Designing a data-enabled interactive tool for the early identification and referral of (expectant) families living in vulnerable circumstances

Supporting the potential of the promising first 1000 days of a child's life

Erasmus MC
Universitair Medisch Centrum Rotterdam

TU Delft

Master Thesis

Designing a data-enabled interactive tool for the early identification and referral of (expectant) families living in vulnerable circumstances

Supporting the potential of the promising first 1000 days of a child's life

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PREFACE

The healthcare industry has increasingly recognized the potential of big data. Using big data can lead to early identification and prevention of adverse outcomes, with significant opportunities in the first 1000 days of life.

How can big data facilitate earlier identification and referral? How can we design with big data in a user-centred approach?
These were questions and challenges which I faced during this graduation project which were both complex and exciting at the same time. I would like to express my gratitude to Erasmus Medical Centre (MC) in collaboration with the research team "Making Big Data Meaningful for a Promising Start" and the University of Technology Delft for offering me this opportunity to design in a meaningful and emerging context.

This opportunity was only made possible through my supervisory team: Fernando Secomandi (TU Delft), Lara van der Veen (TU Delft), and Lisan Hidding (Erasmus MC).

To Fernando and Lara, thank you for consistently engaging in discussions with me regarding numerous challenges during my thesis. Through your feedback, I gained valuable insights into design project organisation, particularly in areas such as planning and stakeholder management.
Additionally, I would like to express my gratitude to Lisan Hidding. Your active involvement in the project and your ongoing assistance in reaching out to families as well as involving me in the research team, made this thesis process more engaging and rewarding.

Furthermore, I would like to express my gratitude to the parents and healthcare professionals who have shared their valuable insights with me. I would not have been able to design without comprehending their perspectives.

Finally, I would like to thank my family and friends for their unwavering support during this period, which has been a significant source of motivation for me to undertake this project.

During this challenge, I encountered challenges that allowed me to grasp the potential of big data while also understanding the important challenges that accompany it. As a result, a digital concept was created, highlighting on important aspects that should be considered in the project's next phase.

EXECUTIVE SUMMARY

Every child in the Netherlands should receive an equal opportunity to begin their life with the best possible prospects. The first 1000 days of a child's life are of utmost importance in establishing a strong foundation for future development. Children may experience a disadvantageous beginning due to various factors such as exposure to smoking or stress (Ministerie van Volksgezondheid, 2018; Roseboom, 2018).

To offer the best start also for children, the objective of this master thesis is to develop a digital tool that leverages the potential of big data to aid in the early identification and referrals of families living in vulnerable circumstances.

The research initiative known as "Making Big Data Meaningful for a Promising Start" is funded by the Dutch research council known as Nederlandse Organisatie voor Wetenschappelijk Onderzoek (NWO), seeks to detect vulnerable situations at an earlier stage using predictive models that use existing large amounts of data (big data) to identify potential adverse outcomes for children. The prediction model has the potential to estimate the level of risk a family faces for experiencing a negative outcome in the future. In order to cater this model to the parents' needs, various user-centred design methods were used.
The approach of this project was first to understand the context of the first 1000 days and understand who is involved, how the current risk identification and referral works, and the experiences of the parents and the healthcare professionals. Literature research and qualitative research methods such as interviews and observations provided insights into the different perspectives of parents and healthcare professionals in this specific context. This approach led to identifying several significant needs that would guide the design direction for the future conceptual tool. These needs include trust, safety and self-esteem. Parents often face fear regarding the potential outcomes linked to revealing specific information, and they may also experience emotions like shame, guilt, or self-doubt when they believe they are incapable of adequately providing for their child. This may result in parents choosing not to disclose information, which can lead to delayed identification and potential referral.

Once the underlying needs of parents were understood, the following phase involved creating together and exploring the solution space surrounding a digital tool. To achieve this, co-creation sessions were held with parents and healthcare professionals.
During the co-creation sessions, several additional requirements emerged that were deemed essential for the conceptualization of the digital tool.
Among these newly identified requirements was the consideration that if the tool incorporated a prediction model, it must not only identify risk but also offer actionable solutions and be implemented with repetitive use since circumstances can change over time.

Through understanding and aligning the needs of parents, a final digital concept Advies Op Maat was designed. The concept allows parents to fill in their information in a sandbox environment, enabling them to try the tool before committing to sending the information to the healthcare professional. Based on the information filled in, parents can receive preliminary advice and choose whether they want to continue.
By conducting moderated user testing, the experience of the digital concept was evaluated and explored. At the moment, a significant challenge in achieving trust and safety relates to the questions posed within the tool, which can be sensitive and confrontational for parents.

At the conclusion of this project, iterations were made to address and improve these specific aspects to potentially use parts of the concept in the next phases of the research project of the "Big Data and a Promising Start" initiative.

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DISCOVERING the CONTEXT

The first part of the report elaborates on the scope of the master thesis and the various stakeholders involved. Furthermore, it covers the various aspects of the project, including information about the first 1000 days, risk identification, referral, and the role of big data.
The main objective of this first section of the report is to discover the context of the master thesis.

Chapter 1

PROJECT INTRODUCTION

Children who live in vulnerable circumstances can have better opportunities in life if they receive the appropriate assistance and support at the appropriate time.
The "Making Big Data Meaningful for a Promising Start" initiative, funded by the Dutch research council known as Nederlandse Organisatie voor Wetenschappelijk Onderzoek (NWO), aims to explore the potential of big data in assisting individuals who live in vulnerable circumstances at an early stage in order to offer the children a promising start in life (ZonMw, 2019).

The first chapter of this report will introduce the project by discussing its background and the different research methods used.

1.1 Project introduction

PROJECT BACKGROUND

MAKING BIG DATA MEANINGFUL FOR A PROMISING START

The project “Making Big Data Meaningful for a Promising Start” is a multidisciplinary project that encompasses a range of healthcare professionals, such as psychologists and epidemiologists, as well as data scientists and policymakers, as members of the project.

The project started in 2021 and forms a constituent of a larger initiative known as “Big Data en Kansrijke Start” (ZonMw, n.d.).

The overarching objective of this initiative is to use big-data analytics to identify risk factors that may be linked to adverse outcomes early on. Earlier identifying families living in vulnerable circumstances has the potential to lead to earlier assistance (NWO, n.d.).

The project centres on the critical first 1000 days of a child’s life, as these early stages have a significant impact on the child’s subsequent development (Burkuš et al., 2015; Van Oppenraaij et al., 2009; Wehby et al., 2011). Therefore, early preventative measures and policies can have a significant impact on children.

IMPORTANCE OF 1000 DAYS

The first 1000 days of a child’s life encompass the period from conception to the end of the second year. During this phase, significant developments occur in children that can be influenced and can have long-term effects. For instance, the most sensitive periods of brain development occur during this period, which is subject to external effects such as nutrition (Cusick & Georgieff, 2013). If a child in this formative phase is exposed to stress, smoking, poor nutrition, abuse, or other risk factors, then that can be the root of health disparities. The significant variations in the likelihood of attaining a long and healthy life are primarily influenced by circumstances the child develops and grows up rather than genetic factors (Ministerie van Volksgezondheid, 2018; Roseboom, 2023).

These first 1000 days can also be called a ‘window of opportunity’ when the child is still very susceptible to different influences (Burlington & Hosking, 2013). WAVE Trust, a UK-based organization focused on child maltreatment, published a report containing recommendations for the initial 1000 days. Where early provision of parental support and facilitating early intervention can enhance child development.

As there is only one beginning in life, providing a child with the best possible chance during their early stages is crucial.

1.2 Project introduction

PROJECT BRIEF

Having highlighted the broader context and overarching importance of the initiative, this section will discuss the project brief of the master thesis. The project brief defines specific aspects of this thesis.

COLLABORATION

This master’s thesis represents a joint effort between Erasmus University Medical Centre (EMC) and Delft University of Technology (TU Delft).

The graduation project is a contributing factor to the EMC-led initiative titled “Making Big Data Meaningful for a Promising Start,” which is a component of the broader “Big Data en Kansrijke Start” initiative.

OBJECTIVE

The objective of this master’s thesis is to facilitate access to early help for families and enhance the identification of families living in vulnerable conditions during the initial 1000 days. By facilitating early identification, earlier preventative measures can be taken to ensure that a child has a promising beginning.

This master’s thesis explores the current context of early risk identification and referral of vulnerable families and the potential role of big data in this context.

The aim of the project is to design a digital tool to facilitate the timely identification of families living in vulnerable circumstances and refer (expectant) families to healthcare practitioners in a timely manner.

CHALLENGES

The graduation project presents a number of challenges that should be addressed throughout its process. Given that this graduation project is part of a larger research initiative, it is imperative to acknowledge and address the various challenges that can arise throughout the course of the project. Below, three primary challenges are elaborated:

1. Comprehending the complex network of individuals and entities whom expectant families come into contact with during the initial 1000 days.
2. Collaboratively designing a tool concept for the future with multiple stakeholders having diverse perspectives.
3. Envisioning (big) data’s role in a future tool.

1.3 Project introduction

PROJECT APPROACH

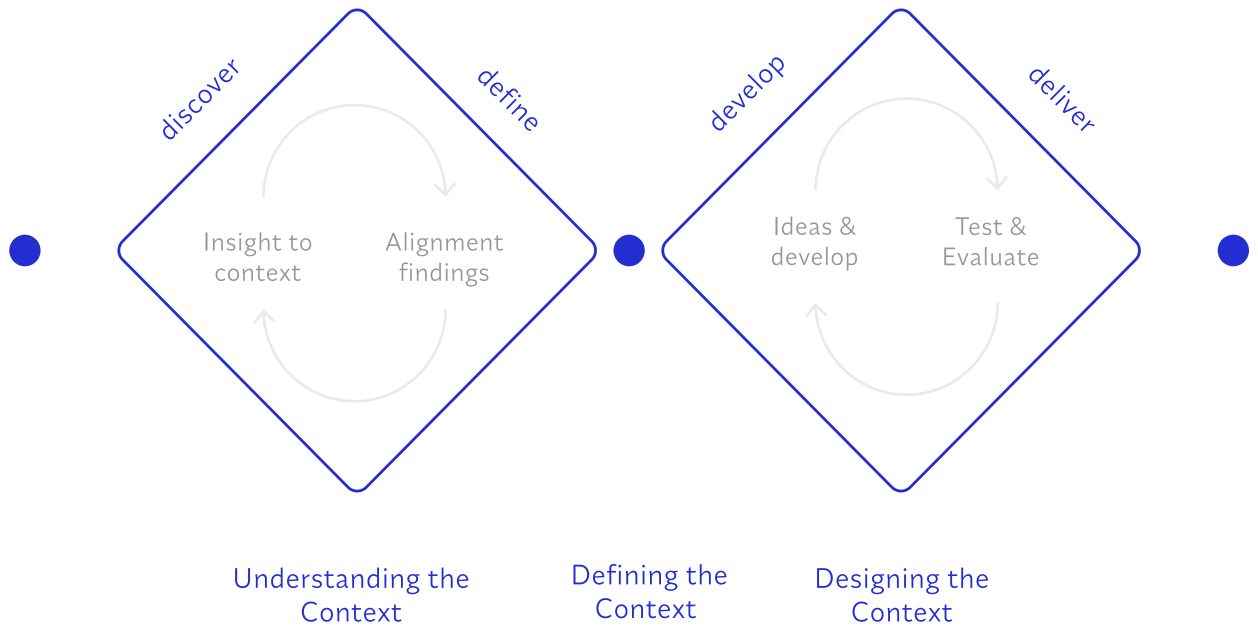


Figure 1: Double Diamond framework used for the graduation project

This section provides an elaboration of the approach for the master project, including a description of the various methodologies used.

The project follows a design methodology known as the double-diamond design process (Design Council, n.d.). The design process is characterized by multiple iterations and non-linearity, whereby the design space is explored through divergent thinking and subsequently narrowed down through convergent thinking.

It is distinguished through four different phases: discovery, define, develop, and deliver phase in which this master project conforms to this methodology interchangeably as seen in Figure 1.

The discovery phase involves the process of understanding the context of the project.

During this phase, various aspects are being analysed. It examines the current process of risk identification and referral for healthcare professionals and the potential impact of big data in the future. During this phase, various research methods were employed. Conducting literature research, making observations, and conducting interviews helped to gain a comprehensive understanding of the diverse viewpoints held by various stakeholders.

The define phase involves around defining the context. The translated data formulated the design direction, including its interaction qualities and requirements. The purpose of this was to gain a better understanding of how the future tool should be designed.

Following, the develop phase consisted of collaborative co-creation sessions with healthcare professionals and parents to generate and design ideas relevant to the context.

These ideas were eventually conceptualized into a digital tool concept.

In the delivery phase, a prototype of a digital tool was tested and iterated upon, providing the research team with valuable insights for the project "Making Big Data Meaningful for a Promising Start."

USER-CENTRED DESIGN

During this project, a user-centred design (UCD) approach is being applied. UCD is a design approach that places emphasis on its user's needs and preferences. It is about actively involving users during the design process. This is performed to prevent making important design decisions without a comprehensive understanding of the user's viewpoint (Gulliksen et al., 2003). Multiple methodologies are being employed, including observations, interviews, and co-creation sessions, to accomplish this perspective.

TRANSITION TO HUMAN CENTERED AI

Given the inclusion of AI in this master's project, it is key to adopt a Human-Computer Interaction (HCI) approach that prioritises human-centred Artificial Intelligence (see Figure 2).
The field of HCI employs the "human-centred design" methodology in order to create computing products that effectively address the needs and preferences of users (Xu et al., 2023). Nevertheless, the emergence of artificial intelligence (AI) has presented additional challenges in the pursuit of a more human-centric approach to design.
For instance, one challenge is the potential occurrence of a black box effect in AI systems, where the output generated by these systems becomes unclear to users. Users may lack understanding of the decision-making process and the rationale behind the decisions made by AI systems. This lack of transparency can make it difficult for users to determine when they should place trust in AI systems (Mueller et al., 2019).

This master's project aims to address the challenge of designing with algorithms such as big data in a human-centred manner. Therefore, in this project, the role of big data is carefully examined by adapting it to the human/parents' needs.

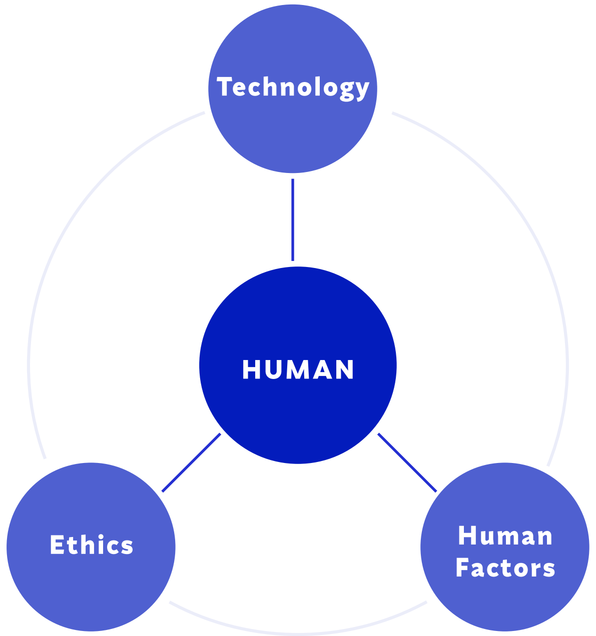


Figure 2: Part of the Human-Centred AI (HCAI) framework

UCD METHODOLOGIES

Using qualitative research methods facilitates comprehension of user perspectives and enables the development of designs in a user-centric manner. Therefore, the following methods were used during this graduation project.

Observations

In this project, observations are used to comprehend the context and various variables that may impact the future tool. Observations were conducted on obstetricians to gain insight into the consultation process for expectant families.
Observations can help designers to emphasize with the users and develop a deeper understanding of their perspectives, which can lead to more meaningful and relevant designs (Mintrom & Luetjens, 2016).

Interviews

The aim is to comprehend the varying viewpoints of healthcare professionals and expectant families regarding risk identification and referral. Healthcare professionals, including obstetricians, maternity nurses, and pediatricians/nurses, were interviewed in the project.

Eventually, the interviews were transcribed for the interview analysis, and statement cards were created and clustered into themes (Appendix B.6 and B.7)

Interview healthcare professionals set up

6 obstetricians, 6 maternity nurses, 2 youth nurses and 1 paediatrician were interviewed online. The aim was to:

- Understand their experience with current risk identification and referral of families living in vulnerable circumstances
- Understand the future of risk identification through their view on it's requirements and wishes

Interview parents set up

10 parents who experienced stressful situations or other vulnerable situations were interviewed online. The aim was to:

- Understand the interactions between different healthcare professionals and the parent
- Understand their perceptions of vulnerable topics
- Understand their experience with risk identification and referral
- Understand their future perspectives on "risk" identifcation and referral

Co-creation sessions

In order to involve the relevant stakeholders in the design process, co-creation sessions provided an opportunity to design with input from various perspectives.
For this graduation project, co-creation sessions facilitated alignment and collective ideation for the future tool. In the co-creation sessions, parents and various healthcare professionals such as obstetricians, maternity nurses, and consultation bureau were involved.

Early engagement of stakeholders during the design process can lead to favourable long-term outcomes (Sanders & Stappers, 2008).In this case, it was still in the early design phase, which presented an ideal opportunity to further explore various design elements for the future tool.

Moderated user testing

The concept was evaluated by parents through a method of user testing, where they had the opportunity to interact with high-fidelity prototypes. The process of user testing facilitated the assessment of the tool's user experience, specifically in relation to the needs of the parents. The moderated user tests were conducted, and parents were instructed think-out-loud, with the aim of obtaining a comprehensive understanding of their overall experience with the concept.

Chapter 2

UNDERSTANDING THE 1000 DAYS

During the first 1000 days, from conception until the second year of a child's life, a significant number of developmental milestones occur. Important changes and developments occur for both the mother and the child during the course of pregnancy. In order to fully comprehend the graduation project, it is important to have a comprehensive understanding of the entirety of the first 1000 days. This chapter will address the following topic.

2.1 Understanding 1000 Days

RESEARCH APPROACH

In order to understand what phases are important in the first 1000 days, it was divided into four phases: preconception period, prenatal period, postnatal period, the infant, and infant and toddlerhood (see Figure 3). Several research questions were set up in order to understand these phases more.

Research Questions
Understanding the context between stakeholders
- What occurs during the various phases of the first 1000 days?
- Who are primarily involved in these phases?

Research Method

Literature Research

2.2 Understanding 1000 Days

1000 DAYS

Figure 3: The first 1000 days timeline

PRECONCEPTION PERIOD

The preconception period is often defined as the three months before conception (Potter & Parker, 1964). There is an extensive amount of evidence indicating that preconception health behaviors can have a significant impact on the subsequent stages of pregnancy. The use of cigarettes, alcohol, and high doses of caffeine can have negative effects on both male and female fertility (Horne et al., 2014; Jensen et al., 2010; La Vignera et al., 2013). Moreover, the consumption of folic acid supplements has been shown to decrease the probability of neural tube defects (Blencowe et al., 2010), and there is evidence suggesting that maternal stress before childbirth is associated with sleep disruption in infants, independent of postnatal depression (Baird et al., 2009). Furthermore, it has been found that maintaining a nutritious diet can have enduring impacts (Vanhees et al., 2014).

The preconception period holds significant importance as women who receive preconception care are more likely to engage in healthy behaviours, resulting in improved pregnancy outcomes (Dean et al., 2013).

PRENATAL PERIOD

The prenatal phase encompasses the duration from conception to delivery (Halldorsdottir et al., 2022).

During this phase, the developing foetus experiences a period of accelerated growth and maturation. For instance, the development of the brain during the prenatal period is primarily regulated by genetic factors. However, it is evident that environmental factors can also impact brain development. Inadequate nutrition, such as insufficient folic acid intake, and exposure to harmful substances, such as alcohol, can have detrimental effects on the developing brain of the foetus (Tierney & Nelson, 2009). Adequate nutrition during pregnancy is imperative to facilitate optimal foetal growth and development (Cusick & Georgieff, 2013).

During this phase, the expectant woman is in contact with the obstetrician or gynaecologist, who will monitor the pregnancy until delivery (Leader & Perales, 1995).

POSTNATAL PERIOD

The postnatal period begins immediately after birth and extends up to six weeks after the birth (World Health Organization, 2010). In the first week, the maternity nurse helps to take care of the child and gives instructions on how to take care of a child (Ministerie van Volksgezondheid, 2017).

INFANT AND TODDLERHOOD

Infancy is typically defined as the developmental stage from birth to approximately 12 months of age. During this developmental stage, infants acquire the skills of crawling and taking their initial steps. During the period of toddlerhood, typically spanning from 12 to 36 months of age, children demonstrate a growing proficiency in both motor and communication abilities as well as social-emotional developments (Malik & Marwaha, 2023; Purdy, 2023).

While it is true that the majority of healthy infants and toddlers achieve developmental milestones within a particular time frame, the milestone of crawling, walking, or talking in infants and toddlers can be influenced by various factors such as culture, environment, socioeconomic status, and genetic predisposition. Children experiencing undernutrition, social deprivation, or inadequate healthcare may exhibit slower developmental progress compared to toddlers growing up in enriched environments. Concerns arise when milestones such as crawling are absent or substantially delayed, since this can indicate a physical or mental conditions (Purdy, 2023).
Throughout these stages, it is the responsibility of Youth Health Care, also known as the Jeugdgezondheitszorg (JGZ) in the Netherlands, to perform regular assessments to determine whether a child is developing in a healthy manner (Opvoed Informatie, 2023).

Chapter 3

UNDERSTANDING STAKEHOLDERS

This chapter will provide a detailed elaboration on the stakeholders who are involved in the initial 1000 days of a child's life.

3,1 Understanding stakeholders

RESEARCH APPROACH

It is important to know who is involved in the trajectory of the first 1000 days. Consequently, it is essential to understand who the relevant stakeholders are and know their roles and interactions. This chapter elaborates on the observations conducted at obstetricians' practices and the first part of the interviews conducted with parents.
During the process of this research, a stakeholder map was created to identify and map the different stakeholders involved.

Research Questions
Understanding the context between stakeholders

- Who are the stakeholders involved in the 1000 day trajectory and what impact do they have on risk identification and referral?
- How does the interaction between the healthcare professional (obstetrician) and expectant family look like?
- What are the perspectives of (expectant) families on the various stakeholders?

Research Method

Literature Research
Observations at obstetrician practices
Interviews with parents

3.2 Understanding stakeholders

HEALTHCARE PROFESSIONALS

Understanding the fundamentals of the Dutch healthcare system and where everyone stands is crucial to understand the role of the various healthcare professionals in the Dutch healthcare system. Therefore, the general Dutch healthcare system will be discussed first, followed by an explanation of the various healthcare professionals who play a role in the first 1000 days.

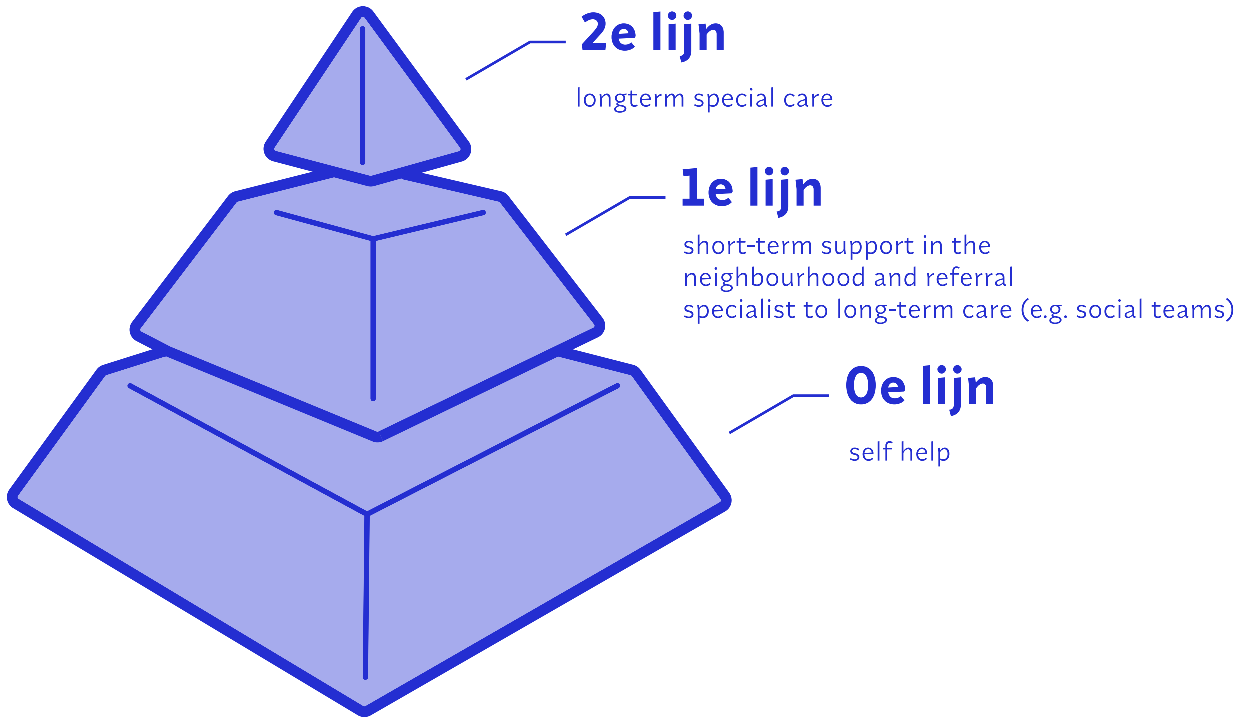


Figure 4: Visualization of the three lines of the Dutch healthcare system

HEALTHCARE SYSTEM

To gain a comprehensive understanding of the Dutch healthcare system, it is important to understand the distinct lines or "lijnen" that constitute the healthcare system. The Dutch healthcare system consists of multiple tiers, tier 0 also known as 0e lijn, tier 1 also known as '1e lijn' and the 2nd tier also known as the '2e lijn'. The provided visual Figure 4 depicts the Dutch healthcare pyramid.

0e lijn

The "Nulde lijn" refers to the primary level of healthcare services, which includes the Municipal health service (Gemeentelijke Gezondheitsdienst (GGD). The GGD is classified as the "Nulde lijn" due to their focus on preventative care. At this tier everyone can access this care.

1e lijn

Healthcare professionals who fall under the category of the "1e lijn" are accessible for immediate consultation by all individuals. The healthcare provided is characterized by a generalist approach, where patients can be referred to another specialist, who operates within the "2e lijn" of healthcare. The healthcare professionals that fall under the category of "1e lijn" include a general practitioner, obstetrician, maternity nurse, and paediatrician.

2e lijn

In the "2e lijn" of healthcare consists of specialised healthcare professionals. Access to the professionals of the "2e lijn" requires a referral from the healthcare professional in the "1e lijn". Examples for the specialists in the '2e lijn' are gynaecologists and psychologists.

There is also a "3e lijn" and "4e lijn" which include healthcare professionals who are in academic hospitals which are not depicted in the visual because they exceed the scope of the project (Wiegers et al., 2012).

Figure 5: Visual representation of various healthcare professionals

1e lijn

GENERAL PRACTITIONER

In the Netherlands, patients typically initiate contact with a general practitioner as their primary point of care for inquiries related to their health (Ministerie van Volksgezondheid,Welzijn en Sport, 2021). Consequently, on occasion, they serve as an entry point for expectant families to receive a referral to obstetricians. Nevertheless, parents have the option to directly contact the obstetrician instead of reaching out to the general practitioner.

1e lijn

OBSTETRICIANS

The obstetrician is responsible for overseeing the healthcare of both the mother and the child. The provision of this care can also be given by gynaecologists. They participate in various stages of pregnancy, prenatal, birth, and postnatal (Zorginstituut Nederland, 2016). The obstetrician frequently conducts various checkups to assess the growth, heartbeat, and other health-related factors of the infant. During these consultation moments, it is common for healthcare professionals to conduct an echo of the baby. Additionally, obstetricians are responsible for identifying risks and referring parents to other healthcare professionals if necessary.

1e lijn

MATERNITY NURSE

The role of the maternity nurse encompasses providing assistance and guidance to parents during both the postpartum period. Occasionally, they may also be present at birth.

Throughout this period, the maternity nurse provides assistance to the mother and the infant and aids in performing basic household tasks. The government provides support for families in which maternity nurses can be allocated up to 80 hours over a period of 10 days (Ministerie van Volksgezondheid, 2017). During this time, the maternity nurse offers assistance to new parents in their homes.

1e lijn

JEUGDGEZONDHEIDSZORG (JGZ)

Following the maternity period, the responsibility for healthcare is continued by the JGZ. The JGZ monitors the growth and progress of the child from birth until reaching the age of 18.

Within the JGZ there exists an additional institution known as the consultation bureau, which is accountable for providing fundamental medical care to children aged between 0 and 4 years old. At the consultation bureau, a paediatrician or youth nurse will supervise the child's growth. They will work together with the parents to monitor the child's motoric skills, social development, and speech and language development (Opvoed Informatie, 2023; Rijksoverheid, 2012).

3.2.1 Understanding stakeholders

OBSERVATIONS OBSTETRICIAN PRACTICES

OBJECTIVE

Observations were used to better comprehend the context of obstetricians' interactions with expecting parents. This aided in empathising with parents and familiarising oneself with the context. In addition, it aided in the identification of potential pain points and other factors that may be important to the design of a digital tool.

SET UP

Three obstetrician practices were visited. During a single day, 12 consultations were observed, ranging from regular consultations to postnatal consultations.
Additional observations were conducted during another practice's intake consultations.
The last observation was carried out during a centering pregnancy event hosted by another obstetrician practice.

Centering pregnancy
Centering pregnancy is a programme that involves an initial individual consultation followed by subsequent group consultations with pregnant women at similar stages of pregnancy. These sessions involve medical care and discussions, including monitoring blood pressure and baby's growth. During a session, women can share experiences and provide mutual support.

To investigate the kinds of objects and materials used. A template for observation was created to document the observations (see Appendix B.1).

KEY INSIGHTS

Several important insights were obtained from the observations. The main findings are condensed into subcategories that correspond to various types of consultation, namely intake consultation, regular consultation, and centering pregnancy.

The intake consultation, which is longer than a regular consultation, covers a range of topics, including medical history and lifestyle. In the context of sensitive queries, the obstetrician would emphasise that she asks such questions to all individuals and that they are not personal.
The duration of the intake consultation was significantly shorter. In this particular instance, it was evident that there was insufficient time available to engage in comprehensive discussions regarding particular topics.
In contrast to regular consultations, centering pregnancy involves a greater number of parents and focuses more on providing detailed information rather than solely addressing medical aspects. The discussion was conducted in an open manner, allowing parents to actively participate by sharing their personal experiences.

Furthermore, based on the observations, there were several noteworthy points of interaction and environmental factors. It was evident that there was a strong sense of trust between the obstetrician and parents, and time limitations emerged as a significant challenge. Additional observation notes can be found in Appendix B.2.

Intake consultation

The intake consultation lasted about 60 minutes and covered several subjects. During this intake consultation, a variety of medical histories as well as the parent's lifestyles, were discussed. Moreover, when inquired about sensitive matters such as negative sexual encounters, **the obstetrician frequently insinuated that she would pose the question to all parents, emphasising that it is not personal.**

During the intake consultation, there was a discussion regarding the necessary forms that parents must complete before the intake consultation. The forms consisted of an intake form, which collects medical history information, and the Mind2Care survey, which assesses psychological risk factors. Nevertheless, it has been observed that some parents did not complete the Mind2Care survey. After speaking with the obstetricians, it was indicated that this could be attributed to either forgetting about it or that the survey is too long and requires **a high level of effort to sign in through two-factor authentication and complete the registration process.**

Furthermore, the obstetrician employed the Gezamelijk Inschatten Zorgbehoeften (GIZ) communication tool to address non-medical risk factors. However, **it was just offered as a chance for parents to discuss numerous other aspects without any obligation to do so** (see Figure 6).

Figure 6: GIZ communication tool

Regular consultation

The regular consultation comprised three parts. The entry where the obstetrician and expectant parent discussed how everything is proceeding, followed by listening to the heartbeat and echo, concluding with a discussion of the next consultation moment. All of this occurs within a 20 to 30-minute window.
Due to this limited window, it was obvious that there was insufficient time to discuss deeper concerns.

Figure 7 : Centering pregnancy set up

Centering Pregnancy

The observations conducted during the centering pregnancy session (Figure 7) resulted in valuable insights. The study presented an alternative approach to conducting regular consultations. The Centering Pregnancy programme consisted of a session that lasted for two hours and involved around 16 mothers. During this session, extensive discussions between mothers were stimulated, and the obstetrician and maternity nurse took the opportunity to clarify any misinformation that emerged.
For each session, certain topics will be discussed among mothers, obstetricians, and maternity nurses. The list underneath provides an overview of the topics discussed, highlighting the adoption of not only conventional medical factors but also social factors.

- Session 1: Lifestyle
- Session 2: Inconveniences, body changes and dental care
- Session 3 : Breastfeeding, relaxing and work
- Session4: Family, sexuality, pre-term birth and birth control
- Session 5: Childbirth and pain during labour
- Session 6: Preparing for childbirth and choices
- Session 7: Birth plan and care for the baby
- Session 8: Preparing for post-partum and emotions
- Session 9: Baby's growth and development
- Session 10: Mother's recovery , baby growth and development

Interaction

There were several observable interaction patterns between the different expectant families and obstetricians.

Calming and Trustworthy

The obstetrician employed a gentle and calm tone while communicating with the parents, who appeared to be at ease and willing to share various personal details about their lives. In addition, the level of familiarity observed in the interaction between the obstetrician and the expectant parent suggested **a trustable relationship** between the obstetrician and expectant parents.

Engaging

When parents brought along their other children, the obstetrician would query about them as well. It was observed that parents would return to the same obstetrician for their second or third child, suggesting that the obstetrician is very involved with the family.

Positivity

During the encounter with the expectant parents, the obstetrician would frequently maintain a positive attitude. During the echo, the obstetrician would make encouraging remarks. This seems to calm or reassure the parents about what they saw on their own echo images.

"Zie je hoe mooi.." "See how pretty..."

"De maag ligt goed" "The stomach lies well"

"Hoofdje zit netjes" "The heads sits nicely"

Environment

Several environmental elements were valuable to point out.

Application of booklets

The obstetrician would give each parent a booklet (see Figure 8), which they would bring to the appointment. The booklet has important information about the obstetrician's practise, such as information about future consultations and how echo images are kept. This item seems to have a special value for parents as a way to remember and think about their journey. It showed that parents would bring information with them all the time.

Figure 8: Booklet at an obsetricians office

Time constraints

The regular appointment lasts between 20 and 30 minutes. Obstetricians don't have much time to ask detailed questions and get ready for the next appointment, which can be a pain point.

Exchange experiences

The observation of centering pregnancy revealed the significance of community among parents undergoing similar life changes. Although it was the initial encounter for the prospective parents, all mothers engaged in social interaction and exchanged experiences on various topics. It was observed that there is a desire for a sense of sharing experiences among mothers in this new stage of their lives (with the supervision of the obstetricians).

Open discussions

Centering pregnancy facilitated the exploration of diverse lifestyle choices and provided parents with the autonomy to express their perspectives. The discussion was conducted in an open manner, without appearing condescending toward parents.

3.3 Understanding stakeholders

PARENTS

It is important to define the key population and focus on this group during the entity of the project. The project brief had pre-established the key population as families who are living in vulnerable circumstances with children younger than 2 years old or who intend to become pregnant. “Vulnerable circumstances” is a broad term that covers families with psychological, psychiatric, addiction, financial, or behavioural challenges, as well as families with intellectual disabilities, teenage mothers, or other situations with multiple problems (Nederlands Centrum Jeugdgezondheid, n.d.-a). There are numerous risk factors that can affect a family’s vulnerability. The next chapter provides a description of these risk factors. In this chapter the perspectives of the parents towards the stakeholders will be discussed.

3.3.1 Understanding stakeholders

INTERVIEW WITH PARENTS

OBJECTIVE

The interview’s primary purpose was to comprehend the context and, more importantly, to comprehend the parents’ interaction with various healthcare professionals. For the interview, 10 parents were invited for a 60-minute session. This was eventually translated into a stakeholder map at the conclusion of this chapter.

The aim was to :

- Understand the interactions between different healthcare professionals and the parent

The participants were parents who had encountered stressful or vulnerable circumstances during or after pregnancy.

For the interview with the parents, a context mapping technique was used (Visser et al., 2005). Visser et al. (2005) proposed the context mapping technique as a means of gaining insight into the needs and aspirations of potential users. In the context mapping technique, Visser suggests the use of sensitising exercises prior to conducting interviews. This approach aims to engage participants and familiarise them with the topic at hand.
One week before the interviews, parents were provided with a sensitization exercise. Figures 9 and 10 depicts parts of the various exercises.

The sensitising exercise helped parents prepare for the interview by encouraging them to reflect on their past experiences. Furthermore, it stimulated parents to think about their experiences more in an abstract way. This sensitising exercise served as a means to discuss individuals’ interactions with various healthcare professionals in a more conceptual manner (Appendix B.4).

Figure 9: Sensitzing tool excersize 1 understanding the interaction with healthcare professional

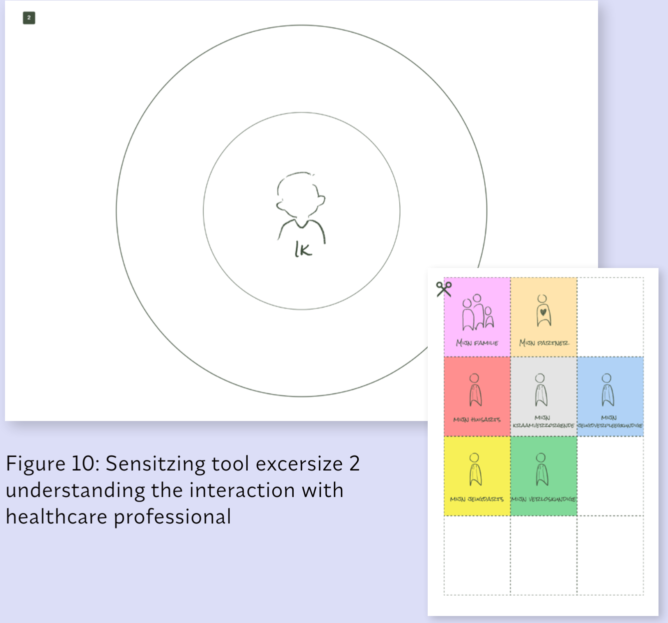


Figure 10: Sensitzing tool excersize 2 understanding the interaction with healthcare professional

KEY INSIGHTS

The primary findings have been categorised into distinct insights for the obstetrician, maternity nurses, and JGZ.

OBSTETRICIANS

Take the parents serious

According to parents, obstetricians often adopt a role in which they possess an empathetic comprehension of parents. Consequently, obstetricians are able to adopt a supportive stance toward parents and approach their concerns with a sense of seriousness.

Trustable

Moreover, obstetricians are often perceived as trustable and serve as primary points of contact for parents, providing them with a dependable source of support and guidance. They actively engage in the parents' most vulnerable moments and think together with parents of alternative options if needed.

"Altijd degene op wie wij het meest konden rekenen"

"Always the one we could count on the most"

"Rots in de branding"

"Rock in the surf"

Own bubble

The interviews revealed varying perspectives, with parents expressing that obstetricians are in their own bubble and only see the parent in one way. When parents have had a lot of problems in the past, which is often called a "backpack" of problems, the obstetrician can see them from one point of view.

"Die zitten in hun eigen bubbel"

"They are in their own bubble"

"Zij zien mij en zij zien mij op een manier en niet anders. Dit is op het moment dat ik zeg ja, maar mijn bevalling loopt anders, dan zeggen ze, nee, want dit is hun bubbel."

"They see me and they see me one way and not another. This is at the point where I say yes, but my delivery is different, then they say, no, because this is their bubble."

MATERNITY NURSES

Purpose not always clear

Parents frequently lacked an understanding of the responsibilities and significance of maternity nurses, often perceiving them as unfamiliar strangers who would be present in their homes for a week.

Empathetic

According to parents, maternity nurses were frequently perceived as empathetic and caring healthcare practitioners.

CONSULTATION BUREAU

Different image

There exists a distinct perception of the consultation bureau among parents. It has been noted that parents tend to disclose less information due to the connection between the consultation bureau and Jeugdzorg. Consequently, parents feel the need to exercise caution when deciding what to share with these organisations.

Not alot of help

Parents are often seen as perceiving the consultation bureau as not as helpful, as they frequently do not provide additional information that the parent may not already be aware of. Parents primarily visit the consultation bureau for the purpose of obtaining vaccinations for their children and for no other reason.

"So the consultation bureau is less likely to share with them (...) they are also more in touch with youth welfare (Jeugdzorg). And those want... Yes, I just want to keep those out as best and as far as possible. So I would then maybe sugarcoat things a bit better than they actually are. Not daring to be completely open as well."

"Het consultatiebureau dus minder snel met hun delen dan dat ze ook meer in contact staan met jeugdzorg. En die wil... Ja, die wil ik gewoon zo zo goed en zo ver mogelijk buiten de deur houden. Dus ik zou dan wel dingen misschien iets mooier maken dan dat ze daadwerkelijk zijn. Niet compleet ook openheid van zaken durven te geven."

3.4 Understanding stakeholders

STAKEHOLDER MAP

The Figure 11 depicted provides an overview of the healthcare professionals who hold significant roles in the first 1000 days.
In addition, it illustrates who parents are typically close to when they are located in close proximity. Few stakeholders, including obstetricians and maternity nurses, are frequently portrayed. This implies that parents typically encounter multiple obstetricians and maternity nurses during their pregnancy and the postpartum period.
The stakeholder map provides a visual representation of the individuals or groups who are best positioned to effectively identify risks.

The importance of the obstetrician in the first 1000 days is evident, as they are often regarded by parents as the healthcare professional with whom they have the closest relationship. The consultation bureau consists of healthcare professionals who have a relatively distant relationship with parents compared to obstetricians.

Blue interaction lines represent contact points originating from one healthcare professional to another, with arrows typically indicating the initiator of the contact in the first 1000 days.

Red interaction lines represent contact points from the parents to the healthcare professionals, with arrows typically indicating the parents as the contact initiator in the first 1000 days.

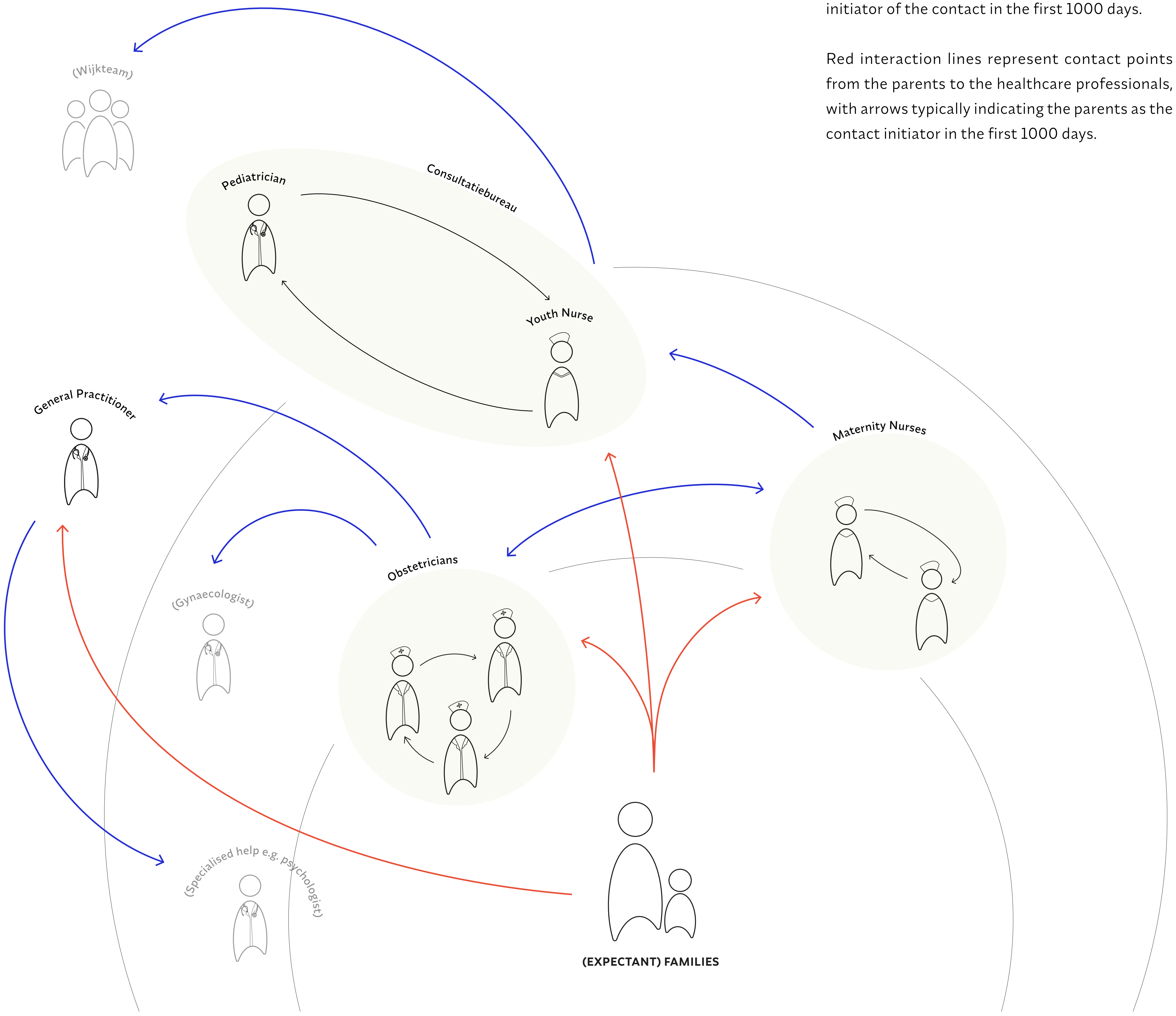


Figure 11: Stakeholder visualizing the relations between the parent and various healthcare professionals

Chapter 4

UNDERSTANDING RISK IDENTIFICATION & REFERRAL

This chapter will address the identification of (non)-medical risks and the process of referral. Conducting literature research and interviews facilitated an understanding of the process of risk identification and referral within the Dutch healthcare system.

4.1 Understanding identification & referral

RESEARCH APPROACH

At the beginning of this chapter, the various risk factors as well as identification tools will be discussed. In order to gain more insight into the experience and process of risk identification, several healthcare professionals and parents were interviewed.To comprehensively understand the context of risk identification and referral, several research questions were formulated.

Research Questions

Understanding the context of current risk identification & referral

- What are the risk factors and protective factors which play a role in the 1000 days?
- How does the current process of identifying (non)-medical risks and referring work?
- How are risk identification tools incorporated?
- How do different healthcare professionals and families experience risk identification tools?

Literature Research

Interviews with healthcare professionals

Interviews with parents

4.2 Understanding identification & referral

RISK FACTORS

The report from the Netherlands Organisation for Applied Scientific Research, also known as the Nederlandse Organisatie voor toegepastnatuurwetenschappelijk onderzoek (TNO), defines risk factors as a background trait, behaviour, or circumstance that is linked to or increases the likelihood of a child's less healthy development.

In addition to risk factors, there exists a category of protective factors that can serve to mitigate the adverse effects of risk factors (Detmar & de Wolff, 2019).

In order to comprehend the numerous factors, several medical factors are included in this report. It is imperative to understand that risk factors are frequently interconnected and related. The TNO report includes and divides the different risk factors on three different levels of the child, parents, and the environment (Detmar & de Wolff, 2019). A few of these risk factors will most likely be used as variables in the "Making Big Data Meaningful for a Promising Start" prediction model.

RISK FACTORS ON THE LEVEL OF CHILDREN

Literature shows that children who are born prematurely and show lower birth weights have an increased risk of experiencing social and emotional difficulties in comparison to children who are born with normal birth weights (van Baar et al., 2009).

Moreover, nutrition also plays an important role in the first 1000 days. According to Grantham-McGregor & Ani (2001), there is a correlation between iron deficiency and cognitive abilities. Obesity in the first two years is also associated with an increased risk of cardiovascular disease later in life (Must & Strauss, 1999).

RISK FACTORS ON THE LEVEL OF THE PARENTS

Several prenatal and perinatal risk factors influence the development of the first 1000 days of a child's life. Exposure to nicotine and alcohol can have a negative impact on foetal development (Mick et al., 2002; Popova et al., 2016).

In addition, a higher level of stress can have a direct influence on the unborn child, and a parent's psychological and psychiatric problems can have a negative impact on the child's social and emotional development (Glover, 2014).

The parenting behaviour of parents with a moderate intellectual disability, also known as licht verstandelijke beperking (LVB)(Detmar & de Wolff, 2019) can be affected. Children of individuals with intellectual disability may face a higher likelihood of experiencing inadequate care, potentially resulting in adverse effects on their health, development, and behavior (Feldman, 2002).

RISK FACTORS ON THE LEVEL OF THE ENVIRONMENT

During the 1000 days, environmental factors can also influence the development of a child.

For instance, the family situation, neighbourhood, or socioeconomic status (SES) can play a role in the development of the child. The literature indicates that single-parent households may be associated with a higher likelihood of problematic behaviour and emotional difficulties (Ezpeleta et al., 2008). Furthermore, prior research in which one analysed the data from foetal life up to the age of 3 years has indicated that families residing in disadvantaged regions, commonly referred to as "achterstandswijken," and those with a low socioeconomic status (SES) are more likely to experience social and emotional difficulties (Reijneveld et al., 2010; Rijlaarsdam et al., 2013).

4.3 Understanding identification & referral

CURRENT RISK IDENTIFICATION & REFERRAL

This section will go deeper into the fundamental aspects of risk identification and referral for vulnerable (expectant) families.

RISK IDENTIFICATION

Risk identification during the 1000 days happens through several healthcare professionals. The obstetrician, gynaecologist, maternity nurse, or the consultation bureau. They play a role in risk identification at different stages of the 1000 days. Risks can be identified through a risk identification questionnaire or through a "niet pluis" feeling by the health care professional.

The "niet pluis" feeling is a non-analytical feeling that can nevertheless initiate a process of diagnostic administration based on rational argumentation. The feeling is founded on medical, experiential, and contextual knowledge of the healthcare professional. This intuition can serve as a third line of diagnostic reasoning (Stolper et al., 2015).

REFERRAL

Various initiatives for healthcare professionals to parents may be referred to depending on the level of risk associated with a given situation (personal communication, May 5, 2023).

Figure 12 provides an overview of the simple referral process in which the referral can happen through the obstetrician, maternity nurse, and consultation bureau. The maternity nurse has the ability to identify potential risks. However, the referral process occurs in consultation with the obstetrician, and they can together decide to make a "warme overdracht" to the consultation bureau. This "warme overdracht" signifies that the consultation bureau must be cautious regarding potential risk factors.

The obstetrician also has the option to refer the identified risk either to the consultation bureau or to other healthcare professionals and social projects, depending on the risk (personal communication, May 5, 2023).

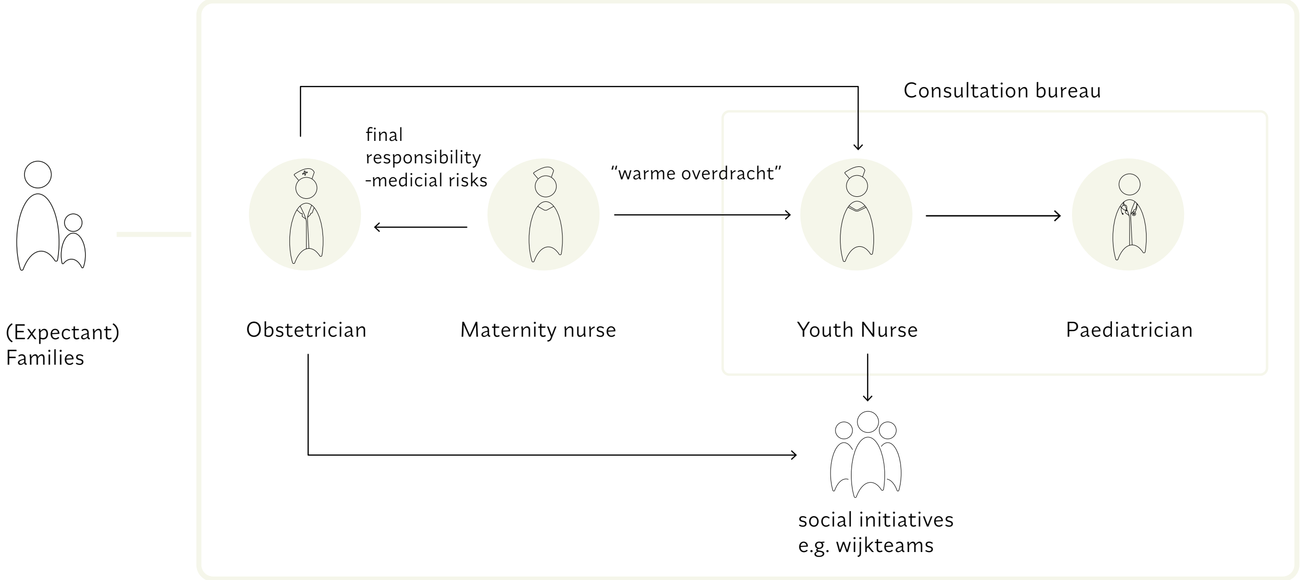


Figure 12: Simplified visual representation of the referral process

Healthcare professionals involve parents in the decision-making process regarding the sharing of information with other healthcare professionals. Nevertheless, it has been suggested that in cases where the risk is clearly apparent, and parents are unwilling to seek assistance in addressing this issue, such as in instances of child abuse, healthcare professionals possess the authority to direct them towards initiatives such as Jeugdzorg. In general, healthcare professionals are liable for managing the referral process to other healthcare professionals.

There exist multiple established organizations that healthcare professionals can consult for expectant families when they identify a family in a vulnerable situation. The following section outlines various interventions/initiatives.

Sociale wijkteam

In the municipality of Rotterdam, various social neighbourhood teams also referred to as wijkteams are established for distinct neighbourhoods within the city. The teams possess a comprehensive understanding of their respective neighbourhoods and are staffed with different professionals who possess expertise in areas such as the use of the JGZ, financial management, and domestic violence. A team member will closely examine the problem with the parents and explore potential outcomes (Gemeente Rotterdam, n.d.).

Prenatal home visits

The consultation bureau conducts a prenatal home visit, wherein a volunteer visits the home of the expectant family. Starting from 2022, it is mandatory for municipalities to provide prenatal home visits facilitated by the consultation bureau. Following the initial consultation, the obstetrician may inquire about both medical and non-medical risk factors, subsequently determining whether a prenatal home visit is advisable (Ministerie van Volksgezondheid,Welzijn en Sport, 2022)

Stevig ouderschap

Stevig ouderschap uses a risk identification tool in the form of a questionnaire coupled with an intervention. Following the postnatal period, parents are typically requested to complete this questionnaire that aims to identify potential risk factors associated with parenting difficulties. These risk factors include experiences of childhood abuse, personal challenges, and social isolation. If the result from the questionnaire indicates the need for additional support, families have the option to seek assistance from Stevig ouderschap. The consultation bureau facilitates the Stevig Ouderschap by conducting home visits to expectant families approximately six times within the initial 18 months. However, there is also an option to recommend a prenatal stevig ouderschap through the advice of the obstetrician (Nederlands Centrum Jeugdgezondheid, n.d.-b).

Other specific interventions

The initiatives listed above are not the only ones available, there are many others, including interventions that are more specialised with regard to the identified risk factors.

Voorzorg

Voorzorg is a programme that involves home visits for expectant women who are highly vulnerable and present with multiple risk factors. The nurse from the Voorzorg can provide assistance throughout the course of pregnancy, promoting the enhancement of parental skills, as well as the monitoring and management of health-related developments. These home visits can start at the beginning of pregnancy and continue through the child's second year (Nederlands Centrum Jeugdgezondheid, n.d.-c).

POP-Poli

The POP-Poli, which encompasses Psychiatry, Obstetrics (obstetricians), and Paediatrics, may offer assistance to expectant women who have a history of psychiatric issues or whose families have a history of such issues. This aid may help to prevent potential risks to both the mother and the foetus, as well as reduce the likelihood of long-term admissions (Erasmus MC, n.d.).

4.4 Understanding identification & referral

RISK IDENTIFICATION TOOLS

There are numerous medical and non-medical risk identification instruments. Multiple methods have been identified for risk identification, including intake consultations and the use of risk identification questionnaires.

INTAKE CONSULTATION

For every pregnancy, an intake consultation is scheduled by the obstetrician.

Prior to the initial consultation, parents are required to complete an intake questionnaire that includes inquiries about their pregnancy, lifestyle, medical history, and family situations. During the initial consultation, the questionnaire is discussed, and the obstetrician subsequently documents the information in their digital system.

All healthcare professionals, including obstetricians, maternity nurses, and the consultation bureau, focus on risk identification during the initial intake consultation (personal communication, May 5, 2023).

QUESTIONNAIRE

At present, there exist multiple risk identification instruments that healthcare professionals can use to detect potential risk factors. These risk factors may exhibit variability in terms of their social and health aspects, as well as the manner in which they are communicated to the patient. The three identified validated questionnaires in the Netherlands are Mind2Care, R4U, and the ALPHA NL. These questionnaires are mainly used by obstetricians.

Maternity nurses and consultation bureaus frequently employ different risk identification tools. Maternity nurses sometimes use a checklist provided by the TNO (Lanting, 2011), and the consultation bureau employs a different "Balans" model to assess various levels of risks, ranging from micro to meta levels (Bakker et al., 1998).

In this section, the risk identification tools of obstetricians are discussed since they play a pivotal role in risk identification.

Mind2Care

The Mind2Care is a screening and advice instrument which contains a questionnaire that expectant women can complete. This questionnaire is intended to assess a pregnant woman's psychological and psychosocial issues and substance use during her pregnancy. Depending on the expectant woman's responses, she receives advice for counselling or treatment during her pregnancy. She can consult with her obstetrician or gynaecologist to be registered for additional counselling or treatment if she so desires (Mind2Care, n.d.).

1 out of 4 expectant women in a sample of 22.141 routinely screened women had one risk factor regarding psychiatric, psychosocial problems, and substance use after using the Mind2Care. Despite the absence of scientifically established evidence regarding the comprehensive long-term impact of using the instrument, it has gained greater acceptance as a methodology (Quispel et al., 2022).

R4U

Rotterdam Reproduction Risk Reduction checklist is a validated risk signalising questionnaire that was developed in 2012 by Erasmus MC.
The aim of the R4U is to identify the risks in the early stages, which allows targeted care for the expectant woman.
During the intake consultation with the expectant woman, the health professional, often an obstetrician, will use the R4U questionnaire. This R4U covers several factors regarding social, psychological, lifestyle, general medical information, obstetric, and care-related risk factors. The utilization of the R4U at the beginning of the pregnancy has been researched. This showed that the use of the R4U within the daily consultation for obstetricians and gynaecologists is possible, and the results are reliable (van Veen et al., 2015).
It is important to note that the R4U is able to integrate with the tools an obstetrician uses, such as Orfeus, Onatal, and Vrumun (KNOV, 2023).

ALPHA-NL

ALPHA-NL is also a tool that is designed to identify early risks for adverse pregnancy outcomes, child abuse, and psychological problems in (expectant) parents. It aims to implement preventive measures during the pregnancy phase.
ALPHA-NL is a brief self-report questionnaire that is completed by the pregnant woman herself early in the pregnancy prior to a consultation with the obstetrician (Nederlands Jeugdinstituut, n.d.). It is filled in either in the waiting room or another separate room. The aim of using ALPHA-NL is to decide together between obstetricians and parents whether additional support or help is needed. Topics that are discussed are their own youth, expectations to be a parent, relationships, alcohol, and drug usage, social support, emotions, stress, and psychological problems. It is filled on a 5-point scale to give a more nuanced answer (Vink, 2019).
There are numerous distinctions between the various questionnaires. The most significant differences are summarised in Table 1.
During this phase, it became evident that the tool could play a role not only in focusing on the initial stages but also at various points in time, addressing a limitation of current tools that only provide a one-time assessment.

	Mind2Care	R4U	ALPHA-NL
Implementation	Expectant parent gets link to survey Yes / No questions 10/8/5 point scale	Obstetrician fills the survey in Yes / No questions	Expectant parent fills it in on paper 5 point scale
Time frame	Fills it in before intake consultation	Fills it in during consultation	Fills it in right before consultation
Focus	Focus lies on psychological risks	Also focuses on medical history	Focuses on various aspects

Table 1: Comparison on implementation, time frame and foncus of the various risk identification tools

4.5 Understanding identification & referral

INTERVIEW PARENTS & HEALTHCARE PROFESSIONALS

OBJECTIVE

Among the other objectives of the interviews with parents was to identify their underlying needs regarding their experience with vulnerable situations, which can affect the risk identification and referral process (Appendix B.3). Moreover, there was a need to gain a deeper understanding of:

- their perceptions of vulnerable topics
- their experience with risk identification and referral
- their future perspectives on "risk" identifcation and referral

These questions were again led by the sensitizing tool which was sent prior.
See Figures 13 and 14.

The interviews with healthcare professionals (Appendix B.5) provided a deeper understanding on:

- their experience with current risk identification and referral of families living in vulnerable circumstances
- the future of risk identification through their view on it's requirements and wishes

All of these aspects come together within a journey map that focuses on the process of risk identification, including its pain points and potential opportunities.

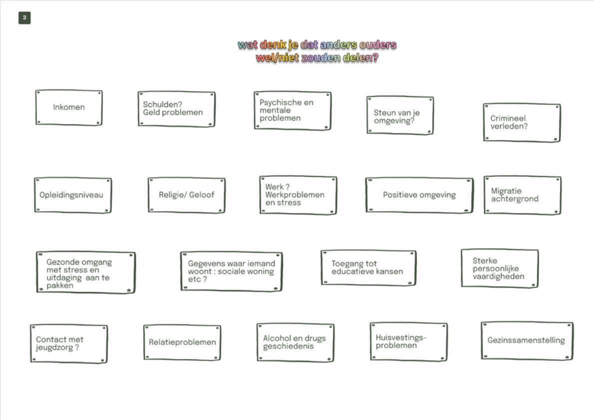
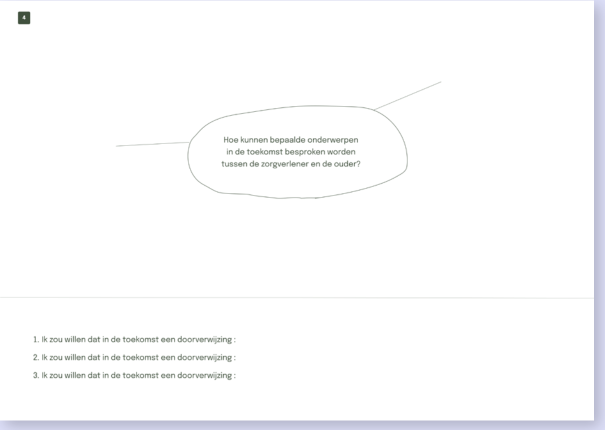


Figure 13: Sensitzing tool excersize 3 understanding parents' perception on various topics



Hoe kunnen bepaalde onderwerpen in de toekomst besproken worden tussen de zorgverlener en de ouder?

1. Ik zou willen dat in de toekomst een doorverwijzing :
2. Ik zou willen dat in de toekomst een doorverwijzing :
3. Ik zou willen dat in de toekomst een doorverwijzing :

Figure 14: Sensitzing tool excersize 4 exploring on how to adress sensitive topics and referral process in the future

KEY INSIGHTS PARENTS

Several significant needs were identified in relation to risk identification and referral.

Needs

Safety and Trust

Parents frequently experience fear regarding the potential consequences associated with the disclosure of certain information. As a result, parents frequently hesitated to disclose all of their information to obstetricians, maternity nurses, or consultation bureau.

Furthermore, parents indicated that it is hard for them to indicate if they need help and admit that they actually need help. Parents shared experiences in which they expressed feelings of having limited room to discuss or uncertainty about whom to contact.

Furthermore, during the interviews, it was clear of the significance of giving consent for parents, which should also be considered when designing a digital tool.

"Dus dan is überhaupt hulpvragen al lastig. Ja en altijd toch maar een beetje doen, dan hoeft dat allemaal goed gaat dat zeg maar promoten van dat er geen problemen..."

"So then asking for help at all is already difficult. Yes, and always doing so as if, then it all has to go well, so you can promote the idea that there are no problems..."

"Ik had zelf wel heel erg die angst Ik dacht ja, dadelijk gaan ze echt verder kijken vinden ze geen goede moeder gebeurt er wat met mijn kinderen komt jeugdzorg erbij dat zeg maar."

"I did have that fear myself I thought yes, next they'll really look further they won't find a good mother something happens to my children and youth welfare comes along"

Self-esteem (worth) and Acknowledgement

Parents frequently experience feelings of shame and guilt when they are unable to adequately provide for their child. When parents find themselves in a state of mental distress or facing other vulnerable circumstances, they may experience a sense of guilt.

Parents can experience feelings of not being good enough or self-doubt, perceiving themselves as falling short in their role as a carer or as a mother/father figure. Moreover, this can be reinforced through the use of social media platforms and other cultural representations that depict an idealized notion of a perfect family.

New parents also often experience feelings of insecurity and vulnerability and are often faced with numerous important decisions. Therefore, parents indicated that having their concerns and difficulties acknowledged by healthcare professionals and realising that they are not alone in facing similar challenges could be helpful.

"De eerste is door meer te vragen en in te gaan wat de ouder zegt. En de tweede. Is door meer serieus Te gaan nemen en zo vertrouwen te geven."

"The first is by asking more and going into what the parent is saying. And the second. Is by starting to take more seriously and so give confidence."

" Dit is eigenlijk Normaal en je mag dit dus voelen en dat wel. dat niet iemand tegen je hebt gezegd meid er zijn zoveel vrouwen Dit dat voelen."

" This is actually Normal and you are allowed to feel this and that. that not someone said to you girl there are so many women who feel that."

Sensitive topics

Multiple themes emerged when parents were asked about difficult subjects to discuss with healthcare professionals.

Don't understand why certain topics are asked

- Financial income: can be a confronting question for parents as it can be interpreted as whether or not they are capable of caring for their child.
- Educational level: says nothing about intellect and does not understand the purpose of the question

Scared of consequences when they share this information

- Criminal activity: parents would most likely not share because of prejudices
- Substance use: alcohol and drugs
- Psychological problems: fear of being labelled

Some information should stay private

- Relationship problems: Some parents said that this is hard to talk about and that they would want to keep it quiet
- Religion: can lead to prejudice and is a personal choice

Future perspective

When asked about their future expectations regarding the various aspects of risk identification and referral, a number of themes were identified. However, the most significant ones that may be of interest to the digital instrument are discussed.

More awareness of help

Parents indicated the need for more indications that help is available and simpler to access, as well as greater awareness of mental health.

Take away the shame

Parents expressed a desire to reduce the emotional burden associated with the fear of being a bad parent or the fear of their child being removed from their care.

Care after birth

In addition, there was a need for a greater emphasis on the postpartum period for parental care.

4.6 Understanding identification & referral

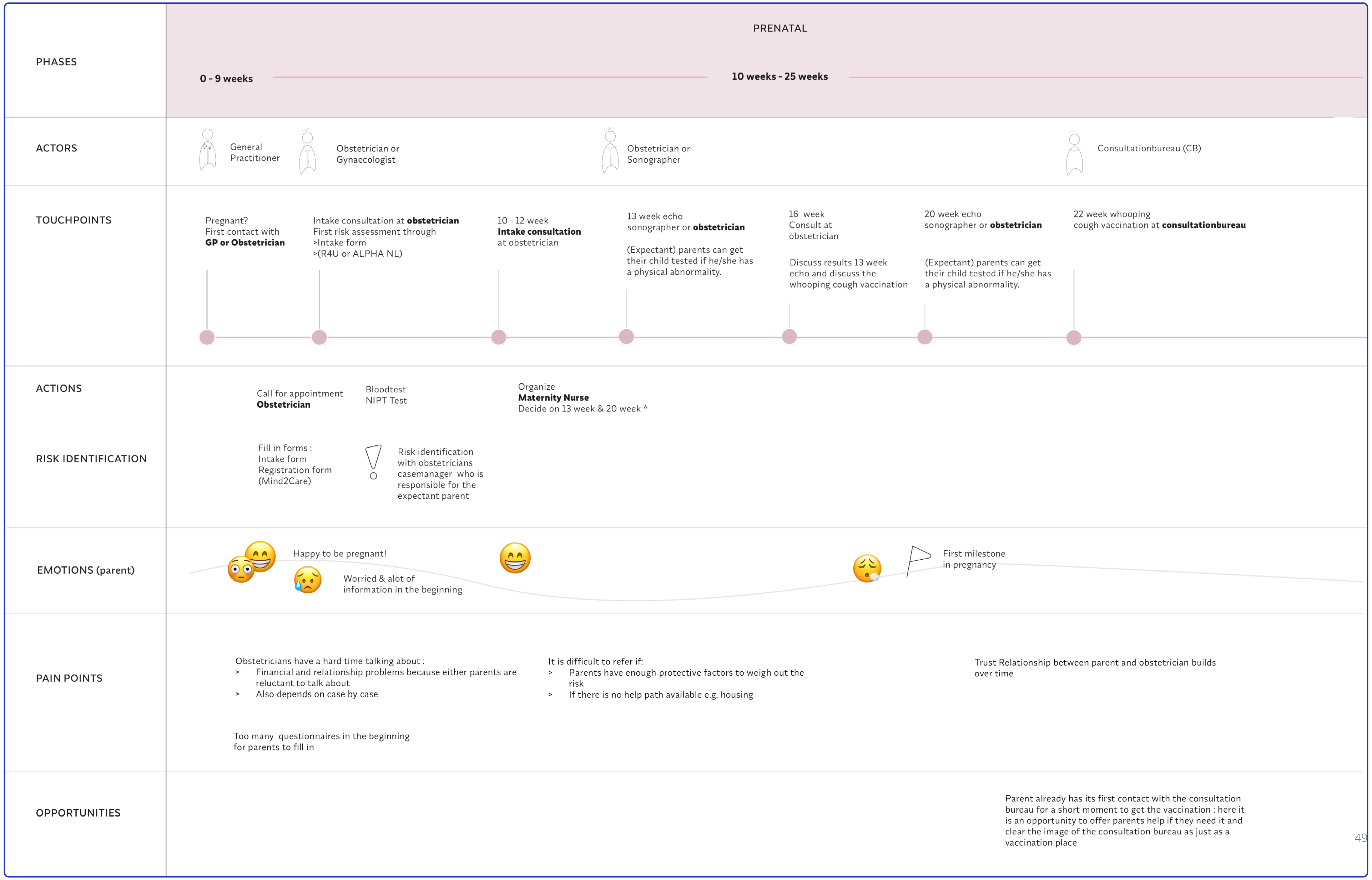
JOURNEY MAP

KEY INSIGHTS HEALTHCARE PROFESSIONALS

The interview conducted with healthcare professionals offered a comprehensive understanding of the individuals involved during specific stages of the first 1000 days, as depicted and elaborated in the Journey Map (Figure 15).

The interviews with healthcare professionals highlighted the involvement of multiple stakeholders during the first 1000 days. Specifically, obstetricians, maternity nurses, and consultation bureaus were found to play an important role in identifying risks for families in vulnerable situations. However, the professionals also pointed out that maternity nurses should play a larger role in risk identification. Maternity nurses themselves emphasized the importance of improving their education and that the skill of identifying risks is often linked to their level of experience.

It is important to note that the participation of different healthcare professionals during different phases of prenatal, postnatal, infant, and toddlerhood care may vary depending on the



PHASES

PRENATAL

0 - 9 weeks

10 weeks - 25 weeks

ACTORS

General Practitioner

Obstetrician or Gynaecologist

Obstetrician or Sonographer

Consultationbureau (CB)

TOUCHPOINTS

Pregnant?
First contact with
GP or Obstetrician

Intake consultation at **obstetrician**
First risk assessment through
>Intake form
>(R4U or ALPHA NL)

10 - 12 week
Intake consultation
at obstetrician

13 week echo
sonographer or **obstetrician**

(Expectant) parents can get their child tested if he/she has a physical abnormality.

16 week
Consult at obstetrician

Discuss results 13 week echo and discuss the whooping cough vaccination

20 week echo
sonographer or **obstetrician**

(Expectant) parents can get their child tested if he/she has a physical abnormality.

22 week whooping cough vaccination at **consultationbureau**

ACTIONS

Call for appointment
Obstetrician

Bloodtest
NIPT Test

Organize
Maternity Nurse
Decide on 13 week & 20 week ^

RISK IDENTIFICATION

Fill in forms :
Intake form
Registration form
(Mind2Care)

Risk identification with obstetricians casemanager who is responsible for the expectant parent

EMOTIONS (parent)

Happy to be pregnant!

Worried & alot of information in the beginning

First milestone in pregnancy

PAIN POINTS

Obstetricians have a hard time talking about :
> Financial and relationship problems because either parents are reluctant to talk about
> Also depends on case by case

It is difficult to refer if:
> Parents have enough protective factors to weigh out the risk
> If there is no help path available e.g. housing

Trust Relationship between parent and obstetrician builds over time

Too many questionnaires in the beginning for parents to fill in

OPPORTUNITIES

Parent already has its first contact with the consultation bureau for a short moment to get the vaccination : here it is an opportunity to offer parents help if they need it and clear the image of the consultation bureau as just as a vaccination place

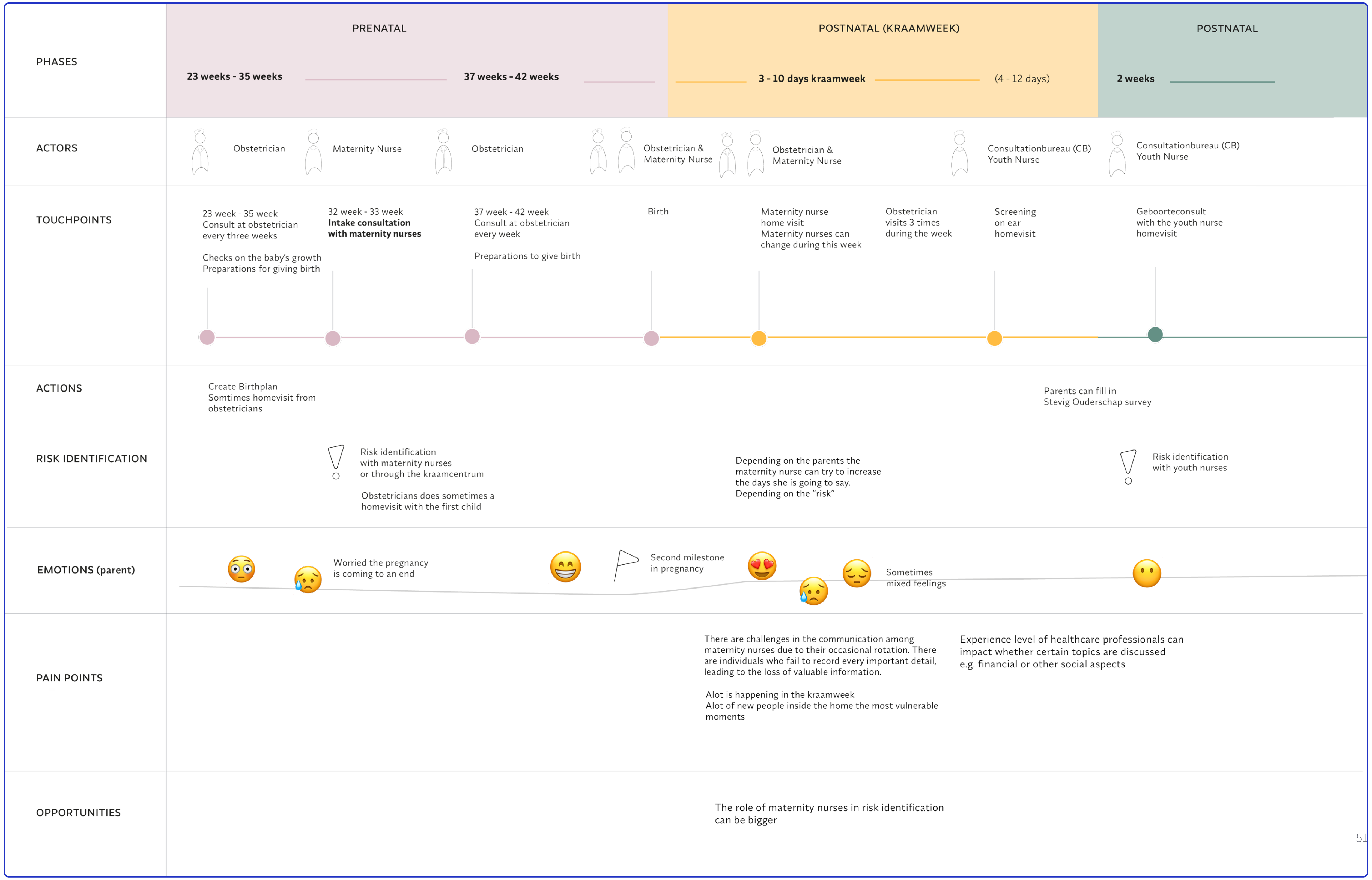
Figure 15: Journey Map on the first 1000 days

JOURNEY MAP

municipality and healthcare practices. It was said that the consultation bureau's level of engagement varies across obstetrician practices during the prenatal stages. In some practices, the consultation bureau is more actively involved. In other practices, this level of engagement has yet to be fully established.
Furthermore, several additional pain points which can hinder the risk identification process were revealed:

Addressing sensitive topics such as financial matters and relationship problems can be difficult for healthcare professionals, as parents tend to be more hesitant to engage in discussions surrounding these issues.

Communication transparency between the healthcare professionals themselves.
It was clear that healthcare professionals must consistently seek consent before disclosing certain information to one another. This has the potential to hinder effective communication among healthcare professionals.



PHASES

PRENATAL: 23 weeks - 35 weeks; 37 weeks - 42 weeks

POSTNATAL (KRAAMWEEK): 3 - 10 days kraamweek; (4 - 12 days)

POSTNATAL: 2 weeks

ACTORS

Obstetrician
Maternity Nurse
Obstetrician
Obstetrician & Maternity Nurse
Obstetrician & Maternity Nurse
Consultationbureau (CB) Youth Nurse
Consultationbureau (CB) Youth Nurse

TOUCHPOINTS

23 week - 35 week
Consult at obstetrician
every three weeks
Checks on the baby's growth
Preparations for giving birth

32 week - 33 week
Intake consultation
with maternity nurses

37 week - 42 week
Consult at obstetrician
every week
Preparations to give birth

Birth

Maternity nurse
home visit
Maternity nurses can
change during this week

Obstetrician
visits 3 times
during the week

Screening
on ear
homevisit

Geboorteconsult
with the youth nurse
homevisit

ACTIONS

Create Birthplan
Somtimes homevisit from
obstetricians

Parents can fill in
Stevig Ouderschap survey

RISK IDENTIFICATION

Risk identification
with maternity nurses
or through the kraamcentrum

Obstetricians does sometimes a
homevisit with the first child

Depending on the parents the
maternity nurse can try to increase
the days she is going to say.
Depending on the "risk"

Risk identification
with youth nurses

EMOTIONS (parent)

😳
😢 Worried the pregnancy
is coming to an end
😁
Second milestone
in pregnancy
😍
😥
😔 Sometimes
mixed feelings
😶

PAIN POINTS

There are challenges in the communication among
maternity nurses due to their occasional rotation. There
are individuals who fail to record every important detail,
leading to the loss of valuable information.

Alot is happening in the kraamweek
Alot of new people inside the home the most vulnerable
moments

Experience level of healthcare professionals can
impact whether certain topics are discussed
e.g. financial or other social aspects

OPPORTUNITIES

The role of maternity nurses in risk identification
can be bigger

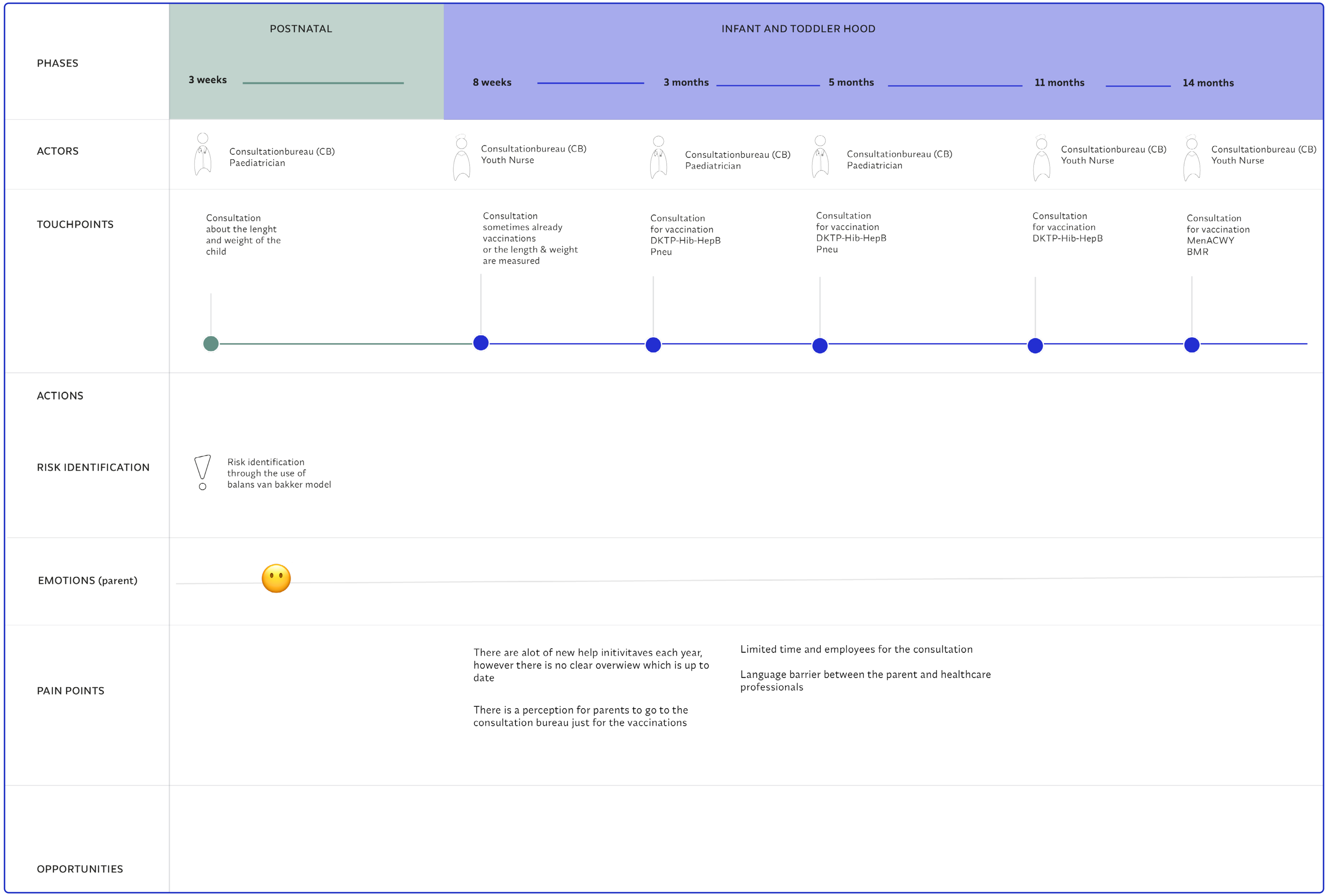
Figure 15: Journey Map on the first 1000 days

4.6 Understanding identification & referral

JOURNEY MAP

Experiences of parents during the first 1000 days

Based on the insights provided by the parents, it is evident that they receive a significant amount of information at the beginning of their pregnancy. Additionally, various milestones are identified during this time. A significant moment for parents can occur following the 20-week echo, during which potential physical anomaly can be identified. Another milestone can arise after birth. However, it was frequently indicated that in the period following childbirth, a range of emotions may arise, as some parents experience joy while others may be susceptible to post-partum depression.
Nevertheless, it was indicated that there were previous indications, such as previous childbirth experiences, that may have contributed to this situation. This shows that risk identification can play a crucial role in the beginning stages of pregnancy.



	POSTNATAL	INFANT AND TODDLER HOOD				
PHASES	3 weeks	8 weeks	3 months	5 months	11 months	14 months
ACTORS	Consultationbureau (CB) Paediatrician	Consultationbureau (CB) Youth Nurse	Consultationbureau (CB) Paediatrician	Consultationbureau (CB) Paediatrician	Consultationbureau (CB) Youth Nurse	Consultationbureau (CB) Youth Nurse
TOUCHPOINTS	Consultation about the lenght and weight of the child	Consultation sometimes already vaccinations or the length & weight are measured	Consultation for vaccination DKTP-Hib-HepB Pneu	Consultation for vaccination DKTP-Hib-HepB Pneu	Consultation for vaccination DKTP-Hib-HepB	Consultation for vaccination MenACWY BMR
ACTIONS						
RISK IDENTIFICATION	Risk identification through the use of balans van bakker model					
EMOTIONS (parent)	😶					
PAIN POINTS		There are alot of new help initivitaves each year, however there is no clear overwiew which is up to date There is a perception for parents to go to the consultation bureau just for the vaccinations		Limited time and employees for the consultation Language barrier between the parent and healthcare professionals		
OPPORTUNITIES						

Figure 15: Journey Map on the first 1000 days

Chapter 5

UNDERSTANDING BIG DATA

The meaning and function of big data will be discussed in greater depth in this chapter. In addition, the role of big data in the future and its impact on the design process will be examined.

5,1 Understanding Big Data

RESEARCH APPROACH

There are multiple research questions aimed at comprehending the prospective function of big data within the design process. Comprehending the fundamental structure of big data both in healthcare and the current project will facilitate the future design process to look out for risks and requirements.

Research Questions

Understanding the context of big data

- What considerations are important to be taken into account when designing with (big) data?
- How do (expectant) families perceive and view the use of (big) data (for a future tool)?

Research Method

Literature Research

Data Dialogues Parents (unpublished, conducted through Erasmus MC

5.2 Understanding Big Data

BIG DATA

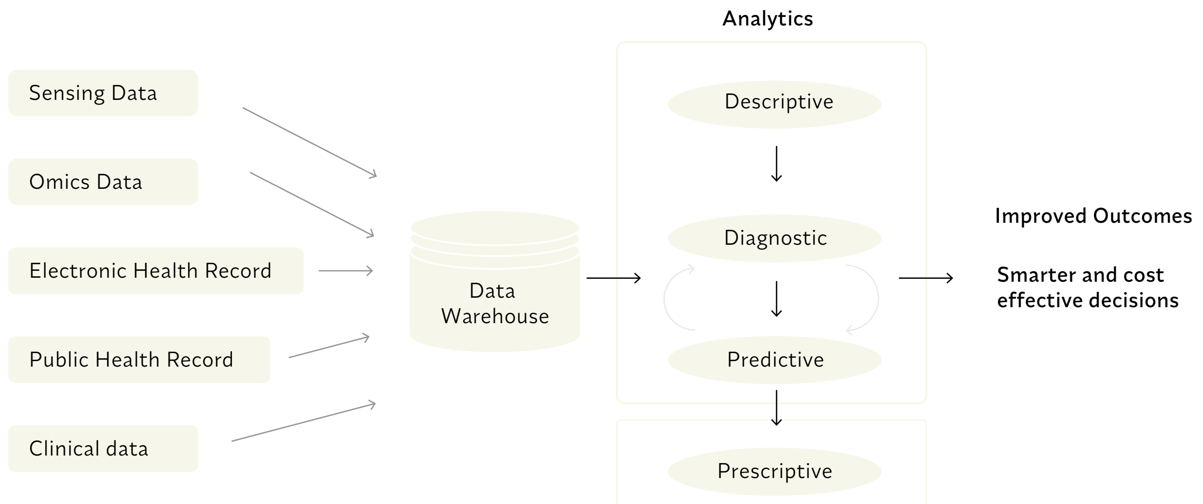


Figure 16: Adapted from “Big data in healthcare: Management, analysis and future prospects,” by Dash, S. et al., 2019, *Journal of Big Data, 6*(1), 43.

Every day people around the world generate a vast amount of data. Due to technological advancements in fields such as telecommunication, digital sensors, computing, and storage possibilities, it has become possible to collect data (Bryant et al., 2008). The total amount of data has increased nine times within five years, this alone in 2011 (Gantz & Reinsel, 2011). Such vast quantities of data are referred to as “big data.”

The definition of big data is, according to (De Mauro et al., 2016) as follows “Big Data is the information asset characterised by such a High Volume, Velocity, and Variety to require specific Technology and Analytical Methods for its transformation into Value.”

Various definitions of big data have been proposed in the academic literature. The three V’s, volume, variety, and velocity, which define the concept of big data, are, however, frequently mentioned as a common pattern (Dash et al., 2019). Below, the 3Vs are defined within the context of the healthcare industry.

- Volume: Health care data like personal medical records increases significantly.
- Variety: Healthcare data can be complex. There are differences in structured, unstructured, and semi-structured data. Whereas structured data can be clinical data which is easy to analyse compared to unstructured data such as doctors’ notes or medical images.
- Velocity: The speed of healthcare data collection and making it accessible for further analysis.

(Asri et al., 2015)

In the context of healthcare, big data can originate from various sources starting from clinical trials and electronic health records (EHR) to patient registries (Auffray et al., 2016). In recent times, there has been an integration of data from social media and occupational sources (Fernández-Luque & Bau, 2015). Figure 16, illustrates the manner in which big data can be effectively stored and analyzed to enhance the overall efficacy of decision-making processes within the healthcare domain (Dash et al., 2019).

However, in the context of the "Making Big Data Meaningful for a Promising Start" initiative, it is crucial to establish where the big data is coming from in order to understand its magnitude. The project integrates multiple datasets from various companies, such as the Central Bureau of Statistics (CBS) and Perined.
The "Making Big Data Meaningful for a Promising Start" initiative specifically excludes commercial information sourced from social media platforms such as Facebook and Instagram.

For this "Big Data & Kansrijke Start" initiative, predictive models are being developed from the big data from these various sources. The ongoing research project aims to develop a predictive model for anticipating adverse outcomes in the later stage of a child.
The following list provides a summary of the adverse outcomes that the research project wants to predict.

- Teenage motherhood
- Youth protection
- Receiving social benefits
- Health insurance default
- Social, emotional and cognitive and motor development
- Obesity

To anticipate different outcomes, the research project has been choosing specific variables from big data to construct a predictive model. The objective of the research team is to develop a prediction model that can identify families at an earlier stage by assessing the level of risk faced by parents and children in terms of potential negative outcomes for their children.

Figure 17 depicts a visual representation on how the prediction model could work.

The prediction model is currently in the developmental stage, and the research team is in the process of preparing the dataset from CBS. At this point, the team does not have complete knowledge of the variables that will be considered and calculated for the adverse outcome.

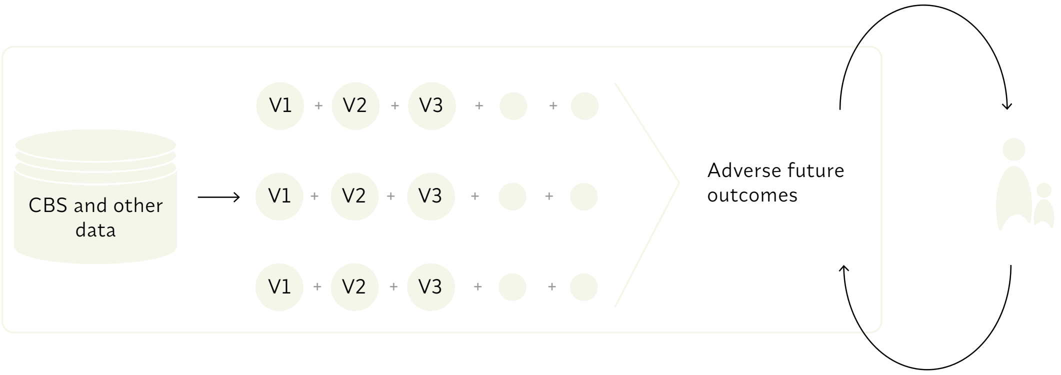


Figure 17: Visual representation on how the system of the prediction model could look like: using various variables from CBS and Perined adverse outcomes can be potentially predicted

5.3 Understanding Big Data

BENEFITS AND RISKS OF BIG DATA

Having established the definition and foundation of big data, it is crucial to comprehend the extent of its potential benefits and risks when applied in the healthcare context.

As per the European Commission directorate general for health and food safety (Habl et al., 2016), the use of big data in the healthcare sector has been found to contribute to various levels.
The use of big data can enhance the timely identification of early indicators and preventative measures to improve the efficacy and quality of medical interventions and decisions. Furthermore, big data can enable the identification of risk factors for diseases, which has the potential to broaden the scope of preventative measures available. For instance, available evidence indicates that big data has the potential to be used for disease identification, such as human immunodeficiency virus (HIV) (Qiao et al., 2021).
Another opportunity for using big data in health care is that there is an opportunity to uncover patterns that may have gone unnoticed if only smaller data sets had been used (Bertolucci, 2013; Roski et al., 2014).
Upon conducting research on the attitudes of people in the European Union regarding the use of health data, it has been observed that there exist favourable perspectives, though with certain conditions. Most people show favourable attitudes toward the use of health data for various purposes, provided that such data is employed to improve the welfare of the common good. However, the primary points of concern pertain the commercialisation of data, safeguarding the data, and the potential misuse of the data against the people's interests (Skovgaard et al., 2019).

The use of big data and the development of prediction models present numerous prospects for the future of healthcare. Nevertheless, it is crucial to acknowledge the challenges that accompany the usage and analysis of big data. The subsequent section will elaborate on various challenges, including those related to management, security, and privacy.

BIG DATA MANAGEMENT

It might take a lot of time and effort to manage the data and adapt the information technology (IT) infrastructure to the procedures and rules to accommodate new policies (Roski et al., 2014). Further critical technological and infrastructural concerns that might jeopardise a Big-Data-driven healthcare system include data heterogeneity, data protection, and analytical processes in data analysis (Habl et al., 2016).

BIG DATA SECURITY

There are risks associated with using and storing large amounts of data that cannot be ignored while discussing the topic of big data. The healthcare sector remains highly vulnerable to publicly disclosed data breaches making secure storage of sensitive data crucial (Abouelmehdi et al., 2018).

BIG DATA PRIVACY

The issue of compromising patient privacy has emerged as a significant concern in the context of employing big data in healthcare. The European Union Data Protection Regulation is currently attempting to find a balance between safeguarding patient privacy and facilitating the sharing of patient data for healthcare and research purposes.
There are various techniques that can ensure privacy in big data.
Data anonymization is a process that can be implemented prior to conducting analytics, with the aim of safeguarding the confidentiality of patient identity. Secondly, it is crucial to implement privacy-preserving encryption techniques, and lastly, the implementation of new privacy regulations is necessary to safeguard patient confidentiality. An example of ethical practice in the context of healthcare analytics is the implementation of informed consent as a prerequisite for accessing patient data (Kupwade Patil & Seshadri, 2014).

A summary of what security and privacy mean for big data is shown in the Table 2 below (Abouelmehdi et al., 2018).

Security	**Privacy**
Security is the "confidentiality, integrity and availability" of data	Privacy is the appropriate use of user's information
Various techniques like Encryption, Firewall, etc. are used in order to prevent data compromise from technology or vulnerabilities in the network of an organization	The organization can't sell its patient/user's information to a third party without prior consent of the user
It may provide for confidentiality or protect an enterprise or agency	It concerns with patient's right to safeguard their information from any other parties
Security offers the ability to be confident that decisions are respected	Privacy is the ability to decide what information of an individual goes and where to

Table 2: From "Big healthcare data: Preserving security and privacy," by Abouelmehdi, K. et al., 2018, *Journal of Big Data, 5*(1),1.

5.4 Understanding Big Data

CONSIDERATIONS

When contemplating the integration of prediction models, which can take the form of Artificial Intelligence (AI), it is imperative to take into account various factors, such as guidelines for designing with AI.

GUIDELINES

The progress made in the field of AI has facilitated the incorporation of diverse AI functionalities into systems. Several guidelines were proposed to comprehend and design with these systems (Amershi et al., 2019). The guidelines underwent validation through multiple rounds of evaluation with design practitioners and were created through publicly available articles and scholarly papers. The guidelines in Figure 18 provide a comprehensive overview of the system's four touchpoints.

First touchpoint

Initial

- Make clear what the systems can do
- Make clear how well the system can do what it can do

Second touchpoint

During interaction

- Time services based on context
- Show contextually relevant information
- Match relevant social norms
- Mitigate social biases

Third touchpoint

When wrong

- Support efficient invocation
- Support efficient dismissal
- Support efficient correction
- Scope services when in doubt
- Make clear why the system did what it did

Fourth touchpoint

Over time

- Remember recent interactions
- Learn from user behaviour
- Update and adapt cautiously
- Encourage granular feedback
- Convey consequences of user actions
- Provide global controls
- Notify users about changes

Figure 18: Adapted from "Guidelines for Human-AI Interaction," by Amershi, S. et al., 2019, *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*, 1–13.

EXPLAINABLE (XAI)

Providing an explanation is particularly important when it comes to AI systems, as they have a substantial influence on decisions such as disease prognosis. When AI systems are employed to assist in making decisions that have an impact on individuals' lives, it becomes crucial for individuals to comprehend the process behind those decisions (Smith & Shum, 2018). There exist guidelines for the implementation of explanation in the context of artificial intelligence, commonly referred to as Explainable Artificial Intelligence (XAI).
XAI refers to a collection of processes and methods that enable human users to understand and have trust in the outcomes and outputs generated by machine learning algorithms (IBM, 2023).

In order to foster trust and acceptance of decision support systems on AI, the literature emphasises the significance of providing explanations for AI predictions. According to a study conducted by Zhang et al. (2021), it was discovered that offering local explanations for the reasoning behind a prediction resulted in improved understanding. However, this approach did not effectively cultivate trust. Several studies have discovered contrasting outcomes, indicating that offering explanations could potentially undermine a user's trust in a system (Cramer et al., 2008; Kizilcec, 2016).

Hence, achieving a balance between providing explanations that promote user trust and transparency poses a significant design challenge.

However, according to Kore (2022) there are several guidelines for designing AI explanations to think of. There are several methods that can be beneficial to take during the design process.

Make clear what the system can do
It is beneficial to ensure that the users have a clear understanding of the system's capabilities. It is important for users to have a comprehensive understanding of the complete range of features offered by the system.

Make clear how well the system does its job
Assisting users in comprehending the circumstances under which an AI model exhibits high performance and when it encounters limitations.
Merely providing a confidence score to showcase the AI performance may not adequately enable users to comprehend the dependability of the system (Zhang et al., 2021). Hence, another design challenge is to carefully examine the manner in which the performance of the prediction model will be presented to the users.

Be transparent
It is important for users to have an understanding of the methods employed in data collection. In situations where it is deemed essential, it is advisable to employ non-black box models. By doing so, the intermediate steps involved in the modelling process become more interpretable, and the resulting outcomes are more transparent and evident. This approach enhances the overall transparency of the process.
The extent of transparency will vary based on the various stakeholders involved.

ETHICS

The use of big data in the healthcare sector presents novel ethical and legal predicaments due to the incorporation of personal information. The possibility of compromising one's privacy and autonomy, as well as the consequences on the public's need for openness, trust, and fairness, are among the ethical and legal concerns associated (Pastorino et al., 2019). Therefore, it is imperative to consider ethical implications. The literature has identified five ethical principles that converge and should be taken into consideration (Jobin et al., 2019). Having a comprehension of AI's ethical stance is important for the design process.

Transparency

According to Jobin et al. (2019), transparency is a widely recognized principle that is advocated as a means to reduce harm and enhance the performance of AI (Institute of Business Ethics, 2018; PwC, n.d.). Several sources advocate for increased transparency from individuals involved in the development or implementation of AI systems through the disclosure of information (IBM, 2017; Internet Society, 2017; Matsuo, 2017). It is encouraged to provide explanations that are either in non-technical language (Diakopoulos et al., 2016) or can be audited by humans (UNI Global, 2017).

Non-maleficence

Literature suggests that AI should adhere to the principle of non-maleficence, which entails avoiding foreseeable or unintentional harm. (Matsuo, 2017).
The implementation of solutions involves the assessment of quality (GOV.UK, Department of Health & Social Care, 2021) and the advancement of industry standards (Federal Minister of Transport and Digital Infrastructure, 2017). Another solution relates to the aforementioned collaboration among diverse disciplines.

Justice and fairness

The concept of justice is primarily conveyed through the principles of fairness (Matsuo, 2017) and the proactive measures taken to prevent, monitor and mitigate undesired biases (Institute of Business Ethics, 2018). Other sources place significant emphasis on the value of diversity (Crawford et al., 2016) and inclusion (Albrecht et al., 2016). The promotion of justice can be facilitated through various means such as transparency, testing (Institute of Business Ethics, 2018), monitoring (PwC, n.d.), interdisciplinary approaches (Crawford et al., 2016), and the inclusion of relevant parties involved.

Responsibility

Although responsible AI is frequently mentioned, the terms responsibility and accountability are seldom clearly defined (Jobin et al., 2019).
In literature, there exists a divergence of perspectives regarding the party responsible and accountable for the actions and decisions of AI. Various sources attribute the responsibility of AI to either the developers themselves (Matsuo, 2017), the designers(Internet Society, 2017), or the institutions (Association for Computing Machinery US Public Policy Council (USACM), 2017).

BIAS

In the context of the design project, gaining an understanding of AI bias was crucial. This comprehension helped understand potential pitfalls.

In the healthcare sector, bias can be analysed in three distinct dimensions: those driven by data, those influenced by algorithms, and those stemming from human factors (Norori et al., 2021). Furthermore, bias can be characterized from both a statistical and social perspective. From a statistical perspective, bias pertains to situations where the distribution of a particular dataset does not accurately reflect the actual distribution of the population. Hence, the presence of statistical bias has the potential to result in an algorithm generating an output that deviates from the accurate estimation (Parikh et al., 2019).

Compared to statistical bias, social bias pertains to disparities that could lead to less than ideal results for specific groups in society.

Also, in the healthcare sector, the use of AI is susceptible to biases such as data-driven bias, algorithmic bias, and human bias. See Figure 19 for a visual representation of various sources of bias.

Data-driven bias

Often human research has been done with the inclination towards groups with Western, Educated, Industrialised, Rich, Democratic (WEIRD) profiles. This bias results in a lack of representation of the entire human population. Hence, many AI algorithms that use these datasets are, as a result, biased (Henrich et al., 2010).

Algorithmic bias

As previously stated, if an algorithm is trained on a dataset that contains bias, it is probable that the algorithm will perpetuate patterns that are also biased. To enhance algorithmic fairness and mitigate bias, it is feasible to integrate protected attributes, such as gender and ethnicity, into the training process to guarantee that algorithmic predictions are statistically uncorrelated with these attributes (Agarwal et al., 2019).

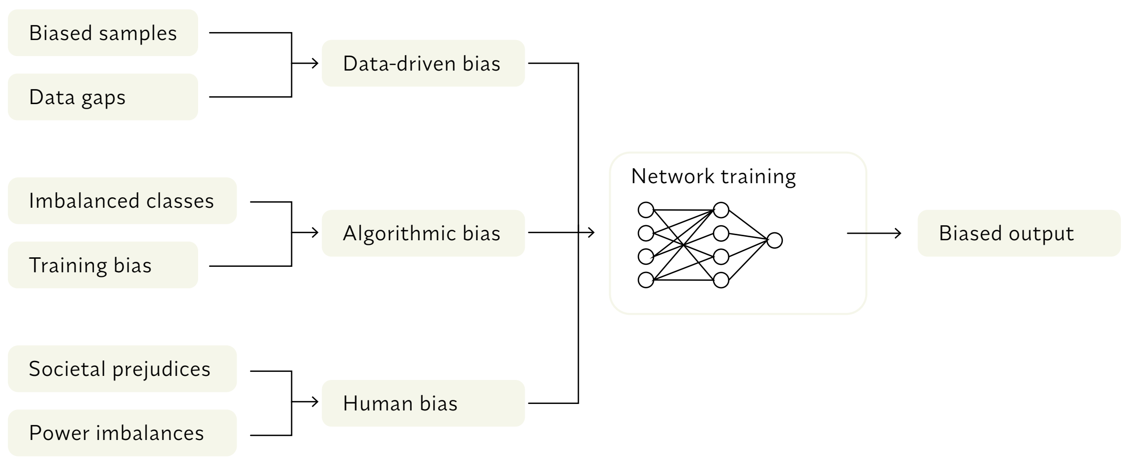


Figure 19: Adapted from "Addressing bias in big data and AI for health care: A call for open science," by Norori, N. et al., 2021, *Patterns, 2*(10).

Human bias

Since AI algorithms are designed by humans, they frequently exhibit human biases. The detection and mitigation of human bias can pose a significant challenge, as it might stem from deeply ingrained societal prejudices (Norori et al., 2021).

Algorithmic bias in a welfare system - Toeslagen affaire

The Toeslagen affaire, alternatively referred to as the childcare allowance scandal, represents a significant political scandal and algorithmic bias within the Netherlands. The scandal pertained to a variety of households who were incorrectly charged with fraudulent activity in their pursuit of childcare allowance, leading to considerable monetary and psychological distress for the impacted families (Ten Seldam & Brenninkmeijer, 2021).

Nevertheless, it has been reported that the tax authority used algorithms to inform their decision-making process. The algorithm designed for autonomous learning was intended to categorise benefit claims based on risk classifications. However, it was found that parents holding dual citizenship were consistently identified as being at a higher risk level and categorized as fraudulent (Autoriteit Persoonsgegevens, n.d.).

The mitigation of bias in any tool, including those designed to assist in decision-making, is a crucial aspect to consider.

Mitigate bias

In order to mitigate bias in healthcare, the paper by Parikh et al. (2019) describes two methods to reduce bias in AI. Decision-support systems based on AI possess the capability to identify instances of bias in real-time during physician decision-making processes. This has the potential that clinicians can receive alerts regarding decisions that may be vulnerable to bias. For example, if there exists a disparity between the rational prediction made by AI and the clinical judgement. An alternative approach involves examining data that has been obtained from neutral sources, such as vital sign data gathered during surgical procedures.

As previously stated, bias can be mitigated if the aforementioned **principles of transparency,** justice, non-maleficence, and **responsibility** are incorporated into the design of an AI-infused system.

DATA DIALOGUES PARENTS

Prior to the graduation project, the research team at Erasmus MC engaged in data dialogues with parents and diverse healthcare professionals. The following findings are from an earlier unpublished study conducted by the research team.

The main objective of the data dialogues was to understand the opinions of parents and healthcare professionals regarding data registration and to determine circumstances under which the use of registered data is both meaningful and acceptable in the first 1000 days.

It is important to note that the analysis of the raw data from the data dialogues is still pending.
For this master's thesis, access to the raw data was permitted in order to examine and identify recurring themes in the data dialogues for the design process.
The data dialogues played an important role in facilitating the graduation project's comprehension of the diverse perspectives expressed by parents.

After reviewing the raw data, three themes concerning data interaction were identified. These three main themes are as follows: 1) data input, 2) usage of data, and 3) outcome of data.

Due to time limiation, only the data dialogues of parents were taken into account as they represent the primary group of the graduation project.

INPUT DATA

> How to ask for data?

The way of asking for the data from parents is important since this can also impact how they fill in data. Parents can experience shame regarding certain topics, which could prompt them to give socially desirable responses.

In addition, special consideration should be given to designing for accessibility. It should be comprehensible and legible to the majority of people.

"Manier van vragen over je gegevens zijn belangrijk"

"Way of asking about your data are important"

USAGE OF DATA

> How will the data be treated?

It is important to take into account how the data will be handled. Parents understand that data is not neutral and often falls short in capturing the complete reality.

"(...) data is ook niet neutraal ofzo. het is een getal, het is een statistiek maar het beschrijft niet helemaal de werkelijkheid"

"(...) data is not neutral or anything either. it's a number, it's a statistic but it doesn't quite describe reality"

> Who can see the data?

Additionally, it is imoprtant to consider who can view the data, as some parents may be reluctant to share information with certain healthcare professionals.

"Consultatiebureau. Ik zou het juist een beetje eng vinden, want dan dan ben ik voel ik me heel kwetsbaar.."

"Consultation bureau. I would just find it a bit scary, because then I feel very vulnerable..."

> More control to the parents?

When data is involved, parents expressed the need to feel a sense of ownership over it. Consent is also a critical component, although it may not be necessary to obtain it repeatedly. Parents may perceive the obligation to reiterate their narrative to each new healthcare provider as a burden.

"Voor mij eens te meer de conclusie dat je altijd zelf eigenaar moet voelen van die gegevens"

"For me once again the conclusion that you should always feel ownership of that data yourself"

OUTCOME OF DATA

> How will the outcome effect the parents?

It is important to consider the potential impact of the outcome on parents in both the short term and the long term. Parents indicated a risk of misinterpretations and bias that may result in false conclusions. Furthermore, the Toeslagen Affaire has raised concerns among some parents regarding the potential impact of algorithms.

"een duidelijk doel moet hebben. Van, wat wil je onderzoeken? Eh wat, wat wil je? Met de data doen"

"should have a clear purpose. Of, what do you want to research? Um what, what do you want? To do with the data"

> How can the outcome not inflict parents without giving them labels?

Parents may face labelling based on their children's outcomes, and there may be pressure to achieve an ideal family. The tool's outcome may negatively impact users by inducing feelings of shame or humiliation. Hence, it is crucial to consider the presentation of the algorithm's output in the future tool.

"(...) dan kreeg ik een bepaald cijfer alsof van zo : nou we hebben je beoordeeld en je hebt een 3 ja je faalt"

"(...) then I got a certain grade like: well we graded you and you got a 3 yes you fail"

"(...) niet doorschieten dat we perfecte kinderen willen creeren van en dan neerkijken op ouders van hoezo heb je dat niet gedaan"

"(...) don't want to create perfect children of and then look down on parents of how did you not do that"

2

DEFINE the CONTEXT

Having established an understanding of the context and the target group, several requirements have emerged as crucial for the progression of this project. In this second part, the most important decisions for the tool based on prior research will explained.

Chapter 6

DEFINE THE CONTEXT

This chapter focuses on the main challenges by defining the problem and examining the qualities and requirements for the tool. At the end of this chapter, the design direction, which includes the recurring themes for the tool, will be discussed.

6.1 Define the context

PROBLEM DEFINITION

Based on the interviews and data dialogues, there have been several challenges regarding the risk identification of families living in vulnerable circumstances. Figure 20 shows a simplified thought process that a parent can experience, which can challenge the overall risk identification and referral of parents.

(Expectant) parents find it challenging to discuss certain topics, such as mental challenges, due to the fear of consequences that institutions like the Jeugdzorg could get involved and, worst case, take their child away.

Moreover, they frequently experience discomfort when discussing sensitive topics, as they wish to avoid being labelled or perceived in a specific manner, especially when they already feel vulnerable. This can lead to not parents not sharing information which is important for identifying vulnerable circumstances.

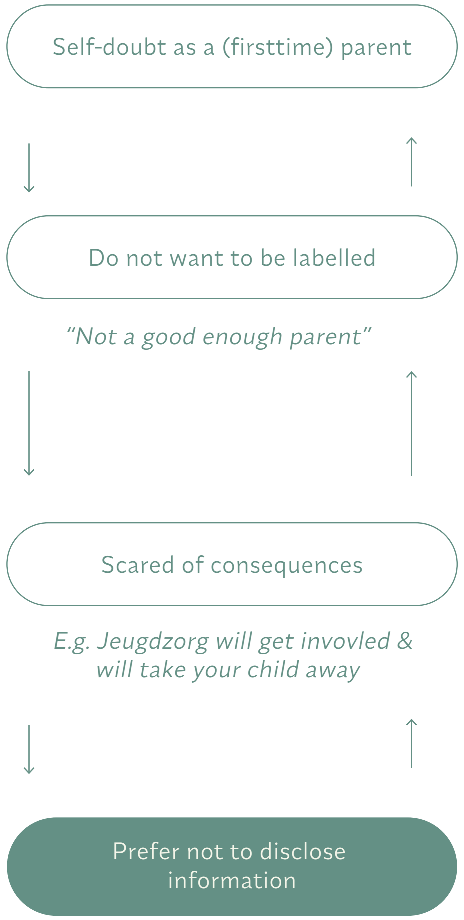


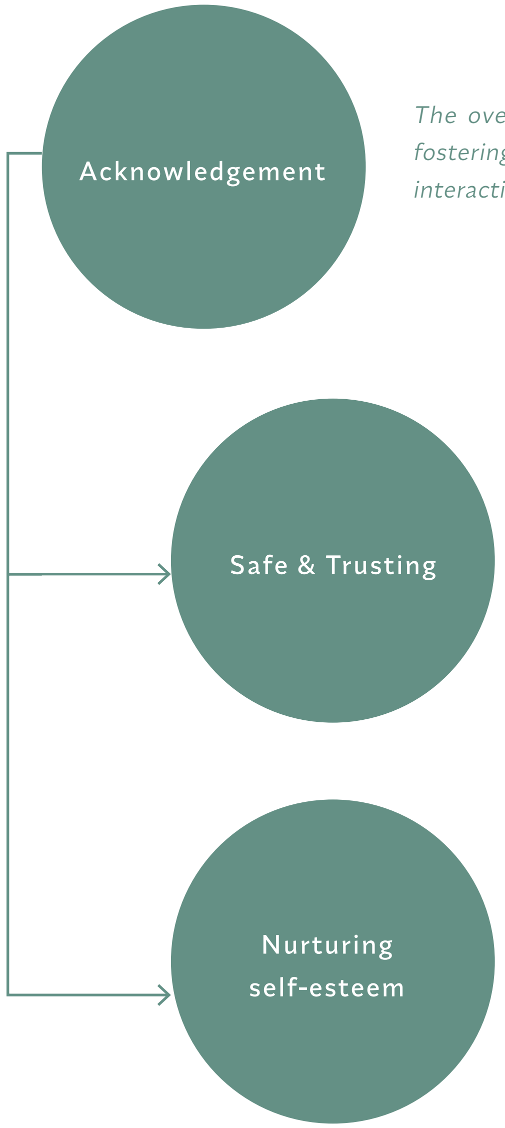
Figure 20: Visual representation of a possible thought process of parents

6.2 Define the context

INTERACTION QUALITIES & REQUIREMENTS

INTERACTION QUALITIES

The interaction qualities refer to the desired characteristics of the interaction between the tool and the parent.



The overarching theme revolves around acknowledging parents and fostering an environment where parents feel safe and do not feel labelled interacting with the tool.

Ensuring a sense of safety and trust is crucial in the interaction between the parents and the tool. The parents' hesitation to share information with healthcare professionals stems from their concerns about the potential involvement of Jeugdzorg. Hence, it is imperative for parents to have a sense of safety in using this tool.

The interaction between the tool and the parent should not create the perception that the parent will be categorised or labelled. However, it should nurture their sense of self-worth in relation to the parents. Parents sometimes experience self-doubt regarding their ability to effectively fulfil their parental role for their children.

DESIGN REQUIREMENTS

As a result of the qualitative research conducted, there are several requirements for the tool that must be considered during this creation:

- **The tool is going to be digital and predict adverse outcomes**
  The tool will be digitally designed and will not prioritise a physical component. Therefore, the design phase primarily centres around the digital tool, as stated in the project brief. It is important to bear in mind that the "Making Big Data Meaningful for a Promising Start" is developing a model to predict adverse outcomes.

- **Filled in at multiple moments instead of one moment**
  All of the current risk identification tools focus on a single moment (see journey map). However, for this tool to distinguish itself from other risk identification tools, it must facilitate the tool at multiple stages and also has attention to postnatal care.

- **Give parents the power and sense of control**
  It is important to acknowledge the significance of parents feeling a sense of power and in control when using this tool, as they should have the authority to provide consent. The interviews also revealed that parents expressed a desire to maintain control over the healthcare professionals who are granted access to the data.

- **Level of transparency**
  It was evident from the literature review, parent interviews, and data dialogues that a certain degree of transparency is required to discuss topics such as financial elements or any other difficult topics which were difficult for parents to discuss. To mitigate this, it was apparent that, particularly for sensitive topics such as finances, careful consideration must be given as to why this question is being posed so that the parent understands its purpose.
    - The fear of consequences should be minimized
    - Avoid the feelings of shame or being labelled

- **Awareness of help availability and help regarding other healthcare professionals**
  The availability that parents can communicate to various healthcare professionals should be apparent when using the tool. Additionally, the roles of the maternity nurse and the consultation bureau as entry points for assistance could be made clear.

A number of questions should be addressed by the tool based on the data dialogues and kept in mind when designing the tool.

- How to ask for data?
- How will the data be treated?
- Who can see the data?
- More control to the parents?
- How will the outcome effect the parents?
- How can the outcome not inflict parents without labelling thems?

BEYOND THE SCOPE

There are several factors which are beyond the scope of this design project:

- **Bias and Ethical considerations**
  In order to address bias and ethical considerations, the design project will prioritise transparency and explainability. However, the examination of bias within the data and the ethical implications of regulations e.g., in the law, are beyond the scope of this master's project. Nevertheless, it is crucial for the designer to be mindful of and recognise these factors.

- **Design healthcare / referral trajectory**
  The design of a referral trajectory is not within the scope of this project, as the prediction model of "Making Big Data Meaningful for a Promising Start" is still in the developmental phase. Therefore, a recommendation will be created based on the prediction model's output on how the referral/advice could look like.

- **Tool for healthcare professionals**
  The tool will exclusively prioritise the information visible to parents rather than the information accessible to healthcare professionals. The choice was made to prioritise designing for the target group due to time constraints.

6.3 Define the context

DESIGN DIRECTION

The primary objective of the design goal is to establish a more specific and focused direction for the design process. Based on the research as well as on the define phase, the following design goal was formulated with the main themes/ interaction qualities (Figure 21).

> Design a digital tool concept that enables expectant parents potentially living invulnerable circumstances to share their information, facilitating the identification of potential risks at an early stage which can have an impact on the later stage of a child's life and referral. The tool's interaction with the parents should evoke a sense of **acknowledgement** through nurturing feelings of **safety, trust** and **self-esteem** of the parent.

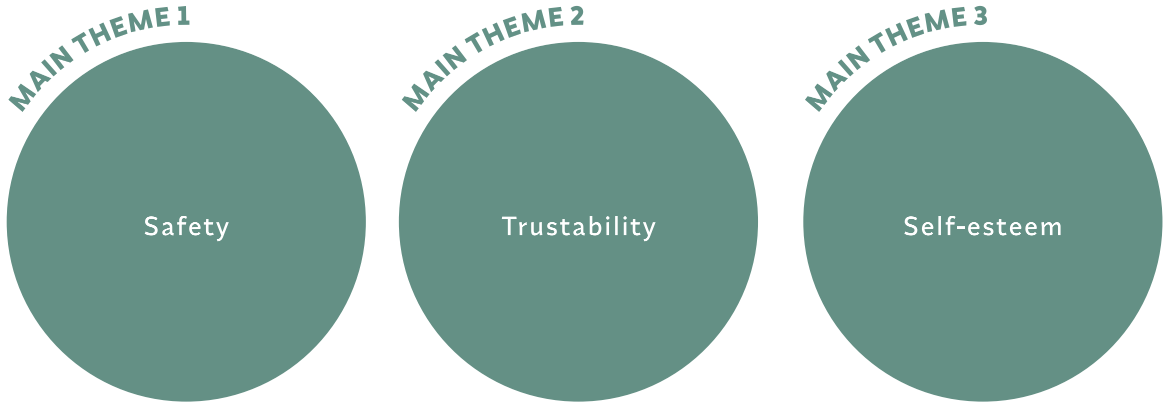


Figure 21: VIsual representation of the main themes for the graduation project

3

DESIGN / DELIVER in the CONTEXT

In this third part of the project, the ideation and conceptualization process of the design project will be elaborated. It will be concluded with a design evaluation and a final iteration of the concept.

Chapter 7

IDEATION

This chapter will discuss the ideation process. To explore the design space, ideation methods involving co-creation sessions with parents and healthcare professionals were used.
Using the outcomes from the co-creation session, an iteration was made in the design direction. Subsequently, ideas for various concepts were generated through wireframing, eventually leading to a single concept flow.

7.1 Design in Context

DESIGN APPROACH

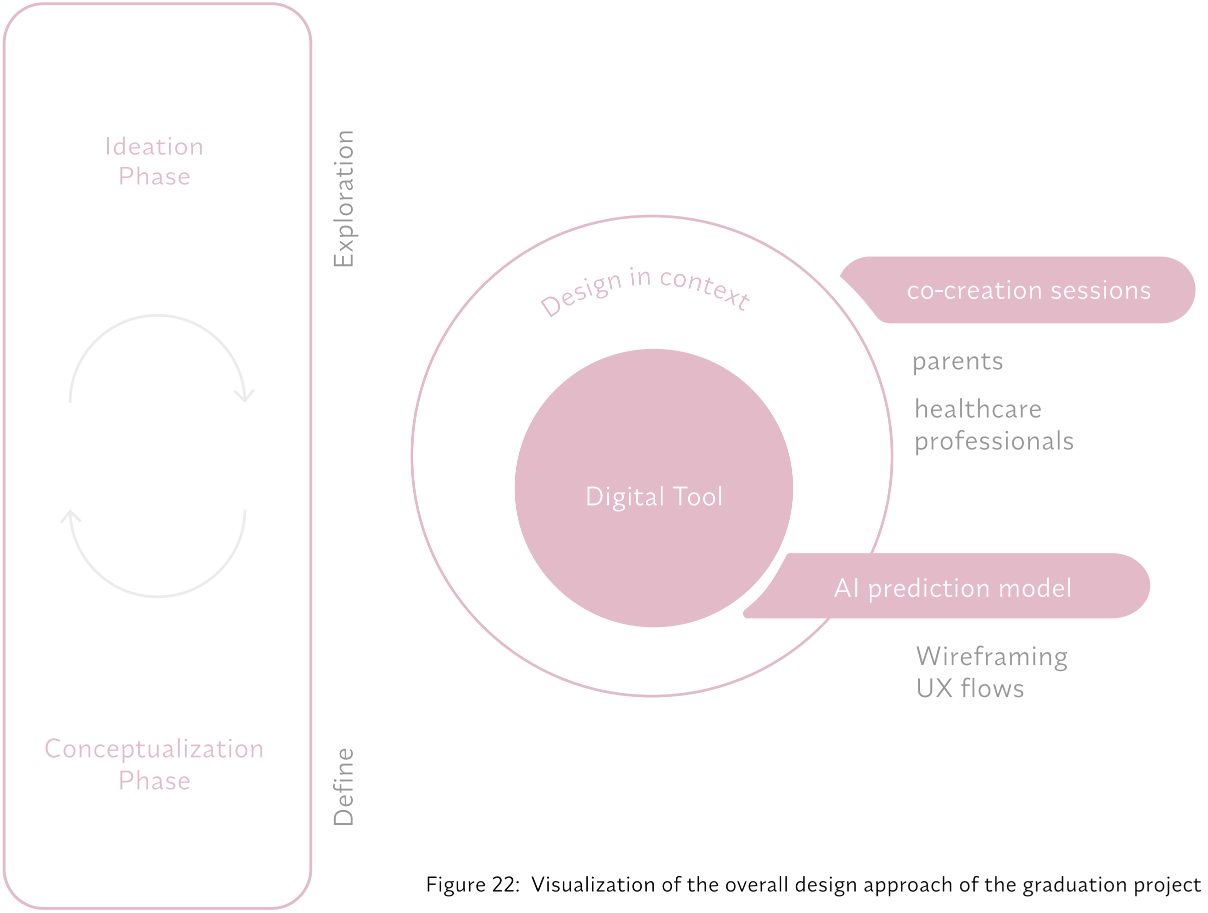


Figure 22: Visualization of the overall design approach of the graduation project

The ideation approach began by conducting co-creation sessions with parents and healthcare professionals in order to gain insight into their ideas, needs, and requirements pertaining to a digital tool. This approach involves the collaboration of a wide range of stakeholders to collectively generate ideas and solutions. The purpose of this was to examine various options related to tools and investigate the design possibilities within this domain.

Subsequently, the design approach transitioned towards a converging phase, focusing on the design of using the prediction model in a digital tool which the “Making Big Data Meaningful for a Promising Start” research team is developing.

Wireframing and user experience (UX) flows were used to design the conceptual framework for the digital tool with considerations of the prediction model. Wireframing is the process of producing simplified, low-fidelity visual representations of the user interface, whereas the UX flow depicts the journey through the concept.

The ideation process and conceptualization of the digital tool were performed in an interchangeable manner rather than a linear one.

In Figure 22, an overview of the design process is represented graphically.

7.2 Design in Context : Ideation

CO-CREATION SESSIONS

OBJECTIVE

The objective of the co-creation session is to understand further and gain insights into parents' and healthcare professionals' ideas, needs, and requirements regarding the digital tool. Furthermore, the aim was to identify the most important touchpoints and ideas regarding the various prompts, which are based on the results from the interviews and data dialogues such as:

- How can the tool keep parents from feeling labelled?
- How can the tool enhance parental self-esteem?
- How can the tool alleviate parental fear of consequences?
- How can parents be assured that their data is safe?

Parents previously sensitized through earlier interviews were asked to participate.
Multidisciplinary co-creation sessions were conducted with healthcare professionals such as obstetricians, maternity nurses, youth nurses, and a paediatrician.

The co-creation session was conducted online using Teams and the online collaboration tool Miro. A series of four (in total eight) sessions were conducted, with varying group sizes ranging up to four parents or healthcare professionals per session.
The co-creation session, which could have included both parents and healthcare professionals, was not conducted due to potential hesitance among parents to share their thoughts.

The general methodology employed in all co-creation sessions involved an introductory phase, an ice-breaking activity, and a gradual transition from a broad perspective to more specific ideas, leading up to a more detailed alignment of the idea (see Figure 23). The session used the context mapping technique (Visser et al., 2005), which involved prompting participants to reflect first on the past and generate ideas for the present and future. The comprehensive plan can be found in Appendix C.1 and Appendix C.2 .

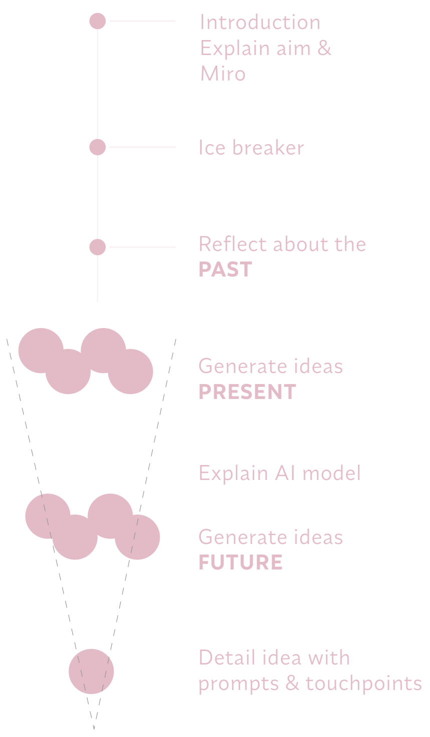


Figure 23: The overall process of the co-creation session

PILOT SESSION WITH RESEARCH TEAM

In order to find pain points and time limitations for the co-creation plan, a pilot session was carried out with the research team. The co-creation plan was tested in advance by allowing the research team to participate in various exercises. During this process, several adjustments were made to the co-creation plan. For example, one adjustment which was made was to readjust the ideation methods in a shorter time. Another adjustment involved modifying the questions asked to parents, specifically those that require reflection on their past experiences.

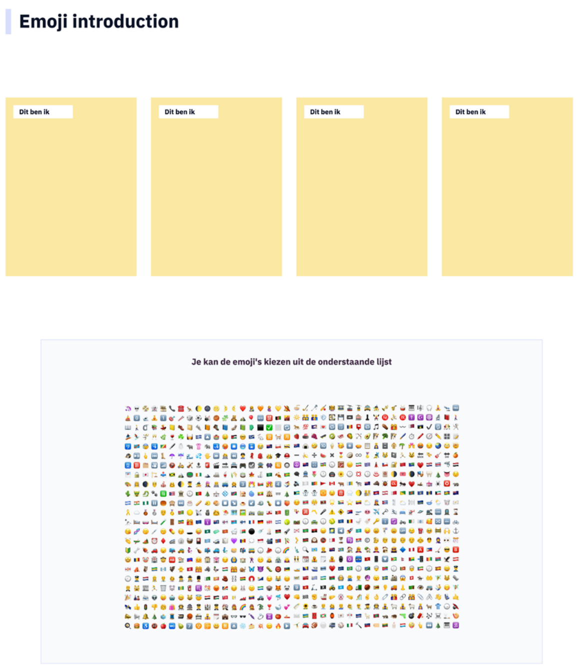
CO-CREATION SESSION

Introductory phase

During the introductory phase, the project was introduced and explained, with a particular emphasis on clearly communicating the objective to parents. However, at this stage, information regarding the prediction model was not yet disclosed to them. This was done to enable parents to generate ideas more freely and then to ideate more focused after learning about the prediction model.
In addition, the co-creation plan and the basic functions of Miro and how it can be used were discussed.

Icebreaker

Since neither the parents nor the healthcare practitioners knew each other, it was necessary to introduce them in a light-hearted manner that did not take too much time. Thus, an emoji introduction exercise was implemented. This exercise required participants to select several emojis that represent them as a person. Simultaneously, participants were able to familiarise themselves with the basic features of Miro through this approach (see Figure 24).


Emoji introduction

Je kan de emoji's kiezen uit de onderstaande lijst

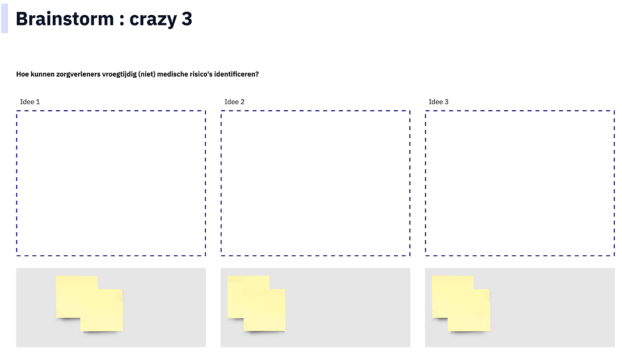
Figure 24: Co-creation session - Ice breaker exercise

Reflection Question (Past)

For this exercise, participants were instructed to reflect on the past. Due to the personal and sensitive aspect of this exercise, participants were instructed to think about it and write down their thoughts on a piece of paper. In this activity, participants were asked to reflect on the following questions:

Looking back on stressful and vulnerable moments (parents)
Think about the stressful or difficult moments you went through during the first 1000 days. What could have been different?

Looking back on risk identification and referral (healthcare professionals)
Can you think of moments when you identified a (non-medical) risk? How did that turn out?


Brainstorm : crazy 3

Hoe kunnen zorgverleners vroegtijdig (niet) medische risico's identificeren?

Idee 1

Idee 2

Idee 3

Figure 25: Co-creation session - Crazy 3 ideation template


Stap 2 : Idee uitwerken

Welke eigenschappen heeft jullie tool?

Wat voor informatie worden hierbij opgeslagen?

Welke dingen kan je tool doen?

Hoe geeft jullie tool vertrouwen in het invullen van informatie?

Welke zorgverlener mag jullie informatie zien?

Hoe kan de ouder er zeker van zijn dat er veilig met de gegevens wordt omgegaan?

hoe kan jullie tool voorkomen dat ouders zich in een hokje geplaatst voelen of label krijgen?

Op welk manier kunnen ouders de gegevens invullen?

Hoe versterkt jullie tool het zelfvertrouwen van ouders?

Op welke manier helpt jullie tool bij het verminderen van angst voor gevolgen voor ouders?

Figure 26: Co-creation session - Various prompts for detailing the design

Ideate (Crazy 3)

The "Crazy 8" is a design method that is used for creative brainstorming sessions (Share and Engage with the Design Sprint Community, n.d.). This is a rapid and dynamic way to generate ideas quickly. In this method, one idea is generated in 1 minute. Due to time constraints, it was chosen to do a crazy 3 where in 3 minutes, 3 ideas were generated (Figure 25). During the brainstorming sessions, participants were asked to think more explorative about how risk identification of vulnerable moments can be achieved. Afterwards, the generated ideas were discussed and presented to each other.

Prediction model introduction & Ideate (Crazy 4)

After exploring the various ideas, the overall prediction model of the "Making Big Data Meaningful for a Promising Start" was explained. After explaining the model, participants were asked to generate 4 ideas in 4 minutes on how this tool could look like in the future.

Elaborate on idea

Following the exploration of various ideas related to the prediction model and risk identification in a broader context, the participants engaged in a collaborative discussion to determine the idea they would like to focus on. The participants were instructed to focus on the digital aspect as the main objective while also allowing for the combination of ideas. Subsequently, the parents were presented with a range of prompts to elaborate upon (Figure 26). Some of the significant prompts are described below:

- How can you prevent parents from feeling labelled?
- How does your tool strengthen parents' self-confidence?
- How can the parent be assured that data is handled safely?
- How does your tool give confidence in completing information?

At the conclusion of the co-creation session, participants were asked to provide a brief scenario describing when and how this tool could be used. If there was extra time, participants were requested to provide descriptions of potential features that could be incorporated into the tool's interface.

KEY INSIGHTS

There are several key themes that were prevalent in the co-creation sessions regarding the future view on risk identification as well as in relation to the prediction model.
The initial three primary insights were identified as overlapping themes that emerged from the co-creation sessions involving healthcare professionals and parents. The additional noteworthy observations consist of distinct insights that emerged from both the co-creation sessions involving healthcare professionals and the healthcare professionals themselves (Appendix C.3 and Appendix C.4).

IDEAS FROM PARENTS & HEALTHCARE PROFESSIONALS

Facilitation of communication

The significance of communication in the identification of risks remains prominent for healthcare professionals and parents. Hence, when designing a digital tool, it is important to ensure that it does not hinder the interaction between healthcare professionals and parents. Rather, the tool should be developed to enhance and create opportunities for communication.

Unlocking solution-based systems: care paths for the predictions being made

Parents placed a stronger emphasis on the practical application of the prediction rather than solely focusing on the prediction's outcome. When using an AI prediction model, it is imperative to not only focus on the outcome but also to carefully contemplate the subsequent actions that need to be taken. It is crucial to ensure that parents do not experience feelings of being stigmatised or labelled.

Cultivating relatability

During the co-creation session, it was crucial to gain an understanding that parents expressed a desire to perceive themselves as not being the sole individuals experiencing risk factors or encountering difficulties. There existed a distinct necessity to establish connections with fellow parents in order to comprehend that certain emotions or challenges are common and do not indicate inadequacy as a parent.

KEY TOUCHPOINTS

It was generally indicated that the periods before birth, after birth, and during the first and second years of a child's life are opportune times for parents to use the tool (Figure 27).

Figure 27: Various key touchpoints for the tool

IDEAS FROM PARENTS

A way to prepare the parent

Multiple ideas were put forth by parents regarding the digital tool, focusing on preparing them for specific situations and increasing awareness of various challenges, including mental health issues.

A moment to evaluate

Additional suggestions proposed by parents revolved around parents using the digital tool as an opportunity for reflection, which healthcare professionals can subsequently review.

IDEAS FROM HEALTHCARE PROFESSIONALS

Design for accessibility

Healthcare professionals have emphasised the significance of ensuring that parents have convenient access to the digital tool while also allowing multiple healthcare professionals to access the information. Moreover, it is crucial to emphasise the importance of ensuring that the information is comprehensible for the majority of users.

Design for non overlap

Concerns were expressed during the co-creation sessions about the possibility of the tool overlapping with the questions already asked during the intake consultation or other risk identification tools. This overlap should be avoided to prevent parents from having to provide the same information twice, as well as to ensure that the obstetrician's limited time is not further burdened.

PROMPTS

How can the tool keep parents from feeling labelled? (Hoekje geplaatst worden)

Participants noted three elements that could help reduce the feeling of being labelled: inclusive images, the **option to provide feedback** afterwards, and **positivity.**

How can the tool alleviate parental fear of consequences?

The participants expressed their preference for **anonymity** when filling in the information, as they believed it could help alleviate their fear of potential consequences. Moreover, granting parents the authority to provide **consent** for specific healthcare professionals to access their data can help alleviate this sentiment. In addition, it was indicated that clear communication regarding the handling of collected information and empowering^ them to make decisions regarding their data can also potentially alleviate this fear.

How can the tool enhance parental self-esteem?

Participants indicated that **positive reinforcement and acknowledgement of the issues were notable features.** Moreover, improving comprehensibility and providing opportunities for improvement could potentially enhance parental self-esteem.

How can parents develop a sense of safety and trust in the digital tool?

The participants expressed that certain factors, including disclaimers, AVG certificates, use of DigiD, and **reviews,** contribute to a perception of safety among parents.
Moreover, it has been **suggested that providing explanations** grounded in scientific research can be beneficial in cultivating parental trust. To foster trust, it is essential to grant parents the authority to exercise control over the deletion of options and provide them with information regarding the handling of data.

7.3 Design in Context : Ideation

DESIGN ELEMENTS

Several additional design elements will be considered during the conceptualization of the digital tool.

Design for accessibility

Healthcare professionals have emphasised the significance of incorporating accessibility considerations into the design process. It is crucial to emphasize the design considerations for individuals with low literacy levels and ensure that the survey has a low entry barrier.

Design for fostering relatability

It was crucial for the parents to not feel alone with the challenges they face. They frequently referenced parents in the same situation as themselves and desired to know whether other parents shared similar experiences.

7.4 Design in Context : Ideation

ITERATION DESIGN DIRECTION

During the co-creation sessions, several additional design elements were identified. These elements, relatability, and accessibility, are categorized as subthemes under the main interaction themes of safety, trust, and self-esteem. The categorization as subthemes is due to the greater importance of the first main themes, supported by prior research, including data dialogues with parents, where the underlying needs of parents were determined (Figure 28).

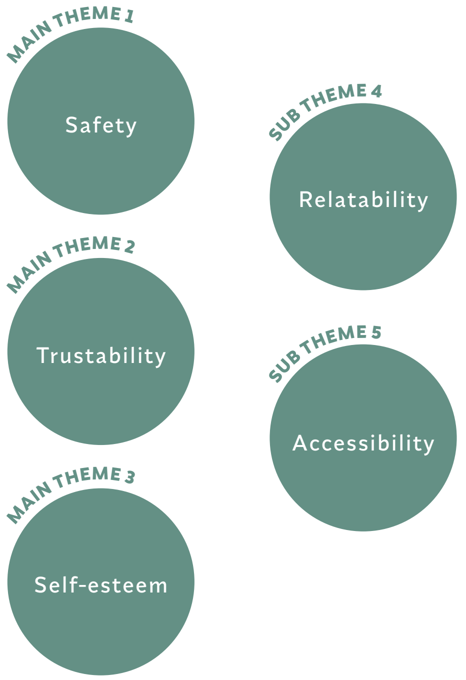


Figure 28: Representation of the main themes and subthemes

Design a digital tool concept with **low accessibility** that enables expectant parents potentially living invulnerable circumstances to share their information, facilitating the identification of potential risks at an early stage which can have an impact on the later stage of a child's life and referral. Trough enabling easy accessibility in the contact with the tool the tool's interaction with the parents should evoke a sense of acknowledgement through nurturing feelings of **safety, trust**, **self-esteem and relatability.**

7.5 Design in Context Ideation

WIREFRAMING & UX FLOW

WIREFRAMING

During the co-creation sessions as well as through brainstorm sessions, which diverged and converged between investigating the design space described in the design approach, the wireframing technique was used synchronously.

Wireframing is a visual representation of a digital display interface. It is a low-fidelity representation of a digital product's fundamental structure and architecture (Figure 29).

Several key functionalities were crucial to consider in this instance:

- Parents should be able to provide data
- Parents should receive a solution-based result
- Parents should be able to have control over the data

The brainstorming sessions were conducted alone, during which the variables of the prediction model were considered. Additionally, there was some exploration on the more exploratory side.

The wireframes and brainstorm mindmap can be found in Appendix D.1 and Appendix D.2.

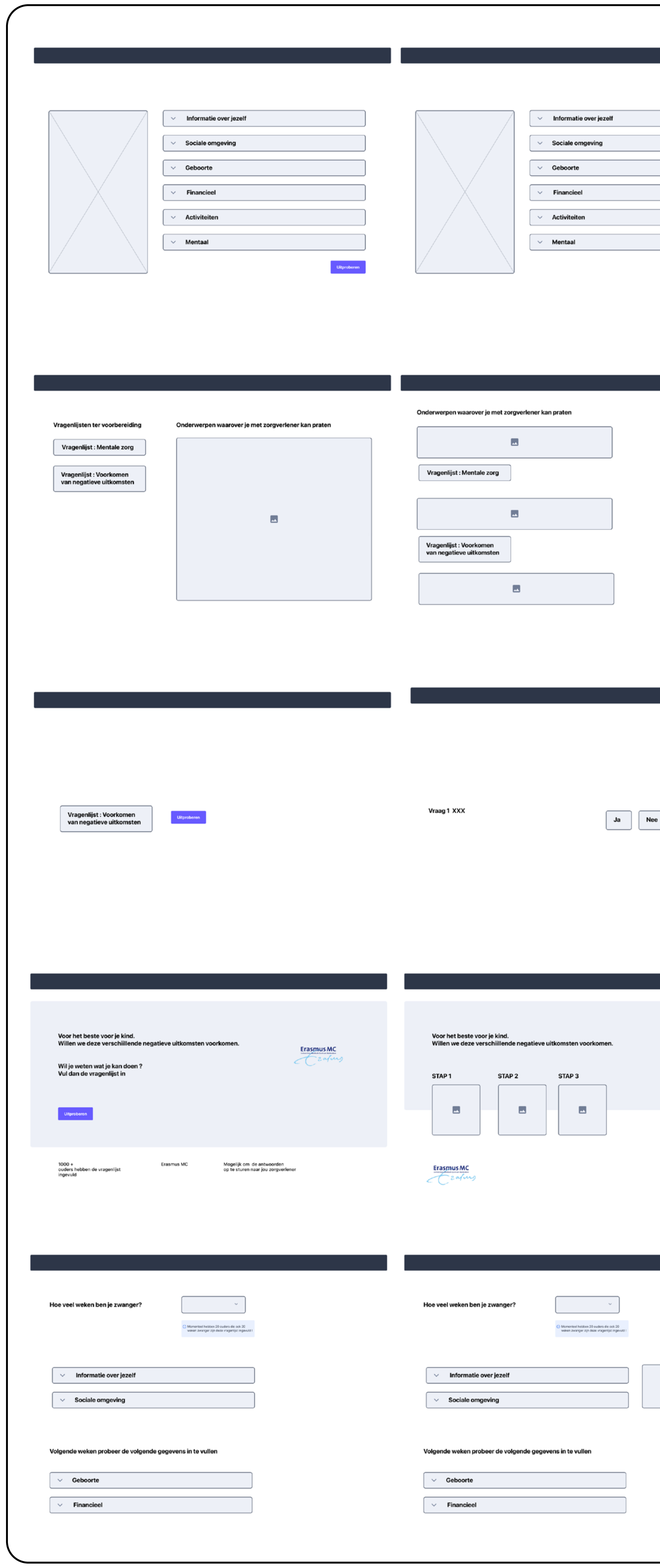
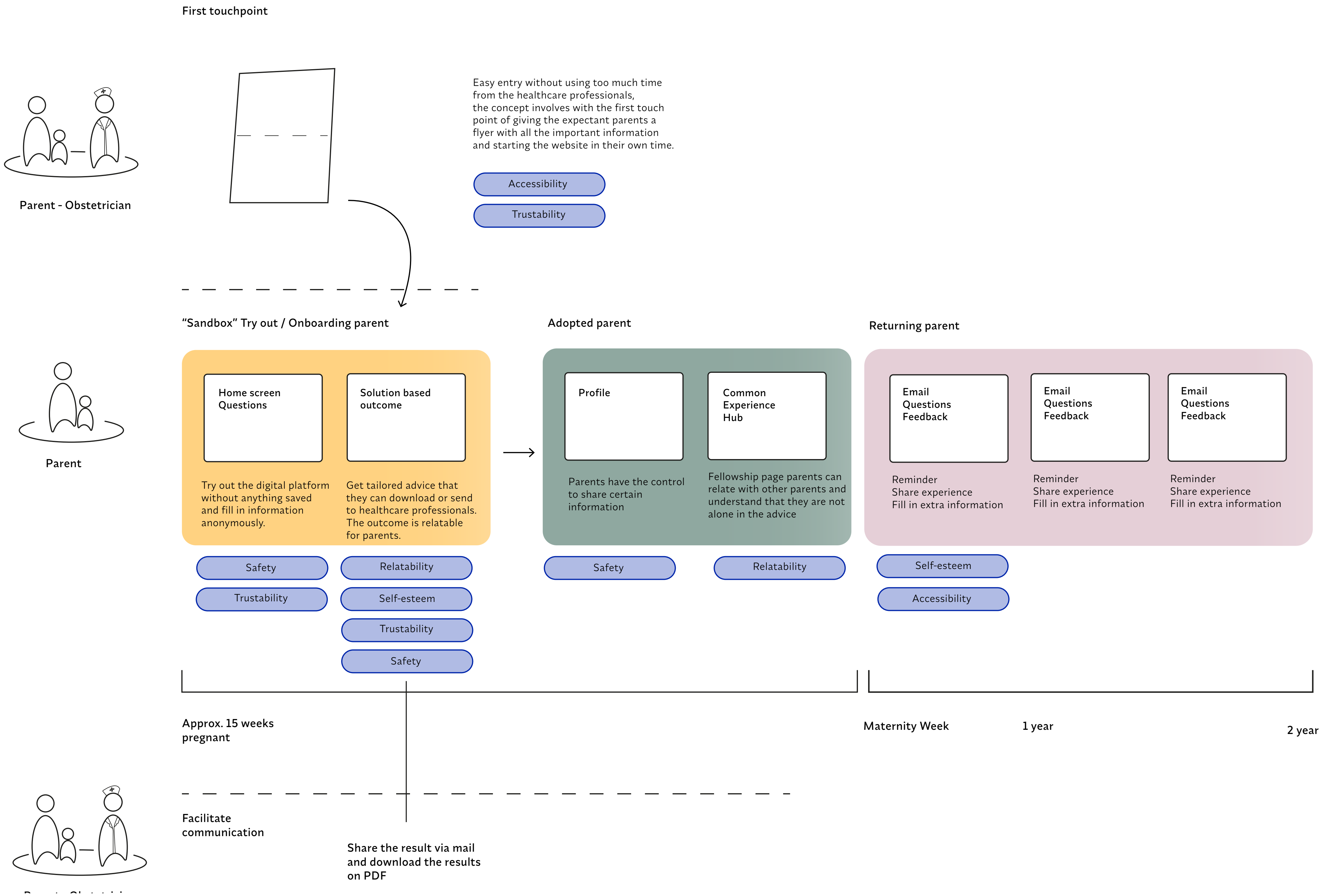


Figure 29: Examples of various wireframes created

CONVERGING IDEAS TO UX FLOW

After ideating as well as wireframing eventually a user experience (UX) flow was made for the concept framework. A UX flow, is a visual representation of the steps a user takes but in this case on a more holistic level. This diagram (Figure 30) depicts the user's progression of interactions.
This framework identifies the touchpoints and important aspects considered by the concept.



Easy entry without using too much time from the healthcare professionals, the concept involves with the first touch point of giving the expectant parents a flyer with all the important information and starting the website in their own time.

Try out the digital platform without anything saved and fill in information anonymously.

Get tailored advice that they can download or send to healthcare professionals. The outcome is relatable for parents.

Parents have the control to share certain information

Fellowship page parents can relate with other parents and understand that they are not alone in the advice

Share the result via mail and download the results on PDF

Figure 30: UX Flow of the concept

Chapter 8

CONCEPTUALIZATION

The concept will be introduced in this chapter by presenting and discussing various elements of the concept. The concept is divided into three primary experiences: the onboarding experience, the adopted experience, and the returning experience (Appendix D.3)..

8.1 Deliver in Context - Conceptualization

CONCEPT

AIM

The main aim of this concept "Advies op maat" is to support the early identification of (expectant) families living in vulnerable circumstances. This concept demonstrates how the prediction model can be integrated into a broader structure.
Based on responses from previous research, parents expressed a preference for a solution-based approach. Therefore, the concept includes a feature allowing parents to receive tailored advice by completing a questionnaire. The broader structure would involve using the prediction model to provide tailored advice for parents on how they can reduce adverse outcomes.

advies
op maat

Figure 31: Logo for Advies Op Maat

The onboarding experience includes how parents will first learn about the concept and go through the process of answering questions and receiving advice. The onboarding experience allows parents to try out the digital tool before committing to it.

This experience is about when the parent decides to create an account. They have control over who can access specific data. In addition, they can access the fellowship page. In this fellowship page, parents can gain insights into what other parents did.

The concept includes implementation at various times during the first 1000 days. An email will direct parents back to the website to provide feedback and update information that could have changed over time.

LOOK AND FEEL

Due to the fact that the concept is made from the beginning, in the sense that there are no other house styles to which it should adhere, the look and feel of the concept incooperated trustable colors e.g., blue, with a touch of cheerful yellow.

The logo was kept as simple as possible stating what the tool can do: provide tailored advice (Figure 31).

Colours

#ddc0cb

#0026ab

#fec459

8.2 Design in Context - Conceptualization

ONBOARDING EXPERIENCE

The diagram provided below explains a flow outlining how the onboarding experience would work.

1

FIRST TOUCH POINT

At around week 15 of pregnancy, parents receive information about the tool from the obstetrician through a flyer. Using the flyer, parents can individually access the tool via a website in their own time at home.

2

SANDBOX ENVIRONMENT

Parents have the option to start the tool in a safe (website)environment, allowing them to first explore the website without any data being saved.

2.1 Questions

Several questions will be asked, which the parent fills in.

2.2 Solution-based outcome

Based on their answers, the tool will provide tailored advice for the parent.

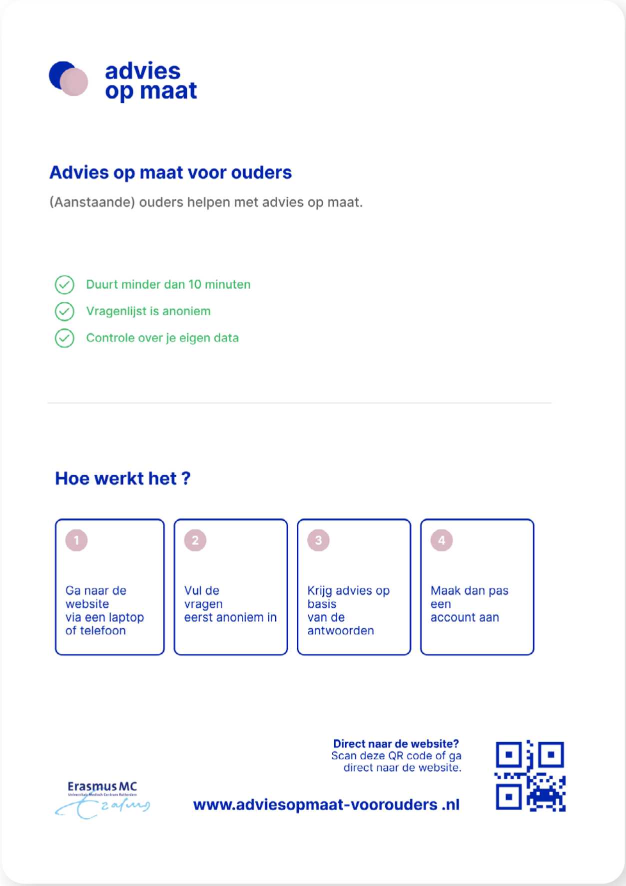
Afterwards, parents will have the choice to share their results with the healthcare professional and create an account to save the data.

1. FIRST TOUCH POINT

The first touch point between the parent and the tool is with the flyer which they can receive from the obstetrician. The flyer contains information about the tool and answers to the most important questions defined in the previous chapter. To make it simple for parents to access the tool, it can be accessed through a QR code or a link that does not require prior registration.

The distribution would occur around the 15th week of pregnancy, as parents in the co-creation sessions suggested this would be an ideal time to introduce a tool. This timing comes after getting a lot of information from the obstetricians at the beginning of pregnancy.

Furthermore, the flyer does not interfere with the obstetricians' limited time.



advies
op maat

Advies op maat voor ouders

(Aanstaande) ouders helpen met advies op maat.

✓ Duurt minder dan 10 minuten
✓ Vragenlijst is anoniem
✓ Controle over je eigen data

Hoe werkt het ?

① Ga naar de website via een laptop of telefoon

② Vul de vragen eerst anoniem in

③ Krijg advies op basis van de antwoorden

④ Maak dan pas een account aan

Direct naar de website?
Scan deze QR code of ga direct naar de website.

Erasmus MC

www.adviesopmaat-voorouders .nl

Figure 32: Flyer design front

Accessibility

The flyer can easily introduce the tool by integrating it into the obstetrician's contact point. Moreover, the flyer provides parents with convenient access to the tool via a link or QR code (Figure 32).

Trustability

Transparency on the fyler regarding the functionality and development process of the tool, along with acknowledging that it is a predictive model, can foster trust among parents. Additionally, explaining what will happen with the data may encourage this feature (Figure 33).

advies
op maat

Hoe is de vragenlijst gemaakt ?

Met behulp van bestaande gegevens van het Centraal Bureau voor de Statistiek kun je voorspellingen doen over de toekomst van je kind.
Deze voorspellingen kunnen je helpen mogelijke uitdagingen te identificeren en proactieve stappen te nemen om de toekomst van je kind te verbeteren.

Door te kijken naar de informatie die je hebt ingevuld, kunnen we zien waar je als ouder mogelijk hulp bij kunt vragen.

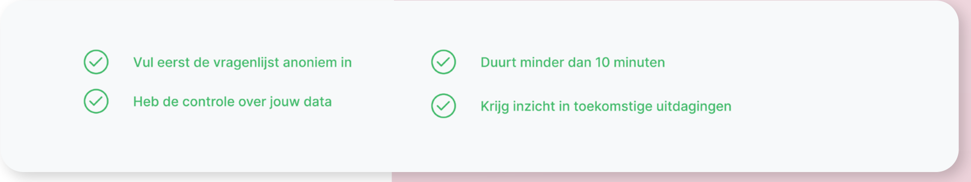
Wat gebeurd er met de gegevens?

Als je geen account aanmaakt, worden de gegevens niet opgeslagen. Zelfs as je wel een account aanmaakt, kunnen zorgverleners jouw informatie niet bekijken, **tenzij je hiervoor toestemming geeft.**

Erasmus MC

www.adviesopmaat-voorouders .nl

Figure 33: Flyer design back



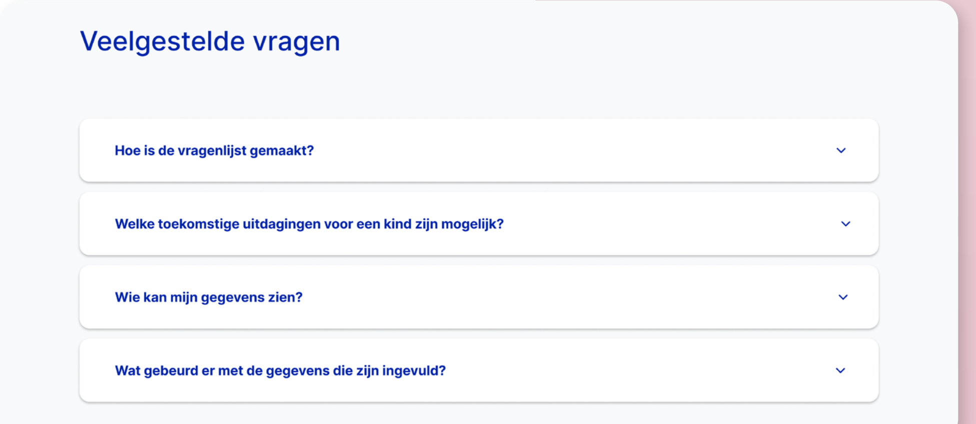
Vul eerst de vragenlijst anoniem in

Heb de controle over jouw data

Duurt minder dan 10 minuten

Krijg inzicht in toekomstige uitdagingen

Figure 34: Benefits for parents



Veelgestelde vragen

Hoe is de vragenlijst gemaakt?

Welke toekomstige uitdagingen voor een kind zijn mogelijk?

Wie kan mijn gegevens zien?

Wat gebeurd er met de gegevens die zijn ingevuld?

Figure 35: Frequently Asked Question

SANDBOX ENVIRONMENT:

In order to gain a better understanding of the tool, parents have the opportunity to freely input their information and explore it's functionality and advice before fully committing to it. This is why it is called the sandbox environment where they can try out the tool in a safe environment first without the need to register (Figure 36).

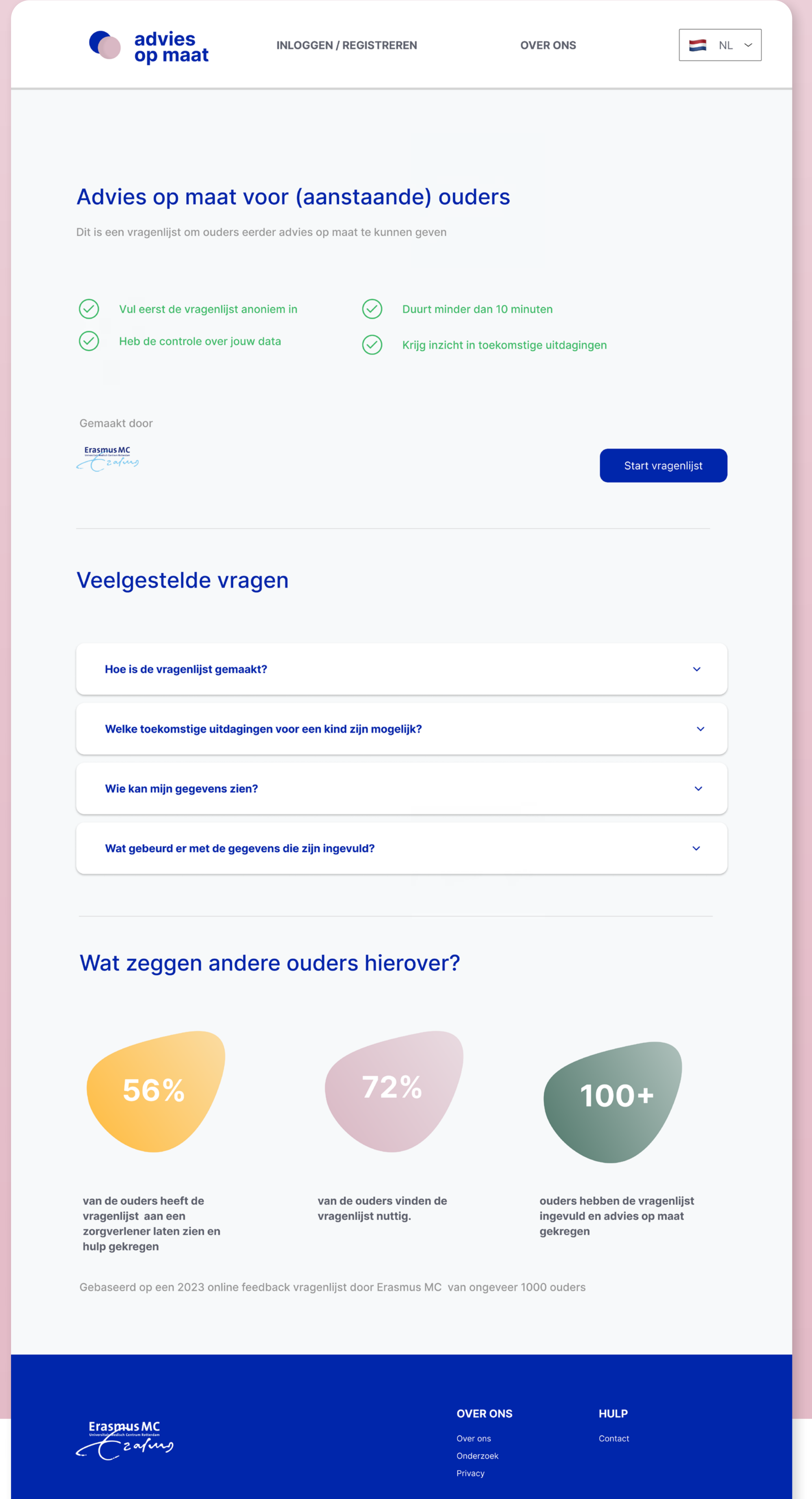
Trustability & Safety
The overall approach to gaining the trust and feeling of safety of parents involves granting them the ability to provide information or input anonymously, without facing any negative repercussions.

The home screen should prioritise clarity and comprehensibility as it serves as the initial connection for parents. Hence, the initial section will present the benefits for the parents and what they can expect (Figure 34).

Additionally, it is crucial to empower parents by providing them with a straightforward means to understand the underlying algorithm used to create this questionnaire. The frequently asked questions dialogue will address the key questions identified (Figure 35).

Trustability & Safety
This aims to enhance algorithm transparency and empower parents to make informed decisions, thereby fostering trust.

Figure 36: Home screen of the concept



advies op maat

INLOGGEN / REGISTREREN

OVER ONS

NL

Advies op maat voor (aanstaande) ouders

Dit is een vragenlijst om ouders eerder advies op maat te kunnen geven

Vul eerst de vragenlijst anoniem in

Heb de controle over jouw data

Duurt minder dan 10 minuten

Krijg inzicht in toekomstige uitdagingen

Gemaakt door

Erasmus MC

Start vragenlijst

Veelgestelde vragen

Hoe is de vragenlijst gemaakt?

Welke toekomstige uitdagingen voor een kind zijn mogelijk?

Wie kan mijn gegevens zien?

Wat gebeurd er met de gegevens die zijn ingevuld?

Wat zeggen andere ouders hierover?

56% van de ouders heeft de vragenlijst aan een zorgverlener laten zien en hulp gekregen

72% van de ouders vinden de vragenlijst nuttig.

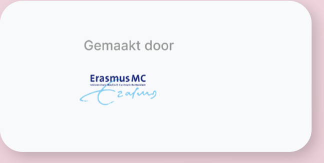
100+ ouders hebben de vragenlijst ingevuld en advies op maat gekregen

Gebaseerd op een 2023 online feedback vragenlijst door Erasmus MC van ongeveer 1000 ouders

Erasmus MC

OVER ONS
Over ons
Onderzoek
Privacy

HULP
Contact



Gemaakt door

Erasmus MC

Figure 37: Erasmus Logo

Trustability & Safety
Previous research indicates that parents view Erasmus MC as a reputable and trustworthy organisation. Therefore, displaying the organization at the beginning could facilitate trust in the tool (Figure 37).

NL

Figure 38: Various languages

Accessibility
This concept proposes that parents should be able to switch between different languages to enhance accessibility for individuals of various nationalities (Figure 38).

The concept envisions the potential implementation of a tool that would benefit from gathering feedback from parents after one or two years. This feedback could be used to demonstrate the parents' experiences with the tool.

Trustability & Safety
The co-creation sessions indicated that allowing parents to access testimonials from other parents would be advantageous in building trust.

Hoe is de vragenlijst gemaakt?

Met behulp van bestaande gegevens vanuit het CBS en literatuur zijn er berekeningen gemaakt die kunnen voorspellen wat voor negatieve uitkomsten er kunnen zijn en die we willen voorkomen.

Om persoonlijk advies op maat te kunnen geven, vragen we de ouder om bepaalde informatie in de vragenlijst te beantwoorden. Deze ingevulde gegevens zijn strikt vertrouwelijk en alleen bedoeld voor de ouder zelf.

met berekeningen proberen we de kans op toekomstige negatieve uitkomsten te voorspellen, zodat we ze kunnen voorkomen

Ingevulde gegevens worden niet gebruikt om nieuwe berekenigen te maken

Figure 39: In the Frequently asked Question the tool is explained

Welke toekomstige uitdagingen voor een kind zijn mogelijk?

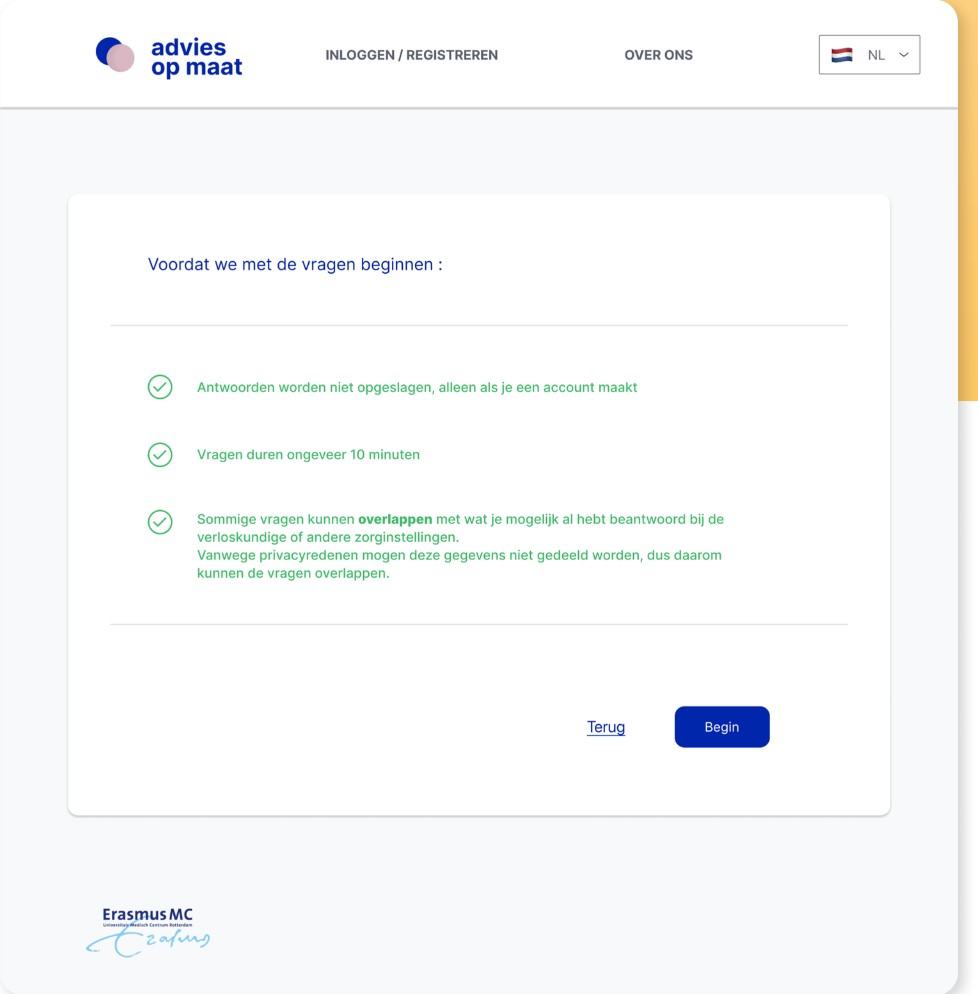
Om je kind de beste kansen te bieden, kun je de kans op de volgende uitdagingen verminderen:

- kans op later tiener moeder
- kans op latere contact met Jeugdzorg
- kans op latere school uitval
- kans op uitkering
- kans op wanbetaler zorgverzekering
- kans op sociaal-emotionele, cognitieve & motorische ontwikkeling
- kans op overgewicht

Figure 40: Frequently asked Questions the various (adverse) outcomes of the tool are shown

Trustability

Again, a transparent approach is employed to provide a straightforward means of explaining the algorithm used to create this questionnaire (See Figure 39 and Figure 40).
The frequently asked questions dialogue will address the central concerns raised in the data dialogues by explaining the tool, its outcomes, and what will be done with the data. This is intended to increase algorithm transparency and allow parents to make informed decisions, fostering trust.



Voordat we met de vragen beginnen :

✓ Antwoorden worden niet opgeslagen, alleen als je een account maakt

✓ Vragen duren ongeveer 10 minuten

✓ Sommige vragen kunnen **overlappen** met wat je mogelijk al hebt beantwoord bij de verloskundige of andere zorginstellingen.
Vanwege privacyredenen mogen deze gegevens niet gedeeld worden, dus daarom kunnen de vragen overlappen.

Figure 41: Additional reminder before starting the questionnaire

Safety

Prior to delving into the questions, it is important to emphasize that the data will not be stored at this stage. Parents are reminded that they can fill in everything without consequences (Figure 41). Additionally, it is important for parents to have clear expectations regarding what they can anticipate.

Questions

A question-based form is used to collect parental information.

The prediction model is currently under development. Hence, predicting the precise questions can differ from reality. The questions asked can be found in Appendix D.3.

Certain variables that are likely to influence the prediction model have been identified and categorized into distinct themes (Figure 42).

This categorization aims to provide transparency for parents regarding the questions that will be asked and to establish appropriate expectations.

Furthermore, the more sensitive questions that were identified during the interviews, such as income, were introduced later in order to avoid confronting parents with the most difficult question immediately.

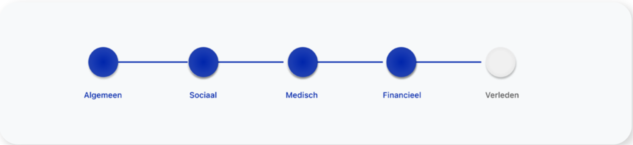
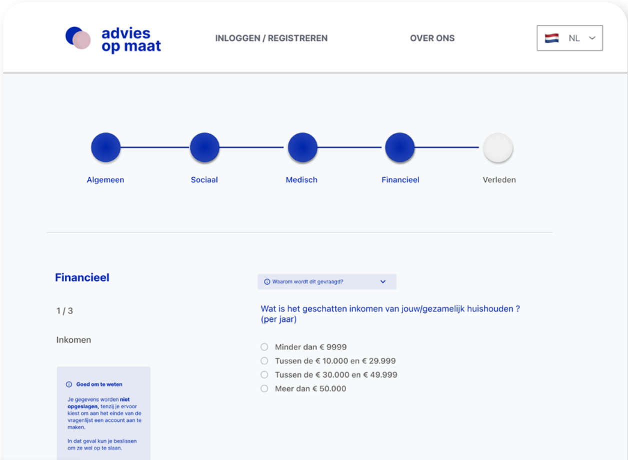


Figure 42: Categorized themes



Financieel

1 / 3

Inkomen

Wat is het geschatten inkomen van jouw/gezamelijk huishouden ? (per jaar)

○ Minder dan € 9999
○ Tussen de € 10.000 en € 29.999
○ Tussen de € 30.000 en € 49.999
○ Meer dan € 50.000

Goed om te weten

Je gegevens worden **niet opgeslagen,** tenzij je ervoor kiest om aan het einde van de vragenlijst een account aan te maken.

In dat geval kun je beslissen om ze wel op te slaan.


Waarom vragen wij dit?

Voor het geven van beter advies kan het belangrijk zijn om te weten wat je etnische achtergrond is, evenals die van je ouders.

Eerdere onderzoeken hebben aangetoond dat etnische achtergrond een rol kan spelen bij obesitas/overgewicht (Retnakaran et al., 2006; Singh et al., 2008)

Jouw ingevulde gegevens zijn vertrouwelijk en jij hebt de controle over wie er toegang tot mag hebben.

Figure 43: Why is this asked pop up


Goed om te weten

Je gegevens worden **niet opgeslagen,** tenzij je ervoor kiest om aan het einde van de vragenlijst een account aan te maken.

In dat geval kun je beslissen om ze wel op te slaan.

Figure 44: Reminder information will not be saved

Trustability & Safety

It was evident from the interviews that parents feel uncomfortable discussing certain topics, such as their income or past criminal activity. For these sensitive topics, it is essential to provide explanations as to why certain information is requested and why it is advisable to provide it (Figure 43), as well as reiterating that the information will not be stored (Figure 44) fostering their trust in the tool.

Solution-based outcome

The co-creation session revealed that the tool needed to be more solution-oriented in order to be suitable for parents.

However, because the healthcare trajectory for each adverse outcome that "Making Big Data Meaningful for a Promising Start" aims to anticipate is not yet clear, it was chosen to a give recommendation to parents rather than health trajectories. Because some variables such as income or mental trajectory, can be altered, the concept focuses on modifiable variables/risk factors as a recommendation for parents (Figure 46).


Op basis van je **inkomen**, **woonplaats** en je **opleiding** kunnen we de volgende adviezen geven.

Figure 45: Explanation on the reason of the outcome

Trustability

Transparency in disclosing the reasoning behind these recommendations can enhance parental trust (Figure 45).

Relatability

The reason for presenting the percentage of parents who have received similar advice is to provide reassurance that parents are not alone in experiencing these outcomes. The purpose of this is to foster a feeling of relatability for parents.

Self-esteem

To mitigate the potential negative impact on parental self-esteem, it is important to positively frame the prevention of adverse outcomes rather than focusing on the potential risks associated with their child. Additionally, emphasizing that this advice is meant to provide advice rather than serve as an evaluation as a parent can enhance this viewpoint.

Dit is alleen een advies en NIET een beoordeling van jou als ouder!

Op basis van je **inkomen**, **woonplaats** en je **opleiding** kunnen we de volgende adviezen geven.

Je kunt ervoor zorgen dat je kind minder kans heeft op toekomstige gebeurtenissen zoals :

70% van de ouders die de vragenlijst hebben ingevuld hadden dezelfde adviezen.

Wil je weten wat zij hebben gedaan?

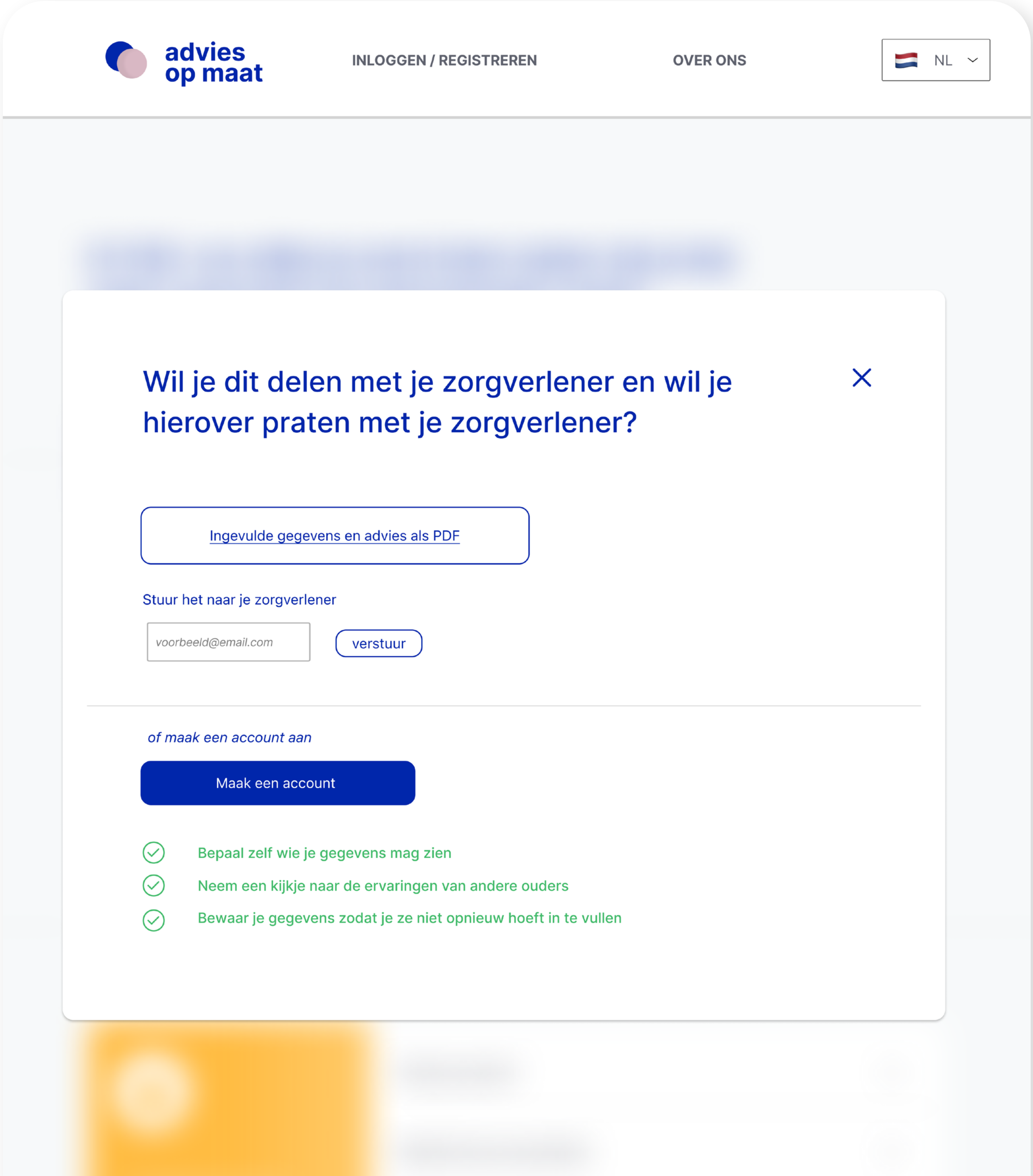
Zou jij graag financiele steun willen ontvangen ? En wil je graag hulp hierbij ?

Heb je mentale klachten? En wil je graag hulp hiervoor?

Figure 46: Outcome of the tool

Trustability & Safety
Giving the parent the ability to choose whether or not to share and communicate with healthcare experts can facilitate a sense of trust and safety to the parent. In addition, parents are encouraged to create an account in order to have the ability to choose what information to share and what to keep private.
This approach makes it obvious to the parent that by sharing this information with healthcare experts, they can help to facilitate dialogue (Figure 47).

Figure 47: Pop up request whether parents want to make an account or send it to their healthcare professional



Wil je dit delen met je zorgverlener en wil je hierover praten met je zorgverlener?

Stuur het naar je zorgverlener

of maak een account aan

- ✓ Bepaal zelf wie je gegevens mag zien
- ✓ Neem een kijkje naar de ervaringen van andere ouders
- ✓ Bewaar je gegevens zodat je ze niet opnieuw hoeft in te vullen

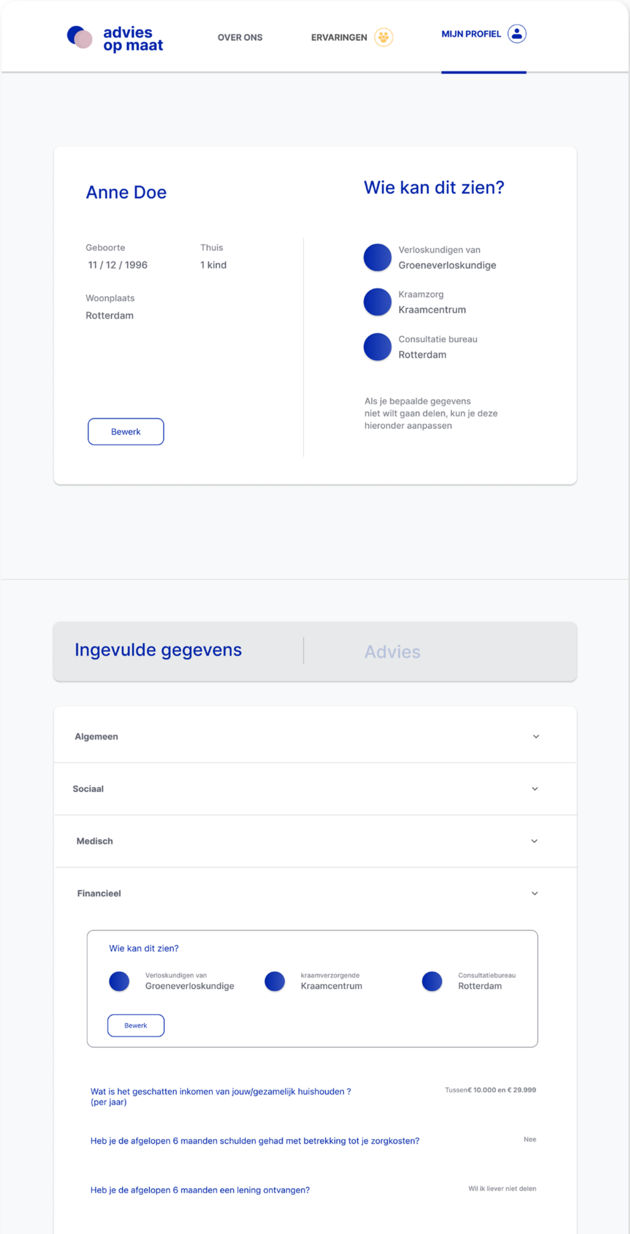
8.3 Design in Context - Conceptualization

ADOPTED EXPERIENCE

1 PROFILE
Presumably, when parents create an account, they can view their own profile.

2 FELLOWSHIP PAGE
Parents have the option to visit the fellowship page and see what other parents have done with the advice provided.

Figure 48: Parents' own profile



Anne Doe

Geboorte: 11 / 12 / 1996
Thuis: 1 kind
Woonplaats: Rotterdam

Wie kan dit zien?

Verloskundigen van Groeneverloskundige
Kraamzorg Kraamcentrum
Consultatie bureau Rotterdam

Als je bepaalde gegevens niet wilt gaan delen, kun je deze hieronder aanpassen

Wie kan dit zien?

Verloskundigen van Groeneverloskundige
kraamverzorgende Kraamcentrum
Consultatiebureau Rotterdam

Wat is het geschatten inkomen van jouw/gezamelijk huishouden ? (per jaar) — Tussen€ 10.000 en € 29.999

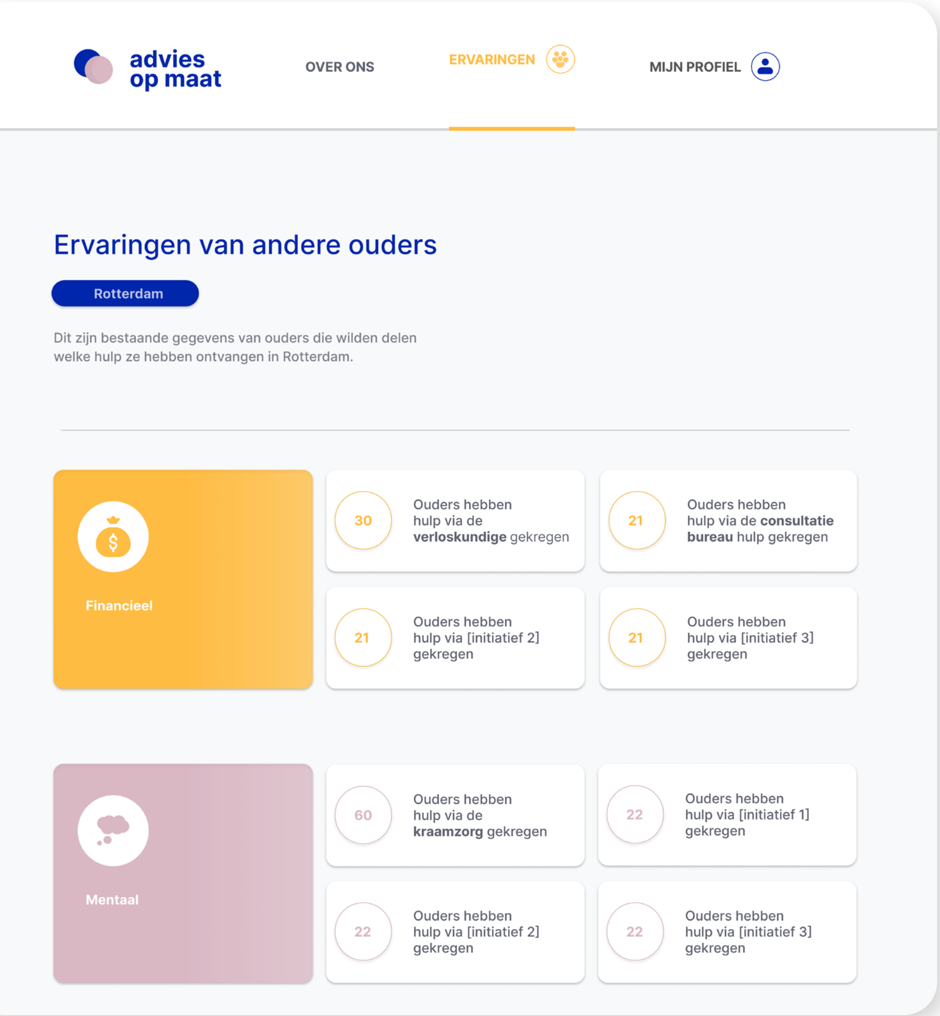
Heb je de afgelopen 6 maanden schulden gehad met betrekking tot je zorgkosten? — Nee

Heb je de afgelopen 6 maanden een lening ontvangen? — Wil ik liever niet delen

PROFILE

Upon consenting to create an account, parents may choose to share their information with healthcare professionals.
The concept allows for the selective display and hiding of certain data for different healthcare professionals, taking into consideration the concerns of parents regarding specific healthcare professionals (Figure 48).

Safety
Parental control and data visibility can ensure parents trust and feeling of safety.



Ervaringen van andere ouders

Rotterdam

Dit zijn bestaande gegevens van ouders die wilden delen welke hulp ze hebben ontvangen in Rotterdam.

Financieel	30 Ouders hebben hulp via de **verloskundige** gekregen	21 Ouders hebben hulp via de **consultatie bureau** hulp gekregen
	21 Ouders hebben hulp via [initiatief 2] gekregen	21 Ouders hebben hulp via [initiatief 3] gekregen
Mentaal	60 Ouders hebben hulp via de **kraamzorg** gekregen	22 Ouders hebben hulp via [initiatief 1] gekregen
	22 Ouders hebben hulp via [initiatief 2] gekregen	22 Ouders hebben hulp via [initiatief 3] gekregen

Figure 49: Fellowship page

FELLOWSHIP PAGE

A fellowship page was created with the aim of providing support and alleviating the sense of loneliness experienced by parents in their various challenges (Figure 49).
The purpose of this fellowship page was to provide parents with the opportunity to learn from the insights of other parents, in which they can see how many parents received similar advice and how they got help from this advice.

The choice was made to abstain from establishing a discussion forum where parents could exchange comments on their experiences. The reason behind this decision stems from the fact that the topic of this discussion forum was brought up during a co-creation session. However, parents preferred to exclude negative comments and any form of judgment from other parents. Instead, by focusing on creating a platform that allows parents to connect with one another on a more holistic level could mitigate this fear.

Furthermore this way parents can also see that they could receive help from other healthcare professionals such as the consultation bureau and the maternity nurses.

Relatability

By enabling parents to see how many other parents received useful advice and seeing how they used this information can create a sense of relatability which can be fostered among parents in a more anonymous way.

8.4 Design in Context - Conceptualization

RETURNING EXPERIENCE

1 **MAIL**
Parents will receive a mail

2 **QUESTIONS**
On the website several additional questions will be asked.

The concept intended to explore the potential implementation in postnatal and first years. Based on the co-creation sessions, the concept's touchstones would be beneficial at the touchpoints seen in Figure 50. Currently, the concept depicts what a potential flow could appear like at those times.

The email (Figure 51) will direct individuals to the platform, which consists of three primary components (Figure 52).

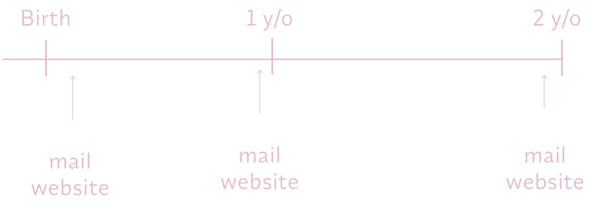
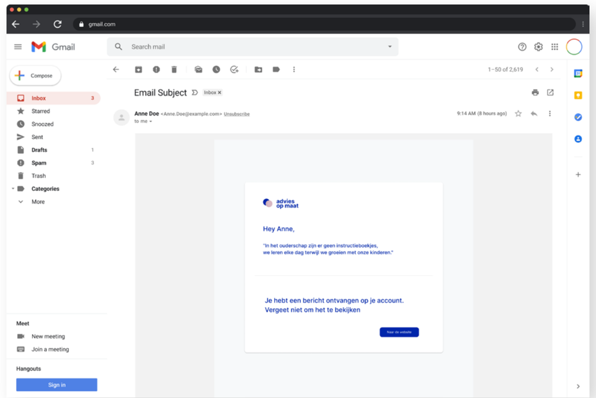


Figure 50: Implementation flow

1. How they feel as a parent
2. What they did with the advice they received, which can be shared on the fellowship page.
3. Additional questions regarding circumstances that may have changed over time. This can help the prediction model to generate an outcome that can lead to additional advice when needed.

Figure 51: Email which parents would receive



Email Subject

Anne Doe <Anne.Doe@example.com> Unsubscribe
to me

Hey Anne,

"In het ouderschap zijn er geen instructieboekjes, we leren elke dag terwijl we groeien met onze kinderen."

Je hebt een bericht ontvangen op je account. Vergeet niet om het te bekijken

Self-esteem

By asking how they feel as a parent, parents can feel valued, with the option to express their current emotions, as parents have indicated that the focus often shifts to the child after birth.

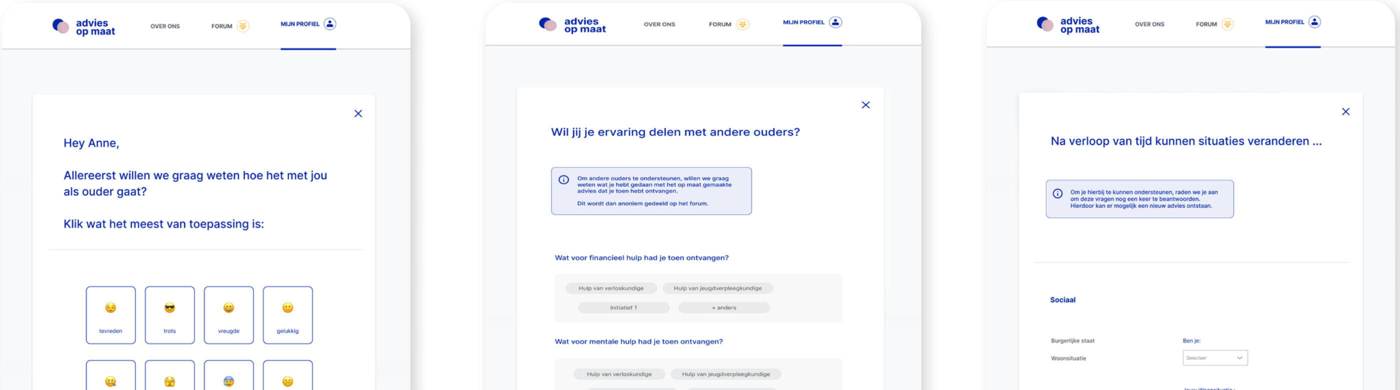
Self-esteem

Parents can assist other parents by asking about the specific type of guidance they received. This way, parents can feel empowered to helping others in similar situations.

Accessibility

Parents can receive earlier help by proactively asking about changes in situations at these specific moments. This can reduce the threshold for seeking assistance.

Figure 52: Three question components



Hey Anne,

Allereerst willen we graag weten hoe het met jou als ouder gaat?

Klik wat het meest van toepassing is:

Wil jij je ervaring delen met andere ouders?

Om andere ouders te ondersteunen, willen we graag weten wat je hebt gedaan met het op maat gemaakte advies dat je toen hebt ontvangen.

Dit wordt dan anoniem gedeeld op het forum.

Wat voor financieel hulp had je toen ontvangen?

Wat voor mentale hulp had je toen ontvangen?

Na verloop van tijd kunnen situaties veranderen ...

Om je hierbij te kunnen ondersteunen, raden we je aan om deze vragen nog een keer te beantwoorden. Hierdoor kan er mogelijk een nieuw advies ontstaan.

Sociaal

Burgerlijke staat

Woonsituatie

Ben je:

Chapter 9

EVALUATION

This chapter will focus on the evaluation of the concept, specifically the user testing conducted with parents and the discussion held with mijnkindonline.

9.1 Deliver

EVALUATION APPROACH

For the evaluation of the concept two main important aspects were considered:

Desirability
Does it address the users' values and needs?

In order to assess the desirability of the concept, it was essential to examine the needs of the parents, which were identified in the prior research. Therefore, moderated user tests were conducted with parents who had faced vulnerable or stressful situations in order to test the concept on the different interaction qualities on safety, trust, and self-esteem.

Feasibility
Can it be done?

Through a discussion with mijnkindonline, who is responsible for the technical aspects of Mind2Care, the technical feasibility could be assessed. During the discussion, the feasibility of certain features was explored, with one of the features being the implementation of the sandbox environment.

9.2 Deliver

MODERATED USER TESTING

OBJECTIVE

To gain insight into parental perceptions of the tool, a moderated user testing approach was employed, utilising a partially interactive high fidelity prototype. A high fidelity prototype refers to a comprehensive and detailed representation of a possible final design.

The user testing was conducted through a 60-minute online moderated approach on Teams. Parents were invited to engage with the concept through three different prototype flows while I was present during this process. The comprehensive user test plan can be found in the Appendix E.1. The reason for deciding on a moderated user testing approach comes from its ability to directly observe and understand the actions and experiences of users. This makes it possible to pose in-depth questions about why they perceive specific elements of the concept in a certain way.

Parents were prompted to think-out-loud by expressing their thoughts and potential actions that they would take within the prototype. Open-ended questions were asked to gain a deeper understanding of how they perceive the concept. Five new parents who have not previously been involved in the research and experienced vulnerable or stressful situations were invited to participate. In addition, three parents who had previously participated in the research also took part in the user test.

The main objective of this user test is to gain insight into the experiences of parents when using the tool. For the user test several research goals and open questions were defined which are outlined in the three flows of the concept.

First flow

Due to the difficulty of evaluating the initial contact of the concept of the flyer, an alternative was chosen in which the parents received the scenario and the flyers in pdf format via email prior to the user test. In this manner, parents were already sensitized for the user test as well as having certain expectations.

From the start of the user test, parents were asked about their experience with the flyer and expectations of the tool. The test did not include an assessment of the interaction between the obstetrician and the parent. Instead, it was presented as a hypothetical scenario, assuming that the parent received the flyer through the obstetrician. The parents were then directed to the prototype, where they explored the homescreen, which included explanations of the tool and testimonials from other parents.

In the second task, parents were asked to start the questions. Due to the sensitivity of the questions parents went through pre-filled questions. During this parents were asked to share their perception of the different topics asked. At the end they would receive an result and a prompt to make an account. Here it was important to understand how parents would interpret the advice, the outcome of the prediction model, and whether they would have sufficient trust to create an account (Figure 53).

Second flow

For the second flow the scenario was that parents would have made an account. Parents were requested to examine their own profile and comprehend their perception of control when they have the ability to authorize access to different healthcare professionals. In addition, parents were asked about their expectations regarding the fellowship page prior to clicking on it. Subsequently, it was crucial to assess the extent to which parents found the relatability of the fellowship page adequate (Figure 54).

Third flow:

For the last flow, the scenario was given that parents would receive an email after one year. Following the email, parents were directed back to the website. They were prompted with a question about their well-being, feedback questions regarding their approach on the received advice, and more questions about any changes they may have experienced. For this flow it was important to understand whether parents would perceive a sense of acknowledgment in fostering their self-esteem through these questions (Figure 55).

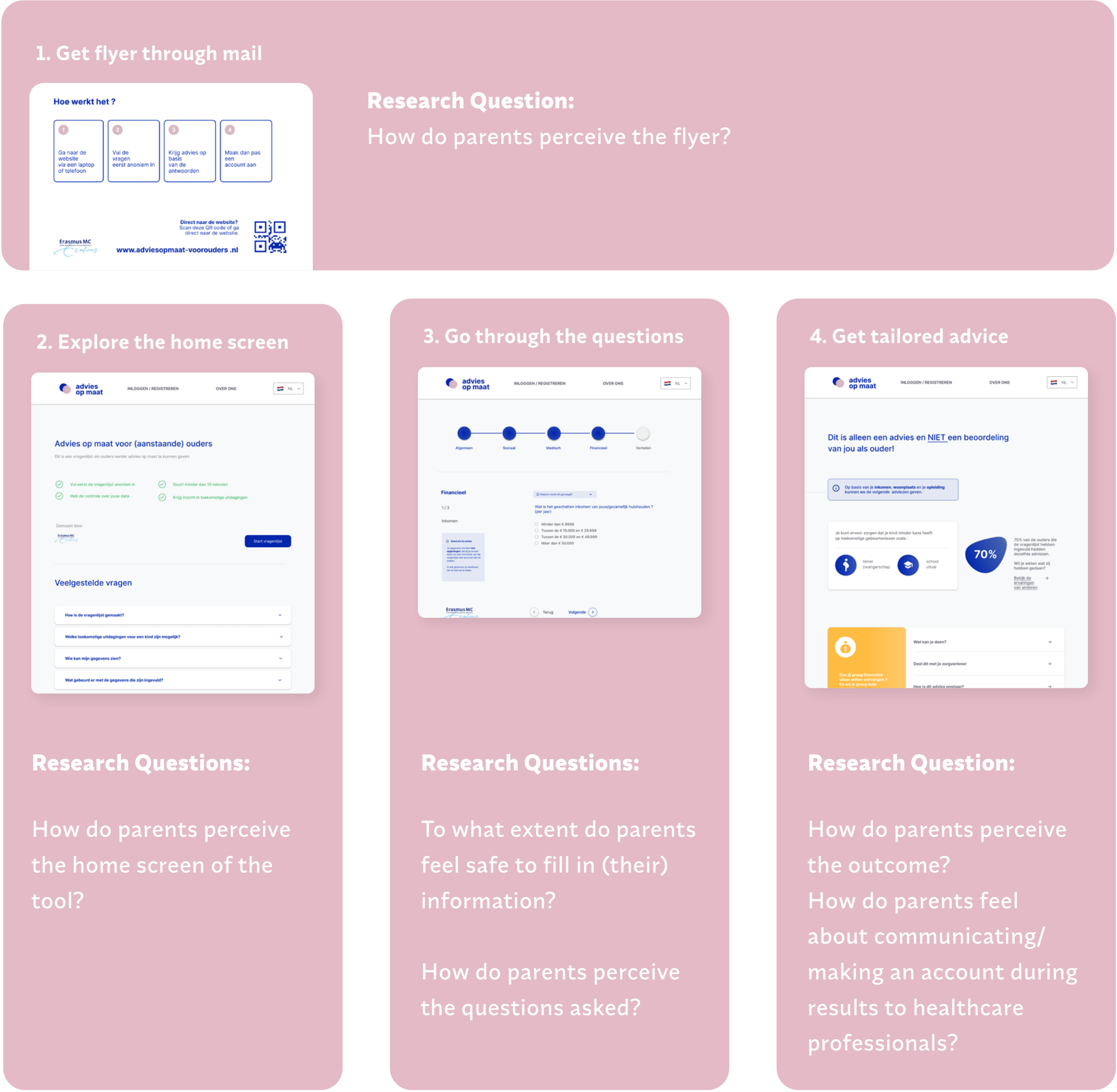
FIRST FLOW: ONBOARDING EXPERIENCE

First Flow: Link to prototype[1]

Research goal

Understand the onboarding experience:

- Assess sense of **safety & trust** when getting a flyer, exploring the homescreen and going through the questions
- Evaluate sense of **self-esteem** when receiving the tailored advice



1. Get flyer through mail

Research Question:
How do parents perceive the flyer?

2. Explore the home screen

Research Questions:

How do parents perceive the home screen of the tool?

3. Go through the questions

Research Questions:

To what extent do parents feel safe to fill in (their) information?

How do parents perceive the questions asked?

4. Get tailored advice

Research Question:

How do parents perceive the outcome?
How do parents feel about communicating/ making an account during results to healthcare professionals?

Figure 53: Moderated user test plan - onboarding experience

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[1] **First Flow:** https://www.figma.com/proto/ODodReu2eG7uRfN9qU2C0U/Wireframe-3?page-id=171%3A476&type=design&node-id=171-477&viewport=-1595%2C-293%2C0.15&t=aepYUJFTjXL4Ra21-1&scaling=min-zoom&starting-point-node-id=171%3A477&mode=design

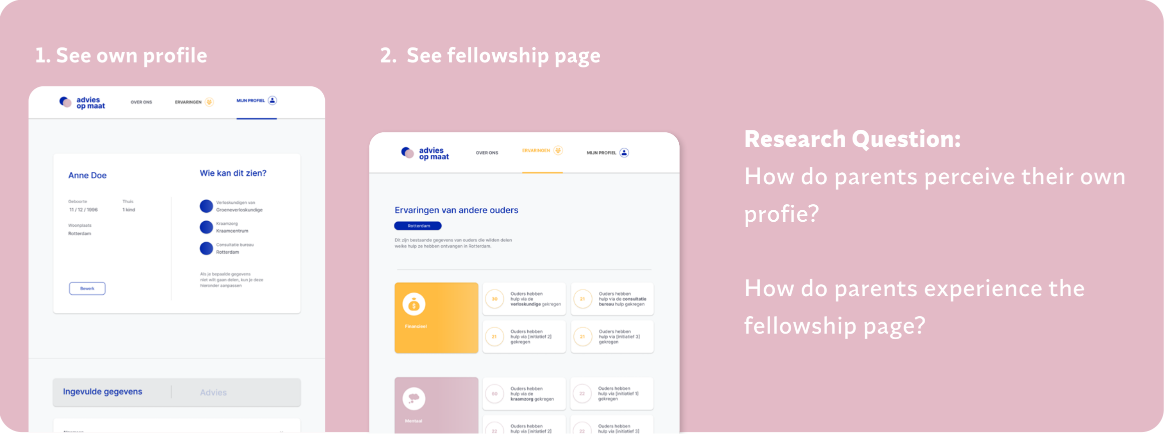
SECOND FLOW: ADOPTED EXPERIENCE

Second Flow: Link to prototype[2]

Research goal

Understand the adopted experience:

- Assess sense of **safety & trust** when parents are able to authorize who can see their information
- Evaluate **sense of relatability** when parents see the fellowship page



Research Question:
How do parents perceive their own profie?

How do parents experience the fellowship page?

Figure 54: Moderated user test plan - adopted experience

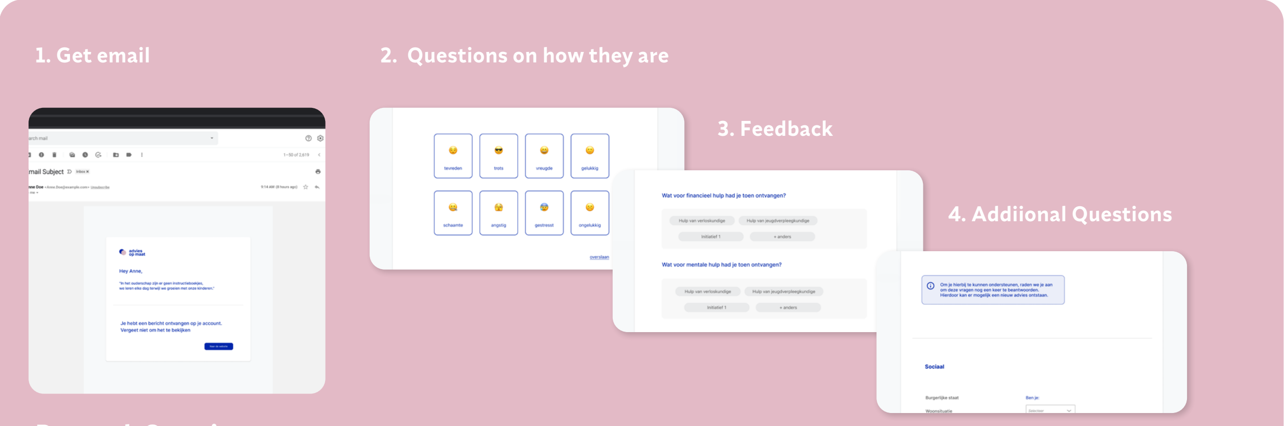
THIRD FLOW: RETURNING EXPERIENCE

Third Flow: Link to prototype[3]

Research goal

Understand the returing experience:

- Evaluate **sense of self-esteem** when parents are asked about them and provide feedback



Research Questions
How do parents perceive their experience with the email received after one year, and how do they evaluate the additional questions asked?

Figure 55: Moderated user test plan - returning experience

KEY INSIGHTS

During the user tests, annotations were taken on what parents said and did. This resulted in insights on onboarding, adoption, and return aspecified research questions. The detailed annotations can be found in Appendix E.2.

Onboarding experience

How do parents perceive the flyer?

After parents read the flyer (prior to the test), a noticeable distinction emerged in the comprehensibility of the tool. Some parents indicated that the instructions given were straightforward and comprehensible. On the other hand, parents also expressed uncertainty regarding the tool's intended purpose.

> *"Geeft indicate op iets"*
> *"Gives indication on something"*

!

Could be too ambiguous for parents in terms of potential advice/purpose of the tool

> *"Huiverig, persoonlijke ervaring pakt het niet zo goed uit, zou alsnog invullen want ben nieuwsgierig"*
> *"Reluctant, personal experience doesn't turn out so well, would still fill in because I am curious"*
>
> *"Op basis van de vragenlijst voorspellingen doet"*
> *"Makes predictions based on the questionnaire"*
>
> *"Met vooroordelen werkt (...) hoe kan je het anders inschatten"*
> *"Works with prejudices (...) how else can you estimate it"*
>
> *"Redenatie is duidelijk, alleen zal ik sceptisch zijn"*
> *"Reasoning is clear, only I will be skeptical"*

Hoe is de vragenlijst gemaakt?

Met behulp van bestaande gegevens vanuit het CBS en literatuur zijn er berekenigen gemaakt die kunnen voorspellen wat voor negatieve uitkomsten er kunnen zijn en die we willen voorkomen.

Om persoonlijk advies op maat te kunnen geven, vragen we de ouder om bepaalde informatie in de vragenlijst te beantwoorden. Deze ingevulde gegevens zijn strikt vertrouwelijk en alleen bedoeld voor de ouder zelf.

Figure 56: Frequently asked qustion - explanation of the tool

How do parents perceive the home screen of the tool?

By referring to the frequently asked questions, parents could understand that it was a prediction model behind the tool (Figure 56). They acknowledged that the predictions were derived from existing data, but this aspect did not necessarily instil a sense of trust. One parent raised concerns about the potential reliance on assumptions when the idea of using existing data was mentioned.

Additionally, concerning the description of risk outcomes, parents expressed a preference for a more positive framing and found the explanation to be excessively lengthy and visually too complex.

!

The need for a positive and easier framing can influence parents to feel less sceptical about the tool

---

[2] **Second Flow:** https://www.figma.com/proto/ODodReu2eG7uRfN9qU2C0U/Wireframe-3?page-id=256%3A3653&type=design&node-id=286-3866&viewport=94%2C217%2C0.1&t=dodxIPwDH6DtSylm-1&scaling=min-zoom&starting-point-node-id=286%3A3866&mode=design

[3] **Third Flow:** https://www.figma.com/proto/ODodReu2eG7uRfN9qU2C0U/Wireframe-3?page-id=317%3A4392&type=design&node-id=317-5537&viewport=89%2C412%2C0.08&t=k2Zzpj9smFErzPy8-1&scaling=min-zoom&starting-point-node-id=317%3A5537&mode=design

To what extent do parents feel safe to fill in (their) information?

The sandbox concept had an overall positive impact on lowering the threshold for parents to fill in the questions, primarily because they could do so anonymously. Parents were aware that the questions did not request personally identifiable information, and they frequently encountered reminders that their data would not be stored (Figure 57). However, there was one sceptical parent who doubted whether their data would truly remain unsaved, considering the presence of cookies on websites. Parents also pointed out Erasmus MC on the flyer and on the home screen which instilled trust.

An interesting observation from the questionnaire was that parents considered the consequences of not answering a question when they were given the option to not share, recognizing that such choices could lead to consequences as well.

"Ze weten nog steeds niet wie ik ben dus..."
"They still don't know who I am so..."

"Tot nu toe geen persoonlijk data ingevuld"
"No personal data entered so far"

"Sowieso, het is nu wel redelijk anoniem"
"Anyway, it's pretty anonymous now"

"Antwoorden worden niet opgeslagen.."
"Answers are not stored..."

"Ja zo lang ik mijn naam niet invul, ligt er puur aan van wie ik dit heb gekregen"
"Yes as long as I don't fill in my name, it purely depends on who I got this from"

"Stel je voor ik vul het niet in, heel groot stuk die het niet hebben ingevuld is ook een conclusie"

"Imagine I don't fill it in, were a lot of people not to fill it in, is also a conclusion"

Je gegevens worden **niet opgeslagen,** tenzij je ervoor kiest om aan het einde van de vragenlijst een account aan te maken.

In dat geval kun je beslissen om ze wel op te slaan.

Figure 57: Reminders of data not being stored

How do parents perceive the questions asked?

Although parents were able to answer some topics without difficulty, they found some questions challenging. This sometimes led to **parents considering stopping their use of the tool.**

Voor het geven van beter advies kan het belangrijk zijn om te weten wat je etnische achtergrond is, evenals die van je ouders.

Eerdere onderzoeken hebben aangetoond dat etnische achtergrond een rol kan spelen bij obesitas/overgewicht (Retnakaran et al., 2006; Singh et al., 2008)

Jouw ingevulde gegevens zijn vertrouwelijk en jij hebt de controle over wie er toegang tot mag hebben.

Figure 58: Explanation of why this topic is asked

The following topics are ones to which parents would respond without difficulty, as they have indicated that they understand why they may be asked for advice.

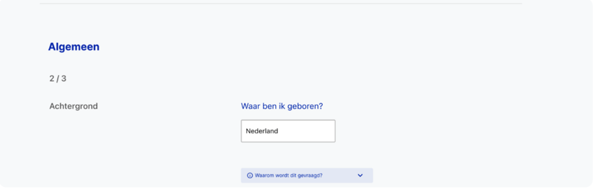
- Gender
- Zip code
- Some parents wanted it to be even more anonymous by displaying only the last two digits of the zipcode.
- Civil status
- Profession
- Medical information such as earlier pregnancies, outcomes, medications and diagnosis

"Waarom wordt dit gevraagd? Hier zou ik stoppen met de vragenlijst"
"Why is this asked? I would quit here with the questionnaire"

"(...) etnische profileren om die informatie te delen"
"(...) ethnic profiling to share that information"

There was a general notion from parents regarding the reasons for asking specific information and its impact on the outcome. The lack of specific details in the additional information feature was not sufficient enough to foster trust (Figure 58).

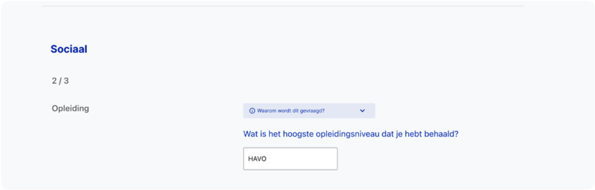
Topics which parents had difficulties in potentially answering:



Waar ben ik geboren?
Nederland

Figure 59: Question on ethnic background

Ethnic background
Different viewpoints existed regarding the topic of ethnicity. Some parents understood the reason for this questioning, as diverse ethnic backgrounds can impact growth patterns and may be customary to disclose to the obstetrician. However, some parents have expressed major concerns about potential consequences, such as ethnic profiling. A parent expressed their intention to discontinue the use of the tool upon encountering a question on where they were born or where their parents are born. (Figure 59).


Sociaal

2 / 3

Opleiding

Wat is het hoogste opleidingsniveau dat je hebt behaald?

HAVO

Figure 60: Question on education level

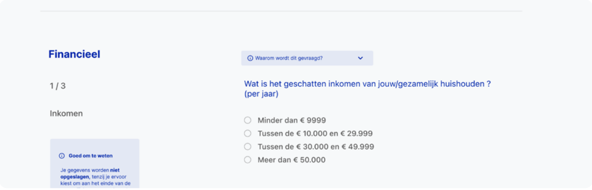
Education level

Most parents had negative attitudes towards discussing their highest level of education. Parents perceived the question as confrontational and felt that it labelled them, as it did not show the entire picture of a parent. (Figure 60).

Parents can experience a sense of being categorised when they are only able to respond to one aspect of a question.

"Je wilt het niet zo hard neer zetten"
"You don't want to put it so harshly"

"Zegt zeker niet alles omdat wat is met mensen die bijna hun opleiding hebben afgerond"
"Certainly doesn't say everything because what about people who have almost completed their education"


Financieel

1 / 3

Inkomen

Wat is het geschatten inkomen van jouw/gezamelijk huishouden ? (per jaar)

○ Minder dan € 9999
○ Tussen de € 10.000 en € 29.999
○ Tussen de € 30.000 en € 49.999
○ Meer dan € 50.000

Goed om te weten

Je gegevens worden **niet opgeslagen**, tenzij je ervoor kiest om aan het einde van de

Figure 61: Question on financials

Financials

Parents comprehended the reason behind the question about income and debt due to its potential impact on the advice's outcome. However, a parent expressed reluctance to provide an accurate response. This could be attributed to parents' feedback during the later stage of the user test, where they expressed that income and debt do not concern healthcare professionals. (Figure 61).

Parents could have increased levels of acceptance once they comprehend the potential connections between the questions and the subsequent advice.

"Zou het wel invullen, geen logisch antwoord geven"
"Would fill it in, would not give a logical answer"

"Gevoelige vraag"
"Sensitive question"

"Verloskundige (...) hebben niks te maken met inkomen en politie"
"Obstetrician (...) have nothing to do with income and police"


Verleden

1 / 3

Verleden

Ben je ooit verdacht geweest door de politie?

○ Ja ○ Nee ○ Wil ik liever niet delen

Goed om te weten

Je gegevens worden **niet opgeslagen**, tenzij je ervoor kiest om aan het einde van de vragenlijst een account aan te

Figure 62: Question on their past

Past

Parents expressed that asking whether they have been suspected by the police is a difficult and no-go question. While some parents showed a degree of understanding regarding the reason, it is possible that they have not experienced this particular situation. (Figure 62)

In the Netherlands, asking about someone's record or past suspicions might be subject to privacy laws and regulations. Eventhough, this variable is being considered in the prediction model, this should be carefully considered whether this should be included at all due to ethical reasons.

"Lastige, merkte wel dat ik halverwege, politie, toen merkte ik dat ik meer ging denken wil ik dit invullen wat gebeurd er verder mee"
"Tricky, I did notice that halfway through, police, then I noticed that I started thinking do I want to fill this in and what will happen with it"

"Vind ik wel een goeie, (...) je wilt toch weten of hetzelfde cirkel zitten of het niet een eenmalig iets is geweest"
"I think this is a good one (...) you want to know if they are in the same circle or if it was one a one time thing"

"Euhh ingewikkeld, wederom zou ik niet klikken. waarom wordt dit gevraagd?"
"Euhh complicated, again I wouldn't click. why is this being asked?"

"No go!"


Verleden

3 / 3

Verleden

Ben je ooit zelf met de Jeugdzorg in contact geweest?

○ Ja ○ Nee ○ Wil ik liever niet delen

Goed om te weten

Je gegevens worden **niet opgeslagen**, tenzij je ervoor kiest om aan het einde van de

Figure 63: Question on their contact with youth care

Youth care

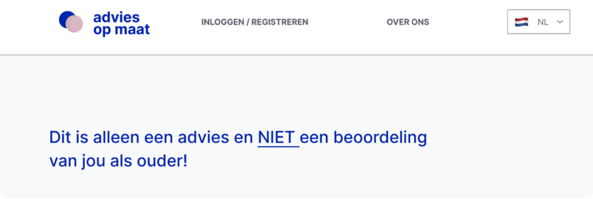
The parents expressed concerns regarding the negative perception of the youth care institution and the potential repercussions associated with addressing this issue. Hence, parents displayed considerable hesitation regarding this issue and voiced worries about potential tracking if they were to indicate their earlier involvement with youth care. (Figure 63).

"(Als ik ja zou klikken) dat er dan in beter in de gaten wordt gehouden, sta ik al op een bepaalde lijst"
"(If I would click yes) that it will be monitored and then I am already on a certain list"

"Ik zou serieus afvragen wat gebeurd er met de gegevens er worden daar veel fouten daar gemaakt. Heftige vraag, het triggerde zou hiermee stoppen"
"I would seriously wonder what happens to the data, there are a lot of mistakes made there (Jeugdzorg). Heavy question, it triggered me, because of this I would stop"

How do parents perceive the outcome?

The majority of parents positively received the quote at the beginning of the outcome (Figure 64). Furthermore, parents also indicated that the numeric value and that other parents made them feel not alone in this context.



Dit is alleen een advies en NIET een beoordeling van jou als ouder!

Figure 64: Statement at the beginning of the outcome

> *"Fijn dat je niet alleen bent, wel een aantal mensen zijn en ook niet perfect zijn"*
> *"Nice that you are not alone, a number of people are not perfect either"*

Parents expressed that they found the outcomes to be too far-fetched and confrontational (Figure 65). They also frequently searched for a connection between the outcomes and the advice they were given. Furthermore, parents were taken aback by the fact that the advice provided was solely based on just three factors from the survey.

Op basis van je **inkomen**, **woonplaats** en je **opleiding** kunnen we de volgende adviezen geven.

Je kunt ervoor zorgen dat je kind minder kans heeft op toekomstige gebeurtenissen zoals :

70% van de ouders die de vragenlijst hebben ingevuld hadden dezelfde adviezen.

Wil je weten wat zij hebben gedaan?

Zou jij graag financiele steun willen ontvangen ? En wil je graag hulp hierbij ?

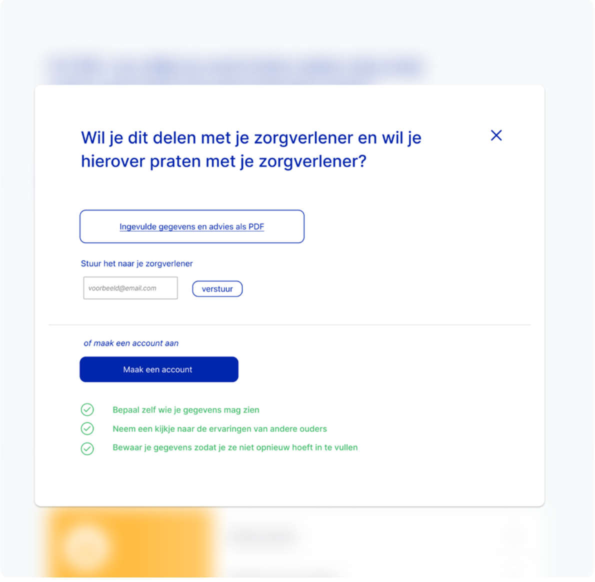
Figure 65: Tailored advice for parents

However parents indicated that the advice would lower the threshold of asking for help if they would receive this outcome.

> *"Laagdrempelig hulp om te vragen om het te gaan doen, wil je die hulp gaan vragen ja graag"*
> *"Easy to ask for help, do you want to get this help, yes please"*
>
> *"Hoeft niet face to face, meer afstand. (...) Je hoeft die drempel niet over"*
> *"Don't need to do it face to face, more distance. (...) You don't have to cross that threshold"*

How do parents feel about communicating/ making an account during results to healthcare professionals?

Based on the results of the user tests, it was observed that parents refrain from creating an account due to the ambiguity surrounding the advice they have received. However, four parents expressed their intention to create an account primarily out of curiosity or to seek assistance (Figure 66).



Wil je dit delen met je zorgverlener en wil je hierover praten met je zorgverlener?

- ✓ Bepaal zelf wie je gegevens mag zien
- ✓ Neem een kijkje naar de ervaringen van andere ouders
- ✓ Bewaar je gegevens zodat je ze niet opnieuw hoeft in te vullen

Figure 66: Request to make an account or share with healthcare professional

Trustability & Safety

The user tests showed that parents were more open to filling in information when they are able to fill it in anonymously before committing to the tool. **However, the questions asked in the form made parents sceptical and concerned about how the data will be used and even leading to quitting the tool.**
This poses a significant risk that should be taken into account, highlighting the need of careful consideration of the wording and whether specific topics should be included in the tool.

Self-esteem

Parents expressed that the questions and outcomes were confrontational, emphasizing the importance of focusing more on the positive aspects of the tool. However, they also indicated that it lowered the threshold to seek for help.

Adopted experience

How do parents experience their own profile?

All parents acknowledged their ability to control which healthcare professional could access specific information, which was perceived positively as it allowed them to have control over their data.

"Fijn, schept vertrouwen. Fijn dat je die controle gewoon hebt"
"Nice, gives trust. Good that you have the control"

How do parents experience the fellowship page?

In general parents did not perceive a strong sense of connection or identification with other parents. This was because certain parents expressed that the numbers shows as an indication of how many parents already received care and how well they are doing. Nevertheless, parents expressed that it mitigated the stigma of reaching out for help.

To enhance the sense of relatability with other parents, incorporating more personal stories can foster a stronger sense of connection and understanding.

"Leuk dat wel 30 ouders hebben die hulp gekregen..."
"NIce, 30 parents have received help..."

"Fijn om te lezen hoe en wat: zichtbaar (...) ik wilde dit al bespreken, ik twijfelde toch.... dat je toch ziet dan ga ik het ook doen"
"Nice to read how and what: visible (...) I wanted to discuss this, I was still hesitant.... when you see it, I'm going to do it too."

Trustability & Safety
Being able to show certain information to certain healthcare professionals helped for parents to have a sense of control.

Relatability
Parents did not feel entirely related to the fellowship page as intended. One possible explanation could be the absence of personal stories of other parents for them to relate to. Nevertheless, parents indicated that it reduced the stigma of reaching out for help.

Returning experience

How do parents perceive their experience with the email received after one year, and how do they evaluate the additional questions asked?

Overall, parents did not appear to be greatly bothered by the email and sharing about what they did as a parent.
However, some mentioned whether they have given consent for it or felt that an email had association with an advertisement. On the other hand, the use of emoji's in the questions about their feelings as parents was well-received and viewed positively.

"Vriendelijk komt het over"
"It come across as friendly"

"Grappig met de emojis, ups en downs leuk dat het gevraagd wordt"
"Funny with the emojis, ups and downs nice to be asked"

Furthermore, parents found the question about their experiences as a parent to be clear and straightforward. Parents understood the purpose of seeking information when circumstances change, as this enables them to obtain further guidance.

The use of more visuals could potentially lower the confrontational aspect of certain questions since the Emojis were very well received.

"Prima, denk ik snap dat die vraag er is zou het ook wel invullen"
"Fine, I understand why this is asked. I would fill it in too"

"Reminder, joh, het kan dus veranderen je kan een nieuw advies kan krijgen"
"Reminder, hey, it can change, you can get a new advice"

Self-esteem
Parents received the emojis very well and understood why certain questions were asked again. Nonetheless, their indication of whether they felt valued could not be truly evaluated.

9.1 Deliver

DIALOGUE

In order to assess the feasibility of the concept, a dialogue was conducted with Mijnkindonline. Mijnkindonline was chosen for a dialogue because, if this digital concept were to be implemented, it would be most likely developed within their secure environment. They have already integrated several risk identification tools like Mind2Care.
During this dialogue we discussed several functionalities of the concept and also discussed the future implementation and possible obstacles.

The discussion revolved around the technical feasibility of implementing different features, pointing out several viability aspects which are important to consider in the future.

Sandbox feature
The technical implementation of the sandbox concept, wherein parents can input information prior to saving data and creating an account, may pose a potential challenge. According to mijnkindonline, it is important to note that even if you only fill in information without saving it, this may not be entirely accurate. This is because the IP address and the time at which a parent fills in the information will be sent to the servers of mijnkindonline. Hence, before implementing this feature, it is imperative to conduct a thorough evaluation with a security officer from mijnkindonline and a data protection officer from erasmus MC.
The purpose of this is to ensure that parents can still provide their information in and secure environment. Therefore, the statement made in the information box regarding that the data will not be saved is inherently misleading to parents. In reality, the data will be transmitted to the server, but it will not be used for any other aims.

Receive advice
Receiving advice through a survey is technically feasible, as demonstrated by the implementation of this aspect in Mind2Care by mijnkindonline.

Testimonials
The considerations regarding the testimonials would be dependent upon the type of data being used, specifically whether it is real-time data or data collected at regular intervals, such as every couple of months. Creating a real-time testimonials section that allows parents to observe changing percentages based on factors such as the number of completed surveys can present challenges and increase the cost of implementation.

Various languages
The need for the tool to be available in multiple languages, as expressed by parents, presents a challenging obstacle that could take time to implement. According to mijnkindonline, it is important to undertake a professional translation of the entire tool and also carry out comprehensive testing in various languages to guarantee the precision of the language used in each specific context.

Outcome depending on various variables
It is technically feasible to retrieve information regarding the variables that played a significant role in providing advice.

Retrieving PDF
It is also feasible to obtain PDF files, but it is important to prioritize safety precautions in this regard as well. When a PDF document is downloaded, it is stored in a local file on a computer. Therefore, if a parent were to download their data on a public computer, it would be stored on that particular computer, potentially compromising the security of the feature.

Showing certain information to certain healthcare professionals
At present, it is not feasible within their existing technical infrastructure. Currently, there is a limitation in the survey display options, where users can only choose between showing the complete survey or not displaying it at all. Therefore, implementing this feature could pose an additional technical challenge.

Multiple moments
It would be technically feasible for mijnkindonline to implement a feature that allows parents to ask questions at multiple timestamps.

Fellowhip page
In the proposed framework, the fellowship feature would be location-based to display relevant initiatives for parents in their respective areas. However, obtaining parental consent beforehand would be necessary. Hence, it is crucial to thoroughly review the consent that parents would give in accordance with the specifications provided by Mijnkindonline.

In conclusion, there are several technical challenges to consider in the future. For example, the technical feasibility of displaying specific results information to particular healthcare professionals may be limited. Nevertheless, the implementation of the sandbox concept is theoretically possible, although it would require developmental work and careful attention to safety considerations. This also applies to the fellowship page, testimonials, and the functionality to download the PDF files.

Chapter 10

ITERATIONS

The main objective of the iteration phase was to refine the concept by addressing specific details that emerged as primary challenges during the moderated user testing. In Appendix E.3 several iterations can be found.

During the iteration phase, the main focus will be on improving the onboarding experience, addressing key pain points related to the safety, trustability, and self-esteem of the parent (Figure 67).

Specifically, the iteration will concentrate on iterating on the tool's explanation, refining the questions asked, and improving the outcomes presented to parents.

The previous explanations were found to be too vague, overly negative, and the outcomes were confronting for parents, potentially impacting their self-esteem.
More importantly, the questions asked were identified as significant pain points, leading some parents to consider quitting the tool, indicating that their trust and sense of safety in the tool were insufficient.

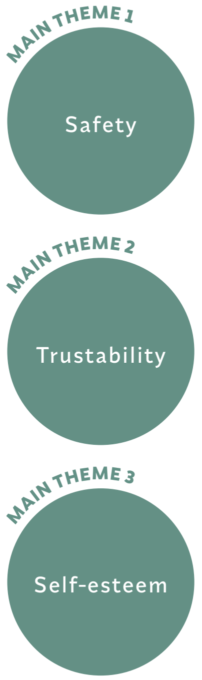


Figure 67: Main themes of the graduation project

ITERATION 1: EXPLANATION OF THE TOOL

Hoe is de vragenlijst gemaakt?

Met behulp van bestaande gegevens vanuit het CBS en literatuur zijn er berekenigen gemaakt die kunnen voorspellen wat voor negatieve uitkomsten er kunnen zijn en die we willen voorkomen.

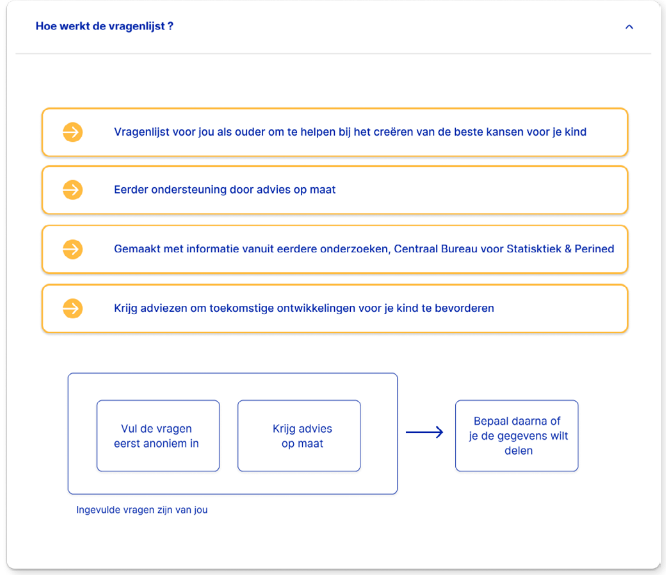
Om persoonlijk advies op maat te kunnen geven, vragen we de ouder om bepaalde informatie in de vragenlijst te beantwoorden. Deze ingevulde gegevens zijn strikt vertrouwelijk en alleen bedoeld voor de ouder zelf.

Ingevulde gegevens worden niet gebruikt om nieuwe berekenigen te maken

Figure 68: Previous design on the explanation of the tool

Parents perceived the explanation of the tool too lengthy and the visual too complex. This could have led that parents were more apprehensive about the tool itself (Figure 68).

Therefore, this iteration aims to provide a more clear and easily understandable explanation.
Given the importance of transparency regarding the type of data used and the fact that it contains a prediction model, it was significant to convey this information in the simplest and most comprehensible way possible (Figure 69).



Hoe werkt de vragenlijst ?

- Vragenlijst voor jou als ouder om te helpen bij het creëren van de beste kansen voor je kind
- Eerder ondersteuning door advies op maat
- Gemaakt met informatie vanuit eerdere onderzoeken, Centraal Bureau voor Statisktiek & Perined
- Krijg adviezen om toekomstige ontwikkelingen voor je kind te bevorderen

Figure 69: Recommended design on the explanation of the tool

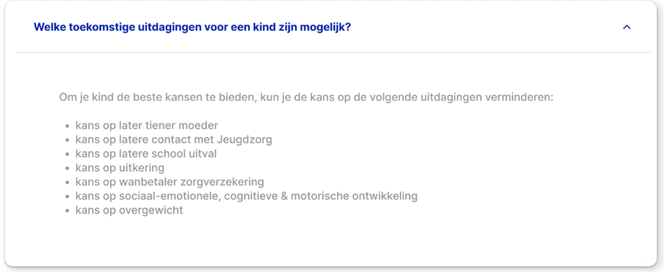
Easy and short explanations
Use short sentences and easy words to improve parents' understanding and engagement.

Clear aim & expectations
Ensure parents understand the benefits the can gain from using the tool.

Avoid "we want"
Even though the tool is developed by the research team, adopting a personalized tonality can make parents feel acknowledged and more in control, knowing that it is in their hands.

Easy visual for the parent
Using simple images that focus not necessarily on the background process but on the effects for them can reduce apprehension.

ITERATION 2: EXPLANATION



Welke toekomstige uitdagingen voor een kind zijn mogelijk?

Om je kind de beste kansen te bieden, kun je de kans op de volgende uitdagingen verminderen:

- kans op later tiener moeder
- kans op latere contact met Jeugdzorg
- kans op latere school uitval
- kans op uitkering
- kans op wanbetaler zorgverzekering
- kans op sociaal-emotionele, cognitieve & motorische ontwikkeling
- kans op overgewicht

Figure 70: Previous design on the explanation of the tool's outcomes

The outcomes of the tool were not always obvious, and were more confrontational for parents (Figure 70). Although it was worded to minimize the likelihood of certain negative outcomes, there was a greater need to positively define the tool's outcomes rather than indicating the risk outcomes.

Welke mogelijke toekomstige ontwikkelingen kun je bevorderen voor je kind?

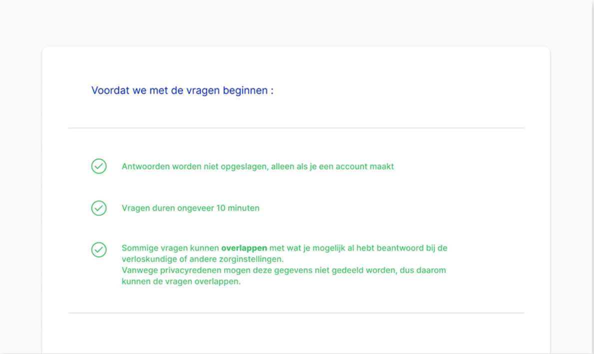
- Het stimuleren van een positieve sociale en emotionele ontwikkeling van je kind
- Het bevorderen van gezonde mentale en lichamelijke ontwikkeling van je kind
- Het waarborgen van financiële stabiliteit voor de toekomst van je kind
- Het vergroten van de kansen op een succesvolle schoolloopbaan voor je kind
- Het beschermen van je kind tegen contact met Jeugdzorg
- Het bevorderen van het ouderschap op een later moment in het leven van je kind

Figure 71: Recommended design on the explanation of the tool's outcomes

Reversed risk outcomes

Empower parents with the sense that they can contribute to the positive outcomes rather than focusing on preventing the risk outcomes (Figure 71).

ITERATION 3: EXPLANATION



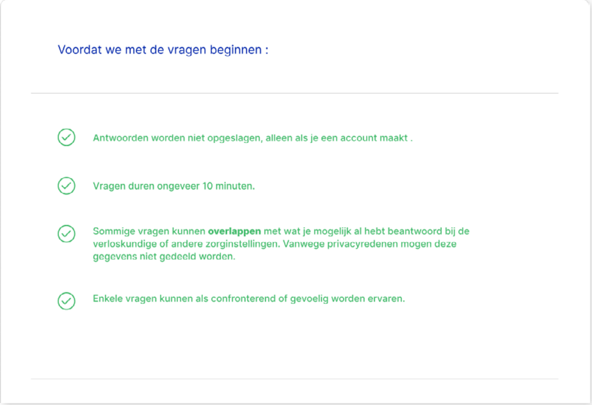
Voordat we met de vragen beginnen :

- Antwoorden worden niet opgeslagen, alleen als je een account maakt
- Vragen duren ongeveer 10 minuten
- Sommige vragen kunnen **overlappen** met wat je mogelijk al hebt beantwoord bij de verloskundige of andere zorginstellingen.
  Vanwege privacyredenen mogen deze gegevens niet gedeeld worden, dus daarom kunnen de vragen overlappen.

Figure 72: Previous design reminder before starting the questionnaire

The reminder before entering the questionnaire, allowed parents to be reassured of the anonymity of the information and the duration of the questionnaire.

Given that parents felt confronted and unease with certain topics, using this section as an opportunity to prepare them beforehand could be beneficial (Figure 72).



Voordat we met de vragen beginnen :

- Antwoorden worden niet opgeslagen, alleen als je een account maakt .
- Vragen duren ongeveer 10 minuten.
- Sommige vragen kunnen **overlappen** met wat je mogelijk al hebt beantwoord bij de verloskundige of andere zorginstellingen. Vanwege privacyredenen mogen deze gegevens niet gedeeld worden.
- Enkele vragen kunnen als confronterend of gevoelig worden ervaren.

Figure 73: Recommended design reminder before starting the questionnaire

Prepare parents

Acknowledge that certain topics may be perceived as sensitive and confrontational for parents (Figure 73).

ITERATION 4: QUESTIONS

For specific sensitive topics such as:

- Educational background
- Financial topics
- Police or Youth care involvement
- (Ethnic background - it remains unclear whether this will be asked)

It is recommended to offer more explanation on why these questions were included, as parents expressed scepticism and concern regarding these topics. The current design's explanation about that these topics can have an affect on the advice was too vague and not sufficient for parents (Figure 74).

Waarom wordt dit gevraagd?

- Je wilt ervoor zorgen dat je kind een succesvolle schoolloopbaan heeft

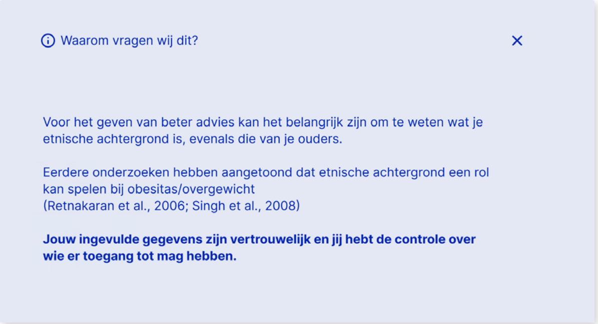
Niet alleen jouw opleiding kan invloed hebben op je kind, maar ook andere factoren spelen hierbij een rol. Een opleiding kan slechts een indicatie geven van het mogelijke adviezen dat je kunt krijgen als ouder.

Mogelijke adviezen:

- Advies voor stress
- Advies voor balans tussen school en ouderschap

Jouw ingevulde gegevens zijn vertrouwelijk en momenteel niet toegankelijk voor anderen

Figure 75: Recommended design on "why is this asked" pop up



Waarom vragen wij dit?

Voor het geven van beter advies kan het belangrijk zijn om te weten wat je etnische achtergrond is, evenals die van je ouders.

Eerdere onderzoeken hebben aangetoond dat etnische achtergrond een rol kan spelen bij obesitas/overgewicht
(Retnakaran et al., 2006; Singh et al., 2008)

Jouw ingevulde gegevens zijn vertrouwelijk en jij hebt de controle over wie er toegang tot mag hebben.

Figure 74: Previous design on "why is this asked" pop up

First start of positive

By reminding parents about the outcomes they can positively influence, sensitive questions can become less confrontational and more approachable (Figure 75).

Second give possible outcomes

Highlight the benefits in terms of possible advice they can receive by answering this question.

Third explain more about the factor

Make parents understand that the advice is not only based on one factor but is a culmination of various factors.

Lastly explain safety of their data

Remind parents that their information is confidential and not visible to anyone.

For sensitive questions, parents were provided with the option to select "would not like to share." However, they raised concerns that choosing this option might result in conclusions and consequences regarding their decision not to share the information (Figure 76).

Ben je ooit zelf met de Jeugdzorg in contact geweest?

○ Ja ○ Nee ○ Wil ik liever niet delen

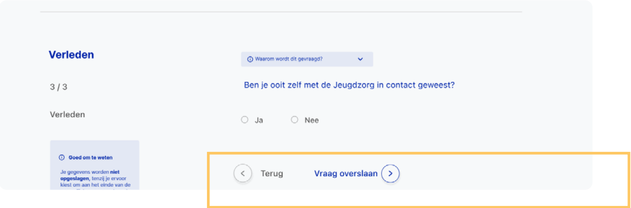
Je gegevens worden **niet opgeslagen**, tenzij je ervoor kiest om aan het einde van de

Figure 76: Previous design on "would not like to share" option

Option to skip question

Instead of using the phrase "would like not to share" it is recommended to include a skip button. This can potentially alleviate the burden on the respondent (Amos, 2018; Manski & Molinari, 2008).

However, using the skip button might lead to the risk of providing inaccurate advice. Therefore, including the a "why is this asked" option can help mitigate this issue (Figure 77).



Ben je ooit zelf met de Jeugdzorg in contact geweest?

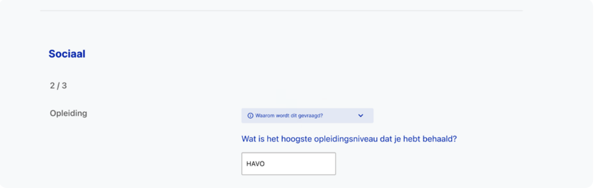
○ Ja ○ Nee

Je gegevens worden **niet opgeslagen**, tenzij je ervoor kiest om aan het einde van de

Figure 77: Recommended design on "would not like to share" option

Iteration on question education

Only providing the option to answer the highest obtained degree parents can feel cornered that and that it does not represent their situation (Figure 78).



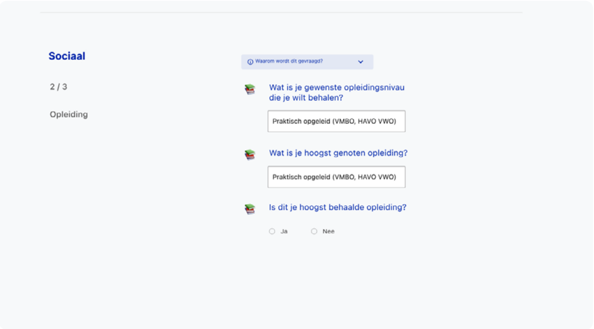
Wat is het hoogste opleidingsniveau dat je hebt behaald?

HAVO

Figure 78: Previous design question on education

Make questions well rounded

Chose to start the question by asking about the parents' desired and current educational pursuits, building towards whether this would be their highest degree obtained. Applying an adaptive method to the question before can improve responses (Early et al., 2017) and allow parents to give a broader explanation of their situation (Figure 79). Additionally, alternative wording such as "theoretically educated" or "practically educated" instead of "lower" or "higher" education could be considered for inclusivity (Centraal Bureau voor de Statistiek, 2021).



Wat is je gewenste opleidingsniveau die je wilt behalen?

Praktisch opgeleid (VMBO, HAVO VWO)

Wat is je hoogst genoten opleiding?

Praktisch opgeleid (VMBO, HAVO VWO)

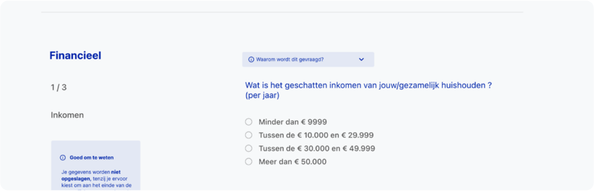
Is dit je hoogst behaalde opleiding?

○ Ja ○ Nee

Figure 79: Recommended design question on education

Iteration on question financials

Parents expressed significant apprehension regarding the question regarding their income, as they were unconvinced why healthcare providers would need access to this information (Figure 80).



Wat is het geschatten inkomen van jouw/gezamelijk huishouden ? (per jaar)

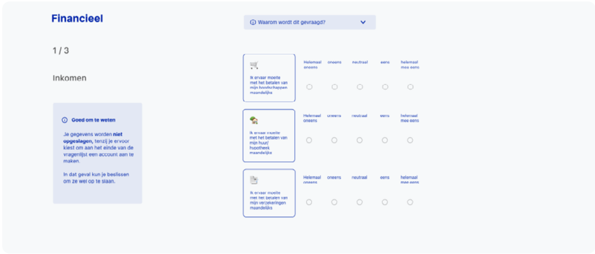
○ Minder dan € 9999
○ Tussen de € 10.000 en € 29.999
○ Tussen de € 30.000 en € 49.999
○ Meer dan € 50.000

Je gegevens worden **niet opgeslagen**, tenzij je ervoor kiest om aan het einde van de

Figure 80: Previous design question on financials

Use proxy questions

Instead of asking about the value of their income, proxy questions such as household expenditure on basic needs in life could be used (Zere & McIntyre, 2003). This can potentially aid in determining if parents might require help/advice concerning this matter (Figure 81).



Ik ervaar moeite met het betalen van mijn boodschappen maandelijks

Ik ervaar moeite met het betalen van mijn huur/ hypotheek maandelijks

Ik ervaar moeite met het betalen van mijn verzekeringen maandelijks

Je gegevens worden **niet opgeslagen**, tenzij je ervoor kiest om aan het einde van de vragenlijst een account aan te maken.

In dat geval kun je beslissen om ze wel op te slaan.

Figure 81: Recommended design question on financials

Iteration on question police or youth care involvement

Parents were sceptical and concerned about where the data regarding their previous contact with the police or youth care would be used when answering these questions (Figure 82).

Ben je ooit zelf met de Jeugdzorg in contact geweest?

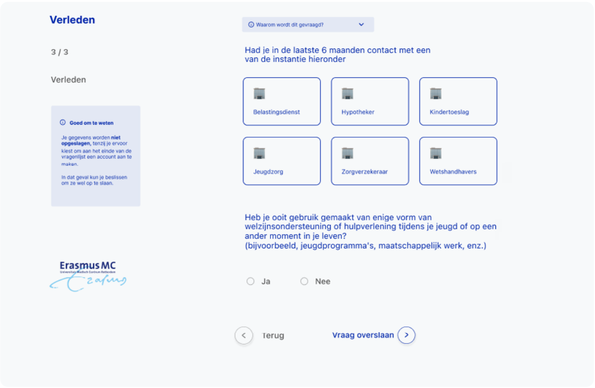
○ Ja ○ Nee ○ Wil ik liever niet delen

Je gegevens worden **niet opgeslagen**, tenzij je ervoor kiest om aan het einde van de

Figure 82: Previous design question on youth care

Listing possible institutions

An effective solution could involve providing an alternative by allowing parents to list relevant institutions they have been in contact with, including the sensitive item (Blair et al., 2014). This approach can reduce the confrontational nature of asking directly about their contact with youth care or the police (Figure 83).



Had je in de laatste 6 maanden contact met een van de instantie hieronder

Heb je ooit gebruik gemaakt van enige vorm van welzijnsondersteuning of hulpverlening tijdens je jeugd of op een ander moment in je leven? (bijvoorbeeld, jeugdprogramma's, maatschappelijk werk, enz.)

○ Ja ○ Nee

Je gegevens worden **niet opgeslagen**, tenzij je ervoor kiest om aan het einde van de vragenlijst een account aan te maken.

In dat geval kun je beslissen om ze wel op te slaan.

Figure 83: Recommended design question on youth care

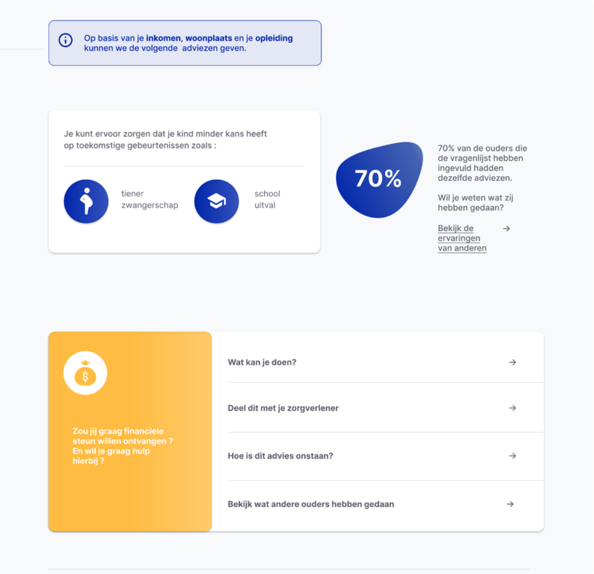
Use proxy questions

Instead of directly asking about the invovlement of the youth care, alternative solutions could entail referring to other institutions which can be related to youthcare such as youth programs (Figure 83).

Parents were often looking for the relation between the outcome and the advice and tried to relate those two aspects with each other. Furthermore, the outcomes were perceived as confrontational and not too far fetched (Figure 84).

Connect advice with outcomes

By connecting the advice with the outcomes, parents can better understand its benefits and may be more inclined to continue using the tool. This approach can lead to parents being more inclined to continue with this tool without being overly confrontational (Figure 85).



Op basis van je **inkomen, woonplaats** en je **opleiding** kunnen we de volgende adviezen geven.

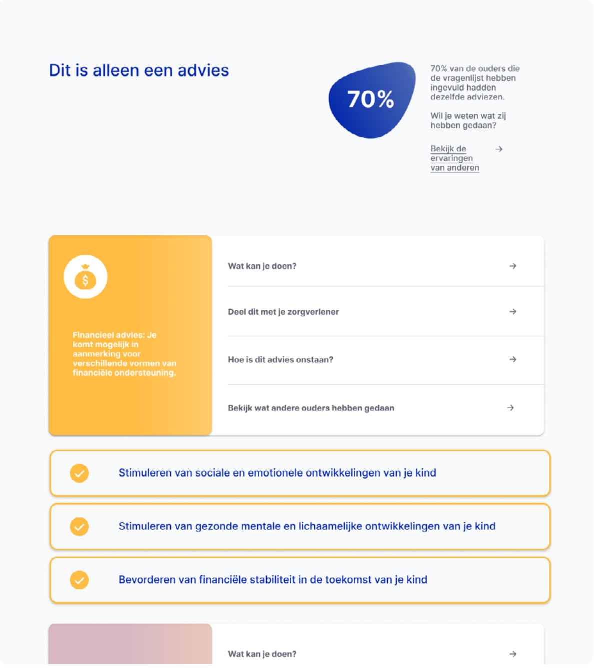
Je kunt ervoor zorgen dat je kind minder kans heeft op toekomstige gebeurtenissen zoals :

70% van de ouders die de vragenlijst hebben ingevuld hadden dezelfde adviezen.

Wil je weten wat zij hebben gedaan?

Zou jij graag financiele steun willen ontvangen ? En wil je graag hulp hierbij ?

Figure 84: Previous design of the outcome of the tool



Dit is alleen een advies

70% van de ouders die de vragenlijst hebben ingevuld hadden dezelfde adviezen.

Wil je weten wat zij hebben gedaan?

Financieel advies: Je komt mogelijk in aanmerking voor verschillende vormen van financiële ondersteuning.

✓ Stimuleren van sociale en emotionele ontwikkelingen van je kind

✓ Stimuleren van gezonde mentale en lichaamelijke ontwikkelingen van je kind

✓ Bevorderen van financiële stabiliteit in de toekomst van je kind

Figure 85: Recommended design of the outcome of the tool

In conclusion, these recommendations cover certain aspects of the variables that could be included in the prediction model. However, it is essential to give additional thought to the phrasing and arrangement, as these factors can significantly influence the tool's perception.

4

DISCUSSION

The final phase of this thesis discusses the limitations of the graduation project and presents the subsequent steps in the recommendations section. Moreover, it provides a reflection of the project, delving into the difficulties encountered and the valuable insights gained as designer.

Chapter 11

LIMITATIONS

This chapter discusses limitations of the concept as well as the various methods used in the graduation project.

One persistent challenge is the development stage of the prediction model proposed by the "Making Big Data Meaningful for a Promising Start" research team. Consequently, the concept relies on a theoretical prediction model that lacks the necessary variables or information required for the tool. Therefore currently, in the concept, the questions asked are preliminary questions that might or might not be necessary for the prediction model.
Furthermore, the tool has another limitation. It is currently unable to offer specific advice to parents. Presently, it only provides a general potential outcome, failing to deliver a more personalized health trajectory that would be more beneficial for parents.

A limitation of the graduation project is the need for more input from general practitioners during the interviews and co-creation sessions. Considering their role in the first 1000-day trajectory and potential involvement in risk identification and referral, their perspective would have contributed to a deeper understanding of the complexities around this context.
Furthermore, the interviews were restricted to just three participants from the consultation bureau, which have an important role in the infant and toddler hood phase. The small sample size is a limitation to drawing clear conclusions from these interviews, but it did provide preliminary insights into their risk identification and referral process. Additionally, it is important to note that all healthcare professionals involved in the graduation project belonged to different municipalities, each operating in different processes. This variability posed a challenge in creating a comprehensive journey map, as the experiences could differ from one municipality to another.

During the co-creation sessions, certain limitations should also be considered. For example, certain co-creation sessions were conducted on a one-on-one basis due to the unpredictability of parents and healthcare professionals attending due to last-minute cancellations by participants. Additionally, slight modifications were implemented in the exercises based on the participants' level of ideation regarding specific questions. This was necessary since parents were not able to creatively express their ideas in every situation. Another aspect was that in larger groups with more than four participants, some parents/healthcare professionals appeared less engaged during the collaboration phase. This observation raised questions about whether my presence as a facilitator could have influenced their ideation process.

In the concept evaluation phase, a small sample size of participants was included for the online moderated user test. The participants consisted of three parents who were previously involved in this project and four parents who were new to the project. The user test aimed to explore participants' experiences and perceptions through open-ended questions. However, given the mix of participants with varying experiences with the project and the exploratory nature of the test, reaching a significant conclusion from the test proved to be difficult.
Furthermore, the user test was carried out in a controlled setting, which led to the oversight of important contextual factors. Presenting parents with short scenarios might not have fully captured the real-life experience.
Lastly, the pre-filled and sensitive nature of the questions in the tool, coupled with my presence as the facilitator, could have influenced their perceptions of the tool. As a consequence, the outcome may not have been entirely perceived as personal since it was not based on what they would have filled in themselves.

Chapter 12

RECOMMENDATIONS

This chapter will focus on recommendations for the research team "Making Big Data Meaningful for a Promising Start" regarding the next steps for the tool and considering the viability of the tool in the long term.

There are several steps that are important to take into account when continuing with this concept. The recommendation is categorized into three different categories: internal realignment, target group alignment, and external alignment.

Internal realignment

The initial recommendation involves internal realignment with the research team on the prediction model. As the model is still under development and certain variables remain undecided, a crucial discussion point is whether to exclude sensitive and ethically questionable variables from the prediction model or refrain from asking those variables, which might result in reduced accuracy but still guide parents toward a health trajectory in the first 1000 days.

Some variables are considered sensitive and challenging, and although they were reiterated, there remains a risk that parents may feel too uncomfortable to respond, potentially hindering the main objective of providing early help and identifying risks earlier on.

Moreover, there have been discussions of the possibility of the future tool integrating the prediction model with other research studies. This combined approach could offer valuable insights and can enhance the tool's effectiveness.

Once specific variables and determinants are decided, additional discussions could take place with policymakers who are already part of the "Making Big Data Meaningful for a Promising Start"research team. These discussions can explore the possibility of integrating research on the "sociale kaart" (social map) with its possible initiatives to integrate it with the outcomes of the prediction model and prior studies.

There have already been conversations with Mind2Care in terms of cooperation. However, the next step would be to decide internally in the research team what this cooperation could look like and whether it should be introduced together for parents or as two separate tools.

Target group alignment

The suggested approach is to iteratively refine the concept until it reaches a level of safety and trustworthiness that would encourage participants to feel comfortable filling it in. However, given the time constraints and the financial considerations of the research team, this recommendation focuses on prioritizing the most critical aspects deemed essential for achieving the desired level of safety and trust in the system.

The concept iterations can be initially tested through interviews with parents, using open-ended questions to understand their experiences and perspectives on the questions asked. Once the concrete variables and determinants for the tool are finalized, it is recommended to conduct another round of testing with parents to assess their perspective of the entire tool with the selected variables.

Additionally, engaging in discussions with healthcare professionals is important to understand how they would prefer to receive the information and to potentially implement it into their consultation if parents choose to create an account and share it with the specific healthcare professional.
These discussions will ensure that the tool is well-aligned with the needs of both parents and healthcare professionals.

External realignment

Considering the concept's feasibility, numerous features could be incorporated in the long run. However, it is essential to discuss with the research team the developmental costs with Mijnkindonline. After the discussions with Mind2Care and potential collaboration opportunities, the implementation of these features can be carefully evaluated.

Chapter 13

REFLECTION

REFLECTION ON THE PROJECT

The graduation project provided a significant opportunity for learning and personal growth for me as a designer. When I first began, I had no idea how intricate the first 1000 days can be, both in terms of the healthcare system and the varying experiences of healthcare professionals and parents. More importantly, I had no notion of what it was like for families, especially those living in vulnerable circumstances. The complexity of the context around the various stakeholders involved in the first 1000 days led me to adapt to a design approach where I shifted between researching and designing at micro and meta levels. While this was not always easy since the focus sometimes felt elusive, this experience has shaped me to be a more versatile designer.

Through the process of conducting interviews with healthcare professionals and parents, I gained valuable insights into their perspectives and experiences during the initial 1000 days. As a designer, I found that being exposed to such personal experiences taught me a great deal about how to conduct interviews and better comprehend the stories being shared. Their stories were powerful and made me realize that their stories should be treated with utmost care. During this project, I never imagined I would have the opportunity to engage with so many parents. To be completely honest, at the beginning of the graduation project, I was a bit anxious about this aspect. I knew that connecting with groups living in vulnerable circumstances could be challenging. However, thanks to my company supervisor, Lisan, I successfully reached and communicated with numerous parents, surpassing my expectations.

During this journey, one of the more challenging aspects was designing a prediction model that was still in development. The unpredictability of required variables posed challenges in envisioning the model's impact on parents. However, it also encouraged discussions about handling sensitive topics with care and potentially excluding certain variables from the model. Despite these challenges, the research team from Erasmus MC demonstrated an openness to address parental concerns and consider alternative options, particularly when some variables were ethically questionable. The adaptability shows promise for future improvement and a more thoughtful approach to the model's implementation in reality.

REFLECTION ON MY PERSONAL LEARNING AMBITIONS

Moreover, in this section, I want to reflect on my personal learning objectives derived from the project brief and discuss my learning trajectory, highlighting both the valuable lessons I have acquired and the areas in which I wish to continue to develop as a designer.

1. Lead my own project forward while strengthening my time management skill set

Throughout this project, I had the opportunity to shape and execute my design project using the design methods I intended to apply. However, leading my own project also entailed valuable lessons in time management. I realized the importance of being more realistic with time, avoiding overly ambitious plans. Despite the challenges, I gained confidence from completing my project within the desired time frame.

2. Enhance my qualitative research capabilities

By actively involving parents in the design process, I acquired valuable experience interacting with groups who are living in vulnerable circumstances. Using methods such as co-creation sessions and user testing allowed me to further refine my organizational and empathic research skills. The hands-on experience proved to be an unforgettable learning journey, enhancing my abilities as a designer to address the needs and concerns of those in vulnerable circumstances.

3. Develop my stakeholder management skills

This master's project taught me valuable lessons about stakeholder management. Initially, I aimed to keep my supervisory team updated and involve them more during the design phase. However, I discovered that stakeholder management is more versatile. Clear communication and discussing expectations with everyone beforehand proved essential. This experience has made me more aware of the importance of communication and handling diverse stakeholder needs effectively.

4. Strengthen my adaptability and flexibility in a variety of situations

Being flexible in various situations was a challenge for me. For instance, co-creation sessions and interviews required adjustments to the initial plan due to unexpected time constraints. The overlap led to a more exploratory co-creation session than I intended.
Additionally, I learned to be adaptable during the sessions and user testing by making necessary adjustments based on the actions of participants. This experience taught me the skills to further refine my adaptability and responsiveness in a design process.

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