During the evaluation with the physicians, several areas for improvement were identified, of which some have already been incorporated into the final concept in Chapter 16. These include:

- Presenting question stickers per room rather than per test and prioritizing them to prevent too many questions that a doctor may not have time for. (included)
- Ensuring that animal facts are more relevant to why the animal is compared with the child (in the case of the penguin, it worked, but not for the koala). (included)
- Paying attention to (a)symmetry in gait mat results. (semi-included)
- Prevent that children won't use the My Self-portrait page and make it more meaningful (included)
- Integrating the questions into HiX so that it can be reviewed together during a consultation.
- Addressing what happens with the Self-portrait when a measurement has failed.

17.4 Design goal validation

By combining the findings from both final evaluation sessions, it became possible to assess whether the design goal was successfully achieved. The key elements of the design goal are outlined below.

*The goal is to create a **personally rewarding** visualization of the test-data of the EEG, IQ-test and walking mat for each child that visits the CBL,*

*by **highlighting their personal achievements** and **empowering children to become aware of and accept who they are**,*

*in a form that is **integrated in the clinical workflow** of the Pediatric Brain Centre, and **supportive during the full care journey**, so that HCPs see the Selfportrait as **an enrichment** to their work.*

Personally rewarding

The child participants expressed their happiness with the way results are presented in the app, thanks to the cheerful colours and the use of lively images and animals. Furthermore, receiving stickers feels like a reward and serves as motivation to use the app and participate in the CBL again in the future.

"I think it can be a reason for younger children to say, 'I'm excited to do it because I'll get a sticker.'" – C15

"It makes it more enjoyable because you can look like a koala in terms of speed. It's more fun than hearing that you're walking slowly." – C3

"...and because you can earn all those stickers with each result. It brightens your day a bit." – C3

Highlighting personal achievements

Children are aware that the results they receive reflect their own achievements. Secondly, according to the parents and healthcare professionals, the information was presented in a way that effectively shows what the child has accomplished without passing judgment.

"I don't think you can draw a wrong conclusion from what you read in the app. It's informative for children, like, 'This is what it looks like, this is what you've shown, you can compare it to a koala or a penguin.' This helps children better understand, 'Oh, now I indeed get how it works.'" – P2

Empowering to become aware of and accept who they are

According to both child participants, the app can encourage children to delve deeper into the results than usual, such as by comparing their new results to previous ones.

"This way, you keep track of the questions you've had, how it went last time, and whether you did things differently this time. Otherwise, you might just think, 'Oh, whatever,' and not really compare them." - C15

Doctors also expect that the design will motivate children to participate more in their healthcare.

"It's good that you provide those simple prompts with the question stickers; it works well." – E20

"In this way, children become much more engaged and gain more interest in their own results." – E4

Integrated in the clinical workflow:

According to doctors, a good balance has been struck between playfulness and information presentation. The information presented is accurate and relevant to the practice.

"Attention to what a test actually measures but still presented in a playful and engaging way." – E17

"As for EEG, the data aligns nicely with the information provided in the lab." – E4

"The information in the app aligns well with the measurements." – E8

Additionally, the design can serve as a support during a consultation. To make it even better integrated, a link with HiX should be established so that the question stickers children place go directly to the doctor. However, doctors still have concerns about how much time it will take to fill out the Self-Portrait, as well as how many questions children will ask and whether doctors will have enough time to answer everything.

Supportive during full care journey:

Both participants expect to use the app primarily when the results have just arrived and during the conversation with the doctor. It was positively noted that both participants mentioned that this app would help them remember all the information better. When you only receive information during a hospital visit, you tend to forget it quickly. However, because you can save and review information in this app, they expect that they will remember everything better. In that case, the Self-Portrait also contributes in the long term.

An enrichment to their work

The answers from the questionnaire (table 22) seem to indicate that the doctors view the design as a valuable addition to their work.

I not only find the app visually appealing and friendly, but I believe it genuinely provides added value (even for parents). – E8

17.4.1 Wishes evaluation

The results of the sessions also allowed us to evaluate whether the various wishes from paragraph 12.2 have been fulfilled. Table 23 below illustrates each wish along with the related responses from the stakeholders. It shows that most of the wishes are fulfilled, but that again the time required from HCP's is an issue.

Table 23 Wishes evaluation

Wish	Fullfilled?	Illustrative quote?
Children feel empowered to think about and react on their results	●	*"The design is very interactive, it makes you think!"* – *E17* *"What do you learn as a child from this app?"* *"**To ask your questions.**" - C15*
The Selfportrait supports the HCP in their explanations during consultation	●	*"It seems like a valuable way to open a conversation with the child (and parents)."* - E18
The visualisation is easy for children to link to the test-experience	●	"How well does it match your memory of the test?" *"Very well. I think it's the same little monsters. You recognize some things, like that EEG screen; you saw that there too." - C15* *"Regarding EEG, the data aligns nicely with the information provided in the lab"- E4*
The time and effort to edit the Selfportrait should be minimized / It is easy to process for HCP's	●	*"It will probably require some effort and energy to implement this in the CBL. There's a challenge there, I think, such as selecting the correct EEG screenshot."* *- E5*
Children can actively assess and engage with information in a fun way	●	*"I find it very appealing with those colors; it's very inviting for children. It seems like a sort of game."* – *P2*
The visualisations of the results are recognizeable / easy to link to daily life	●	*"I can easily see which animal I am being compared to; it's fun for children. And I find it quite easy to understand. You have some idea about how animals move, so it's fun to see it like this." - C1*
The app has a positive influence on the self-image of a child (The app focusses mainly on the strenghts of the child)	●	*"It's especially helpful for your parents and yourself to know that you struggle more with it than others. Of course, you might feel bad about it, but knowing about it might help you do something about it. In a way, it can also help you." -C1*
The app invites parents to discuss results with their children	●	*"Maybe I would remind my daughter, like 'Is it already in, have you checked it?' But apart from that, I would leave it up to her. I would ask her, 'do you have any questions about it?', and then together we can decide if she wants to write it down for the doctor."*– P2
The Selfportrait stays interesting over multiple years of use	●	*"Then I would like to know what my new results are, and I can compare them with the previous results. It seems interesting to know if there's any progress. And if there is, it's good to understand why it has changed. - C15* *It's convenient that you can adjust the difficulty yourself because then you can look back and remind yourself of how it was." - C1*
The app allows caregivers of multiple disciplines to collaborate efficiently	●	*"For some aspects, it might be challenging for clinicians to explain everything properly"* - E13

17.5 Desirability and viability of the design

Good design thinking brings together what is desirable from a human point of view with what is technologically feasible and economically viable (IDEO, n.d.). In paragraph 16.6, the technological feasibility has already been discussed. Based on the evaluation in this chapter, the desirability and viability of the design will be discussed.

17.5.1 Desirability: addressing user values and needs

To ensure desirability, the final design should align with the values and needs of both children, who are the primary users, and HCPs at the PBC, who play a crucial role in the app's realization.

Children

For children, the key considerations include enjoying their interaction with the app, ensuring its user-friendliness, and presenting information in a meaningful and non-confrontational manner. To achieve this, the design process involved continuous input from children within the target audience. Early research into their experiences, test comprehension, and expectations allowed for insights to be integrated into the design.

Evaluations of the final design and classroom assessments confirmed that children found the presented information understandable and engaging due to the selected visualizations. The results presentation did not lead to discomfort but rather provided valuable insights. Moreover, the design assists children in understanding their physicians better and encourages active participation in their healthcare through question stickers.

Parents

From a parental perspective, the design avoids value judgements in presenting results, ensuring children's self-confidence remains intact. Instead, it facilitates children's and parents' understanding of the child's brain condition and enhances their comprehension of what the physician tells them.

HCPs

Physicians' primary needs include ensuring medically justified information in the app, minimizing unwarranted concerns, and the app provides support for the consultations. Evaluations indicate a well-balanced design, providing accurate information while remaining child-appropriate. This design supports consultations by offering a clear, efficient overview of the results, alongside an organized question page.

17.5.2 Viability of the design: Fit in and add value to the working practices of the healthcare workers

When evaluating the viability of this Self-portrait design for the long term, the primary consideration revolves around the value it offers to patients. Essentially, we can harken back to the definition of VBHC: do the outcomes outweigh the costs? Below, the key points are explained.

Outcomes

The key outcomes that also provide value in the long term are as follows:

1. Improving Child Participation in Healthcare: Evaluations indicate that the Self-portrait enhances children's understanding of their brains, tests, and encourages them to actively participate in their healthcare. By offering an overview over time, children are motivated to compare their results with previous ones. Providing question stickers reduces the threshold for children to ask questions and

helps them remember and organize their queries for the consultation. All of these factors contribute to increasing child participation, thereby aiding in the implementation of Shared Decision-Making (SDM) in pediatric healthcare at Erasmus MC.

2. Motivating Participation in the CBL: Evaluations revealed that children enjoy using the app. The stickers they can earn reward them for their participation and motivate them to return next time. Particularly with the walking mat, earning an animal sticker based on their walking pattern can pique curiosity about which animal sticker they'll earn next time. For the CBL, it's beneficial if children enjoy participating, ensuring a higher number of participants who return more frequently. This yields valuable data that can be used for research to ultimately improve treatments at the SKZ.
3. Extracting Research Data from the Self-portrait: There is a possibility that children's active use of the Self-portrait may contribute to scientific research as well. If children actively engage with the app, certain data can be collected and provide insights into children's attitudes towards various test results. For instance, patterns can be identified regarding which test components children have the most questions about.

Costs

The major costs include:

1. Analysing test data: Adapting the data to make it suitable for the Self-portrait will likely be the most time-consuming aspect. Therefore, efforts were made to align this process with existing data processing processes in research as closely as possible. The EEG is the test where this poses the greatest challenge. The analysis performed for scientific research does not provide suitable data for the Self-portrait. Scientific analysis yields population-level insights, making it unsuitable for individual child communication based on one test. Consequently, the Self-portrait presents the detected basic waves. As described in the feasibility section (Section 16.6), obtaining this data is feasible but will require additional time.
2. Providing feedback on test data: Providing feedback on test data to children will also be time-consuming. The app offers only a concise version of the results, which may raise questions. Moreover, the app actively encourages children to ask questions. This feedback is currently not provided in many cases (see Section 7.3) and will thus require additional time, as will answering all questions. On the other hand, improved preparation by children may facilitate more efficient consultations. Linking the Self-portrait with HiX, and allowing children to prioritize their questions, can contribute to more efficient preparation for the conversation.

Conclusion on Viability

Costs will primarily play a role during the development and initial usage phases of the Self-portrait. However, the design has taken measures to minimize costs, and ultimately, the outcomes that this design provides will outweigh the costs, signifying that it is a viable design.

To conclude

This section concludes the research and design chapters. It looks back at the project goal and reflects on whether it has been successfully achieved. In the discussion, we go beyond the design goal and reflect on the implications of the results for the bigger picture. Additionally, the limitations of this project are adressed, followed by recommendations for the future. The report concludes with a personal reflection.

18 Conclusion

This project focused on communicating medical test results to children in a playful manner within the context of the Child Brain Lab at the Erasmus MC Sophia Children's Hospital. The aim of the project was to

Design a digital solution that translates the results from three tests that are performed in the Child Brain Lab into a meaningful contribution for children of 6-12 years old (developmental age) with brain conditions, that will increase their participation in their care path, and positively supports their developing self-image."

To generate the most valuable outcome within the project scope, a deliberate selection of three tests was made to focus on: the EEG test, IQ test, and walking mat. These were selected because each presented different challenges and thus together they covered the full potential of communicating the Child Brain Lab results.

To achieve the project aim, research was conducted, starting with an understanding of the target group. This involved a literature review on the cognitive development and self-image development of children aged six to twelve, complemented by insights about brain conditions from literature and interviews with children with brain conditions. In addition, knowledge was gathered about the Child Brain Lab and the content of the tests. This was achieved through observations in the CBL and interviews with experts regarding the EEG, IQ test, and walking mat test. Information from literature was also integrated into this knowledge, resulting in a list of potential elements that could be communicated in the Self-portrait for each test. Additionally, research was conducted on how data is currently collected and processed in the CBL.

After delving into the target audience and data, the next question was how the data could best reach the target audience. This involved an analysis of existing literature on communicating medical information to children, as well as conducting independent research with children who had experienced the tests in the CBL. The goal was to gain an understanding of the current perception of the tests, as well as the desires and needs of children for communicating the test results.

The research phase revealed several challenges, including five trade-offs that summarize the considerations to be made when communicating medical information to young children. To guide the design process, a design goal, an interaction vision, and a list of requirements and desires were established. The design goal read as follows:

The goal is to create a personally rewarding visualization of the test-data of the EEG, IQ-test and walking mat for each child that visits the CBL, by highlighting their personal achievements and empowering children to become aware of and accept who they are, in a form that is integrated in the clinical workflow of the Pediatric Brain Centre, and supportive during the full care journey, so that HCPs see the Self-portrait as an enrichment to their work.

The final result is a comprehensive concept where children are invited to explore the world of their brain. A pathway guides children through the various tests of the Child Brain Lab, including the EEG, IQ test, and walking mat. The EEG focuses on creating awareness of the different brain waves visible in a child's brain, using small 'brain cell characters' to represent the waves. The IQ test is visualized in the form of a 'thought pond,' where cheerful coloured fish represent the five domains of the IQ test. This representation serves as a metaphor for the 'reflection of oneself' since the goal of the IQ section is to make children aware of their own strengths and weaknesses. For the walking mat test, the results are presented in the context of the backgrounds that children can choose in the Child Brain Lab. Additionally, animals are used to indicate whether children scored above, below, or at the average in a playful and light-hearted manner. To ensure that the app adds value for each child, three development levels are introduced, each with a layered approach to information. Children are encouraged to explore all the information through stickers they can earn and are empowered to ask questions using question stickers they can place in the app.

Evaluations with children, parents, and healthcare providers have shown that this design successfully achieved the design goal. A good balance has been struck between providing accurate information and playful engagement for children, making the concept being positively received by all stakeholders. The further insights from this evaluation have been incorporated into the presented design or are addressed in the recommendations.

In conclusion, this project provides a comprehensive view of how test results can be presented in a way that is personally rewarding, empowers children to actively participate in their care path, and aligns with the clinical workflow of the Pediatric Brain Centre. The research findings from this project serve as a solid foundation for translating the other tests from the Child Brain Lab, while the final design provides a practical example of what such a translation might look like. Most questions that are left still revolve around how much time is needed to process the results for the Self-portrait and what the practical implementation of providing test results will look like. In this regard, this project has undoubtedly provided much food for thought.

19 Discussion

19.1 Reflection on the project results

Reflecting on the results unveils the significance of the research and design insights within the broader context, and demonstrates the value of design when difficult decisions must be made.

19.1.1 The broader perspective – Providing CBL test-results to children

The insights gathered during this project, originally aimed at the EEG, the IQ test, and the walking mat, reveal their relevance within a more extensive context. The project sheds light on the significant considerations that arise when conveying medical information to children. This is not only valuable for translating other tests from the Child Brain Lab but can ultimately encourage the translation and feedback of other commonly used investigations at the Sophia Children's Hospital. Below, the value of all considerations from the project is explained.

1. **Challenges & Trade-offs:** The formulated challenges and trade-offs serve as a valuable reference to keep in mind during discussions regarding what to communicate and what not to. It raises awareness among the conversational partners about existing considerations, enabling them to identify and avoid repetitive cycles.
2. **Opportunities 1, 2, & 3:** These opportunities can serve as sources of inspiration during brainstorming sessions. They offer strategies to overcome challenges, particularly emphasizing the importance of maintaining a positive tone while providing honest information.
3. **Opportunity 4:** This is the framework for contributing self-image (addressed in section 9.2). The categorization of "look what I did," "Look how I did it," and "Look how I did it and what I've learned from it" can be applied as a guideline for communicating a wide range of results in the hospital. It encourages healthcare professionals to contemplate what a test or test result truly means to a child and how a child experiences such assessments.
4. **The takeaways** from the design iterations provide answers to some of the questions that may arise during the design process of other tests.
5. **The list of requirements** comprises a set of criteria applicable to a broader context, suitable for adoption when translating other tests.

The broader picture
4. Take aways

- What to show?
  - Children are most interested in information related to their condition. They do not necessarily mind if their test results are lower than average due to their condition, because they cannot help this.
  - Comparing with 'the average' is desired, because children want to know how they are doing. Comparing with 'other children' is not desired, because this can make children feel insecure. Apparently, children do not link comparison with 'an average' to comparison with other children.
  - Pay attention to (performance during) procedure, since children see this as an integral part of the test experience and results.
- How to show it?
  - The presentation of test-results should be effectively linked to what a child has done during the test but also to what the doctor can and will explain during a consultation
  - Use layering of information, to satisfy the needs of different children
  - Clearly show differences over time, because children are interested in their progress
  - Use facts & figures to positively trigger children
- Don'ts
  - Value judgements or a performance-oriented focus, this enhances the feeling of disappointment when results are lower than expected
  - Ranking or comparing to other children
  - Avoid information overload, because in this case children lose their interest and will not use it
  - The information in the app should not cause troubles for the test participation

The broader picture
5. List of requirements and wishes

Designing for children with brain disorders

- The app must be usable by children with
  - Bad sight
  - Hearing loss
  - Speaking difficulties
  - Less sense of touch or power in hands
  - Epilepsy
  - Colourblindness
- The app must be usable by children with autism:
  - Low-stimulus
  - Clear structure
  - Straight forward language

Communicating medical test results to children

The content should cover the full cycle of care.

- Understanding the tests:
  - Explanations about test procedures
- Receiving the results at home:
  - Personal test results
- During a consultation:
  - A clear overview of personal results (in one screen)
  - Space for personal notes from child, parent and HCP
  - Wish: the design supports the HCP in their explanations during consultation
- Preparing for the next visit
  - Explanations about the lab
- Reflection over the long term
  - Overview of the results from earlier visits
- The app cannot make value-judgements about children
- The app should reward the child's participation
- The app should emphasize the fact that tests are a "snapshot"
- The app cannot give children a diagnosis
- Wish: easy for children to link to the test-experience

Designing an app for children with (sensitive) information

- Children should be able to actively interact with results
- A child must have control over what he/she does (not) want to see
- The app should allow for exploration and deepening of knowledge
- Parents should be able to monitor what their children can see / do in the app.
- The app should be personalizable
- Wish: the visualisations are recognizable / easy to link to daily life

19.1.2 Ontwerp maakt tastbaar

This project also showed the stakeholders of SKZ the value of design. Throughout the process, several unanswered questions lingered: what to share with children (or not), what conclusions can be drawn from tests, and when to communicate results – before or after consultations? Deliberations on these matters often left inquiries unresolved. However, this project demonstrated that a tangible design, making specific choices within these dilemmas, could suddenly provide answers.

For example, psychologists hesitated to disclose a total IQ score, fearing it would lead to comparisons with other children, while on the other hand children were genuinely curious about how 'high' they had scored. Ultimately, the design indicated the total IQ in a manner agreeable to psychologists.

A design like this provides answers to many questions but, on the other hand, raises new ones. It's an ongoing process, leading to a deeper understanding of the core issues. For instance, it encourages contemplation on the potential changes when children become more involved. Improving child participation was one the goals of the Self-portrait, which is why the question stickers were introduced. According to experts, this was a useful approach to enhance child participation. Simultaneously, it also raised the question: what if children start asking so many questions that we don't have enough time to answer them all? Does this imply a need for changes in the clinical practices at the PBC?

19.2 Limitations

This project also had its limitations. Below, the research and design limitations are described, which should be taken into account in the interpretation of the results.

19.2.1 Research limitations

Qualitative research

Conducting qualitative research offers valuable benefits, such as enhancing empathy for the target group, gaining deeper insights into the context, and serving as a rich source of creative inspiration. However, it's essential to acknowledge that the researcher's subjectivity can influence the findings.

Limited access to CBL participants

At the start of the project, the Child Brain Lab was not yet operational, and there were no patients who had experienced the lab. During the course of the project, around ten children participated in the Child Brain Lab, some of whom were outside the target audience of this project. Ultimately, two patients with CBL experience were involved in the project, one of whom was interviewed prior to his appointment. On the other hand, healthy children with CBL experience and children with a brain condition without CBL experience were also involved in the project. However, it cannot be definitively concluded whether the insights found are applicable to the actual participants of the CBL.

'Would you use this?'

The participants who evaluated the concepts were asked to assess something that does not yet exist. They were tasked with envisioning a future scenario and imagining what they would do or how they would feel about it. However, in reality, there are numerous situations in which individuals mispredict their own future feelings (Loewenstein & Schkade, 1999). As such, genuine insights about this app can only be gathered in practice, when children actually receive their test results in the Self-portrait app.

19.2.2 Design limitations

Accuracy of information

All the information presented in the self-portrait is based on literature or interviews with experts. Nevertheless, the texts in the app were written by a designer who is not an expert in medical test results. These texts were primarily composed to illustrate what information should be displayed and what that information entails. Despite the final design being evaluated with experts, the precise content of the texts has not been systematically validated with medical experts. In the context of medical responsibility, it is important to note that the accuracy of the information currently presented in the final design is limited.

Incomplete prototype evaluation

In the prototype that was evaluated with children, parents, and HCPs, not all components of each test were fully developed. Examples of components that were not elaborated on in the final design and therefore were not tested include, for the walking mat - Animation of footsteps, Differences between left and right, and Pressure on heels or toes. For the IQ test, these are all domain explanations other than working memory, and for the EEG, the beta-waves explanations. Although all of these components are well-considered, and the results of the prototype evaluations are promising, the conclusions that can be drawn about the desirability of these components are limited.

Integration of additional CBL Tests into the app

In the current design, three tests have been translated, but ultimately, nearly all tests from the CBL (Section 1.2.3) will be integrated into the Self-portrait. While working on this design, consideration has been given to this aspect, attempting to keep the presented information concise. However, there is limited knowledge about the usability of the app when all tests are incorporated into the Self-portrait in the same manner. It is possible that the content of the three tests in this design may need further revision in such a scenario.

19.3 Recommendations

19.3.1 Design recommendations

Format

The final design in this report is created for a tablet. The target audience consists of children from the age of 6, and children often receive a mobile phone around the age of 9 (sometimes starting with a relatively simple one) (Burgering, 2022). However, ultimately, a smartphone and web version will also need to be developed. This will primarily affect the navigation and the size of buttons and images.

Usability

Overall, there are still improvements to be made in terms of the app's usability. For example, more attention needs to be given to the navigation between different screens. It is recommended to use ISO standards (Moumane et al., 2016) and Nielsen's ten usability heuristics (Nielsen, 1994).

Usability for Special Needs

The design could benefit from an additional iteration focusing specifically on usability aspects for children with special needs (as outlined in section 4.3) such as children with autism. Despite the fact that these needs were kept in mind during the design process and that during the evaluation a participant with autism responded positively to the design, there is still room for improvement.

My Self-portrait

During the design process, most attention was given to the pages of the three tests. Therefore, the "My Self-portrait" section, where stickers from all the tests can be collected, requires additional iterations. The basic concept stands, but it can be further integrated with the theme of "the journey through the brain," for example, by creating postcards from the visits, including earning special 'wavy/breeny/neuro postage stamps' after each visit.

Peer Sharing

During the same period when this project was carried out, another student from TU Delft explored the value and possibilities of peer sharing at the CBL, resulting in an app concept (Hemmes, 2023). This app could be integrated with the Self-portrait app. A suitable place to make this connection is on the "CBL Knowledge" screen. This screen emphasizes the collective contribution of all children participating in the Child Brain Lab, and children could also discuss their experiences here.

Link to HiX (EHR)

The Self-portrait will need to be integrated with the electronic health record so that the questions children ask in the app can be viewed by the doctor and addressed during a consultation. It would be beneficial if the Self-portrait could be integrated in a way that allows both the doctor and the child to view it together via HiX, so the child does not have to bring its device to the consultation.

19.3.2 Further research

Data Processing

In Section 16.6 (data feasibility), a preliminary assessment was conducted regarding the feasibility of the concept, focusing on data analysis and processing. This evaluation demonstrated that many steps are feasible, but there are still many aspects that require further investigation. The next step in bringing the Self-portrait to fruition is to pay attention to data processing, especially in cases where data processing for the Self-portrait does not align with research data processing.

Testing in Practice

The concept of translating and sharing medical test results with children through an app is relatively unconventional. Therefore, there are numerous uncertainties surrounding how the Self-portrait concept will unfold. Questions that remain unanswered include the extent to which children will use it and the impact of sharing results with children. This encompasses both short-term effects, such as how it makes them feel, as well as long-term effects, such as whether it contributes to increased child participation in their healthcare journey. These are all questions that can only be addressed through practical testing of the app. Consequently, it is essential to implement the app in actual practice while concurrently conducting research into its effects.

Personal Reflection

Managing an eight-month project on my own was quite challenging. Determining what constitutes a feasible end result and when to make crucial decisions posed significant challenges and learning opportunities throughout the past eight months. Here, I elaborate on these points.

Challenge 1:

One of the primary challenges I faced was structurally documenting my process. While I tend to work systematically, basing my decisions on methods, evaluations, and literature, I often approach tasks intuitively. It is like my mind houses a library of design knowledge that guides my process, but at times, it's challenging to locate the exact source in this mental library. I also don't always allocate sufficient time for documentation.

This challenge extended to processing my results. I did extensive literature research and conducted interviews, analyzing the information through techniques like clustering and creating frameworks. However, once I had insights, I delved into the design process without thoroughly completing the framework. I believed I already held all the necessary insights in my mind, and producing a comprehensive diagram would be too time-consuming at that point.

Learning 1:

As I wrote my report, I realized that dedicating time to meticulous documentation forced me to think deeply about the essence of my work. Presenting my thought processes to another person in the report emphasized the significance of synthesizing results, selecting key points, and making clear, concise statements. This practice not only enhances communication but also aids in clarifying thoughts. For future projects, I plan to schedule structured "synthesis moments" to compel myself to document research and design activities for an easily report-ready outcome.

Challenge 2

At the project's outset, my goal was to create a high-fidelity prototype, evaluated for cognitive ergonomics, with dynamic animations, precise medical content, and more. In hindsight, I acknowledge that achieving the exact end result I envisioned was possibly unrealistic.

This mindset of wanting to achieve everything simultaneously created a significant hurdle during the project. After gathering substantial insights, forming the foundation for the app, I faced challenges in transitioning to actual app design. I aimed to incorporate correct information, appeal to children, choose the right wording, and optimize navigation, all at once. This overload of considerations resulted in decision paralysis.

Learning 2:

This experience taught me that designing an app is a step-by-step process, and structured work can help avoid overwhelming situations. Initially, designing a single screen might seem simple, but I realized that addressing numerous considerations one by one yields better results. In essence, making informed decisions is more important than indecision. Adhering to Marcus Tullius Cicero's quote that "More is lost by indecision than wrong decision," I learned to make choices and produce a tangible translation of overarching considerations.

More Learnings

During this project, I gained valuable insights into designing for and with children. Through user and literature research, I acquired a better understanding of the children's perspective, particularly in terms of differentiating the perspectives of six-year-olds from those of twelve-year-olds. This knowledge will guide my future projects, enabling me to prepare for interviews with children more effectively.

Additionally, I learned that when evaluating an app with children, it's crucial to communicate explicitly what a prototype entails to prevent feedback from focusing on non-functional buttons.

Highlights

My most cherished experiences in this project were the collaborations with stakeholders. Working with remarkable children who dared to be critical and share personal stories was a highlight. I deeply appreciate their willingness to dedicate their free time to assist me, hopefully benefiting other children as well.

Collaborating with healthcare professionals was another positive aspect. In healthcare-related design projects, stakeholder communication can be challenging due to busy schedules and strict regulations. While scheduling the initial appointments took time, I felt that the doctors genuinely valued my work and made an effort to accommodate me. The level of motivation and involvement from a large group of healthcare professionals in the Zelfportret project was remarkable. I found all these conversations highly valuable and hope that the Zelfportret project continues and is soon realized.

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Appendices

Appendix A: Project Brief

DESIGN FOR our future

TU Delft

IDE Master Graduation

Project team, Procedural checks and personal Project brief

This document contains the agreements made between student and supervisory team about the student's IDE Master Graduation Project. This document can also include the involvement of an external organisation, however, it does not cover any legal employment relationship that the student and the client (might) agree upon. Next to that, this document facilitates the required procedural checks. In this document:

- The student defines the team, what he/she is going to do/deliver and how that will come about.
- SSC E&SA (Shared Service Center, Education & Student Affairs) reports on the student's registration and study progress.
- IDE's Board of Examiners confirms if the student is allowed to start the Graduation Project.

USE ADOBE ACROBAT READER TO OPEN, EDIT AND SAVE THIS DOCUMENT
Download again and reopen in case you tried other software, such as Preview (Mac) or a webbrowser.

STUDENT DATA & MASTER PROGRAMME
Save this form according the format "IDE Master Graduation Project Brief_familyname_firstname_studentnumber_dd-mm-yyyy".
Complete all blue parts of the form and include the approved Project Brief in your Graduation Report as Appendix 1 !

family name: Plat 6296
initials: B.R. given name: Benthe
student number: 4563077
street & no.:
zipcode & city:
country:
phone:
email:

Your master programme (only select the options that apply to you):
IDE master(s): ★ IPD ★ DfI ○ SPD
2nd non-IDE master:
individual programme: - - (give date of approval)
honours programme: ○ Honours Programme Master
specialisation / annotation: ★ Medisign ○ Tech. in Sustainable Design ○ Entrepeneurship

SUPERVISORY TEAM **
Fill in the required data for the supervisory team members. Please check the instructions on the right !

** chair: Mathieu Gielen dept. / section: HCD - DCC
** mentor: Marijke Melles dept. / section: HCD - AED
2nd mentor: Marie-Lise van Veelen
organisation: Erasmus MC Sophia Kinderziekenhuis
city: Rotterdam country: Netherlands

comments (optional)

Chair should request the IDE Board of Examiners for approval of a non-IDE mentor, including a motivation letter and c.v..

Second mentor only applies in case the assignment is hosted by an external organisation.

Ensure a heterogeneous team. In case you wish to include two team members from the same section, please explain why.

Procedural Checks - IDE Master Graduation

TU Delft

APPROVAL PROJECT BRIEF

To be filled in by the chair of the supervisory team.

chair Mathieu Gielen date 22 - 02 - 2023 signature Digitaal ondertekend door Mathieu Gielen Datum: 2023.02.22 12:08:50 +01'00'

CHECK STUDY PROGRESS

To be filled in by the SSC E&SA (Shared Service Center, Education & Student Affairs), after approval of the project brief by the Chair.
The study progress will be checked for a 2nd time just before the green light meeting.

Master electives no. of EC accumulated in total: 29 EC

Of which, taking the conditional requirements into account, can be part of the exam programme 29 EC

List of electives obtained before the third semester without approval of the BoE

★ YES all 1st year master courses passed

NO missing 1st year master courses are:

name Robin den Braber date 28 - 02 - 2023 signature Robin den Braber Digitaal ondertekend door Robin den Braber Datum: 2023.02.28 11:16:11 +01'00'

FORMAL APPROVAL GRADUATION PROJECT

To be filled in by the Board of Examiners of IDE TU Delft. Please check the supervisory team and study the parts of the brief marked **.
Next, please assess, (dis)approve and sign this Project Brief, by using the criteria below.

- Does the project fit within the (MSc)-programme of the student (taking into account, if described, the activities done next to the obligatory MSc specific courses)?
- Is the level of the project challenging enough for a MSc IDE graduating student?
- Is the project expected to be doable within 100 working days/20 weeks ?
- Does the composition of the supervisory team comply with the regulations and fit the assignment ?

Content: ★ APPROVED NOT APPROVED

Procedure: ★ APPROVED NOT APPROVED

- also approved for Medisign

comments

name Monique von Morgen date 21 - 03 - 2023 signature

Personal Project Brief - IDE Master Graduation

TU Delft

The Brain Selfportrait - Translating testresults from the 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 21 - 02 - 2023 09 - 11 - 2023 end date

INTRODUCTION **

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

In 2020, the Sophia Children's Hospital realised the Pediatric Brain Centre (PBC), where care for children between 0-18 with all kinds of brain disorders is centralized. As a part of this centre, the Child Brain Lab was opened in June 2022. This research lab consists of three departments, where IQ and speech, neurophysiology and sensory function, and motor function tests are conducted. The results from this lab are used for scientific research, but also to improve the care for children (Erasmus MC, n.d.). Currently, child-targeted information is scarce and available in different amounts between the PBC departments (van Dijk, 2021). Furthermore, this information is currently primarily focussed on diagnosis or treatment. The goal is to provide more and richer child-targeted information, that will increase the child's participation in his/her care process. The experience of the child is central here. That is why the Sophia Children's Hospital is working on a special digital child-patient-dossier: the Brain self-portrait.

The Brain self-portrait will be used by children with a variety of brain disorders, their parents, and the medical professionals of the Child Brain Lab. Each of these stakeholders have their own wishes and needs. Earlier studies related to the Child Brain Lab have investigated the current level of child participation within the Pediatric Brain Centre, and listed influencing factors and opportunities for improving this child participation (van Dijk, 2021). Furthermore, a general understanding of the wishes and needs for the Brain self-portrait app have been established (Tielen, n.d.). Now it is time to take a closer look to the different tests that are performed within the Child Brain Lab, and to find out how the results of those tests can be translated into the Brain self-portrait.

This project is a collaboration between the Sophia Children's Hospital, who acts as the client, and the Play Well Lab, a research lab of the TU Delft. I will be under contract with the Play Well Lab. Here I am expected to contribute to the Play Well Lab's methodological knowledge through insights I gain in my design research process. In return, the lab will provide a budget and will offer its expertise and network to the benefit of the project.

Sources:
1. Erasmus MC. (n.d.). Kinderhersenlab - Kinderhersencentrum - Erasmus MC. https://www.erasmusmc.nl/nl-nl/kinderhersencentrum/kinderhersenlab
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3. Thielen, L. (n.d.). Het Zelfportret [Masterscriptie].

space available for images / figures on next page

introduction (continued): space for images

image / figure 1: Example of test in the Child Brain Lab: the movement room (beweegkamer)

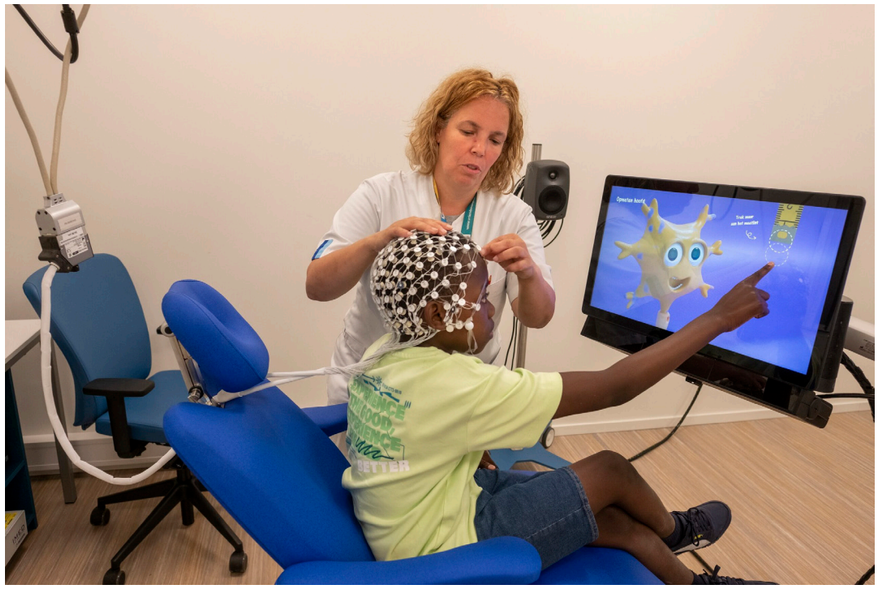


image / figure 2: Example of test in the Child Brain Lab with a digital buddy

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.

Earlier projects related to the Child Brain Lab have established general insights regarding interests of the children, interaction with the app, and suitable ways of communicating. However, this has not yet been related to specific tests within the lab. There are three different departments in which several tests are performed. Each test is different, and could require a different translation. Also, some tests can contain more sensitive or confronting information than others. Parents can be protective over their children, afraid that their children will be emotionally hurt by the information. Test results on their own are quite straight forward numbers, and are currently mostly communicated in relation to diagnosis or treatment. However, there lie opportunities in translating and comparing results, to communicate richer insights in the self-portrait: insights that are not only related to diagnosis, but that can also be valuable for a kids self-image. In order to proceed with the development of the self-portrait's contents, a number of unknowns needs to be addressed.

Firstly, research is needed to find out which tests and results are the most suitable to choose for my project. Secondly, research is needed to discover what the needs of children are in terms of information provision, acceptance, and empowerment related to the specific tests of the lab. Thirdly, research is needed to find out what the thoughts and worries of the parents are, what their reasoning is on why they would or would not want their children to receive certain information. Lastly, research is needed to find out what the medical staff considers to be important (test specific), and how/if the translation of the results into the app can be integrated in their workflow.
Integrating insights from the points above, will create opportunities to create a solution which satisfies the children, parents and medical staff.

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.

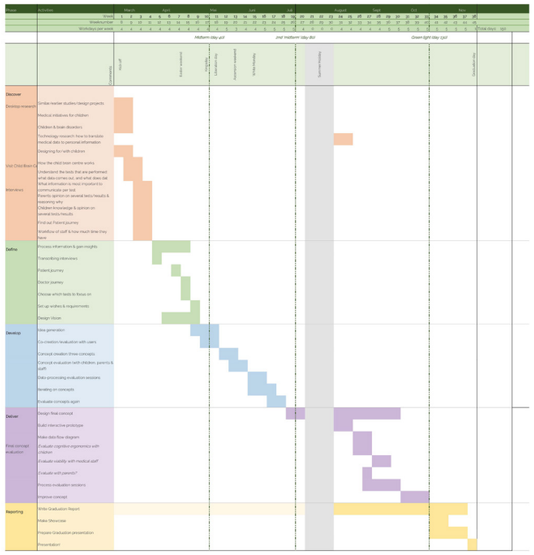
"With this graduation project, I will design a digital solution that translates the results from (a selection of) the tests that are performed in the Child Brain Lab, into a meaningful contribution for children (developmental age 6-12 years old) with brain disorders, that will increase their participation in their care path, and positively support their developing self-image."

The translation of the results should serve children's participation during the full care process; in preparation, during tests & consultations, and after the tests. The design should take into account the needs of doctors, parents and children, where the children are the most important.
It should use the insights from earlier projects (what kind of data children like to see; important factors for child involvement) and combine that with the specific knowledge that I will acquire about several tests in the lab. My solution will not focus on all tests, but will be a worked out example of a selection of about three tests. The selection of tests will be based on insights from the Discover phase. It should include tests with several challenges, like sensitive information or data that is hard to translate. This example will then illustrate the potential of the solution to be used for the other tests as well.
The solution that I aim to deliver is a high fidelity interactive prototype of a digital solution, with the focus on the translation and communication of test results. The solution will have gone through several iterations, where stakeholders will be involved at several stages of the design process. It will be user-tested on cognitive ergonomics by children, parents and medical staff. In addition to that, I will address the feasibility and viability of the design by creating a data flow diagram, and providing an advice in how and by whom the data should be gathered and translated to the self-portrait. In this advice, I will take into account the time and effort that is needed from the healthcare specialists, and the costs for the hospital.

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 21 - 2 - 2023 9 - 11 - 2023 end date



The Gantt-chart above shows the planning for my graduation project. It is divided into four phases, based on the double diamond approach: discover, define, develop, deliver. Within the phases, I defined some sub-tasks that form the basis of my design process. I'm aware that these tasks will probably change a bit, however this planning gives me a good idea of how much work is needed in every phase of the double diamond. Furthermore, I now have an overview of how often I would like to involve stakeholders during my process. This will help me to reach out on time, to hopefully plan my interviews and evaluation sessions according to my planning. I know that it can be a struggle to plan these sessions, so therefore I took some extra time for it in my planning.

This graduation project is for a double-degree, combining Design for Interaction and Integrated Product Design. Therefore my planning consists of 150 days. Usually, the midterm is at day 40. This does not change for a double-degree project, however I would like to add a second 'midterm' at day 80. At the first midterm, I plan to present my research insights and first ideas. At the second midterm, I plan to have finished the 'develop' phase, and choose my final concept.

In the fourth row, I stated how many days per week I plan to work on the project. I chose to mostly work four days a week. Firstly, to be more flexible in planning interviews/evaluations with stakeholders. Secondly, I expect to be more productive during my study days, when I have one extra free day to spend on my extracurricular activities (e.g. committees & work).

MOTIVATION AND PERSONAL AMBITIONS

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

I chose this project because it really fits my personal interests and motivations. I want to be a designer in the healthcare industry, since I feel like designing for healthcare is really meaningful. A hospital can be a stressful context for patients and doctors. Therefore it is extra important that products and services in this context are tailored to the wishes of the user. By collaborating with a hospital as a designer, I want to give patients and medical staff a voice in the products that are designed for them. What I like about this project, is that it has the challenge to satisfy the needs of three different target groups. This requires collaboration with those target groups. Working close with users is what gives me energy during design projects. From earlier projects and from the design course Design for Children's Play, I have already gained some experience in working with children and with doctors. I want to use this experience for a good collaboration, and expect that I will keep on learning about collaborating with these stakeholders.

Personal learning goals:
During this project, I would to improve some of my graphic & app prototyping skills. I plan to make a prototype using Adobe Illustrator and Figma, and these are two programs that I want to become better at. In addition to that, I would like to learn how to make animations, but only if I decide that animations are desirable in my design.

Besides these skills, I want to get deeper insights in the data structures & safety issues that underly an app design. Until now, I have mostly designed apps on an interface level. In this project, I want to dig a bit deeper. I want to think about what data is needed, how this data can be obtained, and consider safety and privacy. This is extra important when designing for a hospital, since privacy and safety have a high priority. Furthermore, there's a shortage in medical staff, so delivering data to the self-portrait app should not take too much time from the doctors. There should be a good structure for that.

Lastly, I think I will learn a lot from managing a 150-days project on my own. A challenge for me will be to keep good track of my process, reporting my thoughts in an organized way and keeping track of the report. My goal is to do this actively throughout the process, instead of having to write the whole report at the end.

FINAL COMMENTS

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

This graduation project is for a double degree of the masters Design for Interaction and Integrated Product Design. In addition to that, I follow the Medisign specialization.

Appendix B: Level 1 questionnaires CBL

Level 1: Questionnaires

Demography
Quality of life
Functioning / Adaptive behaviour
Fatigue
Emotions and behaviour
Executive functioning
Trauma / stress
Environment / Parents
Promis General Health

Appendix C: Evaluation forms proefmetingen CBL

Evaluatieformulier Proefmetingen

Bedankt dat jij/jullie hebben meegedaan met de proefmetingen in het Kinderhersenlab.

Graag horen we of er nog verbeterpunten zijn, of dingen die je al supergoed vindt, zodat wij er een nog mooier lab van kunnen maken.

1. Denkkamer of Cognitieruimte
Wat ging goed? alles

Wat kan beter? niks

Wat werd er volgens jou gemeten in deze kamer? Denk testjes met taal

Wat voor nieuws heb jij (over jezelf) geleerd in deze kamer?
slimmen te maken met meerdere woorden

Kinderhersenlab – versie [1] [01-07-2022]

Kinderhersencentrum Erasmus MC Sophia

2. Machinekamer of Sensoriekruimte
Wat ging goed? alles

Wat kan er beter? niks

Wat werd er volgens jou gemeten in deze kamer? iets met je ogen

Wat voor nieuws heb jij (over jezelf) geleerd in deze kamer? dat je met je ogen kan bewegen

3. Beweegkamer of Motoriekruimte
Wat ging er goed? alles

Wat kan er beter? niks

Wat werd er volgens jou gemeten in deze kamer? hoe vlug je lenig en hoeveel vet je hebt, hoe lang je bent, hoe zwaar je bent

Wat voor nieuws heb jij (over jezelf) geleerd in deze kamer? hoeveel vet ik had

Kinderhersenlab – versie [1] [01-07-2022]

4. Laatste vragen
Wat zou je vertellen aan een leeftijdsgenoot, die ook deze tests gaat doen?
het is soms een beetje saai, en het kan ook leuk zijn
doe je best, je moet goed luisteren.

Welke kamer vond je het leukst? En waarom?
beweeg kamer daar kun je lekker bewegen

Als je verder nog iets aan ons kwijt wilt, mag je dat hier opschrijven:
G

Kinderhersencentrum Erasmus MC Sophia

2. Machinekamer of Sensoriekruimte

Wat ging goed?

alles

Wat kan er beter?

niks

Wat werd er volgens jou gemeten in deze kamer?

je Hersens

Wat voor nieuws heb jij (over jezelf) geleerd in deze kamer?

heel veel

3. Beweegkamer of Motoriekruimte

Wat ging er goed?

alles

Wat kan er beter?

niks

Wat werd er volgens jou gemeten in deze kamer?

Gewicht weegmat ~~sterkte~~

Wat voor nieuws heb jij (over jezelf) geleerd in deze kamer?

?

Kinderhersencentrum Erasmus MC Sophia

4. Laatste vragen

Wat zou je vertellen aan een leeftijdsgenoot, die ook deze tests gaat doen?

?

Welke kamer vond je het leukst? En waarom?

beweegkamer

Als je verder nog iets aan ons kwijt wilt, mag je dat hier opschrijven:

Kinderhersencentrum Erasmus MC Sophia

2. Machinekamer of Sensoriekruimte

Wat ging goed?

~~kleurmeesters~~ de kadmaats

Wat kan er beter?

het apparaat deed het soms niet

Wat werd er volgens jou gemeten in deze kamer?

gehoor & zicht

Wat voor nieuws heb jij (over jezelf) geleerd in deze kamer?

3. Beweegkamer of Motoriekruimte

Wat ging er goed?

mijn soepel/vloeiend

Wat kan er beter?

bed ging niet omhoog

Wat werd er volgens jou gemeten in deze kamer?

Motoriek

Wat voor nieuws heb jij (over jezelf) geleerd in deze kamer?

ik kan geen ballen gooien of vangen

Kinderhersencentrum Erasmus MC Sophia

4. Laatste vragen

Wat zou je vertellen aan een leeftijdsgenoot, die ook deze tests gaat doen?

Dat het niet ongemakkelijk is

Welke kamer vond je het leukst? En waarom?

Motoriek, gezellig en veel afwisseling

Als je verder nog iets aan ons kwijt wilt, mag je dat hier opschrijven:

Sorry dat ik echt geen ballen kan gooien

Kinderhersencentrum Erasmus MC Sophia

2. Machinekamer of Sensoriekruimte

Wat ging goed?

de concentratie

Wat kan er beter?

de tijd soms tussen de oefenopdrachten

Wat werd er volgens jou gemeten in deze kamer?

concentratie en hersengolven

Wat voor nieuws heb jij (over jezelf) geleerd in deze kamer?

dat ik ~~te~~ heel erg geconcentreerd kan zijn

3. Beweegkamer of Motoriekruimte

Wat ging er goed?

knypen en liggen

Wat kan er beter?

mijn evenwicht

Wat werd er volgens jou gemeten in deze kamer?

gewicht, lengte, evenwicht, kop afstand, kracht, spier-massa,

Wat voor nieuws heb jij (over jezelf) geleerd in deze kamer?

dat ik sterker ben~~t~~ dan ~~ca~~s

Kinderhersencentrum Erasmus MC Sophia

4. Laatste vragen

Wat zou je vertellen aan een leeftijdsgenoot, die ook deze tests gaat doen?

je doet veel. Je bent altijd bezig.

Welke kamer vond je het leukst? En waarom?

~~beweegkamer, ik houd van bewegen~~ ~~motoriek~~ ~~andere kamers~~ allebei even leuk

Als je verder nog iets aan ons kwijt wilt, mag je dat hier opschrijven:

ik vond het heel gezellig

Kinderhersencentrum Erasmus MC Sophia

2. Machinekamer of Sensoriekruimte

Wat ging goed?

Blijven zitten

Wat kan er beter?

concentreren

Wat werd er volgens jou gemeten in deze kamer?

je oog ~~D~~druk

Wat voor nieuws heb jij (over jezelf) geleerd in deze kamer?

?

3. Beweegkamer of Motoriekruimte

Wat ging er goed?

Het Bewegen

Wat kan er beter?

Concentreren

Wat werd er volgens jou gemeten in deze kamer?

Het Bewegen

Wat voor nieuws heb jij (over jezelf) geleerd in deze kamer?

?

Kinderhersencentrum Erasmus MC Sophia

4. Laatste vragen

Wat zou je vertellen aan een leeftijdsgenoot, die ook deze tests gaat doen?

Het is leuk

Welke kamer vond je het leukst? En waarom?

~~Het~~ Beweegkamer

Als je verder nog iets aan ons kwijt wilt, mag je dat hier opschrijven:

?

Appendix D: Test research before selection

ANTROPOMETRIE
https://www.hva.nl/urban-vitality/onderzoek/living-labs/anac/antropometrie/antropometrie.html
- measuring the body
  - lengte- en omtrekmaten, huidplooien en lichaamsgewicht bepaald
- BMI - Body Mass Index
- Procedure
  - Measuring tape
  - Scale
  - Huidplooi / Skin fold caliper
- Groeicurve

BIA meting
https://www.radboudumc.nl/afdelingen/maag-darm-en-leverziekten/onze-onderdelen/dietetiek/meer-informatie/toelichting-metingen-dietetiek/bio-elektrische-impedantie-analyse-bia#:~:text=(vetvrije%20massa).-,Een%20Bio%2Delektrische%20Impedantie%20Analyse%20(BIA)%20is%20een%20meting,merkt%20u%20zelf%20niks%20van.

- Measuring fat mass and fat-free mass
  - Om deze vast te kunnen stellen, sturen we via electroden een licht stroompje naar uw lijf. Hier merkt u zelf niks van. Aan de hand van de snelheid waarmee het stroompje door uw lichaam gaat, kunnen we de lichaamsstelling bepalen.
- Results
  - Tells something about the condition of the body
- Procedure
  - Daarna gaat u rustig op een bed liggen, met uw armen en benen licht gespreid. Daarna worden elektroden op uw handen en voeten bevestigd. U hoeft niets te doen en mag rustig blijven liggen. De meting duurt in totaal ongeveer 15 minuten.

	Healthy controls, $n = 30$	UC total, $n = 34$	CD total, $n = 25$
BIA and body composition			
Fat mass (%)	27.45 ± 6.3	23.15 ± 5.5	23.02 ± 4.6
Fat mass (kg)	18.90 ± 6.2	14.90 ± 5.9	14.44 ± 4.4
Fat free mass (%)	72.50 ± 12.1	76.83 ± 10.6	76.80 ± 7.5
Fat free mass (kg)	49.60 ± 3.9	49.60 ± 4.1	48.35 ± 3.3
Body liquid (l)	26 ± 3.1	23 ± 4.8	23 ± 4.2
Anthropometric tests			
Body weight (kg)	68.80 ± 9.2	64.50 ± 6.9	62.80 ± 5.6
BMI (kg/m^2)	25.80 ± 3.2	23.60 ± 3.9	23.30 ± 4.5
TSFT (mm)	1.71 ± 0.5	1.05 ± 0.6	1.02 ± 0.3
MAC (cm)	26.50 ± 4.6	23.20 ± 3.3	22.10 ± 2.8

$P < 0.05$ for healthy controls vs. UC and healthy controls vs. CD when BIA, body composition, and anthropometric tests are considered

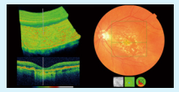
Motoriek
https://www.jeroenboschziekenhuis.nl/onderzoeken/meten-van-het-niveau-van-de-motorische-ontwikkeling-met-de-m-abc-2#paragraph-specific-department-information-35188
- M-ABC-2 test
  - Handvaardigheid, mikken&vangen, evenwicht
  - Children receive several tasks
  - Afhankelijk van de opdracht, bekijken we hoe vaak en/of hoe snel uw kind de opdracht uitvoert. Daarnaast kijken we hoe uw kind de bewegingen uitvoert.
  - Duration around 45 min.
  - Results
    - De uitkomst van de 3 testonderdelen en de totaalscore zetten we om naar een zogenaamde percentielwaarde. Deze waarde geeft aan hoeveel procent van de kinderen van dezelfde leeftijdsgroep eenzelfde of lagere score haalt.
    - Voorbeeld: een percentielscore van 25 (P25) geeft aan dat 25% van de onderzochte kinderen van dezelfde leeftijdsgroep hetzelfde of lager scoort, en dat de rest (75%) dus hoger scoort.

KNIJPKRACHT
- https://voedingenbeweging.nu/uitleg-handknijpkracht/
- Bij de handknijpkrachtmeting houdt u uw arm ontspannen naast het lichaam.
- De elleboog in een hoek van 90 graden en de pols in neutrale positie. U knijpt nu zo hard mogelijk in het apparaat. De persoon die de meting uitvoert, zal u hierbij aanmoedigen.
- De meter kan niet worden ingedrukt, maar de kracht wordt op het display weergegeven.
- We starten met de dominante hand en meten daarna de kracht van de andere hand. Elke hand wordt drie keer gemeten.
- We vergelijken uw hoogste waarde met de waarde in de referentietabel. Deze tabel is gemaakt op basis van metingen bij een grote groep personen van uw geslacht en leeftijd. De handknijpkrachtmeting herhalen we regelmatig tijdens de behandeling zodat we samen kunnen bijhouden hoe het met u gaat en welke voeding- en beweegbehandeling u nodig heeft.

LOOPMAT
- Sensoren en camera's
- Looppatronen analyseren
- Kies een karakter die je ondersteunt. Kies in welke omgeving je wil lopen, waar je naartoe wil lopen. Er is een bos voor de prikkelarme omgeving. Minecraft omgeving. Stad, onderwaterwereld.

• De motoriek kamer en de cognitie kamer vinden ze leuk omdat dat iets zegt over hoe goed je in dingen bent. De sensoriek kamer vinden ze wel interessant maar het is zoals het is. (Loes Thielen)

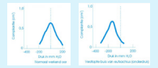
OCT (Optical Coherence Tomography)
https://www.oogziekenhuis.nl/onderzoeken/oct-scan-optical-coherence-tomography



- echography, but with light instead of sound waves
- lightbeam is bounced of by the retina
- used for capturing and analysing the structure of the retina, macula, cornea and optic nerve
- mostly cross-sections of the retina
- Goal
  - diagnosis, deciding on treatment, or following the progress of the treatment
- Procedure:
  - Je krijgt pupilverwijdende oogdruppels om het beter te kunnen zien, 15 minutes till they work
  - Zitten voor een scherm, kin op een steun
  - kijken naar een kruis die oplicht
  - Duurt 5-10 minuutjes, pijnloos

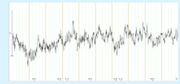
OAE-meting (otoakoestische emissie = verschijnsel waarbij oor zelf geluid voortbrengt)
https://www.antoniusziekenhuis.nl/behandelingen-onderzoeken/oae-meting-bij-kinderen
- How it works
  - The ear produces a little sound itself, after a sound has entered the ear (Kemp-echo)
- Goal
  - Find out if there is an indication for hearing impairments
  - Especially used with young kids, babies or toddlers
- Procedure
  - A soft earbud is placed in the ear
  - The earbud produces 'zachte klikjes' / soft clicks. A microphone records the echo of these clicks.
- Difficulties
  - Echo has a low volume, so body sounds can interfere.
    - Therefore it is important that someone is very relaxed and quiet, and breathes quitly.
- Possible results
  - De OAE-echo is voldoende sterk en in voldoende toonhoogten aanwezig. Het gehoor is hoogst waarschijnlijk goed.
  - De OAE-echo wordt wel gemeten, maar is te zwak en/of bij te weinig toonhoogten aanwezig. Het gehoor is mogelijk onvoldoende. Dit kan veroorzaakt worden door een klein beetje vocht of een andere geluidsbarrière in de gehoorgang of het middenoor, zoals bij een verstopt trommelvliesbuisje. Eventueel kan het gehoorverlies door het binnenoor veroorzaakt worden.
  - De OAE-echo komt niet boven de meetruis uit. In dit geval is het oor op dat moment waarschijnlijk minder horend, om één van de bovengenoemde redenen.

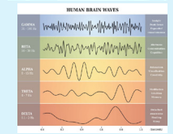
Tympanogram
https://www.radboudumc.nl/patientenzorg/onderzoeken/gehooronderzoek/het-gehooronderzoek/tympanometrie
Tympanometrie wordt gebruikt om de beweeglijkheid van het trommelvlies en de werking van het middenoor te beoordelen. Tijdens het onderzoek sluiten we de gehoorgang af met een dopje en hoort u een zachte bromtoon. Hierna wordt de luchtdruk in de gehoor veranderd. Een goed functionerend trommelvlies beweegt bij luchtdrukveranderingen. Deze beweeglijkheid leggen we vast in een tympanogram.
Duur: ca. 10 minuten



Digit-in-noise (DIN) test (speech-in-noise)
Smits, C., Goverts, S. T., & Festen, J. M. (2013). The digits-in-noise test: Assessing auditory speech recognition abilities in noise. Journal of the Acoustical Society of America, 133(3), 1693–1706. https://doi.org/10.1121/1.4789933
- automated, self-administered hearing screening tool
- Assessing auditory speech recognition abilities in noise
- a full-bandwidth digit-triplet test in long-term average speech spectrum (LTASS) noise
-
- Goal
  - Detection of hearing loss
- Purpose
  - Speech-in-noise testing is necessary to determine a patient's ability to function at work, in classrooms and, in general, in daily life.
  - important in evaluating and optimizing the fitting parameters of hearing aids and cochlear implants
- Linguistic skills contribute to the top-down processes involved in the understanding of sentences in noise. The contribution of linguistic skills in understanding speech in noise has been shown in studies with children (Eisenberg *et al.*, 2000) and non-native listeners (van Wijngaarden *et al.*, 2002; von Hapsburg *et al.*, 2004; Goverts *et al.*, 2011)
- They are in the lists of the most frequently spoken words, are known by children at a young age and are typically among the first words that are learned in a second language.

EEG-MEASUREMENTS
https://www.erasmusmc.nl/nl-nl/sophia/patientenzorg/onderzoeken/eeg-onderzoek-kind#0ff23df4-d13f-45eb-b2d1-62cb241094e0
https://patientenfolders.erasmusmc.nl/folders/eeg_electro_encephalogram_bij_kinderen





- een registratie van de elektrische activiteit van de hersenen
- Technique
  - Measured with electrodes on the scalp/hoofdhuid
- Procedure
  - Electrodes are placed on the scalp
  - Kid is laying down or sitting,
  - doet hij een paar opdrachtjes, zoals ogen dicht, vuisten maken, zuchten of blazen en in een lamp kijken.
  - The child is videotaped, this tape is used when analysing the EEG
  - It takes 90 minutes

COGNITIEVE TESTEN

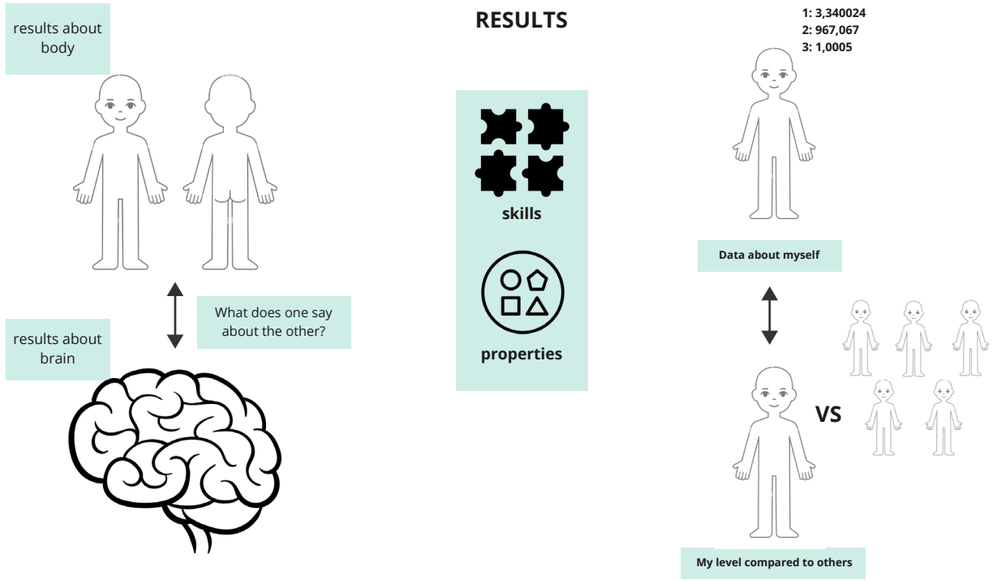
- bij kleine kinderen is het ontwikkelingstest, daar gaat het om ontwikkeling en kun je geen IQ bepalen, bij oudere kinderen is het intelligentietest. Bestaan uit subtaken. bij kleintjes is dat spelen, dan kijk je of de ontwikkeling conform verwachting van de leeftijd verloopt. bij oudere kinderen komt er cognitief profiel uit met sterkes en zwaktes. Dat uurt voor ouderen 1.5-2 uur
- Hoe nu gecommuniceerd?
  - Wat we dan doen, is we schrijven een verslag, daarvoor hebben we een uitslaggesprek . daar bespreek ik eigenlijk het verslag, komt ook echt met cijfers in, wat het betrouwbaarheidsinterval, en de indexen.laag/laaggemiddeld. in dat soort labels. En je maakt onderscheid tussen het kind zelf, en het kind in vergelijking met andere kinderen. daar heb je een gesprek of ouders dat herkennen, ja of nee, dat schrijf ik ook in het verslag.

OBSERVATIE INTERACTIE

- ouder-kind interactie. 10 min vragen of ze verschillende dingen willen doen met hun kind, afhankelijk van de leeftijd. bij 0-3 maanden omkleden, te verschonen, bij ouderen moeten ze echt samenwerken aan spelletje. dit is tot 8 jaar. T2 en T3. ze worden gefilmd met drie camera's. Dan kijkt noor live mee. hoe ouder en kind op elkaar reageren. wordt later gescoord, op bijv schaal van sensitiviteit, of er liefdevol wordt omgegaan met een kind.

TAALONDERZOEK

- afhankelijk van de leeftijd. oudere kinderen is het op de ipad/computer. Voor kinderen die moeite hebben om te spreken, vaak met ernstige motorische problemen, hebben we een specifieke taaltest dat ze kunnen aanwijzen op een touchscreen, of met een knop of met hun nek bewegen om antwoorden aan te geven.



Appendix E: Interview activities brain disorder & self-image

Welke emoji's omschrijven jou het beste?

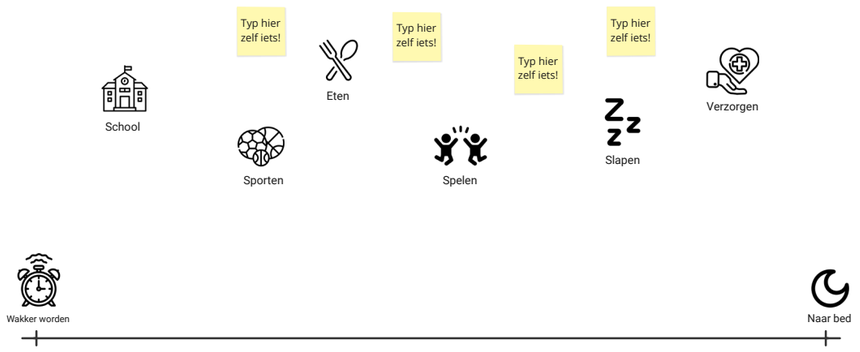
Wat maakt jou bijzonder? 💎

Waar droom jij van? ☁️

Wie ben jij? - Introductie, kind leren kennen
Wat maakt jou anders / bijzonder? - ontdekken of de aandoening hier wordt benoemd, de hoofdrol speelt, of dat andere dingen (ook) worden genoemd
Waar droom jij van? - Past het kind zijn/haar dromen aan, aan de aandoening? Ziet hij/zij het als een beperking of niet?

Ik heb gehoord dat jij af en toe naar het ziekenhuis gaat. Waarom is dat?
Kun je mij uitleggen wat er precies aan de hand is?

Hoe ziet een dag in jouw leven eruit? Vul de tijdlijn hieronder aan.



Denk jij op zo'n dag wel eens aan [je aandoening]? Op welke momenten is dat? Hoe voel je je dan?

Appendix F: Disabilities associated with start groups of the CBL

Cerebrale overgroei

https://encore-expertisecentrum.nl/cases/cerebrale-overgroei-syndromen/#1586285451007-02fb7393-6420
https://www.kinderneurologie.eu/ziektebeelden/syndromen/MCAP.php

- Er groeien dan te veel of te grote zenuwcellen. Deze mutatie kan ontstaan zijn bij de bevruchting, maar ook later tijdens de (hersen)ontwikkeling.
- Er komen elk jaar maar een paar nieuwe gevallen bij in Nederland. Een precies getal is niet bekend.
- Kinderen met een cerebraal overgroei syndroom hebben meestal een verhoogd risico op epilepsie,
- Symptomen MCAP
  - Hoog geboortegewicht
  - Groot hoofd
  - Lagere spierspanning, platvoet
  - Ontwikkelingsachterstand
    - Bewegen, schrijven, knippen
    - Spraak
  - Leerproblemen
  - AD(H)D
  - Autisme
  -

MS

https://www.erasms.nl/kinder-ms-centrum/
https://www.erasmusmc.nl/nl-nl/sophia/patientenzorg/centra/kinder-multiple-sclerose-ms

- een ziekte van de zenuwen waarbij ontstekingen optreden in de hersenen, het ruggenmerg en de oogzenuwen.
- De meeste mensen met MS zijn tussen de 20 en 40 jaar als ze de diagnose krijgen. In een minderheid van de gevallen ontstaat de ziekte echter op de kinderleeftijd, met name bij jongeren ouder dan 11 jaar
- Elk jaar krijgen ongeveer tien kinderen de diagnose MS
- Als bijvoorbeeld de oogzenuw ontstoken is geeft dit problemen met het zien en is het bewegen van dat oog wat vaak pijnlijk is. Als de ontsteking op bepaalde plekken in de hersenen of het ruggenmerg zit, geeft dit vaak problemen met het gevoel, met de kracht of soms ook met het plassen
- RRMS: meest voorkomende vorm, vooral bij kinderen. RRMS kenmerkt zich door herhaaldelijke periodes met klachten, gevolgd door herstel. De periodes met klachten noemen we ook wel aanvallen, relapses, schubs of exacerbaties. Gaat 70% vd gevallen over in secundair progressieve fase'. Tijdens deze fase is er geen sprake meer van aanvallen, maar zien we een langzame achteruitgang (een toename van uitvalsverschijnselen) zonder dat er nog sprake is van herstel
- MS behandelen we met medicijnen die het immuunsysteem beïnvloeden. het doel van deze medicatie is om nieuwe aanvallen in de toekomst zoveel mogelijk te voorkomen
- Naast de lichamelijke vermoeidheid, waardoor er verzuim kan ontstaan, zijn er ook vaak cognitieve problemen (bij 70% van de kinderen met MS).
  - Denk bijvoorbeeld aan problemen met het verwerven, behouden en ophalen van nieuwe informatie. Hiernaast kunnen zich problemen voordoen in de aandacht en concentratie (informatieverwerking), het tempo van het leerproces, de uitvoerende functies (planningen maken en prioriteiten stellen), taalbeheersing/ begrip en in de visueel-ruimtelijke functies.

GRIN/GRIA

https://curegrin.org/what-are-gri-disorders/
GRI Disorders are part of a larger family of genetic diseases related to ionotropic glutamate receptors. These receptors play an important role in learning and memory as well as other critical biological functions.

- GRIA is caused by a change in one of four GRIA genes. These genes contain the code to create AMPA receptors.
- GRIA variants have been associated with intellectual disability and ASD. In addition, some GRIA patients may experience behavioral difficulties including features of autism, reduced attention span, anxiety, and hypersensitivity to stimuli.
- Grin is caused by a change in one of seven GRIN genes. These genes contain the code to create NMDA receptors, which are essential for learning and memory.
- Symptoms of GRIN Disorder include: developmental delay, intellectual disability, autism, speech deficiency, inability to walk, low muscle tone, gastrointestinal issues, feeding difficulties, cortical visual impairments, dystonia, seizures, and neuro storms.
- The most common symptoms are:
  - Developmental Delay
  - Intellectual Disability
  - Epilepsy (Seizures)
  - Hypotonia (Low Muscle Tone)
  - Constipation (GI Issues)
  - Limited Or Non-Verbal Communication
  - Paroxysmal Sympathetic Hyperactivity (Neurostorms)
  - Cortical Visual Impairment (CVI)
  - Dystonia
  - Sleep Disorders
  - Feeding Difficulties
  - Limited Mobility
  - Autism

Spina bifida

https://www.nvvn.org/patienteninfo/wervelkolom-en-ruggenmerg/spina-bifida-open-rug/
https://www.erasmusmc.nl/nl-nl/sophia/patientenzorg/aandoeningen/open-rug-spina-bifida#e22347d9-fb9c-4264-be85-2380f4420d32

- Open ruggetje
- Aangeboren afwijking
- gemiddeld 4,5 per 10.000 geboorten
- In sommige gevallen leidt spina bifida aperta tot een waterhoofdje, waardoor een verstandelijke handicap kan ontstaan
- Intellectuele achterstand
- Urologische afwijkingen
- Verminderde kracht en gevoel in de benen.
- Orthopedische afwijkingen zoals klompvoeten
- vergroeiingen van de benen en rug en seksuele functiestoornissen ontwikkelen

Stotteren

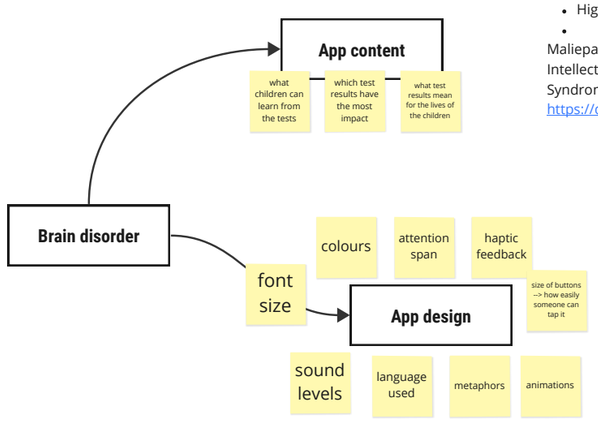
https://www.stotteren.nl/algemene-informatie-stotteren.html

- 170.000 mensen die stotteren in Nederland
- Stoornis in vloeiendheid van spreken: Het bestaat uit opvallende herhalingen , verlengingen en/of blokkades van klanken of lettergrepen. Dit gedrag is onvrijwillig: de persoon die stottert heeft het niet onder controle.
- Wat ook kan spelen: het vermijden van moeilijke woorden, spreekangst en minderwaardigheidsgevoelens.
- Het probleem is dus niet gerelateerd aan spierzwakte of structurele problemen met de spraakorganen, maar een verminderd vermogen om spraakbewegingen efficiënt aan te sturen.

Cerebrale Parese

https://www.hersenstichting.nl/hersenaandoeningen/cerebrale-parese-cp/

- Ontstaat voor tijdens of na geboorte
  - bijv. door gebrek aan zuurstof
  - of ernstig ziek in eerste levensjaar
- Minder kracht in spieren en moeite met bewegen
- Kan voorkomen in één helft, één onderdeel, of alle onderdelen van het lichaam
- Mogelijke klachten
  - stijve spieren, schokkerige bewegingen, of bepaalde bewegingen maken zonder dit te willen
  - problemen met evenwicht bewaren
  - problemen met praten, slikken en eten
  - problemen met zien, horen en voelen
  - problemen met leren
  - late ontwikkeling, zoals laat leren zitten, kruipen en lopen
  - epilepsie
- Behandeling
  - Kinderfysiotherapeut kan leren om makkelijker te bewegen.
  - Kinderlogopedist kan helpen bij problemen met slikken, eten en drinken, of gebarentaal leren
  - Kinderergotherapeut je kind: geschikte hulpmiddelen te vinden, zoals speciale schoenen of spalken.
  - Medisch psycholoog: niveau van begrip en leren onderzoeken
- CP kan verschillende gevolgen hebben voor het leven van je kind:
  - **Iets begrijpen:** dit kan erg lastig zijn als er sprake is van een mentale handicap, problemen met zien en horen, of veel moeite met leren. Je kindje moet dan misschien naar een speciale school. Maar het kan ook zijn dat je kind naar een gewone school kan.
  - **Jezelf verplaatsen:** er kunnen ernstige problemen met lopen en evenwicht zijn. Een hulpmiddel, zoals een looprek, kan dan helpen. Soms is framerunning, een speciale vorm van sport, ook mogelijk.
  - **Jezelf verzorgen:** eten, douchen, tandenpoetsen. Door de problemen met bewegen en slikken kan het lastig zijn om deze dingen zelf of zonder hulpmiddel te doen.
  - **Omgaan met anderen:** als praten moeilijk is, dan is contact met anderen ook een uitdaging. Een speciale app voor de tablet kan dan helpen met het vinden en uitspreken van woorden.
  - **Dagelijkse activiteiten:** een deel van de patiënten kan niets of bijna niets zelf doen. Door de klachten kunnen veel dagelijkse activiteiten dan ook een uitdaging zijn.
  - **Meedoen aan de wereld:** bij ernstige klachten kan het erg lastig zijn om mee te doen aan de wereld zoals anderen dat doen. Dit kan leiden tot een onzeker of eenzaam gevoel. Als vrienden maken lastig is, dan kan het helpen om contact te zoeken met mensen die zelf ook CP hebben.



Sturge Weber

https://huidhuis.nl/aandoeningen/sturge-weber-syndroom/

- Ongeveer 100 kinderen en volwassenen in NL
- Aangeboren afwijking
  - Ontstaat tijdens zwangerschap
  - Niet erfelijk
- Foutje bij aanleg van bloedvaten bij hersenen & ogen
- Meest kenmerkende verschijnsel: wijnvlek in gezicht, ooggebied en voorhoofd
- 75-90% van de gevallen heeft last van epilepsie
- Neurologische verschijnselen:
  - krachtverlies (aan arm of been aan de andere kant van de wijnvlek)
  - ontwikkelingsachterstand
  - gedragsproblemen
- Glaucoom (verhoogde oogboldruk)
  - Kan problemen geven met gezichtsvermogen
- Verschil in verschijnselen tussen kinderen met en zonder epileptische aanvallen ('seizures')
  - Mét seizures: higher severity/frequency of...
    - disruptive behavior
      - conduct disorder, inattention, and oppositional behaviors.
    - problems in social functioning, and academic and cognitive difficulties.
  - Lower IQ

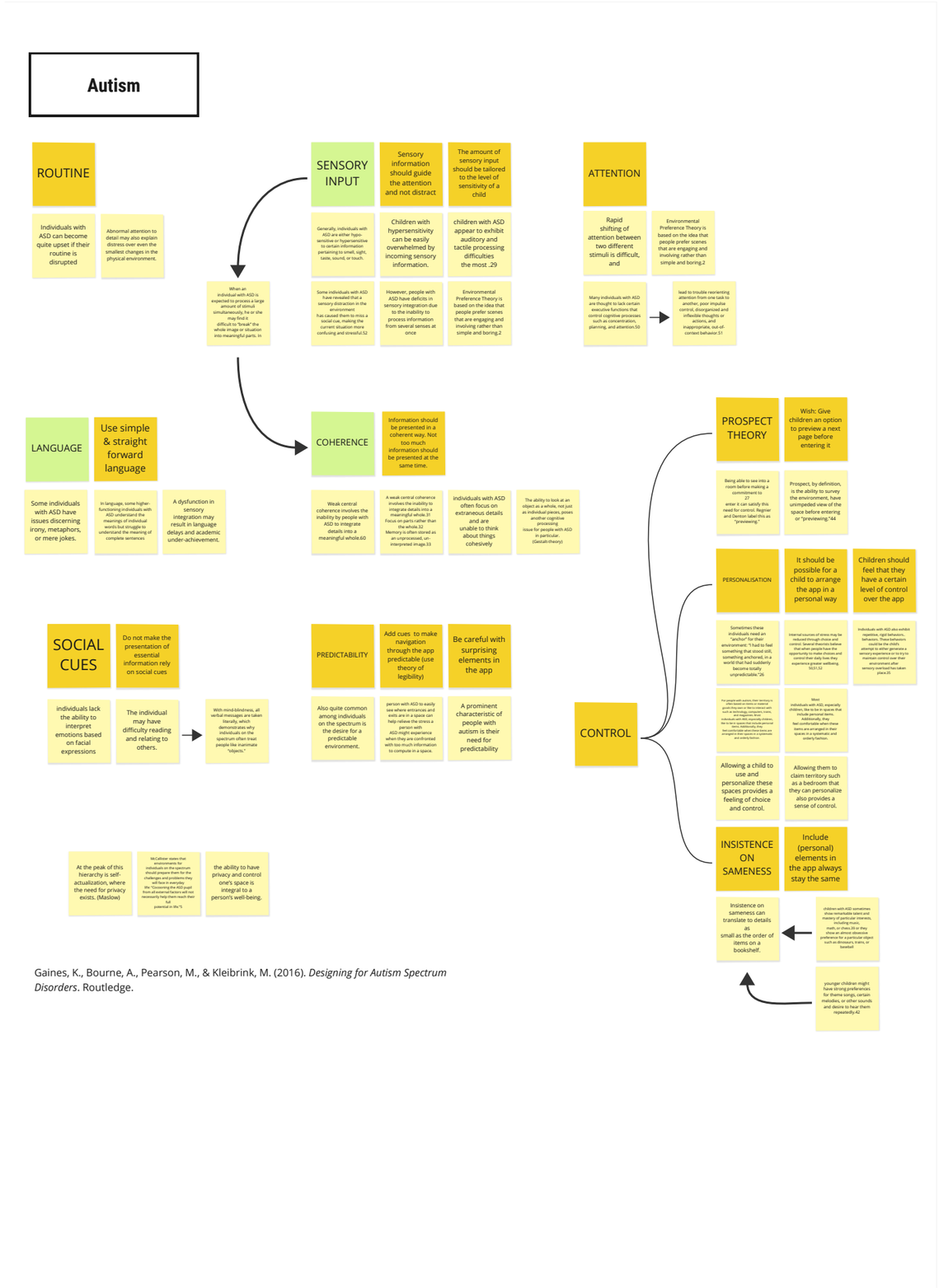
Raches, D., Hiscock, M., & Chapieski, L. (2012). Behavioral and academic problems in children with Sturge-Weber syndrome: Differences between children with and without seizures. *Epilepsy & Behavior*, *25*(3), 457–463. https://doi.org/10.1016/j.yebeh.2012.06.004

Crouzon (/Pfeiffer)

https://www.erasmusmc.nl/nl-nl/sophia/patientenzorg/aandoeningen/crouzon-syndroom#c8c39592-84db-4963-82a1-815ee06c0612

- erfelijk
- te vroege sluiting van de schedelnaden
- Te kleine schedel, te veel hersenvocht, ademhalingsproblemen
- Symptomen
  - Verhoogde hersendruk
  - De lage stand van delen van de kleine hersenen kan klachten geven van de zenuwbanen, waardoor bijvoorbeeld lopen minder goed gaat of het gevoel in de handen verandert.
- De gemiddelde intelligentie is normaal maar varieert van laag tot hoog.
- Higher rates of social and attention problems, behavioral and emotional problems were comparable to the normative population
- Higher prevalence of ADHD-any type
-

Maliepaard, M., Mathijssen, I. M., Oosterlaan, J., & Okkerse, J. M. E. (2014). Intellectual, Behavioral, and Emotional Functioning in Children With Syndromic Craniosynostosis. *Pediatrics*, *133*(6), e1608–e1615. https://doi.org/10.1542/peds.2013-3077



Gaines, K., Bourne, A., Pearson, M., & Kleibrink, M. (2016). *Designing for Autism Spectrum Disorders*. Routledge.

Appendix G: Tasks EEG procedure in the CBL

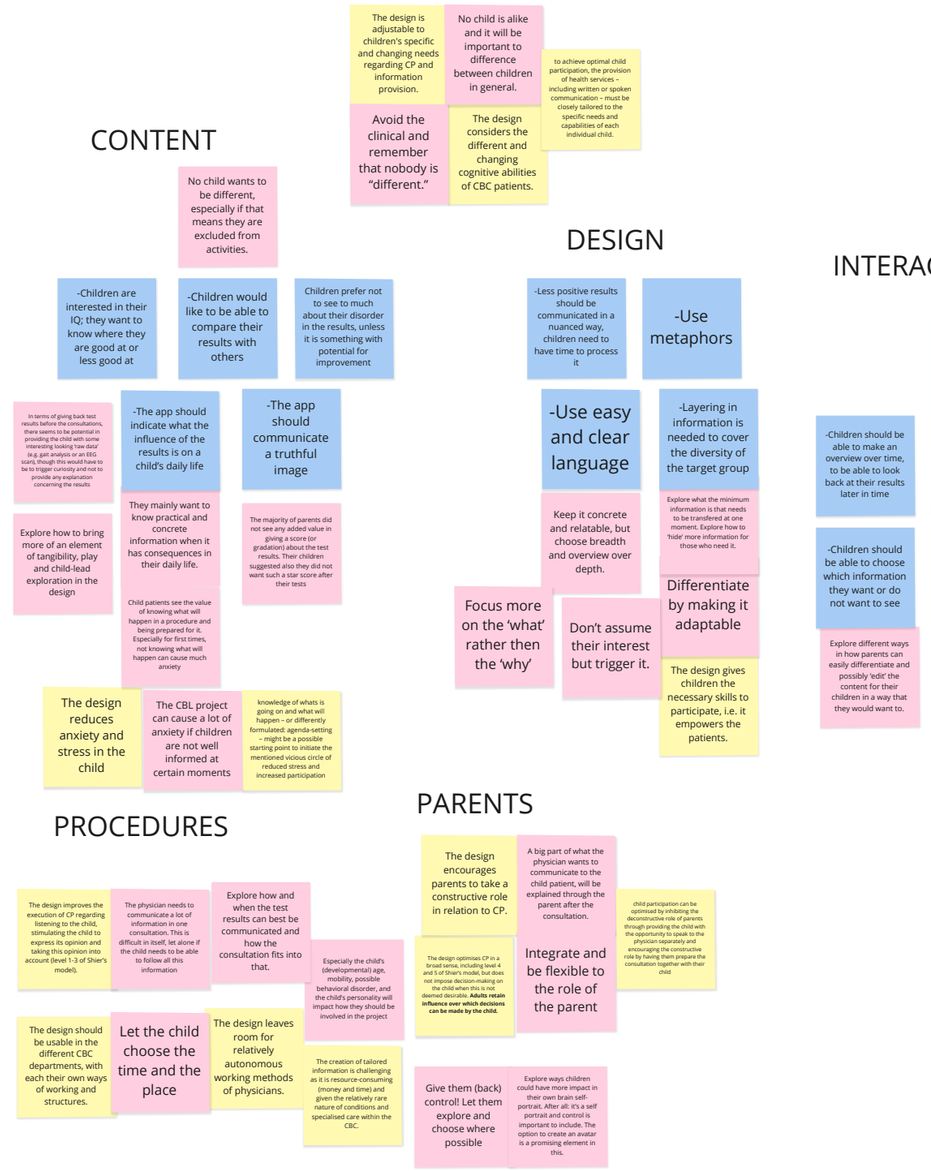
1. Kind krijgt uitleg over plaatsen badmuts
2. Ogen openen & dichtdoen 6x 30s.
3. Oogbewegingen meten
   a. Gezichten: kijk je naar driehoek ogen/neus of niet
   b. Gezichten met emoties herkennen: foto's met verschillende gradaties van emoties, aangeven boos/bang/verdrietig/blij
   c. Mensen vs bewegende objecten: waar kijk je naar? (Meeste gezonde kinderen kijken vooral naar mensen)
4. Vos/egel spel: kinderen zien een vos of een egel op een blauw of geel vlak. Verschillende regels worden toegevoegd wanneer kinderen waar moeten klikken op het touchscreen
   a. Eerst oefensessie, daarna 'echte test'
   b. Meten of kinderen kunnen leren: inhibitie
3. Stippenvolgorde onthouden: memory. Bij oudere kinderen gaat het om tot 8 stippen die onthouden moeten worden.
4. Verschillende patronen herkennen. Kan erg moeilijk worden. Doel: thetagolven meten in het EEG, die ontstaan als je hard nadenkt.
5. ERP: filmpje kijken, ondertussen hoor je piepjes. In het EEG moeten deze piepjes een reactie geven.

Appendix H: Result data Walking mat

Foot Length %	Foot Width (cm.)	Foot Area (cm. x cm.)	Foot Angle (degrees)	Toe In/Out Angle (degrees)	Foot Toe X Location (cm.)	Foot Toe Y Location (cm.)	Foot Heel X Location (cm.)	Foot Heel Y Location (cm.)	Foot Center X Location (cm.)	Foot Center Y Location (cm.)	Step Length (cm.)	Absolute Step Length (cm.)	Step Ratio (cm. x min.)	Stride Length (cm.)	Stride Width (cm.)	Step Time (sec.)	Stride Time (sec.)	Stride Velocity (cm./sec.)
61	61	61	61	45	61	61	61	61	61	61	45	45	45	45	45	45	45	45
30	30	30	30	22	30	30	30	30	30	30	22	22	22	22	22	22	22	22
31	31	31	31	23	31	31	31	31	31	31	23	23	23	23	23	23	23	23
94,803	9,314	199,716	-3,065	2,136	245,601	30,499	246,206	30,55	245,904	30,524	61,237	62,016	0,547	122,614	9,724	0,536	1,076	114,009
94,514	9,344	198,395	-69,747	1,86	248,925	30,534	250,791	30,594	249,858	30,564	60,992	61,779	0,554	122,817	9,764	0,545	1,076	114,178
95,083	9,284	200,994	61,465	2,399	242,385	30,465	241,769	30,507	242,077	30,486	61,472	62,242	0,54	122,419	9,685	0,527	1,076	113,846
0,994	1,006	0,987	-1,135	0,775	1,027	1,002	1,037	1,003	1,032	1,003	0,992	0,993	1,025	1,003	1,008	1,033	1	1,003
0,601	-0,643	1,302		25,316	-2,663	-0,225	-3,663	-0,287	-3,164	-0,256	0,784	0,748	-2,494	-0,324	-0,815	-3,27	-0,038	-0,291
2,252	0,48	9,297	127,589	1,875	136,847	6,029	136,62	5,013	136,04	5,503	1,872	1,826	0,02	3,475	1,117	0,014	0,017	4,265
2,248	0,46	8,926	111,286	1,944	136,168	7,184	136,753	6,098	135,77	6,632	2,001	1,937	0,021	3,506	1,016	0,011	0,017	4,416
2,257	0,504	9,613	108,796	1,81	139,674	4,777	138,602	3,784	138,433	4,248	1,751	1,725	0,016	3,513	1,228	0,01	0,018	4,209
2,375	5,153	4,655	-4162,37	87,798	55,719	19,769	55,49	16,409	55,322	18,028	3,056	2,944	3,58	2,834	11,49	2,539	1,611	3,741
2,378	4,923	4,499	-159,556	104,491	54,702	23,527	54,529	19,93	54,339	21,699	3,281	3,135	3,717	2,855	10,408	2,033	1,572	3,867
2,373	5,431	4,783	177,004	75,453	57,625	15,68	57,328	12,403	57,186	13,933	2,848	2,771	3,025	2,87	12,677	1,859	1,683	3,697
91,368	9,486	197,462	-1,754	1,537	66,695	29,792	40,203	30,603	53,449	30,198	62,273	63,216	0,554	120,286	10,88	0,533	1,083	111,033
96,495	9,61	208,41	2,474	3,588	125,297	41,453	97,71	40,261	111,504	40,857	61,293	62,088	0,562	123,728	9,904	0,55	1,083	114,211
94,8	8,867	191,512	-0,221	-0,526	187,484	29,688	159,985	29,794	173,734	29,741	62,651	63,369	0,566	124,006	9,511	0,542	1,092	113,594
94,177	9,468	200,394	2,107	3,755	248,674	38,947	221,743	37,956	235,209	38,451	60,307	60,907	0,553	123,1	8,524	0,55	1,092	112,764
94,21	10,272	220,477	-5,47	3,619	311,332	26,822	284,129	29,427	297,73	28,124	60,894	61,518	0,533	121,171	8,737	0,525	1,075	112,717
92,801	9,171	191,275	2,102		371,526	35,396	344,989	34,422	358,258	34,909								
94,077	9,918	212,581	-4,66		432,438	23,101	405,238	25,318	418,838	24,209								
95,573	8,89	190,955	-174,441	5,027	426,503	24,736	453,722	27,385	440,113	26,061	59,538	60,452	0,521	121,87	10,477	0,525	1,058	115,153
93,873	9,445	201,995	179,996	-0,023	364,07	35,96	391,301	35,958	377,686	35,959	62,474	63,445	0,547	121,906	11,057	0,525	1,05	116,101
95,069	9,233	197,274	-178,339	1,584	304,651	24,535	331,844	25,324	318,248	24,93	60,103	61,132	0,551	122,556	11,171	0,55	1,075	114,006
95,289	9,417	204,44	179,346	1,187	241,96	36,173	269,599	35,858	255,779	36,016	62,029	62,943	0,543	122,218	10,692	0,525	1,075	113,691
94,957	9,166	195,614	-176,309	4,373	182,134	23,89	209,25	25,639	195,692	24,764	59,934	60,662	0,549	122,176	9,372	0,55	1,075	113,652
99,739	9,302	211,372	175,973	4,924	119,136	35,893	147,997	33,862	133,566	34,877	59,053	59,555	0,509	119,222	7,717	0,517	1,067	111,771
96,205	9,397	203,182	-177,504		59,773	25,62	87,276	26,819	73,525	26,22								
93,618	10,056	214,487	176,03		0,813	33,951	27,904	32,071	14,359	33,011								
93,883	8,509	179,545	1,766	2,21	41,517	36,04	14,665	35,212	28,091	35,626	58,827	59,743	0,523	116,749	10,425	0,533	1,1	106,135

DOP (degrees)	Gait Cycle Time (sec.)	Stance Time (sec.)	Stance %	Swing Time (sec.)	Swing %	Single Support (sec.)	Single Support %	Initial D. Support (sec.)	Initial D. Support %	Terminal D. Support (sec.)	Terminal D. Support %	Total D. Support (sec.)	Total D. Support %	CISP Time (sec.)	CISP AP (%)	CISP ML (%)	Stance COP Dist. (cm.)	SS COP Dist. (cm.)	DS COP Dist. (cm.)
45	45	61	45	45	45	45	37	53	37	53	45	45	37	29	29	29	61	45	53
22	22	30	22	22	22	23	18	26	18	27	22	23	18	14	14	14	30	23	27
23	23	31	23	23	23	22	19	27	19	26	23	22	19	15	15	15	31	22	26
-43,753	1,076	0,685	63,559	0,392	36,441	0,392	36,653	0,144	13,368	0,144	13,355	0,287	26,696	36,76	3,506	4,643	22,259	11,053	48,509
-48,82	1,076	0,678	62,825	0,4	37,175	0,384	35,881	0,143	13,235	0,145	13,445	0,287	26,602	37,574	3,74	4,768	22,14	10,706	48,576
-38,906	1,076	0,692	64,261	0,384	35,739	0,4	37,385	0,145	13,494	0,143	13,27	0,288	26,784	35,999	3,287	4,526	22,374	11,416	48,441
1,255	1	0,979	0,978	1,041	1,04	0,961	0,96	0,985	0,981	1,015	1,013	0,998	0,993	1,044	1,138	1,054	0,99	0,938	1,003
-22,603	-0,038	2,145	2,259	-3,972	-3,938	3,972	4,105	1,467	1,941	-1,467	-1,308	0,189	0,683	-4,281	-12,887	-5,219	1,05	6,415	-0,278
121,752	0,017	0,017	1,049	0,012	1,049	0,012	1,081	0,009	0,692	0,009	0,727	0,012	0,89	23,129	2,215	4,739	0,463	0,66	2,734
125,81	0,017	0,016	0,935	0,01	0,935	0,007	0,67	0,008	0,62	0,009	0,79	0,012	0,898	22,833	2,369	3,899	0,467	0,576	2,917
120,367	0,018	0,015	0,56	0,007	0,56	0,01	0,867	0,009	0,748	0,008	0,668	0,013	0,898	24,177	2,12	5,547	0,435	0,544	2,587
-278,271	1,611	2,506	1,65	2,97	2,879	2,97	2,949	5,937	5,173	5,937	5,445	4,177	3,334	62,92	63,175	102,075	2,078	5,973	5,637
-257,7	1,572	2,423	1,487	2,49	2,514	1,884	1,867	5,638	4,682	6,224	5,88	4,091	3,374	60,768	63,345	81,781	2,109	5,384	6,005
-309,378	1,683	2,138	0,871	1,884	1,567	2,49	2,319	6,224	5,541	5,638	5,031	4,359	3,353	67,16	64,481	122,565	1,946	4,763	5,341
-0,217	1,083	0,708	65,385	0,375	34,615					0,158	14,615						22,86		46,507
-1,114	1,083	0,683	63,077	0,4	36,923	0,375	34,615	0,158	14,615	0,15	13,846	0,308	28,462				22,86	11,442	51,972
-0,747	1,092	0,7	64,122	0,392	35,878	0,4	36,641	0,15	13,74	0,15	13,74	0,3	27,481	2,058	-0,353	-0,617	22,895	11,582	49,36
-1,649	1,092	0,675	61,832	0,417	38,168	0,392	35,878	0,15	13,74	0,133	12,214	0,283	25,954	2,583	-0,416	-0,462	22,245	12,187	47,447
-1,851	1,075	0,7	65,116	0,375	34,884	0,417	38,76	0,133	12,403	0,15	13,953	0,283	26,357	3,15	1,16	3,195	22,598	12,63	42,908
		0,658				0,375		0,15		0,133		0,283					21,59	11,083	47,372
		0,692						0,133									22,71		
-179,468	1,058	0,683	64,567	0,375	35,433					0,15	14,173						22,441		52,556
179,973	1,05	0,675	64,286	0,375	35,714	0,375	35,714	0,15	14,286	0,15	14,286	0,3	28,571				22,908	10,485	48,69
-179,923	1,075	0,667	62,016	0,408	37,984	0,375	34,884	0,15	13,953	0,142	13,178	0,292	27,132	11,008	4,094	3,732	21,162	9,878	51,968
-179,466	1,075	0,692	64,341	0,383	35,659	0,408	37,984	0,142	13,178	0,142	13,178	0,283	26,357	11,575	5,786	8,511	21,59	11,945	43,746
179,317	1,075	0,675	62,791	0,4	37,209	0,383	35,659	0,142	13,178	0,15	13,953	0,292	27,132	12,092	7,026	4,912	22,024	10,946	50,079
-179,103	1,067	0,683	64,063	0,383	35,937	0,4	37,5	0,15	14,063	0,133	12,5	0,283	26,563	12,642	5,019	-0,309	21,856	11,465	47,788
		0,667				0,383		0,133		0,15		0,283					22,094	9,921	46,025
		0,7						0,15									22,376		
-0,443	1,1	0,708	64,394	0,392	35,606					0,142	12,879						21,965		43,824
1,961	1,067	0,683	64,063	0,383	35,937	0,392	36,719	0,142	13,281	0,15	14,063	0,292	27,344				22,099	11,099	48,252
1,741	1,1	0,683	62,121	0,417	37,879	0,383	34,848	0,15	13,636	0,15	13,636	0,3	27,273	20,175	-0,109	14,382	22,902	9,249	49,902
-0,071	1,1	0,717	65,152	0,383	34,848	0,417	37,879	0,15	13,636	0,15	13,636	0,3	27,273	20,742	0,915	17,429	23,001	11,939	44,915
0,579	1,075	0,675	62,791	0,4	37,209	0,383	35,659	0,15	13,953	0,142	13,178	0,292	27,132	21,267	5,416	3,702	21,889	10,728	44,527
0,037	1,067	0,692	64,844	0,375	35,156	0,4	37,5	0,142	13,281	0,15	14,063	0,292	27,344	21,817	3,67	-0,771	21,868	11,429	47,274
		0,683				0,375		0,15		0,158		0,308					22,25	10,855	46,763
		0,717						0,158									21,908		
-178,405	1,108	0,717	64,662	0,392	35,338					0,167	15,038						22,622		48,605
-179,1	1,092	0,7	64,122	0,392	35,878	0,392	35,878	0,167	15,267	0,142	12,977	0,308	28,244				22,225	11,394	47,598
179,759	1,083	0,683	63,077	0,4	36,923	0,392	36,154	0,142	13,077	0,15	13,846	0,292	26,923	29,3	2,989	3,838	22,817	10,602	48,364
-178,312	1,092	0,7	64,122	0,392	35,878	0,4	36,641	0,15	13,74	0,15	13,74	0,3	27,481	29,85	2,905	3,596	22,866	11,074	46,962
-176,93	1,092	0,692	63,359	0,4	36,641	0,392	35,878	0,15	13,74	0,15	13,74	0,3	27,481	30,392	2,71	4,135	22,25	10,951	43,444

Appendix I: Clustered insights earlier projects



Appendix J: Interventions and requirements on child participation

Table 2. Micro-level interventions on child participation by targeted participant

Target	Type of intervention	Examples	Reasoning
Child	**Information provision**	Information on condition, treatment and procedures. *e.g.(online) brochures, videos, booklets (15).*	- Information provision is a necessity for participation and education may improve the child's 'internal locus of control', which can stimulate participation in conversation (45). - Children with more knowledge on their condition, treatment, expected pain and prognosis, cooperate better, are more involved in decision making, more patiently withstand painful procedures, and adults attach more value to their views (5, 20). - Informing children about an upcoming procedure is known to reduce discomfort, improve the accuracy of expectations and improve the child's adjustments (50).
Child	**Skill development and skill support**	Targeting communication and assertiveness skills, an explanation that child is allowed to participate. May include preparation tools or tools that can be used during interaction. *e.g. via (online) programs (e-learning, video, app) with pre-consultation rehearsal questions, question preparation tool (45).*	- Enhancing abilities to participate could prepare the child to participate (45). - According to play specialists, preparing questions that the child can ask the professional will encourage the child to speak up (15).
Child	**Child-friendly hospital design**	Stress-reducing hospital environment. *e.g. light, windows, colourful, toys (19)*	- The hospital design is important in relation to the child's fears and a child-friendly design can increase confidence and possibilities to participate (19). - Reducing stress might help children to absorb information better (45).
Parent	**Information provision**	Information on condition, treatment and medical procedures. *e.g. (online) brochures, videos, presentations (45).*	- Parents with more knowledge may be able to support their child (45).
Parent	**Skill development and motivation enhancing**	Explanation on the relevance of chid participation and on developmental changes in the child's ability to participate. Instructions on how to agenda-set participation, and fostering the child's involvement (44). *e.g. (online) brochures, videos, presentations (45).*	- The parents' values and wishes influence the child's participation. Parents commonly marginalise and rule out children in health care (46). - As the age of the child increases, parents do not adjust their way to act for the child as much as the physician does (21). - Since involving children in medical decisions may be something novel for some parents, it should be clarified to parents that they can allow child participation and they should be reassured that there are several suitable (treatment) options (49). - By improving parental motivation and skills regarding child participation, parents could better enable and support their child to participate (45).
Professional	**Information provision and motivation**	Information and evidence on relevance of participation, education on legislation and children's rights (47)	- Professionals knowledge and attitudes influence their communication with children, which in turn influences child participation (3, 46)

Table 6. Design requirements

Functional and user requirements	Derived from
1. The design improves the execution of CP regarding listening to the child, stimulating the child to express its opinion and taking this opinion into account (level 1-3 of Shier's model).	S,I
2. The design optimises CP in a broad sense, including level 4 and 5 of Shier's model, but does not impose decision-making on the child when this is not deemed desirable. Adults retain influence over which decisions can be made by the child.	S,I
3. The design is adjustable to children's specific and changing needs regarding CP and information provision.	I,FG
4. The design considers the different and changing cognitive abilities of CBC patients.	I,FG
5. The design gives children the necessary skills to participate, i.e. it empowers the patients.	I
6. The design reduces anxiety and stress in the child.	I,L
7. The design encourages parents to take a constructive role in relation to CP.	I,FG
8. The design should be usable in the different CBC departments, with each their own ways of working and structures.	I

Appendix K: Generative research session materials

Wat weet jij nog van... de EEG test?

Wat meet de dokter hier?

en waar denk je aan bij... je hersenen?

Wat weet jij nog van... De intelligentie test?

Wat meet de dokter hier?

en waar denk jij aan bij... intelligentie?

Mijn kinderhersenlab app

Oudere kinderen

Wat heb jij goed je best gedaan tijdens de EEG test! Hier zijn de resultaten!

Wat heb jij goed je best gedaan tijdens de intelligentie test! Hier zijn de resultaten!

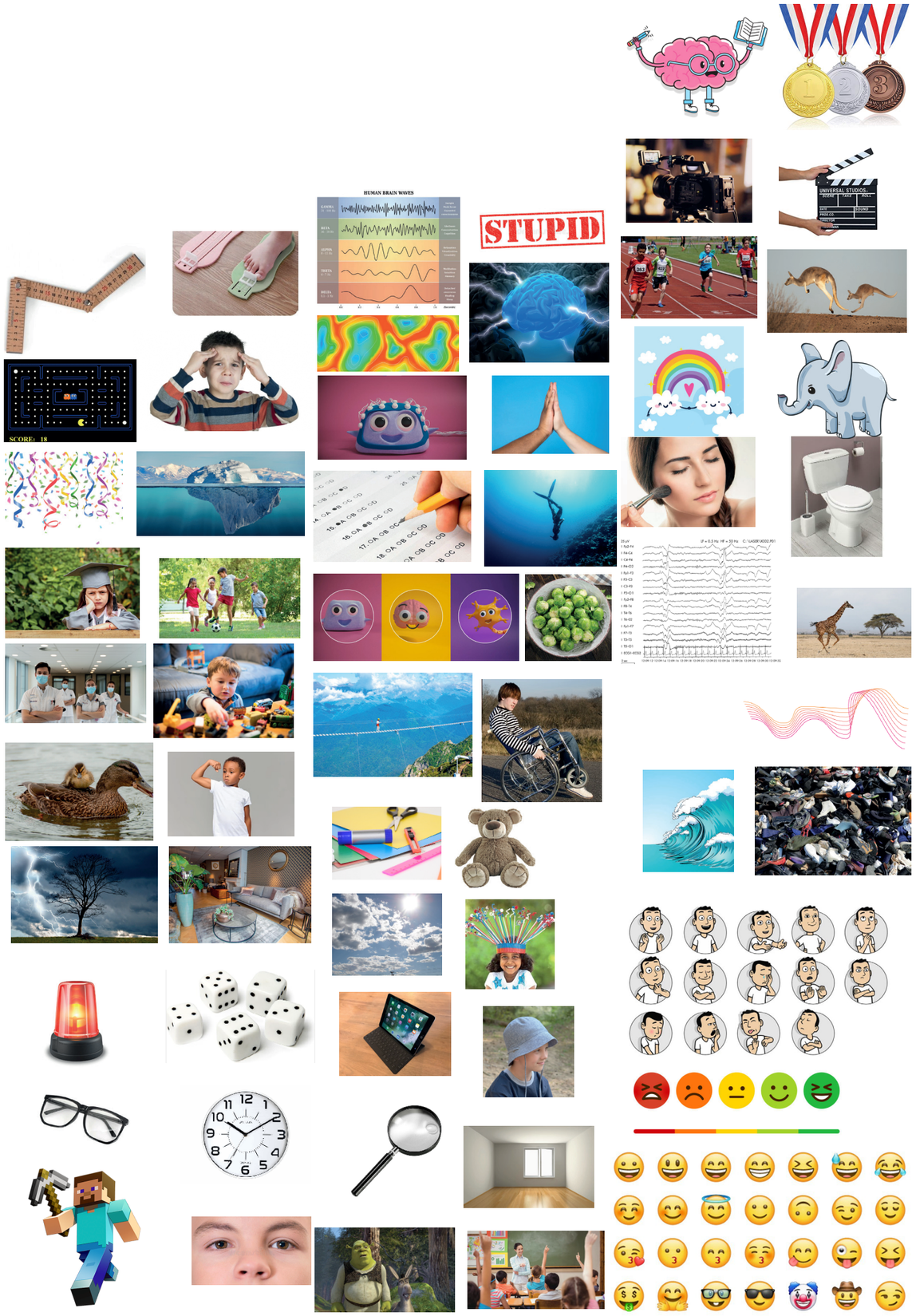
Wat heb jij goed je best gedaan tijdens de loop test! Hier zijn de resultaten!

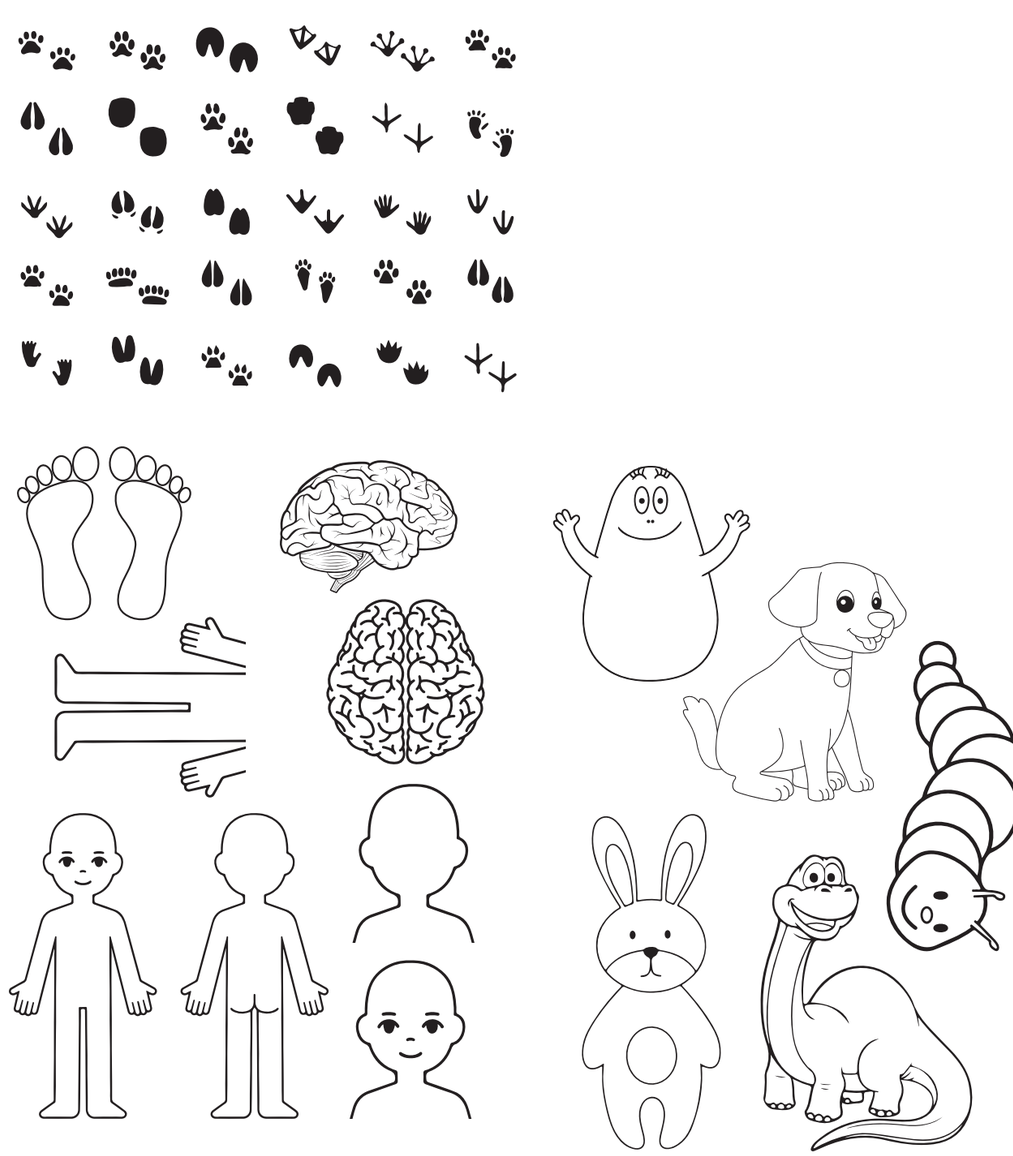
Jongere kinderen

Leer hier wat er in jouw hersenen gebeurt!

Leer hier over hoe jij staat en loopt!

Leer hier over jouw IQ!


HUMAN BRAIN WAVES
STUPID
SCORE: 18
UNIVERSAL STUDIOS



Appendix L: Interview guide HCP's

Interview artsen Kinder HersenLab

1. Wie ben je en wat voor werk doe je?
2. Op welke afdeling werk je en wat wordt hier onderzocht?
3. Hoe wordt op dit moment de data vertaald en/of teruggekoppeld naar de (ouders van de) kinderen?
    a. Wat vind jij van deze manier? Waarom vind je dat?
    b. Wat zijn jouw taken in het vertalen? Hoeveel tijd/moeite kost dit? Wat vind je daarvan?
    c. Wat zijn jouw taken in het terugkoppelen? Hoeveel tijd/moeite kost dit? Wat vind je daarvan?

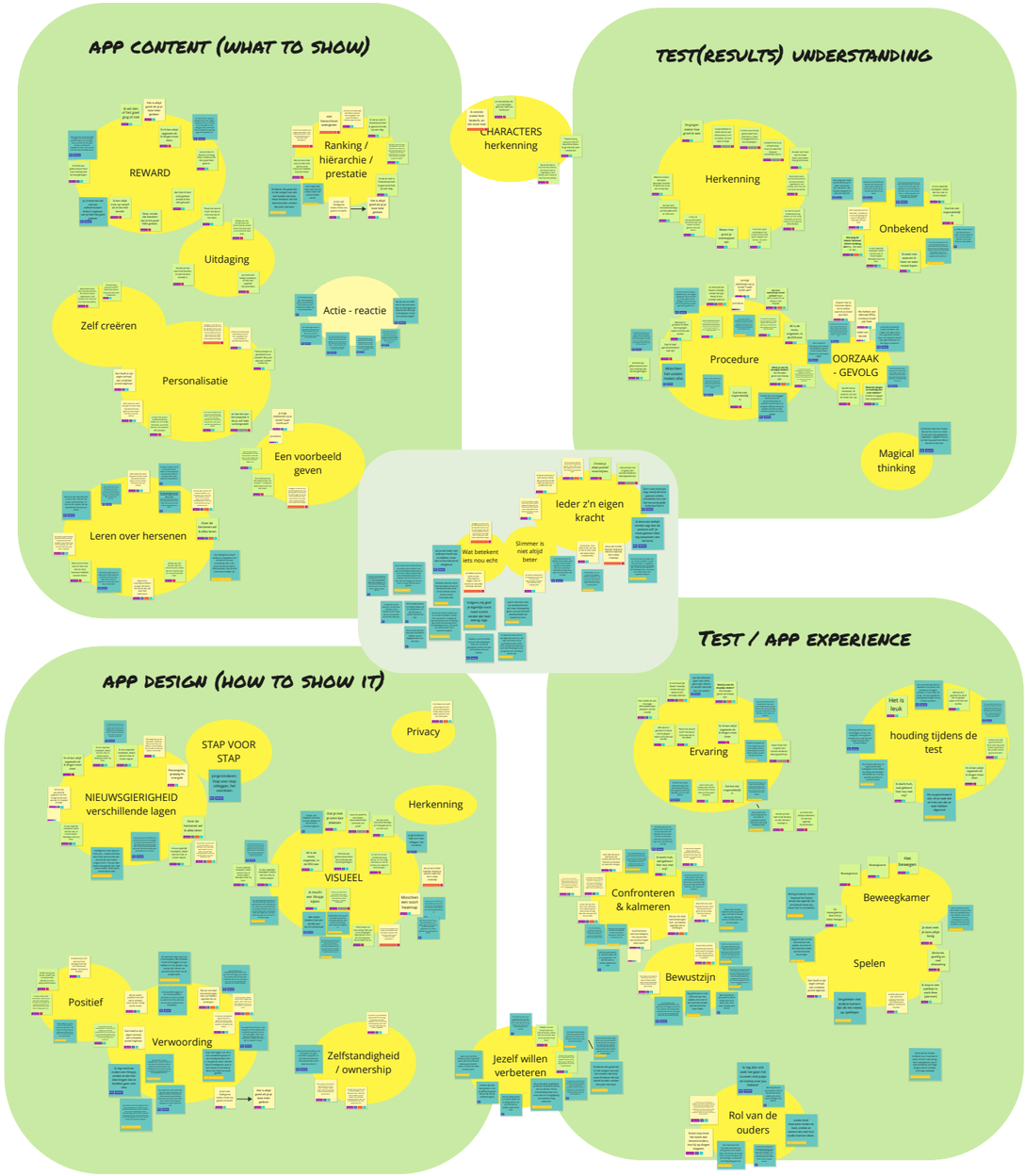
De test

1. Wat voor tests voer je uit?
2. Kun je me uitleggen/laten zien hoe zo'n test in z'n werk gaat?
    a. Welke acties onderneem jij
    b. Welke acties moet een kind ondernemen?
3. Hoe leg je uit wat een EEG is aan een…
    a. 6 jarige
    b. 9 jarige
    c. 12 jarige
4. Wat wordt er gemeten tijdens deze test?
5. Wat voor data komt er uit de test, in welke vorm?
6. Wat zegt de uitslag van deze test over een kind?
7. Wat betekent de uitslag van deze test voor een kind?
    a. Op de korte termijn en lange termijn?
8. Wat kan een kind leren van een EEG-test?
9. Wat vinden kinderen leuk aan EEG-tests?
10. Hoe wordt de data op dit moment gecommuniceerd naar de ouders en/of kinderen?

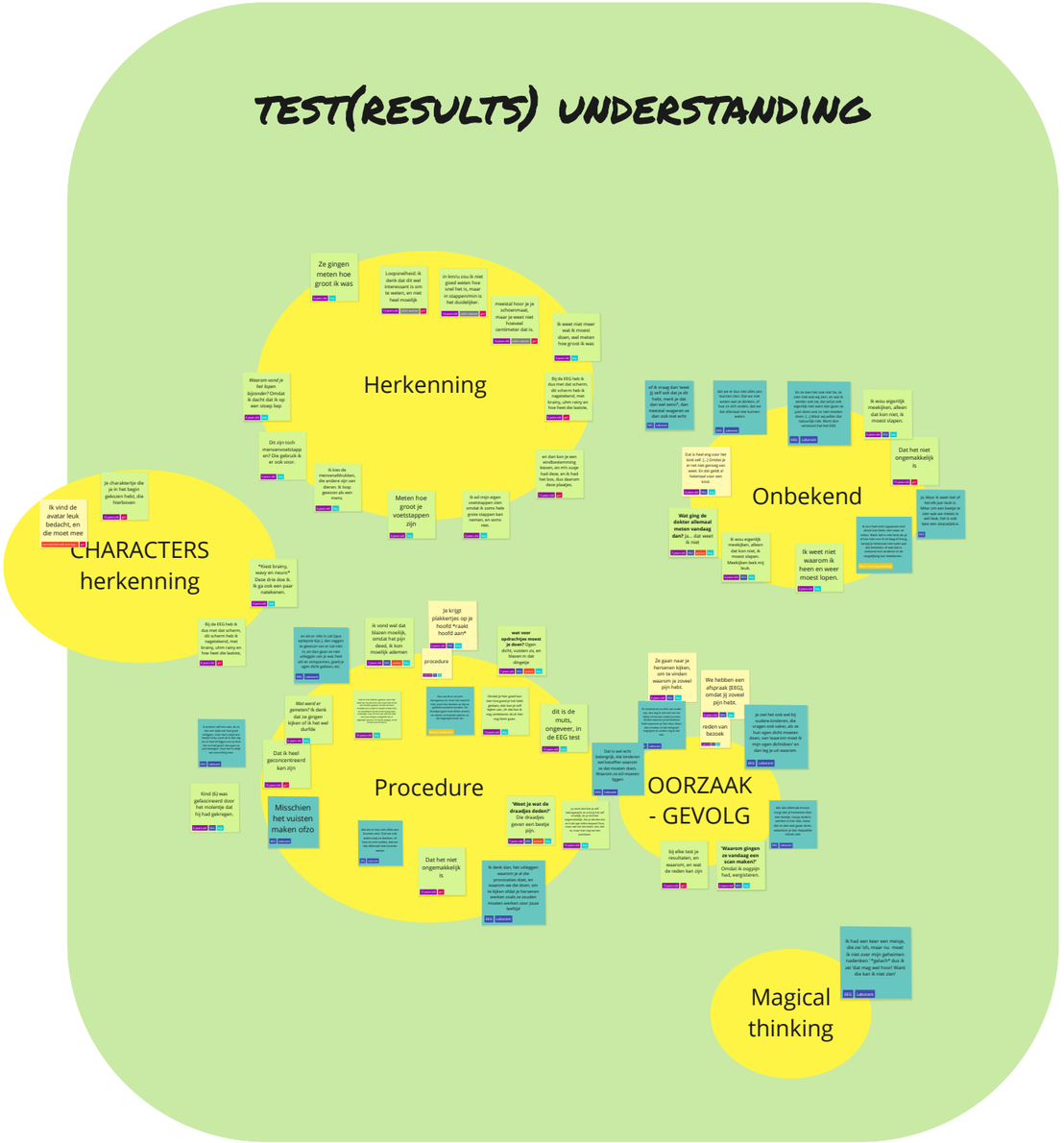
Inhoud zelfportret

4. Hoe zou jij het EEG vertalen naar het kinder-hersen-zelfportret, als het doel is dat…
    a. … een kind iets over zijn/haar hersenen leert
    b. … een kind gerustgesteld wordt
    c. … een kind voorbereid wordt op de behandeling / het consult
    d. … een kind plezier heeft
5. Wat moet er allemaal over deze test gecommuniceerd worden in het zelfportret?
    a. Alleen resultaten, of ook bijvoorbeeld procedure, voorbereiding, of iets anders

Appendix M: Thematic analysis sharing test data with children

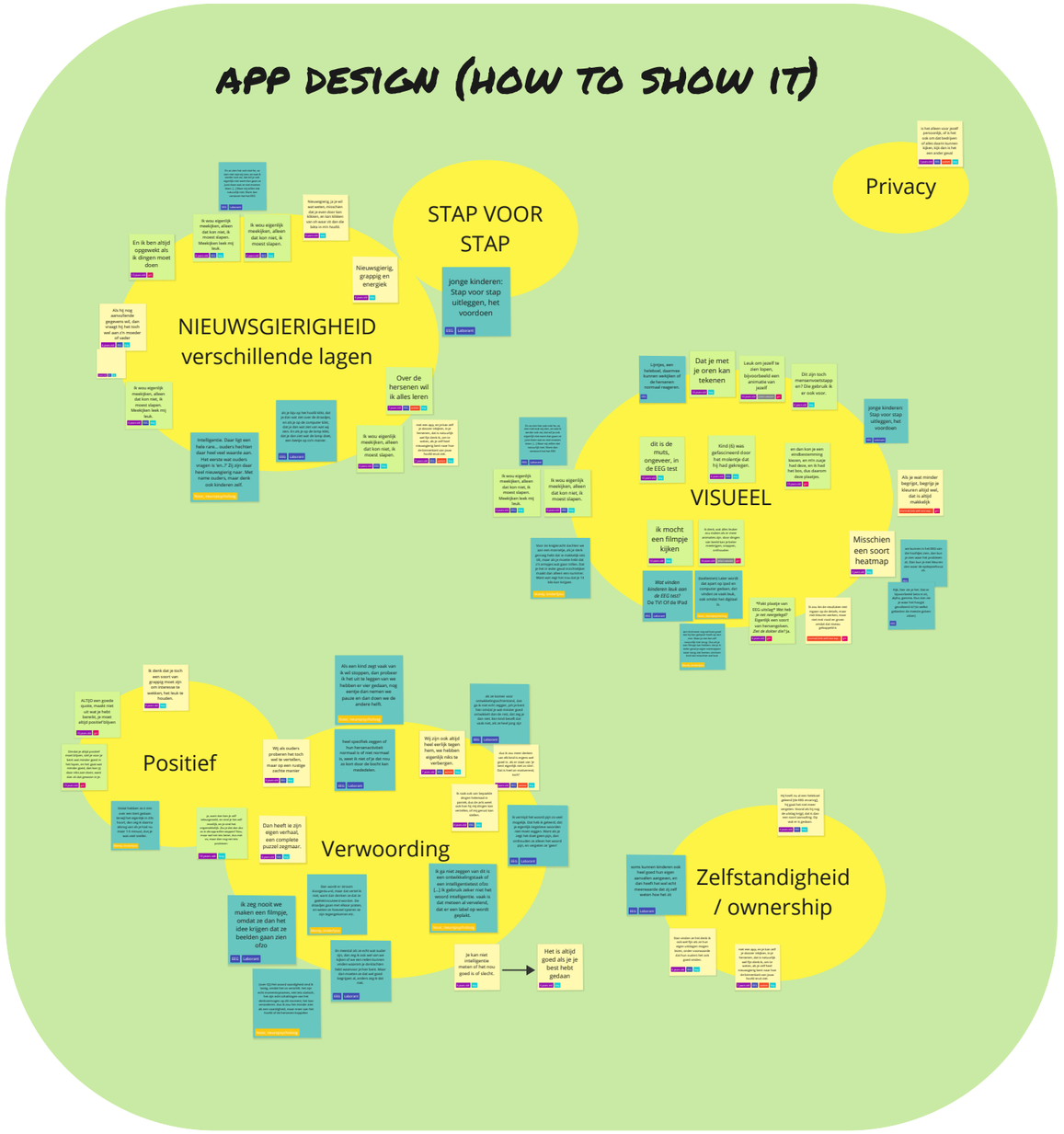



TEST / APP EXPERIENCE
Ervaring
houding tijdens de test
Het is leuk
Confronteren & kalmeren
Beweegkamer
Spelen
Bewustzijn
Jezelf willen verbeteren
Rol van de ouders

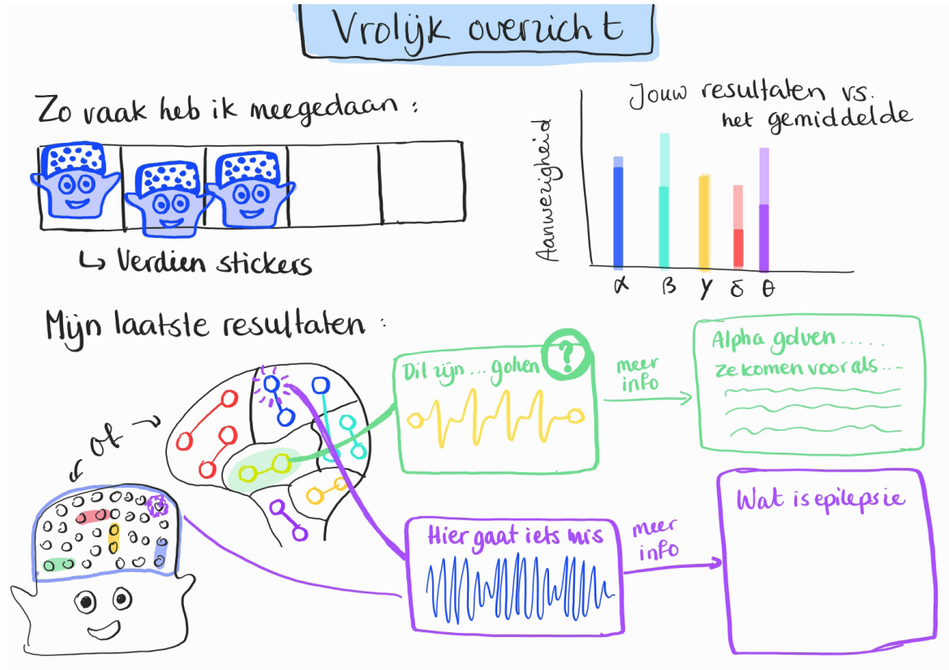

TEST(RESULTS) UNDERSTANDING
Herkenning
CHARACTERS herkenning
Onbekend
Procedure
OORZAAK - GEVOLG
Magical thinking

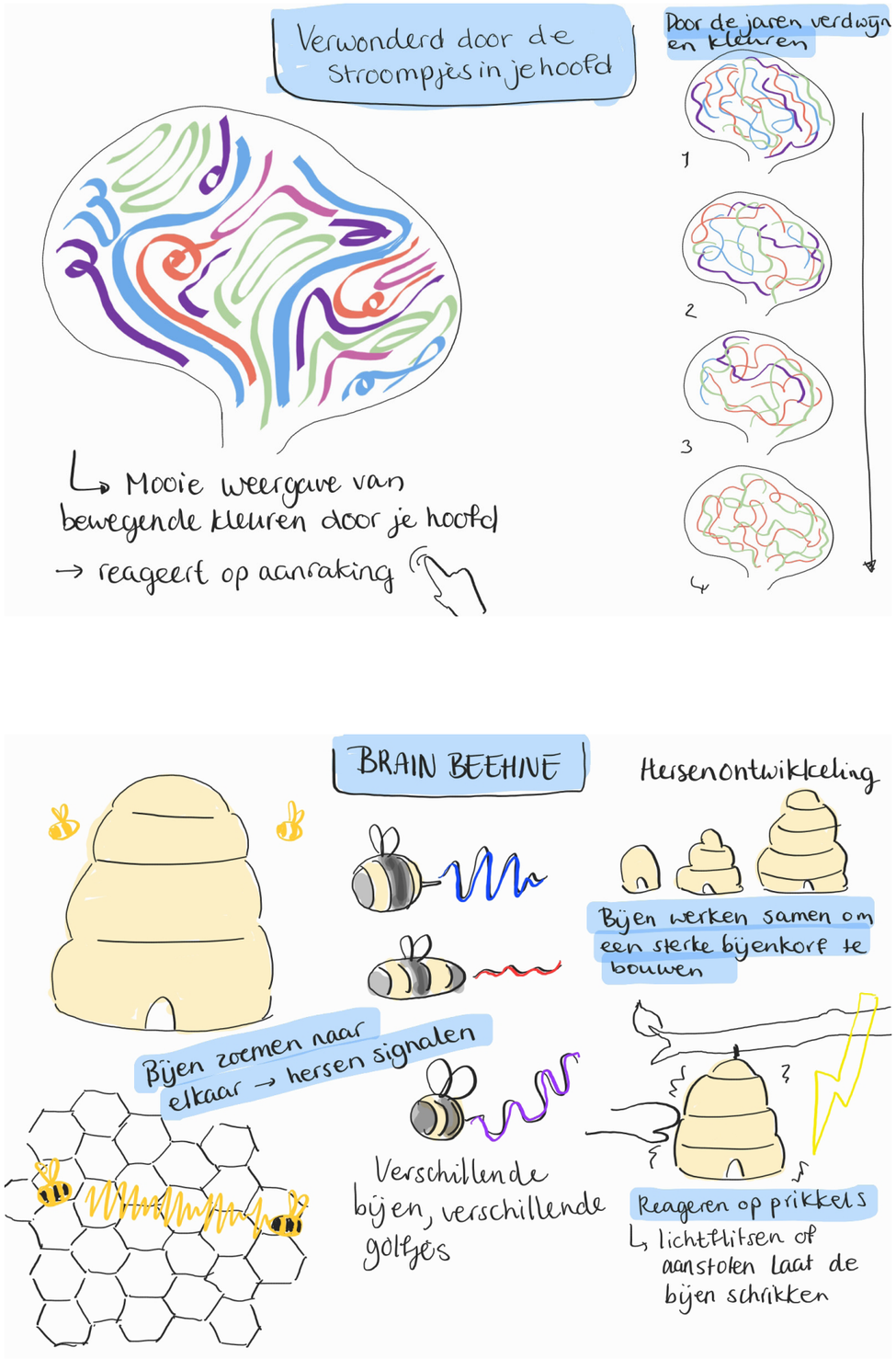
APP CONTENT (WHAT TO SHOW)

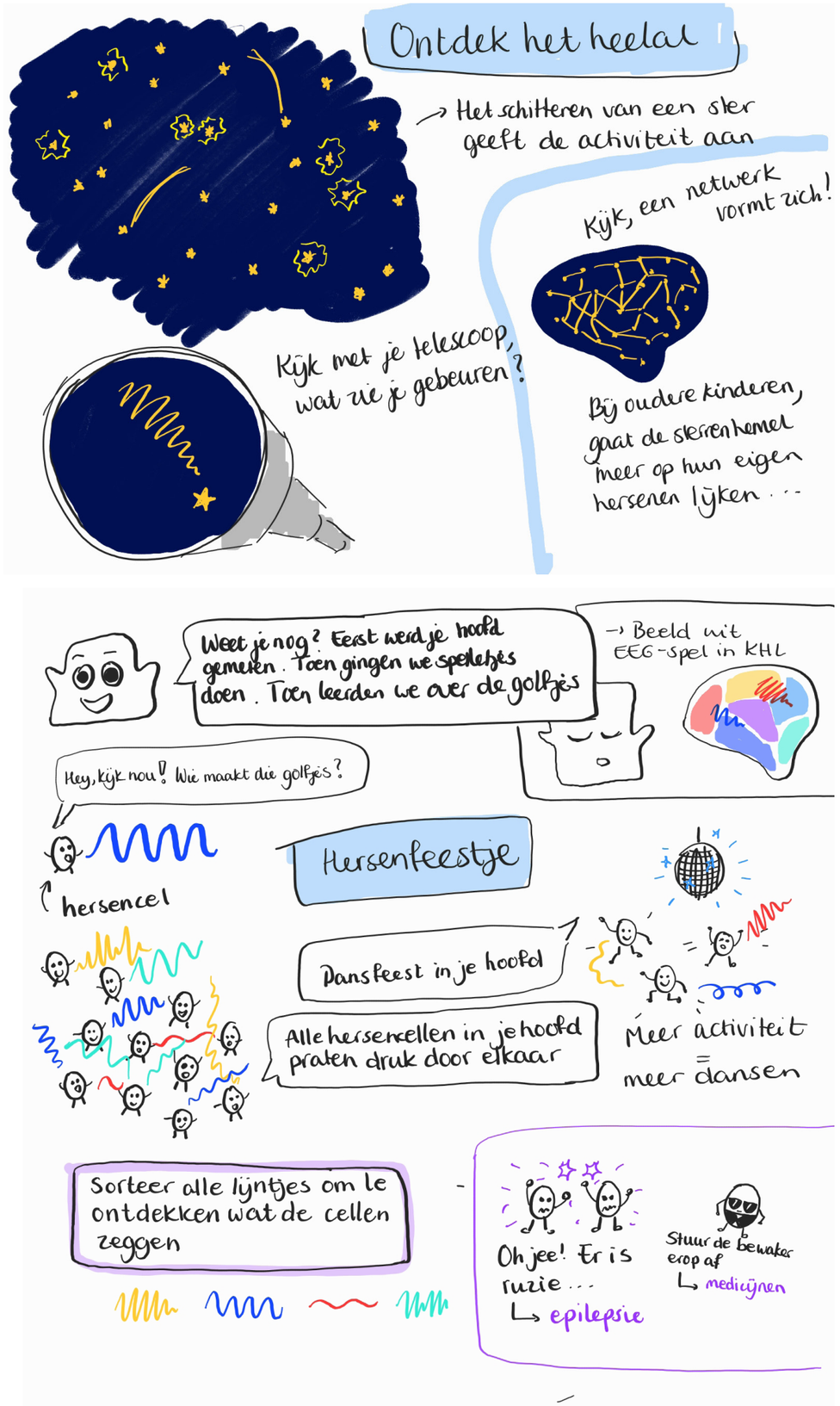
APP DESIGN (HOW TO SHOW IT)



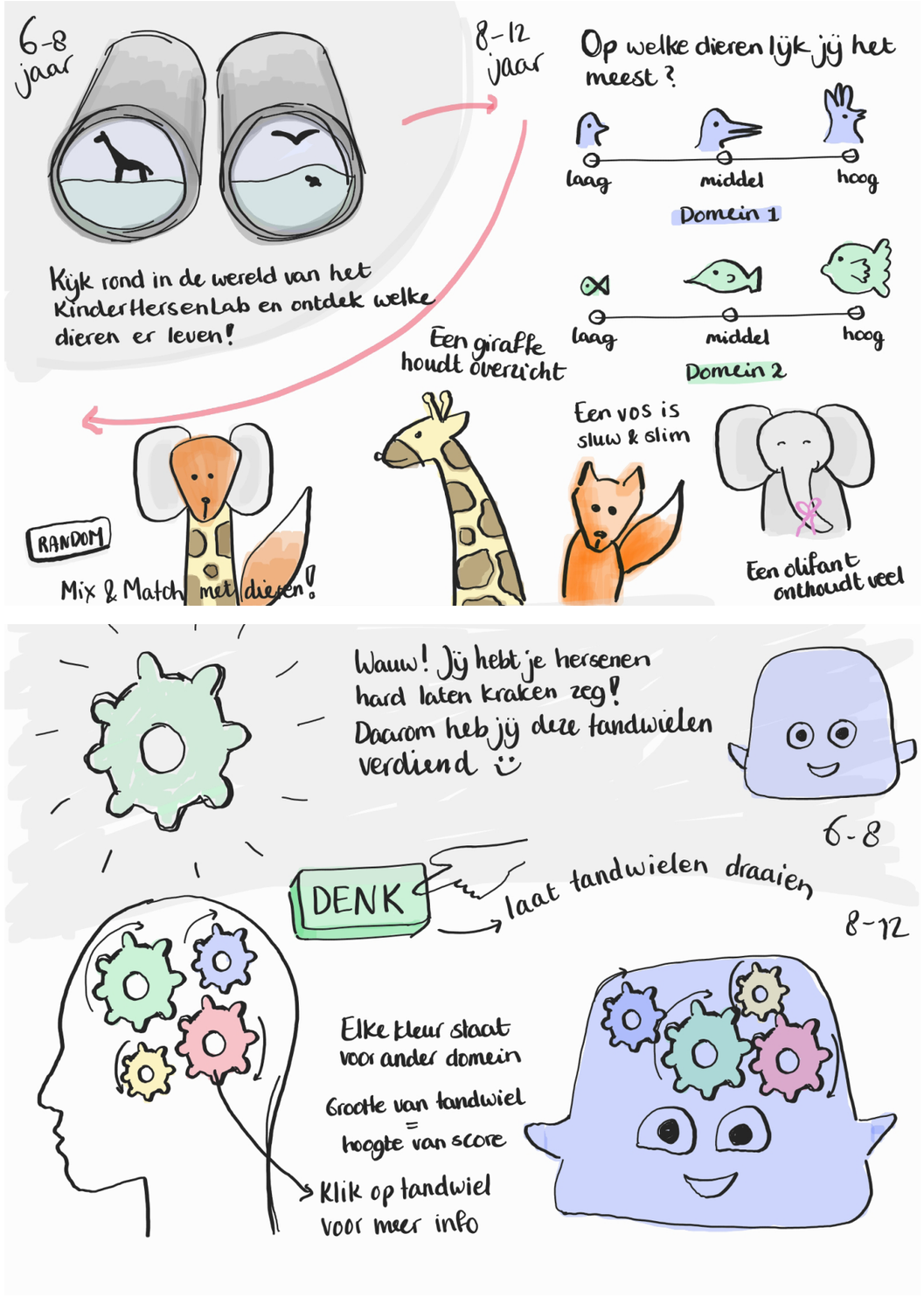
Appendix N: Idea directions for each test



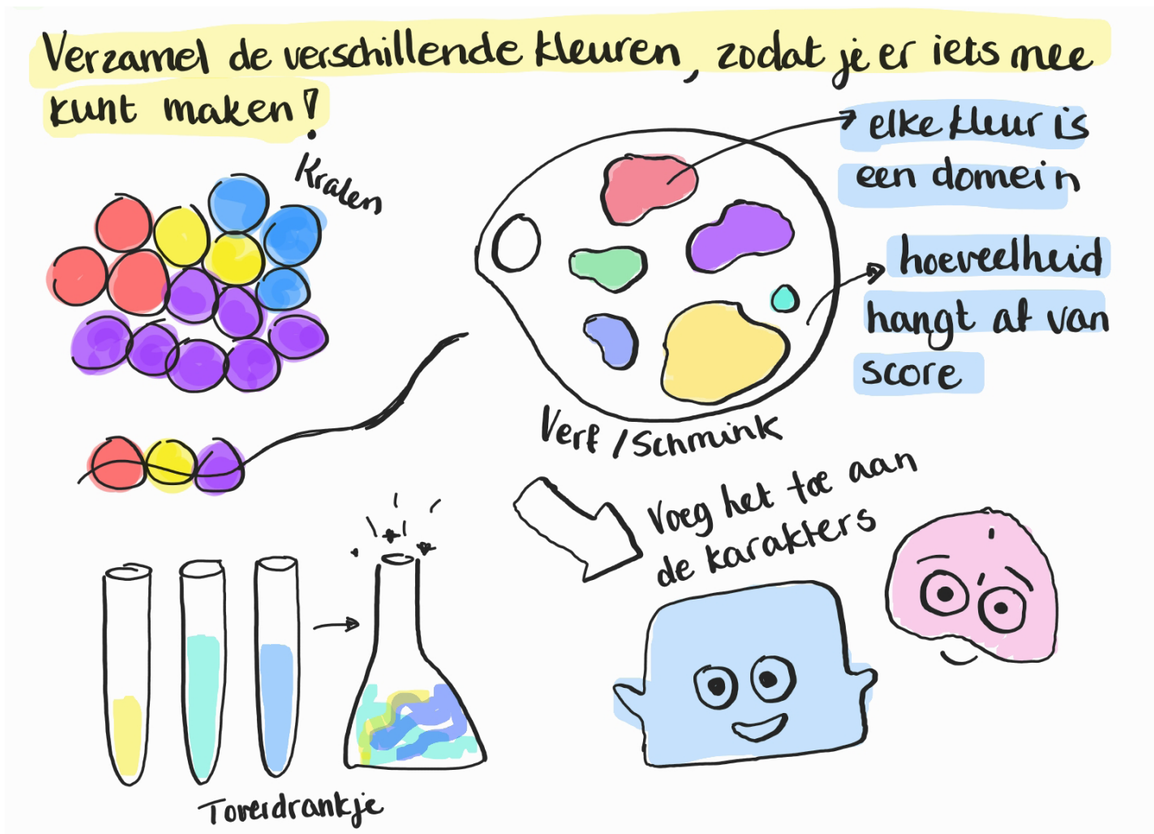

Verwonderd door de stroompjes in je hoofd
Door de jaren verdwijnen kleuren
1
2
3
4
↳ Mooie weergave van bewegende kleuren door je hoofd
→ reageert op aanraking
BRAIN BEEHIVE
Hersenontwikkeling
Bijen werken samen om een sterke bijenkorf te bouwen
Bijen zoemen naar elkaar → hersen signalen
Verschillende bijen, verschillende golfjes
Reageren op prikkels
↳ lichtflitsen of aanstoten laat de bijen schrikken


Ontdek het heelal
→ Het schitteren van een ster geeft de activiteit aan
Kijk, een netwerk vormt zich!
Kijk met je telescoop, wat zie je gebeuren?
Bij oudere kinderen, gaat de sterrenhemel meer op hun eigen hersenen lijken...
Weet je nog? Eerst werd je hoofd gemeten. Toen gingen we spelletjes doen. Toen leerden we over de golfjes
→ Beeld uit EEG-spel in KHL
Hey, kijk nou! Wie maakt die golfjes?
hersencel
Hersenfeestje
Dansfeest in je hoofd
Alle hersencellen in je hoofd praten druk door elkaar
Meer activiteit = meer dansen
Sorteer alle lijntjes om te ontdekken wat de cellen zeggen
Oh jee! Er is ruzie...
↳ epilepsie
Stuur de bewaker erop af
↳ medicijnen

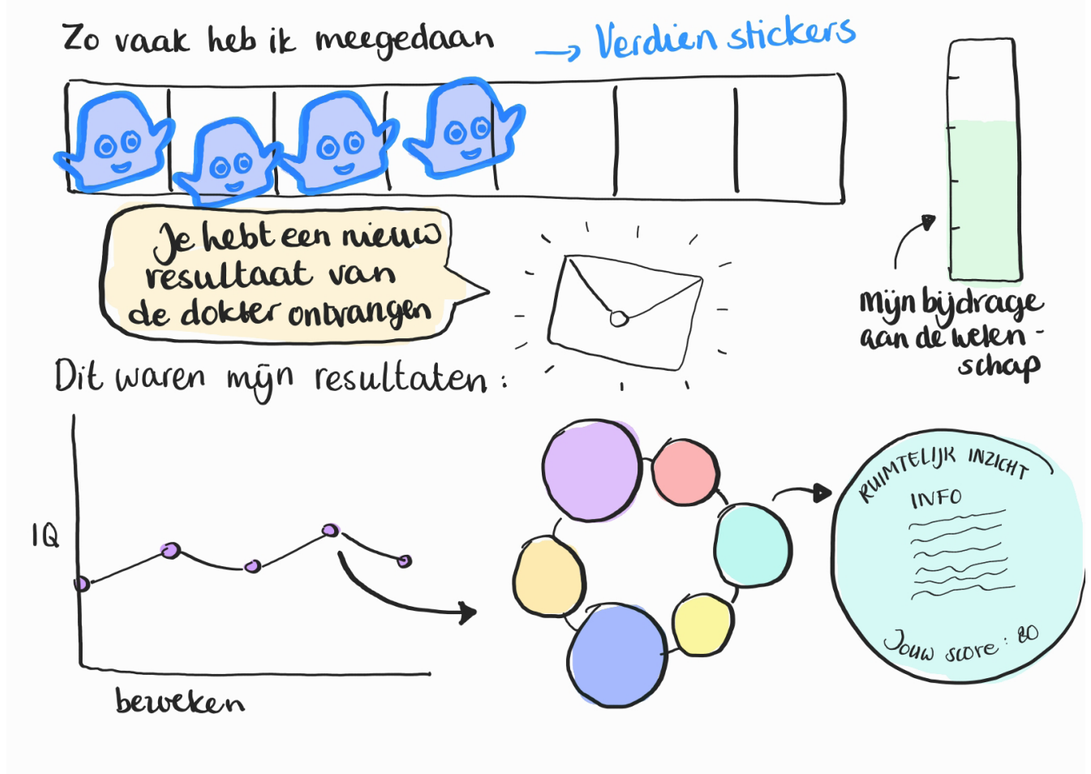
IQ-test


6-8 jaar
8-12 jaar
Kijk rond in de wereld van het KinderHersenLab en ontdek welke dieren er leven!
Op welke dieren lijk jij het meest?
laag
middel
hoog
Domein 1
laag
middel
hoog
Domein 2
Een giraffe houdt overzicht
Een vos is sluw & slim
Een olifant onthoudt veel
RANDOM
Mix & Match met dieren!
Wauw! Jij hebt je hersenen hard laten kraken zeg!
Daarom heb jij deze tandwielen verdiend
6-8
DENK
laat tandwielen draaien
8-12
Elke kleur staat voor ander domein
Grootte van tandwiel = hoogte van score
Klik op tandwiel voor meer info

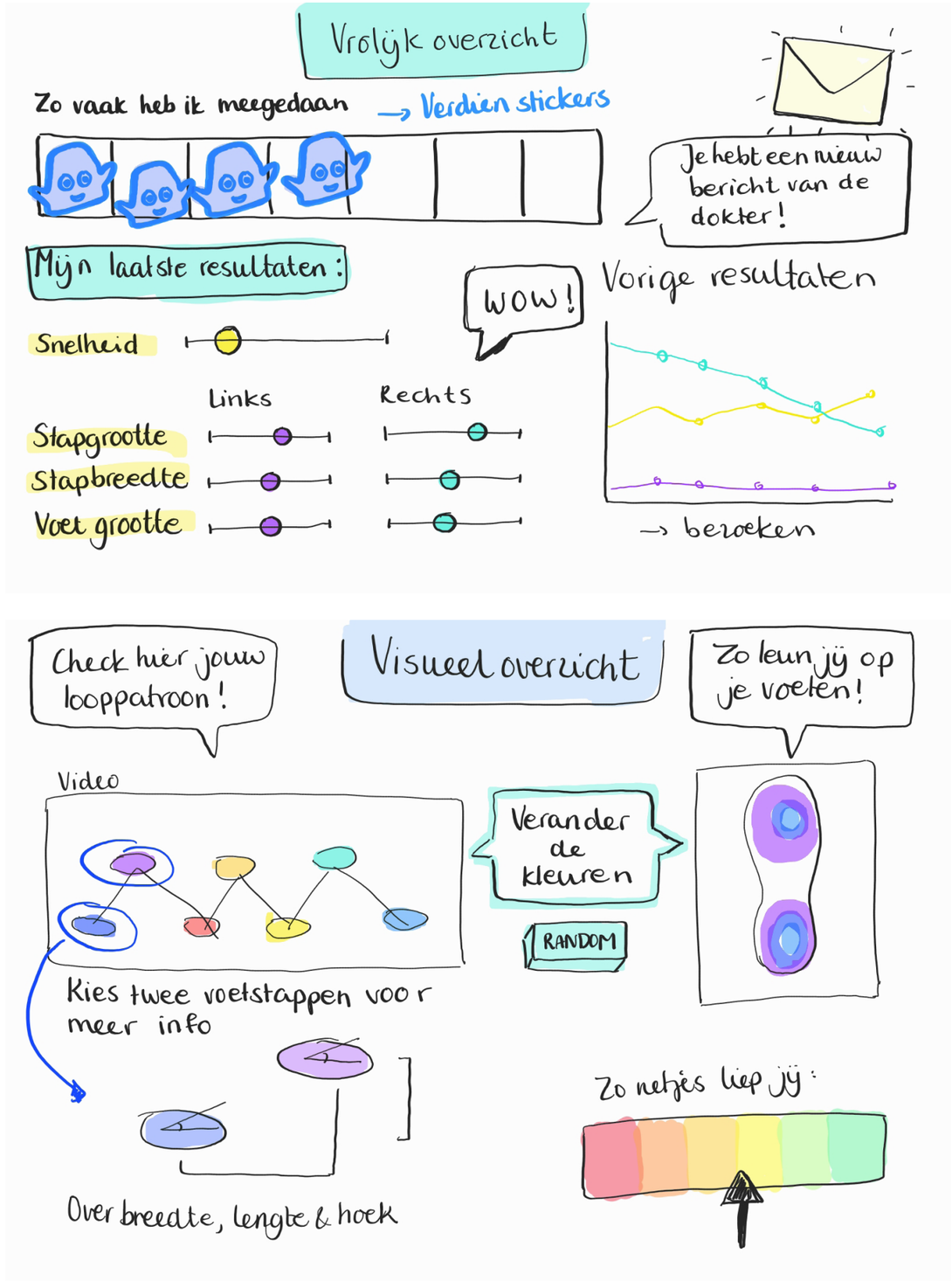

Loop rond door het KHL-bos
en kijk naar de reflectie van jezelf in het water (voor de resultaten van de IQ-test)
Vogels fluiten
Wat verzamelt zich allemaal om je heen?
In de achtergrond zie je dingen die je score mogelijk beïnvloed hebben (zenuwen, ADHD, trauma's)
FLORA & FAUNA
Zoek op in het grote boek wat alles betekent
elk element betekent een (sub)domein
De psycholoog heeft de sleutel


Verzamel de verschillende kleuren, zodat je er iets mee kunt maken!
Kralen
elke kleur is een domein
hoeveelheid hangt af van score
Verf / Schmink
Voeg het toe aan de karakters
Toverdrankje


Word de KHL kampioen!
Medaille voor het meedoen
Scoor punten door
mee te doen
goed mee te werken
een hoge score te halen
over de domeinen te leren
Versla je vrienden
Ranking van deelnemers
1 2 3 4 5 6 7 8 9
10 11 12 13 14 Jij! 15 16 17 18
JOUW SCORE
226 pt
JOUW IQ
84
1
2
3

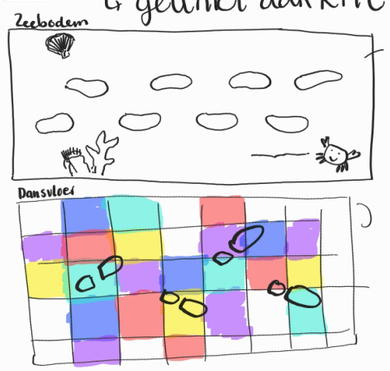

Zo vaak heb ik meegedaan
→ Verdien stickers
Je hebt een nieuw resultaat van de dokter ontvangen
Mijn bijdrage aan de weten-schap
Dit waren mijn resultaten:
IQ
bewerken
RUIMTELIJK INZICHT
INFO
Jouw score: 80

Walking mat


Vrolijk overzicht
Zo vaak heb ik meegedaan
→ Verdien stickers
Je hebt een nieuw bericht van de dokter!
Mijn laatste resultaten:
WOW!
Vorige resultaten
Snelheid
Links
Rechts
Stapgrootte
Stapbreedte
Voet grootte
→ bezoeken
Check hier jouw looppatroon!
Visueel overzicht
Zo leun jij op je voeten!
Video
Verander de kleuren
RANDOM
Kies twee voetstappen voor meer info
Over breedte, lengte & hoek
Zo netjes liep jij:

Wandeling

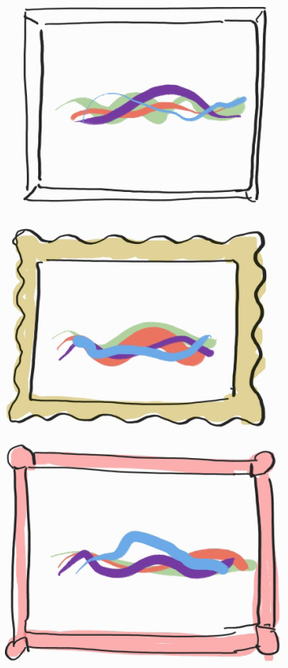
Kies je ondergrond
↳ gelinkt aan KHL

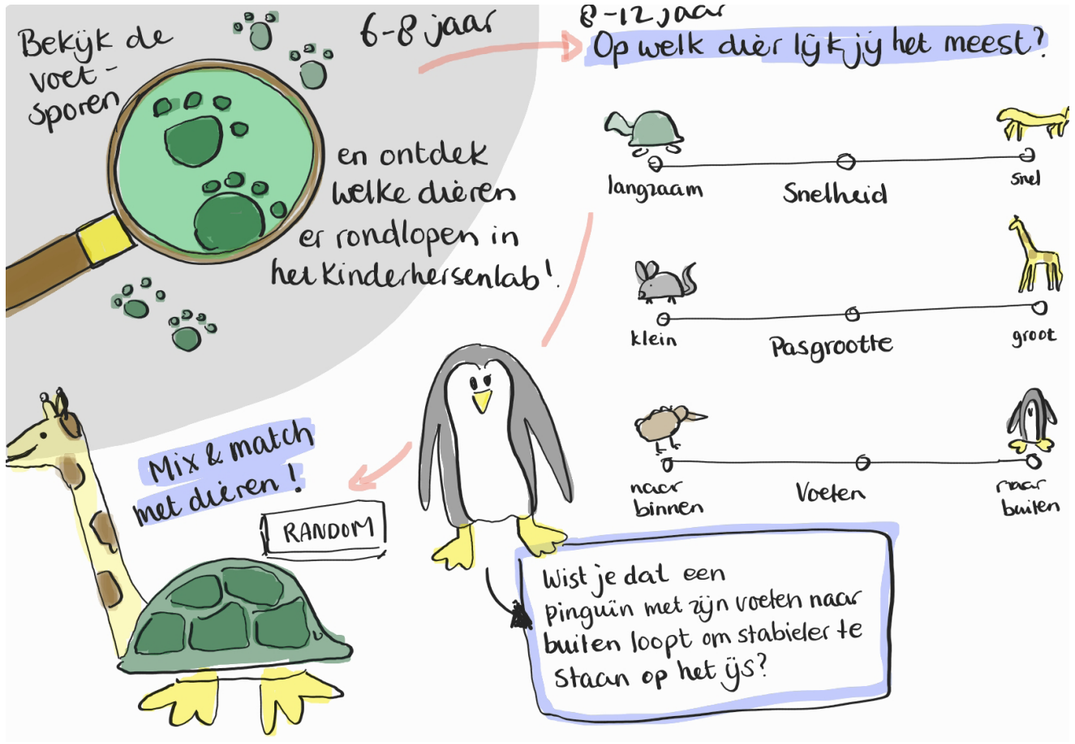


Kunstwerkjes

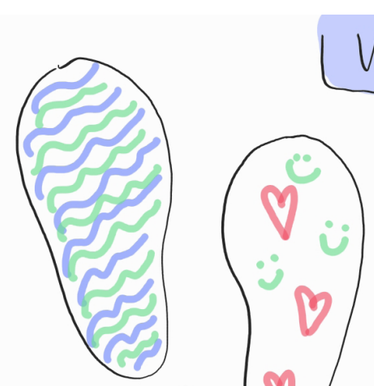
↳ elke keer heen en weer lopen zorgt voor een penseelstreek
Zo vorm je bij elk bezoek een kunstwerkje

Eerdere bezoeken

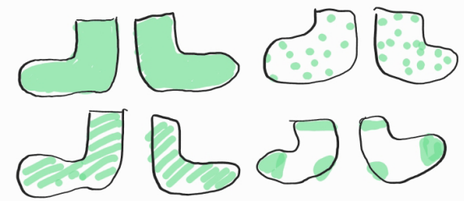




Versier je voetafdruk



Zelf versieren
of..
Kies je sokken uit



Appendix O: Weighted objective decision matrices

Wens	Wensen	Gewicht	Hersenfeestje Score	Hersenfeestje totaal	Ontdek het heelal Score	Ontdek het heelal totaal	Verwonderende stroompjes Score	Verwonderende stroompjes totaal	Wordt KHL kampioen Score	Wordt KHL kampioen totaal	Vrolijk overzicht Score	Vrolijk overzicht totaal	Brain Beehive Score	Brain Beehive totaal	
1	empowererd to react	35	9	315	8	280	4	140	3	105	7	245	8	280	
2	support during consult	35	7	245	5	175	6	210	5	175	7	245	6	210	
3	link to test-experience	25	6	150	8	200	5	125	6	150	2	50	8	200	
4	easy to process for hcp	30	7	210	4	120	5	150	7	210	9	270	4	120	EEG
5	actively assess and engage	30	8	240	7	210	6	180	9	270	5	150	7	210	
6	link to daily life	40	7	280	6	240	5	200	5	200	6	240	6	240	
7	positive influence on self imag	15	7	105	8	120	8	120	2	30	4	60	8	120	
8	invites parents to discuss	15	8	120	6	90	5	75	6	90	7	105	8	120	
9	multiple years	10	7	70	7	70	6	60	6	60	7	70	6	60	
10	hcp collaborate efficiently	10	6	60	6	60	6	60	6	60	6	60	6	60	
totaal		11	245	1795		1565		1320		1350		1495		1620	

Wens		Gewicht	Hersenkraker Score	Hersenkraker totaal	Schmink en kralen Score	Schmink en kralen totaal	De denkvijver Score	De denkvijver totaal	Wordt KHL kampioen Score	Wordt KHL kampioen totaal	Vrolijk overzicht Score	Vrolijk overzicht totaal	De dieren van het KHL Score	De dieren van het KHL totaal	
1	empowererd to react	40	6	240	6	240	8	320	7	280	7	280	9	360	
2	support during consult	35	6	210	5	175	8	280	7	245	7	245	5	175	
3	link to test-experience	20	6	120	6	120	7	140	8	160	9	180	6	120	
4	easy to process for hcp	20	8	160	5	100	7	140	6	120	8	160	6	120	
5	actively assess and engage	30	7	210	10	300	7	210	9	270	5	150	8	240	IQ
6	link to daily life	30	5	150	7	210	7	210	8	240	4	120	7	210	
7	positive influence on self imag	40	6	240	8	320	9	360	2	80	6	240	6	240	
8	invites parents to discuss	30	6	180	7	210	8	240	8	240	7	210	8	240	
9	multiple years	25	2	50	8	200	7	175	7	175	8	200	8	200	
10	hcp collaborate efficiently	10	7	70	6	60	7	70	5	50	7	70	6	60	
totaal		280		1630		1935		2145		1860		1855		1965	

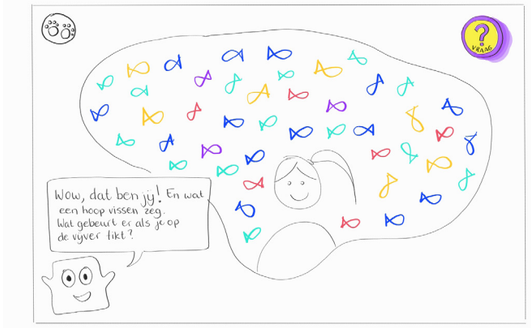
Wens		Gewicht	Wandeling Score	Wandeling totaal	Versier je voetafdruk Score	Versier je voetafdruk totaal	Kunstwerkjes Score	Kunstwerkjes totaal	Wordt KHL kampioen Score	Wordt KHL kampioen totaal	Vrolijk overzicht Score	Vrolijk overzicht totaal	De dieren van het KHL Score	De dieren van het KHL totaal	
1	empowererd to react	30	8	240	7	210	7	210	8	240	6	180	9	270	
2	support during consult	40	8	320	4	160	5	200	5	200	7	280	9	360	
3	link to test-experience	35	10	350	6	210	5	175	7	245	8	280	8	280	
4	easy to process for hcp	25	8	200	7	175	5	125	5	125	8	200	7	175	
5	actively assess and engage	25	7	175	8	200	7	175	7	175	6	150	8	200	LOOPMAT
6	link to daily life	35	8	280	6	210	5	175	6	210	5	175	8	280	
7	positive influence on self imag	25	7	175	7	175	7	175	5	125	6	150	8	200	
8	invites parents to discuss	15	7	105	6	90	6	90	8	120	7	105	8	120	
9	multiple years	30	7	210	8	240	7	210	7	210	7	210	8	240	
10	hcp collaborate efficiently	20	8	160	6	120	7	140	5	100	8	160	6	120	
totaal		280		2215		1790		1675		1750		1890		2245	

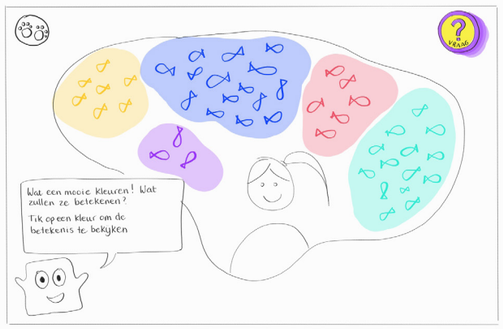
Wensen

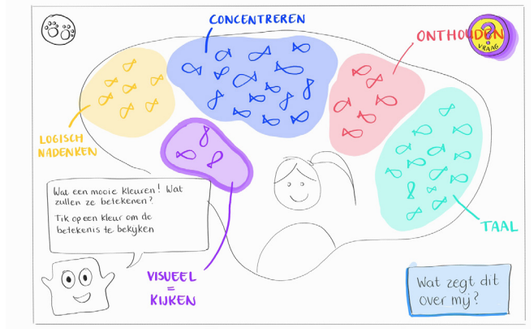
1 Children feel empowered to think about and react on their results
2 The Self-portrait supports the HCP in their explanations during consultation
3 The visualisation is easy for children to link to the test-experience
4 The time and effort to edit the Self-portrait should be minimized / It is easy to process for HCP's
5 Children can actively assess and engage with information in a fun way
6 The visualisations of the results are recognizeable / easy to link to daily life
7 The app has a positive influence on the self-image of a child
8 The app invites parents to discuss results with their children
9 The Self-portrait stays interesting over multiple years of use
10 The app allows caregivers of multiple disciplines to collaborate efficiently

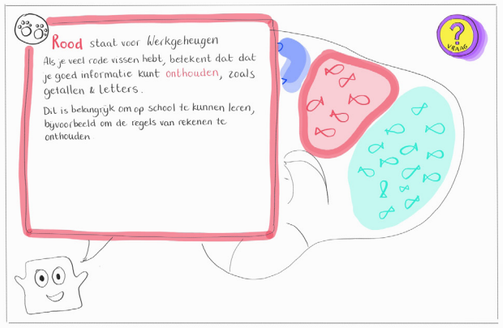
Appendix P: Research set-up concept evaluation with children

Screen drawings iq-test

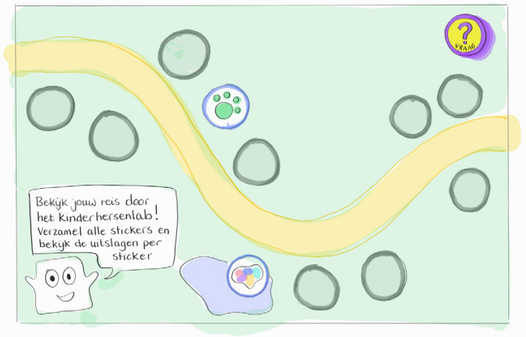


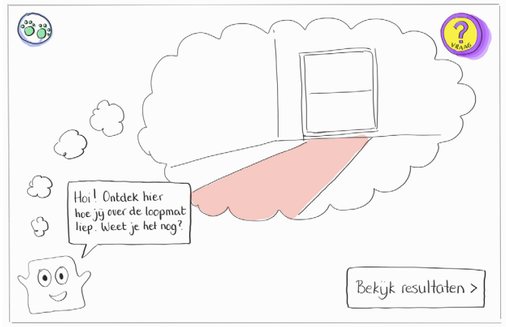


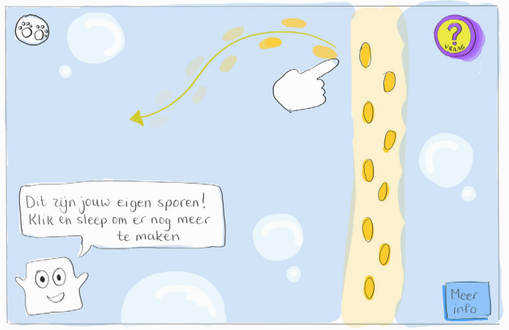


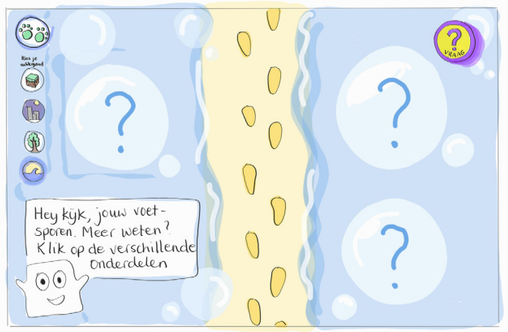


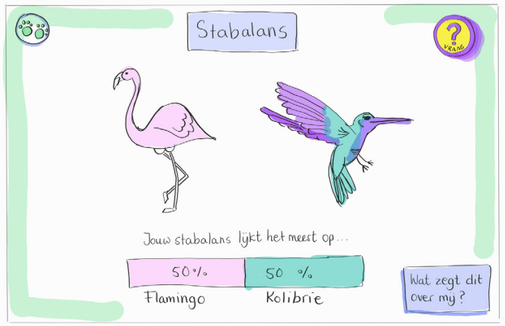
Screen drawings walking mat

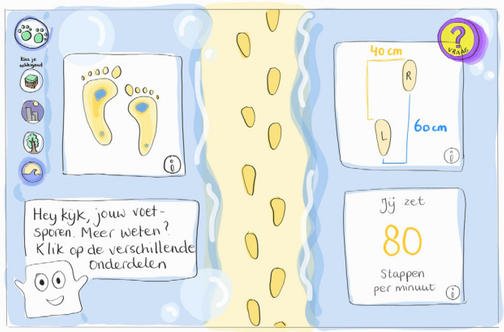


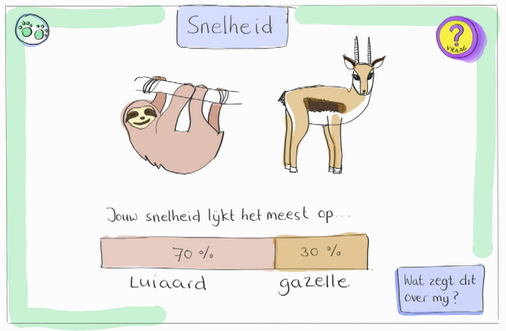




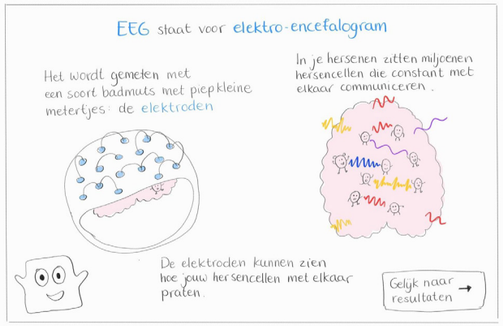


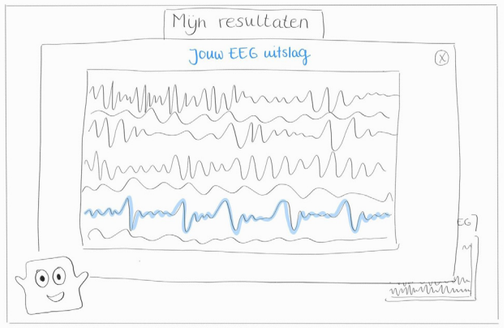


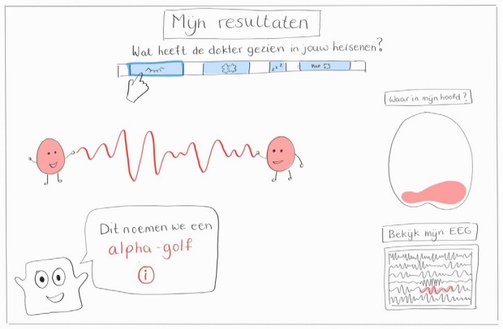


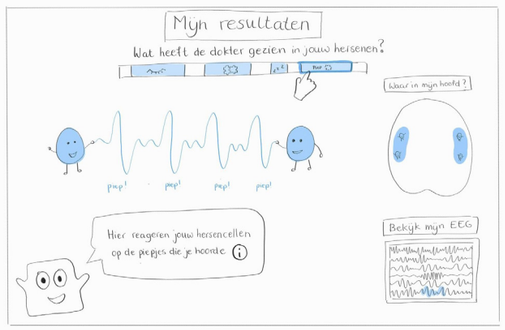


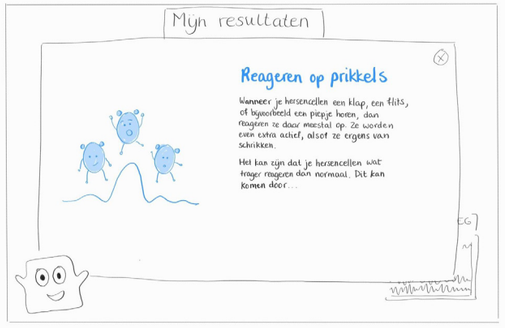
Screen drawings EEG











Conceptevaluatie

Wat wil ik weten?

- Past de taal bij de leeftijd, is het te begrijpen?
- Past de interactie bij de leeftijd?
    - Snap je wat je moet doen?
    - Is het te kinderachtig? Is het te moeilijk?
- Gaat het haar om het spelen of ook om informatie krijgen?
- Is het te relateren aan de testjes?
- Voelt het niet als een waarde-oordeel, is het niet te confronterend?
    - Is het maken van een vergelijking op een goede manier gedaan?
- Zorgt het voor meer begrip over eigen aandoening?

Interview guide 7 jaar:

1. Introductie Kinderhersenlab & ondertekenen toestemmingsverklaring
2. Introductie / leren kennen
    a. Kleurplaat: jezelf natekenen.
        i. Wat maakt nou dat jij dit bent? Wat heb jij getekend?
        ii. Waar ben jij heel goed in?
        iii. Waar ben jij niet zo goed in? Of wat vind je niet leuk om te doen?
        iv. Jij gaat wel eens naar het ziekenhuis, waarom is dat?
            1. En als je dan met de dokter praat, wat voor dingen vertelt de dokter allemaal?
3. Uitleg geven van de test
    a. Vandaag ga jij me helpen met het ontwerpen van het Zelfportret. Dat is een app voor kinderen die net als jij wel eens naar het Sophia Kinderziekenhuis gaan. In het Sophia hebben ze een speciaal Kinderhersenlab, waar kinderen allerlei testjes uitvoeren. Als je als kind meedoet, dan kom je ééns in de paar jaar langs om de testjes te doen. In het Zelfportret, de app waar we het vandaag over hebben, komen de uitslagen van al die testjes te staan, maar dan op een manier die makkelijk te begrijpen is, en leuk is voor kinderen!
    b. Ik heb bedacht hoe die app eruit moet zien, en vandaag wil ik dat graag met jou delen en ben ik benieuwd wat jij er van vindt. Jij bent ten slotte de echte expert! Hoe gaat we dat doen?
    c. Jij hebt natuurlijk nog niet de testjes in het Kinderhersenlab gedaan, maar we gaan doen alsof. Daarom zal ik je duidelijk proberen uit te leggen hoe de testjes in het Kinderhersenlab gaan.
4. Dag 1: Afgelopen vrijdag - Uitleg geven over drie tests in het KHL.
    a. Stel je voor, we doen even alsof, dat jij afgelopen vrijdag naar het Kinderhersenlab bent geweest, samen met jouw mama. Kijk, zo ziet de deur naar het lab eruit. Vrijdag heb je drie verschillende testjes gedaan, en ik zal je uitleggen hoe elk testje werkt.
        i. Zie je die rode mat op de vloer? Dat is de loopmat. Over die mat moet je een paar keer heen en weer lopen. Op het grote scherm mag je zelf kiezen welke achtergrond jij hebt. Bijvoorbeeld in het bos of onder water. Daarnaast moet je ook op één been proberen te staan.
        ii. Na de loopmat ga je door naar de IQ-test. **Weet je wat IQ betekent?** Tijdens een IQ-test moet je verschillende opdrachtjes doen en puzzeltjes oplossen. Er

wordt dan gekeken hoe goed jij bijvoorbeeld kan leren of dingen kan onthouden.

5. Je bent weer thuis, hebt lekker weekend. Wat heb je het afgelopen weekend gedaan?
6. Dag 4: vandaag – Uitslag ontvangen in het Zelfportret
    a. Dan is het vandaag maandag! Vandaag krijg je de uitslagen van de testjes in jouw Zelfportret app! Helaas is er nog geen échte app, maar ik heb hier tekeningen die de app nadoen.
        i. Open de app maar
        ii. Wat ga je als eerste bekijken?
    b. **Loopmat & IQ-test vragen**
        i. Wat zie je hier?
        ii. Wat betekent dat allemaal?
        iii. Wat zou je nu doen met deze informatie?
        iv. Vragensticker: wat denk je dat dit betekent?
            1. Hiermee kun je een sticker plakken in de app als je ergens een vraag over hebt.t
        v. Welke onderdelen van de loopmat vind je leuk om te weten?
        vi. Herken je jezelf in de IQ-vijver?
    c. **Algemene vragen:**
        i. Vind je het leuk om op deze manier naar jouw testjes te kijken?
            1. Wat vind je er leuk aan?
            2. Wat vind je er niet leuk aan?
            3. Hoe kan het leuker worden?
        ii. Helpt dit jou om de dokter beter te snappen?
        iii. Wat zou je uit de app aan de dokter laten zien?
        iv. Welke onderdelen mis je in de app?

Vragen voor ouders

Introductie

Wat is xxx voor kind?

Hoe kijkt xxx tegen haar aandoening aan? Wat snapt ze en hoe spannend of normaal vind ze alles?

Uitleg tests

Loopmat + IQ-test

Concepten laten zien

- Wat vind u van de manier waarop de informatie gepresenteerd wordt?
    - Past het bij de leeftijd van Xxx?
        - Welke manier van informatie zou xxx behoefte aan hebben? De dieren, of meer gedetailleerd?
- Denkt u dat xxx deze app zelfstandig kan gebruiken? Waarom wel/niet?
- IQ-test & loopmat
    - Stel, xxx kan in de app opzoeken hoe de gemiddelde IQ vijver eruit ziet, en die met haar eigen vijver vergelijken. Wat zou u daarvan vinden?
    - Stel, Xxx kan in de app opzoeken hoe het gemiddelde voetenspoor van een kind van 7 eruit ziet en het vergelijken. Wat zou u daarvan vinden?
    - Zou u de uitgebreide informatie samen met Xxx bekijken en bespreken?
    - Denk je dat dit Xxx helpt om vragen te stellen / de dokter te snappen tijdens een gesprek?
- Welke informatie is het lastigste voor Xxx om te begrijpen?
- Welke informatie ligt het meest gevoelig bij Xxx?
- Wat zal Xxx het liefst willen weten?
- Welke onderdelen vind u goed? Waarom?
- Welke onderdelen vind u minder goed? Waarom?
- Mist u nog onderdelen, hoe kan de app verbeterd worden?

Appendix Q: Adjusted System Usability Scale

(Putnam et al., 2020)

Sus - statement	**Child version**	**Nederlandse vertaling**
I think that I would like to use this system frequently	If I had this [app] on my iPad, I think that I would like to play it a lot	Als ik deze [app] op mijn iPad had, denk ik dat ik het graag veel zou willen spelen.
I found the system unnecessarily complex	I was confused many times when I was playing [app]	Ik was vaak in de war toen ik [app] speelde.
I thought the system was easy to use	I thought [app] was easy to use	Ik vond [app] gemakkelijk te gebruiken.
I think that I would need the support of a technical person to be able to use this system	I would need help from an adult to continue to play [app]	Ik zou hulp van een volwassene nodig hebben om [app] verder te kunnen spelen.
I found the various functions in this system were well integrated	I always felt like I knew what to do next when I played [app]	Ik had altijd het gevoel dat ik wist wat de volgende stap moest zijn als ik [app] speelde.
I thought there was too much inconsistency in the system	Some of the things I had to do when playing [app] did not make sense	Sommige dingen die ik moest doen tijdens het spelen van [app] waren niet logisch.
I would imagine that most people would learn to use this system very quickly	I think most of my friends could learn to play [app] very quickly	Ik denk dat de meeste van mijn vrienden snel zouden kunnen leren om [app] te spelen.
I felt the system was cumbersome to use	Some of the things I had to do to play [app] were kind of weird	Sommige van de dingen die ik moest doen om [app] te spelen waren een beetje vreemd.
I felt very confident using the system	I was confident when I was playing [app]	Ik voelde me zelfverzekerd tijdens het spelen van [app].
I needed to learn a lot of things before I could get going with this system	I had to learn a lot of things before playing [app] well	Ik moest veel dingen leren voordat ik [app] goed kon spelen.
Added; enjoyment	I really enjoyed playing [app]	Ik heb echt genoten van het spelen van [app].
Added; enjoyment	If we had more time, I would keep playing [app]	Als we meer tijd hadden, zou ik [app] blijven spelen.
Added; enjoyment	I plan on telling my friends about [app]	Ik ben van plan om mijn vrienden over [app] te vertellen.

Appendix R: Research set-up prototype evaluation in class

12:00-12:30 Voorbereiding

- Klaarzetten op digibord:
  - Presentatie
  - Filmpje jeugdjournaal (test geluid)
- Op elke tafel neerleggen:
  - Ipads voor elk kind
  - Eén extra ipad met het prototype erop
  - Blaadjes met de test-uitleg
- Zorgen dat de link makkelijk naar kinderen verstuurd kan worden (overleg met Nadine)

12:45 – 13:10 Klassikaal onderdeel 1

10 min presentatie door Benthe

- Karlijn foto maken van Benthe die presenteert (geen gezichten van kinderen in beeld)
  - Liefst met scherm over afstudeerproject in beeld

15 min app uitproberen + enquête invullen

- Rondlopen en helpen met het prototype (opnieuw) opstarten
- Observeren en vragen stellen (neem geluid op of notities)
  - Ik zag dat je dit deed (actie)... waarom?
  - Wat valt/viel je als eerste op als je dit ziet?
  - Wat zie je nog meer allemaal?

13:10-13:15 opruimen en klassenwissel

13:15 – 13:40 Klassikaal onderdeel 2

10 min presentatie door Benthe

- Karlijn: enquête uitslagen bekijken en punten noteren die opvallen

15 min app uitproberen + enquête invullen

- Rondlopen en helpen met het prototype (opnieuw) opstarten
- Observeren en vragen stellen (neem geluid op of notities)
  - Ik zag dat je dit deed (actie)... waarom?
  - Wat valt/viel je als eerste op als je dit ziet?
  - Wat zie je nog meer allemaal?

13:40 – 13:45 opruimen en kinderen uitnodigen interview (Nadine)

13:45 – 14:30 Interviews

3 rondes (voor elke test eentje) van 15 minuten met twee of drie kinderen

Klaarleggen:

- Ipad met prototypes
- Laptop voor notuleren
- Blaadje met interviewvragen

Taken Karlijn:

Notuleren (als mogelijk ook observaties opschrijven) & tijd in de gaten houden

Andere kinderen 13:45 – 14:30 Ontwerpopdracht

- Lege blaadjes
- Blaadjes met schermen erop
- tekenspullen

Interview vragen

Topics uit enquête:

- Taalgebruik makkelijk moeilijk: past het bij de leeftijd?
- Als app onlogisch / verwarrend is, waar komt dat door?
- Ik moest veel leren, is het te ingewikkeld? Waar komt dat door?
- Als de app saai is of informatie niet interessant, waarom?
- Waarover laat de app je nadenken?
- Ik word blij van resultaten, waarom?
- Gesprek met dokter, waar helpt het bij?

- Welke dingen vonden jullie niet goed, of onduidelijk aan de app? Waarom?
- Wat vond je goed aan de app? Waarom vond je dat?
- Wat zou je willen veranderen aan de app? Waarom?
- Wat hebben jullie geleerd van deze app?
- Kan de app helpen in het gesprek met de dokter? Zo niet, waarom niet?

Informatiebrief ontwerp-testmiddag in groep 8 (28-9-23)

Beste ouders/verzorgers,

Aanstaande donderdagmiddag zal ik, Benthe Plat, een design-student van de TU Delft, langs komen bij de klas van uw kind. Met deze brief wil ik u graag informeren over deze middag en uw toestemming vragen voor deelname van uw kind.

Als student aan de faculteit Industrieel Ontwerpen leer ik innovaties te creëren die bijdragen aan het welzijn van de samenleving, en die voldoen aan de wensen en behoeften van de gebruiker. Op dit moment werk ik aan mijn afstudeerproject, in opdracht van het Erasmus MC Sophia Kinderziekenhuis in Rotterdam. Hier is kortgeleden het Kinderhersenlab geopend, waar onderzoek wordt gedaan om het ziektebeloop van hersenaandoeningen beter te begrijpen en behandelingen voor kinderen met een hersenaandoening te verbeteren. Hiervoor nemen kinderen met verschillende hersenaandoeningen deel aan een circuit van testjes.

Voor mijn afstuderen werk ik aan “Het Zelfportret”: een app voor de kinderen die deelnemen aan het Kinderhersenlab, waarmee ze op een kindvriendelijke en speelse manier inzicht krijgen in hun eigen testresultaten. Tijdens mijn onderzoek heb ik samengewerkt met de artsen van het Kinderhersenlab, maar ook met verschillende patiënten en hun ouders! Aan de hand van mijn inzichten heb ik een prototype van de app gemaakt, die ik graag in de klas van uw kind zou willen testen.

Tijdens de middag zal ik niet alleen een hoop leren van de feedback van de klas, maar uw kind zal ook een hoop leren over hoe het is om ontwerper te zijn. Hier zal ik een korte presentatie over geven, en kinderen zullen het zelf ervaren door mijn app-prototype uit te testen en na te denken over verbeteringen. Daarnaast dragen ze bij aan een belangrijk doel, ze helpen namelijk hun leeftijdsgenootjes die een hersenaandoening hebben.

Kinderen worden gevraagd feedback te geven in de vorm van een anonieme enquête. Na het invullen van de enquête zullen een aantal kinderen worden uitgenodigd voor een kort interview. Tijdens de gesprekken zal ik geluidsopnames maken. Deze zullen na transcriptie onmiddellijk verwijderd worden, en worden uitsluitend gebruikt voor analyse en documentatie van het project. Kinderen zullen te allen tijde anoniem blijven.

Zou u het bijgevoegde formulier willen invullen/ondertekenen en inleveren bij de leerkracht?

Als u vragen heeft over de testmiddag kunt u mij gerust een mail sturen op b.r.plat@student.tudelft.nl.

Met vriendelijke groeten,

Benthe Plat

Masterstudent Design for Interaction (TU Delft)

User test Zelfportret app

Research goals:

Main goals:

1. Evaluating usability/cognitive ergonomics: what can be improved?
2. Has the design goal been met (in other words: does the app have the desired effect?)
    a. What improvements are needed to meet the design goal?

Questionnaire for children (groep 8)

Welkom bij de vragenlijst die hoort bij het testen van ‘Het Zelfportret – een app voor de kinderen van het Kinderhersenlab’. Superleuk dat je meedoet! Ik wil je vragen om onderstaande vragen zo eerlijk mogelijk in te vullen. Het is geen toets, er is niets goed of fout! Het belangrijkste is dat je eerlijk bent, want jouw antwoorden helpen mij om de app nog beter voor kinderen te maken.

Bij onderstaande vragen moet je steeds antwoord geven op een schaal met vijf bolletjes. Twijfel niet te lang over je antwoord, maar vul gewoon in wat je gevoel zegt. Bij sommige vragen zal ik je vragen om iets meer uitleg te geven over je antwoord. Probeer hier uit te leggen waarom je een bepaalde keuze hebt gemaakt.

Vragen in verschillende categorieën:

Categorie 1a: Gebruiksvriendelijkheid

- De afbeeldingen en tekst in de app zijn duidelijk zichtbaar en leesbaar
    - Helemaal mee oneens … helemaal mee eens
- De taal die gebruikt wordt in de app vind ik…
    - Te makkelijk … te moeilijk
- Ik vind dat de app logisch in elkaar zit
    - Helemaal mee oneens… helemaal mee eens
    - Kun je je antwoord toelichten?
- Het was makkelijk te begrijpen hoe ik de app moest gebruiken
- Als ik niet wist hoe ik de app moest gebruiken was er duidelijke uitleg
- Wat vond je goed of leuk aan de app?
- Wat vond je minder goed of stom aan de app?

Categorie 1b – System Usability Scale

- Als ik deze [app] op mijn iPad had, denk ik dat ik het graag veel zou willen spelen.
- Ik was vaak in de war toen ik [app] speelde.
- Ik vond [app] gemakkelijk te gebruiken.
- Ik zou hulp van een volwassene nodig hebben om [app] verder te kunnen spelen.
- Ik had altijd het gevoel dat ik wist wat de volgende stap moest zijn als ik [app] speelde.
- Sommige dingen die ik moest doen tijdens het spelen van [app] waren niet logisch.
- Ik denk dat de meeste van mijn vrienden snel zouden kunnen leren om [app] te spelen.
- Sommige van de dingen die ik moest doen om [app] te spelen waren een beetje vreemd.
- Ik voelde me zelfverzekerd tijdens het spelen van [app].
- Ik moest veel dingen leren voordat ik [app] goed kon spelen.

Categorie 2: Geschikt/leuk voor kinderen

- Ik vind de informatie in de app interessant
- Ik vond het leuk om te spelen met Het Zelfportret
- Ik ben van plan om mijn vrienden over Het Zelfportret te vertellen
- Ik vond het spelen met Zelfportret saai

Categorie 3: Design goal / Desired effects

- Het ontvangen van mijn resultaten in de app voelt als een beloning voor het meedoen / geeft mij het gevoel dat ik iets heb bereikt.
- Ik ben trots op de resultaten die ik in de app zie / Ik word blij van de resultaten die ik in de app zie
- Ik vond het vervelend om mijn resultaten te bekijken
- Het zien van de resultaten in de app heeft mij aan het denken gezet
    - Waarover?

Geef aan met welk statement je het het meest eens bent:

- De app laat mij zien waar ik slecht in ben
- De app laat mij zien waar ik niet zo goed in ben
- De app laat mij zien waar ik goed en slecht in ben
- De app laat mij zien waar ik goed en minder goed in ben
- De app laat mij zien waar ik goed in ben

Vink aan met welke statements je het eens bent:

- Dankzij deze app leer ik over mezelf
- Dankzij deze app leer ik over mijn hersenaandoening
- Dankzij deze app leer ik over de hersenen
- Dankzij deze app leer ik over het Kinderhersenlab
- Ik leer niet echt iets van deze app

Geef aan met welk statement je het het meest eens bent:

- Het Zelfportret helpt mij om dokters beter begrijpen tijdens een gesprek in het ziekenhuis
- Het Zelfportret helpt mij om meer vragen te stellen aan de dokter
- Het Zelfportret helpt mij om met de dokter in gesprek/discussie te gaan

Rondlopen tijdens het testen van de app

- Ik zag dat je dit deed (actie)... waarom?
- Wat valt/viel je als eerste op als je dit ziet?
    - Wat zie je nog meer allemaal?

Redenering voor vragen kiezen (design goal & literatuur)

Design goal

The goal is to create a personally rewarding visualization of the test-data of the EEG, IQ-test and walking mat for each child that visits the KHL, by highlighting their personal achievements and empowering children become aware of and accept who they are

*in a form that is **integrated in the clinical workflow** of the Pediatric Brain Centre, and **supportive during the full care journey**, so that HCPs see the Selfportrait as **an enrichment** to their work.*

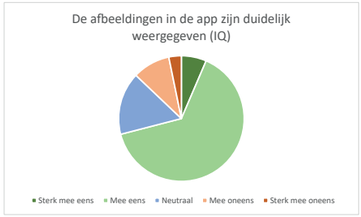
Onderdeel design goal	**Questionnaire statements**	**Interview questions**
Personally rewarding	Ik ben trots op de resultaten die ik in de app zie / Ik word blij van de resultaten die ik in de app zie Ik vond het vervelend om mijn resultaten te bekijken Ik vind het Zelfportret nuttig	Hoe zou jij je voelen als je de resultaten op deze manier zou ontvangen en kunnen bekijken? (trots, blij, geschrokken, teleurgesteld?) Hoe kwam dat? Is dat iets goeds of niet?
Highlighting personal achievements	Het ontvangen van mijn resultaten in de app voelt als een beloning voor het meedoen / geeft mij het gevoel dat ik iets heb bereikt. De app laat mij zien waar ik goed en slecht in ben	
Feeling empowered to participate	Het zien van de resultaten in de app heeft mij aan het denken gezet Het Zelfportret helpt mij om meer vragen te stellen aan de dokter	Op welke momenten / voor welke redenen zou jij de Zelfportret-app gebruiken (als jij een patiënt was die naar het Kinderhersenlab ging)?
Aware of / accept who they are	De app laat mij zien waar ik goed en slecht in ben Dankzij deze app leer ik over…	Wat heb je geleerd van deze app?
Supportive during full care journey		Hoe goed vind je het Zelfportret passen bij de testjes in het Kinderhersenlab?

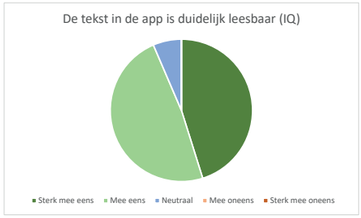
		Op welke momenten / voor welke redenen zou jij de Zelfportret-app gebruiken?

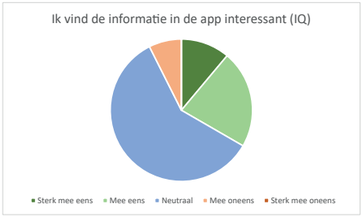
Usability checklist	**Explanation**	**Dutch questionnaire questions**
Visual clarity	Information displayed on the screen should be clear, well organized, and easy to read.	**De tekst en afbeeldingen in de app zijn duidelijk leesbaar** **De taal die gebruikt wordt in de app vind ik…(makkelijk/moeilijk)**
Consistency	The way the system looks and works should be consistent at all times	**Ik vind dat de app logisch in elkaar zit (+toelichting)**
Compatibility	The way the system looks and works should be compatible with user expectations.	**Het was makkelijk te begrijpen hoe ik de app moest gebruiken**
Informative Feedback	Users should be given clear, informative feedback on where they are in the system.	Het is duidelijk welke stappen ik moet zetten om de juiste informatie te vinden
Explicitness	The way the system works and is structured should be clear to the user.	
Appropriate Functionality	The system should meet the needs and requirements of users when carrying out tasks.	
Flexibility and Control	To suit the needs and requirements of all users, the interface should be sufficiently flexible in structure, information presentation, and in terms of what the user can do.	Ik kon de app ontdekken op de manier dat ik het wilde
Error Prevention and Correction	The system should be designed to minimize the possibility of user error; users should be able to check their inputs and to correct errors.	Ik kon mijn fouten herstellen
User Guidance and Support	Informative, easy-to-use, and relevant guidance and support should be provided.	**Als ik niet wist hoe ik de app moest gebruiken was er duidelijke uitleg**
System Usability Problems		Tegen welke problemen liep je aan?
General System Usability ○ Best aspect: ○ Worst aspect: ○ Common mistakes: ○ Recommended changes		**Wat vond je goed aan de app** **Wat vond je niet leuk aan de app** Wat zou je willen veranderen aan de app?

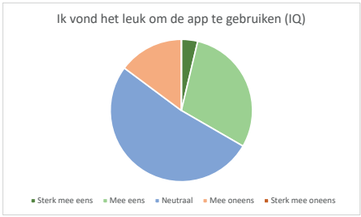
Appendix S: Results class evaluation

IQ-test

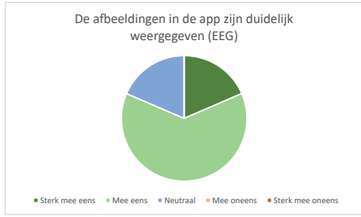


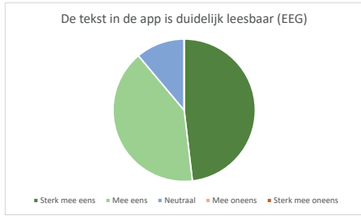


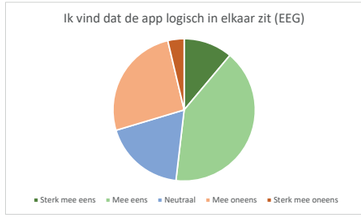


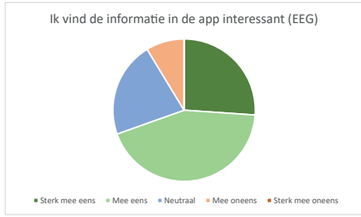


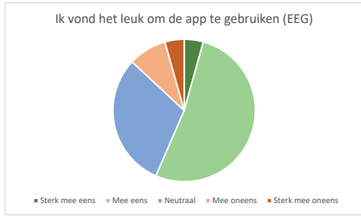
EEG



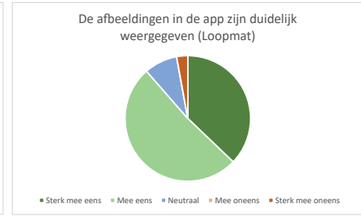


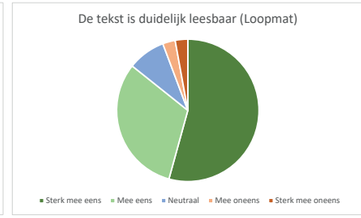


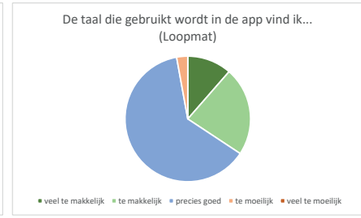


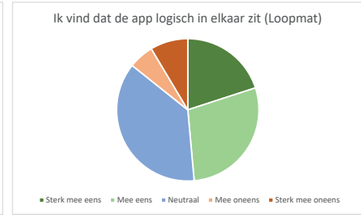


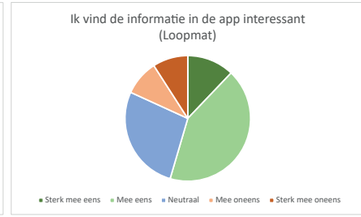
Walking mat

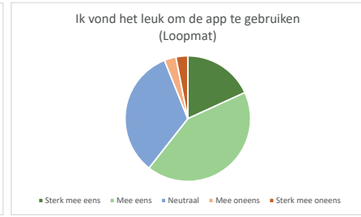


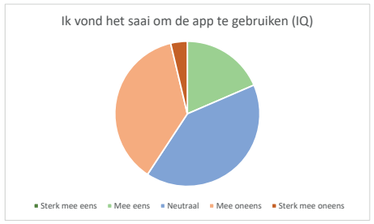


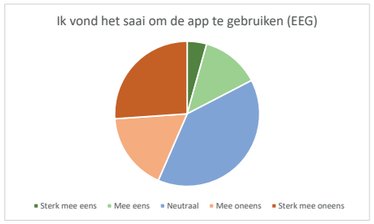


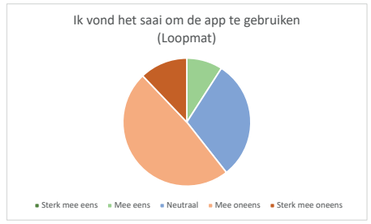


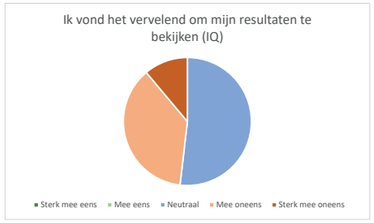


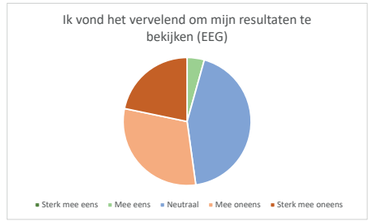


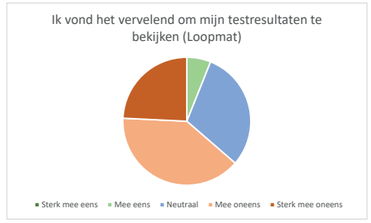


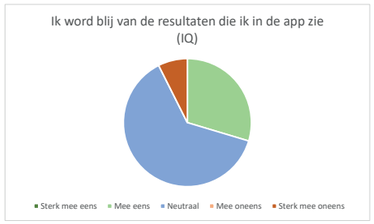


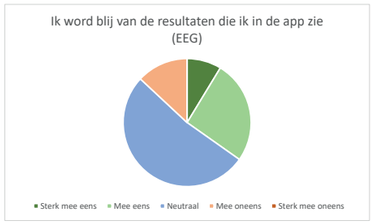


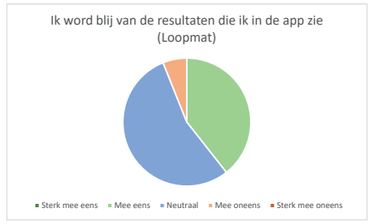


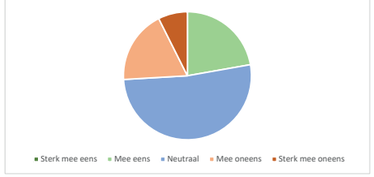


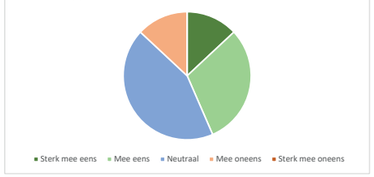


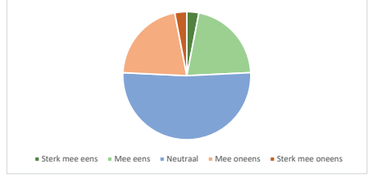


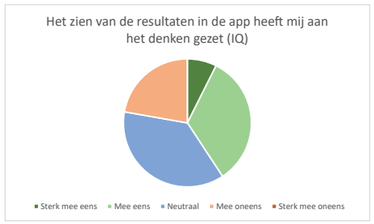


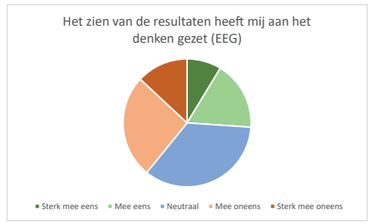


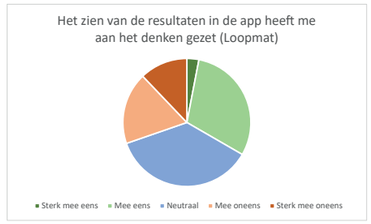












Appendix T: Interview guide final evaluation (children & parents)

Interview guide final evaluation

Intro

Vandaag gaan we het hebben over de app van het Kinderhersenlab: het Zelfportret. Hierin kunnen de kinderen die mee hebben gedaan aan het lab hun eigen testresultaten bekijken, op een manier die past bij hun leeftijd, en leuk en interessant voor ze is. Deze app bestaat nog niet, we zijn nog bezig met hem ontwerpen. En daarvoor heb ik jouw hulp nodig. Ik heb een ontwerp gemaakt voor de app, en wil graag horen wat jij daarvan vindt. Belangrijk om te benoemen is dat de app nog niet af is; nog lang niet alle knopjes werken, en sommige dingen zijn een beetje versimpeld. Maar het moet genoeg zijn om hem voor nu te gebruiken!

We beginnen met een kennismaking, daarna mag jij de app uitproberen aan de hand van een paar opdrachtjes. Tot slot zal ik je een aantal vragen stellen over wat je van de app vond.

Belangrijk is, is dat dit geen toets of test voor jou is. Jij kan geen foute antwoorden geven. Het belangrijkste is dat je eerlijk bent, want zo kan ik het meeste van jou leren en kunnen we er samen voor zorgen dat de app zo leuk en geschikt mogelijk voor kinderen wordt!

Explaining the context

Ik zal even vertellen hoe het scenario ongeveer gaat. Jij hebt nu een afspraak, je kunt dan de Zelfportret app al downloaden en een account aanmaken. Dan is straks in november het moment dat je langskomt bij het KHL en de testjes gaat doen. Als het goed is is dat ongeveer zes weken voor je volgende afspraak in het ziekenhuis, toch? Na de testjes moet je ongeveer twee weken wachten tot jij je uitslagen ontvangt. Dan krijg jij de uitslagen in de app. Vier weken later heb je dan een gesprek met de arts. Exploring the app

Testen van de app

Dan is het nu tijd voor het testen van de app. Voor je heb je een prototype van de Zelfportret app. Ga je gang, en kijk eerst maar eens rond in de app. [geef tijd aan kind om te ontdekken]

Observeren:

- Wat klikt het kind als eerste aan
- Maakt het kind foutjes

Vragen:

- Wat is je eerste indruk van de app?
    - Wat vind je leuk aan de app? Wat vind je minder leuk? Waarom?

Tasks

Ik ga je nu een aantal taken geven, en vragen om die uit te voeren. Tijdens het uitvoeren van de taken wil ik je vragen om hardop te denken. Dus terwijl je in de app rondkijkt, vertel maar hardop wat er in je hoofd om gaat. Wat zie je allemaal, waarom klik je op bepaalde knoppen, wat vind je van wat je ziet?

- Bekijk je laatste resultaten van de IQ-test
    - Je vind de visjes wat te druk en wil liever alleen kleurtjes zien
    - Je wilt weten wat alle kleuren betekenen
    - *Wat valt je hier op?* Het valt je op dat één van de kleuren kleiner is dan de anderen, en wil hier meer over weten.

- Je herkent jezelf niet in de uitslag die je ontvangen hebt, en wil hier een notitie van maken in de app zodat je het later kan bespreken.
- Ga maar terug naar het hoofdmenu. Bekijk nu je laatste resultaten van de Loopmat
  - Je hebt tijdens de loopmat-test in het Kinderhersenlab voor de onderwaterwereld gekozen als achtergrond. Daarom wil je deze wereld ook kiezen in de app.
  - Je bent nieuwsgierig hoe snel jij gelopen hebt.
  - Je wilt de koalasticker opslaan, en weetjes over de koala lezen.
  - Na het krijgen van de sticker ben je nieuwsgierig welke andere stickers je verdiend hebt.
  - Je wilt weten waarom de pinguin met zijn voeten naar buiten loopt
  - Je wilt een animatie van jouw voetafdrukken bekijken. (DOET HET NIET HELAAS)
- Ga weer terug naar het menu en Bekijk je laatste resultaten van de EEG
  - Lees de informatie over het elektro encefalogram
  - Je wilt weten waar de alpha golven in je hoofd zaten tijdens de test
  - Je wilt meer informatie over wat er in jouw hoofd gebeurde tijdens het testjes met de piepjes
    - Je wilt nog meer weten over jouw hersenen en prikkels
  - Je bent nieuwsgierig hoe jouw EEG-grafiek eruit zag tijdens de test met de piepjes

Observeren:

- Welke knoppen gebruikt de persoon om zijn/haar doel te bereiken?

Vragen:

- Wat vind je leuk aan de app? Wat vind je minder leuk? Waarom?
- Waren er dingen onduidelijk of onlogisch?
- Wat zou je willen veranderen aan de app? Waarom?
- Past de taal bij jouw leeftijd, of de leeftijd van 12 jaar oud? Waarom wel/niet?

- Hoe voel jij je als je de resultaten op deze manier zou ontvangen en kunnen bekijken? (trots, blij, geschrokken, teleurgesteld?) Voelt het alsof je iets hebt bereikt? Hoe komt dat? Is dat iets goeds of niet?
- Heeft de app jou aan het denken gezet? Waarover?
- Wat heb je geleerd van deze app?
- Hoe/Op welke momenten / voor welke redenen zou jij de Zelfportret-app gebruiken?
- Stel, je hebt volgende week een gesprek met de dokter over deze uitslag. Hoe zou je je voorbereiden?
  - Helpt deze app jou om de dokter beter te begrijpen?
  - Helpt het je ook om vragen aan de dokter te durven stellen?
- Hoe goed vind je het Zelfportret passen bij de testjes in het Kinderhersenlab? Waarom wel/niet?

Appendix U: Final evaluation questionnaire HCP's

Vragenlijst 'Evaluatie ontwerp Zelfportret'

Geef bij onderstaande uitspraken aan in hoeverre u het eens of oneens bent. Hierbij is het mogelijk onderscheid te maken tussen de verschillende onderdelen van het ontwerp (EEG, IQ-test en Loopmat). Licht daarna uw antwoord toe.

1a. Het gepresenteerde ontwerp is een waardevolle toevoeging tijdens een consult

	Sterk mee oneens	Mee oneens	Neutraal	Mee eens	Sterk mee eens
App algemeen	0	0	0	0	0
Onderdeel EEG	0	0	0	0	0
Onderdeel IQ test	0	0	0	0	0
Onderdeel Loopmat	0	0	0	0	0

1b. Kun u uw antwoord toelichten?

2a. Het gepresenteerde ontwerp past goed binnen de huidige klinische praktijkvoering van het Kinderhersencentrum (denk hierbij bijvoorbeeld aan de data die verzameld / verwerkt moet worden om het portret te vullen)

	Sterk mee oneens	Mee oneens	Neutraal	Mee eens	Sterk mee eens
App algemeen	0	0	0	0	0
Onderdeel EEG	0	0	0	0	0
Onderdeel IQ test	0	0	0	0	0
Onderdeel Loopmat	0	0	0	0	0

2b. Kun u uw antwoord toelichten?

3a. Het ontwerp presenteert de resultaten op een manier die positief bijdraagt aan het zelfbeeld van een kind

	Sterk mee oneens	Mee oneens	Neutraal	Mee eens	Sterk mee eens
App algemeen	0	0	0	0	0
Onderdeel EEG	0	0	0	0	0
Onderdeel IQ test	0	0	0	0	0
Onderdeel Loopmat	0	0	0	0	0

3b. Kun u uw antwoord toelichten?

4a. Met dit ontwerp worden kinderen gestimuleerd om meer te participeren in de zorg

	Sterk mee oneens	Mee oneens	Neutraal	Mee eens	Sterk mee eens
App algemeen	0	0	0	0	0
Onderdeel EEG	0	0	0	0	0
Onderdeel IQ test	0	0	0	0	0
Onderdeel Loopmat	0	0	0	0	0

4b. Kun u uw antwoord toelichten?

Wat is uw functie binnen het ziekenhuis (of daarbuiten)?

Hoe bent u betrokken bij het Kinderhersenlab/zelfportret?

Is er verder nog iets dat u wilt delen?

Bedankt voor het invullen!