THESIS

Designing a strategy for accessible and consistent information provision within sickle cell disease

Master Thesis - Puck van der Veer

Strategic Product Design - Medisign

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Master Thesis - Strategic Product Design
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Thank you very much for taking the time to read my graduation thesis. This project is the largest and most intensive I've worked on in recent years, and I'm proud to present its results. With this thesis, I conclude an important and educational period as a student.

During my studies at the Faculty of Industrial Design Engineering, the Medisign specialization gave me the opportunity to delve deeper into the healthcare sector. My passion for healthcare further developed within this specialization. I was able to directly apply the knowledge, insights, and experiences I gained here in my graduation project, which made this process extra valuable.

First of all, I would like to sincerely thank my supervisors, Armagan and Marina, for their dedication, expert guidance, and valuable feedback throughout this project. Their support was enormously helpful, and I look back fondly on our pleasant and inspiring collaboration.

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Finally, I would like to thank everyone who participated in this project and shared their time, knowledge, and experiences. Without this valuable input, the project would never have been possible to bring to a successful conclusion.

This thesis marks the end of my time as a student. I hope that this project can contribute to further improving sickle cell care and that I can continue to contribute to creating better, more personalized care in the future.

EXECUTIVE SUMMARY

Background and Problem Statement

Sickle cell disease is a chronic hereditary blood disorder that significantly impacts the daily lives of children and their families. Approximately 2000 people in the Netherlands live with sickle cell disease, about half of whom are children. Care is provided in specialized sickle cell centers, where parents and children receive complex medical information that they must apply in daily life. The patient population often consists of families with a migrant background, where language barriers, cultural differences, and low health literacy hinder the understanding of information. This study shows that the current information provision is highly fragmented, varies by healthcare provider and care center, and insufficiently meets the needs of families. The lack of a national standard for which information is provided and when, combined with overly complex and insufficiently accessible materials, leads to misunderstanding, uncertainty, and additional pressure on both families and healthcare providers.

Research Approach

This project followed a human-centered design approach based on the Double Diamond model, focusing on the perspective of healthcare providers. Through literature research, observations at the Sophia Kinderziekenhuis, interviews with healthcare providers from various sickle cell centers, and a context analysis (actor map, work models, and journey map), the current situation was mapped and structural bottlenecks identified. Based on these insights, a clear design direction was chosen, which was then translated into a concrete strategy through co-creation with healthcare providers.

The Solution: A Uniform and Phased Information Strategy

The core of the solution is a newly developed infographic that serves as a blueprint for information provision. This tool is designed to be incorporated into the national guideline for sickle cell disease.

The strategy is characterized by:

1. Phased information provision: Information is not provided all at once, but at meaningful moments that correspond to the child's life stage.
2. National uniformity: Integration into the national guideline ensures that all patients, regardless of care center, receive the same consistent information.
3. Clear division of roles: The infographic supports the care team by assigning education to the nurse practitioner.

Implementation strategy

An implementation strategy, including both a strategic and a tactical roadmap, was developed to support realization. This strategy consists of collective alignment, national development of a standardized information set through co-creation with parents, patients, and healthcare providers, and sustainable anchoring through inclusion in clinical guidelines and integration into existing workflows.

Conclusion

This project offers a concrete answer to the fragmentation in the information provision within sickle cell disease. By introducing a uniform and phased information structure, healthcare providers are supported and parents and children receive the right information at the right time, in an accessible, consistent and understandable manner.

GLOSSARY

The glossary clarifies key terms and abbreviations that are used throughout the thesis.

Co-creation

Process in which different stakeholders jointly contribute creatively to the development of ideas, solutions or designs (Sanders & Stappers, 2008).

Complex

Not easy to deal with or understand (Cambridge dictionary, 2025).

Culture

Learned, shared and transmitted knowledge of values, beliefs, and lifeways of a particular group that are generally transmitted intergenerationally and influence thinking, decisions, and actions in patterned or in certain ways (Singleton & Krause, 2009).

Guideline

information intended to advise people on how something should be done or what something should be (Cambridge dictionary, 2025).

Health literacy

The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions (Singleton & Krause, 2009).

Healthcare provider (Zorgverlener)

A Licensed person that provides health care services working directly with patients (e.g. doctors, specialised nurses, assistants, etc.)

Infographic

A picture, diagram, or group of pictures showing information or data (Cambridge dictionary, 2025).

Information provision

The process of transferring knowledge or facts from one party to another (Van Vliet et al., 2021).

Language

Spoken and written language, but also how easily people can understand systems (Singleton & Krause, 2009).

Outpatient clinic (Polikliniek)

At a outpatient clinic, you can come in for a consultation and treatment for your illness or disorder. This may include examination, diagnosis, treatment or screening. These tend to be short visits, without formal admission or overnight stays (LUMC, n.d.)

Parent

A mother or father of a person or someone who looks after a person in the same way that a parent does (Cambridge dictionary, 2025).

Roadmapping

Strategic design method that provides insight into possible futures and connects these with concrete steps in time

Family

A group of people who are related to each other, such as a mother, a father, and their children (Cambridge dictionary, 2025).

Abbreviations

AI:	Artificial Intelligence
Amsterdam UMC:	Amsterdam Universitair Medisch Centrum
BME:	Black and Minority Ethnic
EPD:	Elektronisch Patiëntendossier
Erasmus MC:	Erasmus medisch centrum
FHIR:	Fast healthcare Interoperability Resources
HbS:	Sickle Hemoglobin
HSCT:	Haematopoietic Stem Cell Transplantation
LUMC:	Leiden Universitair Medisch Centrum
LWHB:	Landelijke Werkgroep Hemoglobinopathie Behandelaren
NVvH:	Nederlandse Vereniging voor Hematologie
NVK:	Nederlandse Vereniging voor Kindergeneeskunde
Radboud UMC:	Radboud Universitair Medisch Centrum
RIVM:	Rijksinstituut voor Volksgezondheid en Milieu
RQ:	Research Question
SAM:	Suitability Assessment of Materials
SCORE:	Sickle Cell Outcome Research
SQ:	Sub Question
T:	Theme
UMCU:	Universitair Medisch Centrum Utrecht
UMCG:	Universitair Medisch Centrum Groningen
VWS:	Ministerie van Volksgezondheid, Welzijn en Sport
WMO:	Wet medisch-wetenschappelijk onderzoek met mensen

TABLE OF CONTENTS

The journey map, strategic roadmap, and tactical roadmap are provided as separate documents, as they are too large and contain a high level of detail.

1 INTRODUCTION

This chapter describes the general scope of the project and explains its context. It explains the rationale for conducting this project and clarifies the approach and methods used. It also provides relevant background information on sickle cell disease, the patient population and sickle cell centers in the Netherlands.

1.1 General scope of the project

1.1.1 Context

Sickle cell disease is a chronic hereditary blood disorder that affects the daily lives of patients and their families. In the Netherlands, approximately 2000 people live with the disease, about 50% are children (Sikkelcelfonds.nl, 2025). The sickle cell disease population consists largely of families with a migration background, who often face additional challenges such as cultural and language barriers, large household sizes and varying levels of health literacy, which make it harder to access, process, and apply medical information (Singleton & Krause, 2009).

In the Netherlands children with sickle cell disease are cared for in specialized sickle cell centers. Within this context, information provision plays a crucial role, as parents and children must cope with the disease at home. Medical decisions must be understood and made independently. Current information provision consists primarily of verbal explanations during consultations supplemented with written leaflets and online information. Medical information often proves difficult to remember: patients forget 40–80% of what is discussed during consultations (Kessels, 2003). Moreover, it does not always meet the health literacy levels and information needs of families (Noordman et al., 2019). As a result, uncertainty often arises in families, which can lead to incorrect actions at home and increased pressure on healthcare providers (Shahid et al., 2022).

1.1.2 Scope & focus

This project aims to identify a strategy that enables accessible information provision for parents and children with sickle cell disease in the Netherlands. The strategy will be focused on information essential for daily life with sickle cell disease. It should support healthcare providers by providing a consistent basis for explanations during consultations, while also empowering parents and children in the challenges of living with sickle cell disease.

In order to make the information provision accessible for parents and children with sickle cell disease, insights are first needed into which information healthcare providers consider essential and how information provision currently works. Healthcare providers determine in practice what information is provided, when and how. Without their perspective, it is difficult to understand where potential opportunities for improvement lie. Therefore the perspectives of healthcare providers are central to this project.

To ensure that the strategy is tailored to more than just one hospital, multiple sickle cell centers in the Netherlands are being involved in this project. By involving multiple centers, differences in working methods, populations, and the organization of information provision are taken into account. This ensures that the strategy is widely applicable across national healthcare practices.

1.1.3 Relevance

Adequate information provision is essential for high-quality and safe care for children with sickle cell disease (Shahine et al., 2014). Insufficient understanding of the disease, medication use, or complications can lead to medical risks, stress within families, and an additional burden on hospitals (Ikediashi et al., 2023). Discussions with healthcare providers of Sophia Kinderziekenhuis reveal that they experience daily that parents and children forget or misinterpret important information because it is presented too complexly or it is too difficult to remember outside the hospital. This underscores the need for understandable and accessible information provision that support parents and children in their daily lives with sickle cell disease. This research also offers added value for healthcare providers: a clear provision can help them convey information more efficiently and consistently. By basing the design on the perspective of healthcare providers, this project aligns with existing clinical practices

1.1.4 Project approach

This project follows a human-centered design approach. Human-centered design is a problem-solving technique that places end-users at the center of the development process. It is about understanding human needs and how design can respond to these needs (Melles et al., 2020). Therefore this technique is suited for this project because it ensures that the strategy addresses the real needs and challenges of information provision according to healthcare providers.

The Double Diamond model (Figure 1) from the British Design Council is used for this purpose. This model illustrates a design process that first involves exploring an issue more widely or deeply (divergent thinking) and then taking focused action (convergent thinking) (Design Council, n.d). The model is divided into two diamonds: problem space and solution space and these two diamonds consist of four phases: Discover, Define, Design, and Validate.

The first diamond, the problem space, consists of the discover and define phases. This diamond focuses on designing the right thing: conducting broad research within the context to truly understand and define the problem, ensuring that the right problem is being addressed. The second diamond, solution space, consists of the design and validate phases. Here the focus is on designing things right: developing and testing solutions that meet the needs of users and practice.

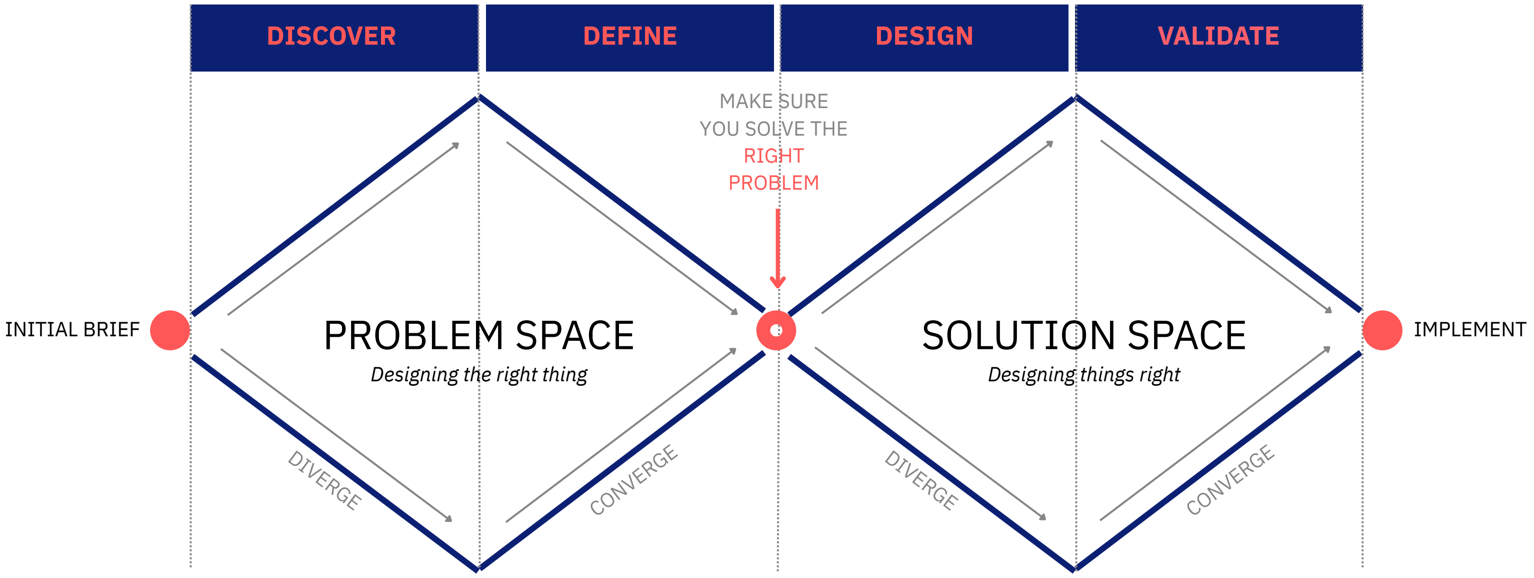


Figure 1: Double diamond model (Health Journeys Lab, 2024)

The Double Diamond model is not intended as a prescriptive or linear approach. The design process itself is iterative, exploratory and experimental. The model simplicity helps to illustrate the principles of the process, while allowing room for flexibility and adaptation (Kochanowska et al., 2021).

In this project the first diamond examined the current information provision. This research combined a literature review of existing research on information provision for sickle cell disease, observations at the outpatient clinic, and interviews with healthcare providers. The collected data was analyzed using thematic analysis. In addition, the context was analysed through an actor map, work models and journey mapping. Based on the insights gained, the problem was defined and a design direction was established that aligns with it.

In the second diamond, a concept was developed through co-creation. This took place within an iterative design process that led to the final concept. In addition, a tactical and strategic roadmap were developed to support the strategy for accessible information provision. Finally, interviews were conducted to evaluate both the concept as its implementation.

Various methods were used throughout this project. Therefore, each chapter begins with a brief introduction to the method used. This is to clarify the approach and underlying choices. An overview of the main methods used in this project, including their purpose and added value for this research is made. The methods used are:

Context Exploration

Context exploration was used to gain a broad understanding of the care context in which information provision for sickle cell disease takes place. This method helps to map organizational structures, routines, limitations, and interactions between stakeholders (Sanders & Stappers, 2008). For this study, context exploration was valuable in understanding how information provision is embedded in daily sickle cell care.

Thematic Analysis

Thematic analysis was used to systematically analyze qualitative data from interviews and observations. This method allows for the identification and organization of patterns and recurring themes in the data (Nowell et al., 2017). Within this project, thematic analysis provided insights into interviews with various healthcare providers.

Actor map

An actor map is designed to map organizations and individuals within a system. Actor mapping is used to show which actors are directly influenced by the system and which actors themselves influence the system (FSG & Schmeer, n.d.). This method was valuable for gaining insight into which actors influence information provision.

Work models

Work models were used to analyze existing work processes, roles and cultural influences within sickle cell care. (Holtzblatt, 2016). Work models make visible how work is actually carried out in practice. In this study, work models helped to identify how information flows and where tensions exist between different perspectives.

Journey mapping

Journey mapping was used to visualize the journey of parents and children with sickle cell disease through care across different phases. This method maps contact moments, experiences and information needs over time. (Davies et al., 2022). For this study, journey mapping provided insight into where the current information provision does not match practice.

Co-creation

Co-creation sessions were conducted to actively involve healthcare providers in developing the information provision strategy. Co-creation is considered an effective method for integrating stakeholder knowledge and increasing ownership (Sanders & Stappers, 2008). Within this project, co-creation ensured that the developed strategy aligned with existing work processes and realistic preconditions.

Design roadmapping

Design roadmapping was used to translate insights and concepts into a phased, future-oriented implementation strategy. Roadmapping provides guidance when communicating a design direction or strategic plan (Simonse, 2017). In this study, design roadmapping helped to work towards an information provision strategy.

1.1.5 Ethics

The study was initiated by the Pediatric Hematology department of Erasmus MC Sophia Kinderziekenhuis. The study was conducted by physicians and researchers from Erasmus MC. The Erasmus MC Non-WMO Review Committee determined that this study did not fall under the scope of the Medical Research Involving Human Subjects Act (WMO), but also reviewed the study's content. Children and adults with a rare disease, parents/guardians, and healthcare providers could participate in this study. Participation was entirely voluntary. All healthcare providers involved have received and signed the Information Letter on Non-WMO Research, including the consent form.

See Appendix J for information letter and consent form.

1.2 Background information

1.2.1 Sickle cell disease

Each year about 300.000 babies are born with sickle cell disease worldwide (Amazing Erasmus MC, 2025). This makes it one of the most common hereditary disorders and the most common hereditary blood disorder (Erasmus MC, n.d.). Nevertheless, sickle cell disease is considered as a rare condition. In addition, there are people who do not have sickle cell disease, but do carry the hereditary gene: the so-called carriers (Figure 2). About 1/7 people with dark skin are carriers of the sickle cell gene (HbS). In the Netherlands the quantity carriers is estimated 60.000. Although carriers are not sick, two carriers can have a child with sickle cell disease (Erasmus MC, n.d.).

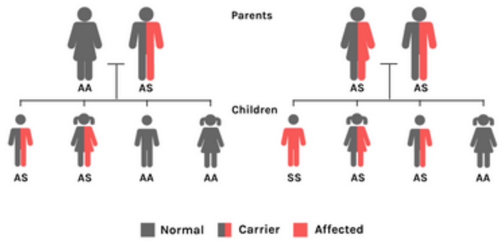


Figure 2: Hereditary gene (Kufuor, 2021)

In the Netherlands a small amount of blood is taken from a baby's heel during the first week after birth via a heel prick (Ministerie van Algemene Zaken, 2023). The purpose of the also called neonatale (newborn) screening is to detect sick children. These include children with sickle cell disease. However the screening can also reveal that a child is a carrier of sickle cell disease (Dragerschap van Sikkelcelziekte, n.d.).

Sickle cell disease is an autosomal recessive, monogenetic disorder that can have serious consequences (Black Lives Matter: ook in de zorg, 2021). In the Netherlands, patients with sickle cell disease have an average life expectancy that is 30 years shorter than that of healthy people (Sikkelcelfonds.nl, 2025). Sickle cell disease is a form of chronic anemia. It involves the production of abnormal hemoglobin in red blood cells. Normally red blood cells have a round, donut-like shape, but in sickle cell disease, they develop a sickle shape. Hence, the name "sickle cell" (Erasmus MC, n.d.) (Figure 3).

The disease is characterized by periodic attacks of pain, also called sickle cell crises. During such crises small blood vessels become blocked by the sickle cells (Figure 3), causing a lack of oxygen in tissues. This can be triggered by cold, infections, fever, pain, dehydration, or stress. The consequences can range from temporary to permanent organ damage and occur in various parts of the body (Sikkelcelziekte | Cyberpoli, n.d.).

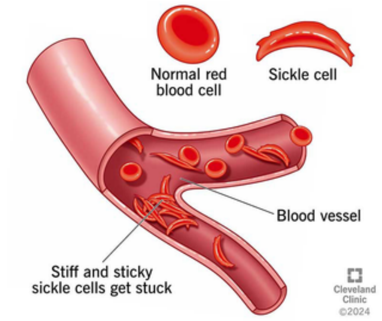


Figure 3: Blood vessel and Sickle cells (Cleveland Clinic, 2024)

Treatment for sickle cell disease is primarily supportive. This means that symptoms are treated as much as possible and prevention is attempted. This is done with medication and advice. Severe symptoms may require hospitalization (Behandeling, n.d.).

Medications used include: antibiotics to fight infections; folinic acid to support red blood cell production; pain relief during crises; hydroxyurea to promote the production of non-sickling hemoglobin and reduce the risk of crises. A blood transfusion may also be necessary in some cases (Behandeling, n.d.). Haematopoietic stem cell transplantation (HSCT) may offer a healing solution, but this treatment carries risks and is only available to a limited extent (Sikkelcelziekte | Cyberpoli, n.d.).

1.2.2 Patient population

Despite being the most common inherited blood disorder in the world, sickle cell disease primarily affects minority groups (Frey et al., 2025). Sickle cell disease is most common in people of non-Western origin. Prof. d.r. M.H. Cnossen states that, the group of non-Western patients is not a homogeneous category, but consists of individuals with very diverse ethnic and cultural backgrounds, including people from Sub-Saharan Africa, the Caribbean, the former Antilles, North Africa, and the Middle East. This group exhibits differences in language, culture, length of stay in the Netherlands, socioeconomic status, and literacy level (Dr. M.H. Cnossen, personal communication, 9 Oct. 2025).

According to a systematic literature review of Da Silva de Jesus et al. (2018) studies show that children and adolescents with sickle cell disease belonged to families with socioeconomic conditions between middle and low level, and most of the parents had some type of schooling, predominating between primary and secondary education. In addition, research by Houwing et al. (2019) shows that 78.6% of caregivers of children with sickle cell disease had low health literacy according to the short assessment of health literacy in Dutch.

In most cases of sickle cell disease, the primary caregiver is the mother, regardless of employment status. The mother often also stays with the patient during hospital stays, while also continuing to care for siblings and with house chores. This is a source of stress in family organization (Impact of sickle cell disease on the families of affeted patients. Qualitative study of their experiences, perceptions and needs, 2022).

1.2.3 Sickle cell centers in the Netherlands

This project is being carried out in collaboration with Erasmus MC Sophia Kinderziekenhuis. This is the largest academic children's hospital in the Netherlands, specializing in the treatment of complex childhood conditions (including sickle cell disease) and focused on providing the best possible care. Treatment of sickle cell disease takes place within the patient clinic at pediatric hematology department. Here top-level specialist care, scientific research and education come together. Care is based on the principles of Patient- and Family-Centered Care (Erasmus MC, n.d.).

In the Netherlands, we have several hospitals with extensive expertise in the prevention, diagnosis, treatment and follow-up of sickle cell disease, both in adults and children. There are 5 centers of expertise centers for hemoglobinopathies: Amsterdam UMC (including Emma Kinderziekenhuis); Erasmus MC (including Sophia Kinderziekenhuis); LUMC, in collaboration with Haga Ziekenhuis; UMC Utrecht (Van Creveld Clinic). In addition, there are shared care centers: Radboud UMC and UMC Groningen. These centres (Figure 4) collaborate and share knowledge (wijzijnMEO, 2024). To provide the multidisciplinary care required for these patients each hospital brings together various specialized teams with expertise (wijzijnMEO, 2024). This allows for a broad perspective on the child's situation and allows for the best possible treatment to be determined together (Erasmus MC, n.d.).

Figure 4: Expertise centers and shared care centers

DISCOVER

2 CONTEXT EXPLORATION

Context exploration was conducted as a broad, exploratory exercise to better understand the context of sickle cell disease in the Netherlands. This involved reviewing and analysing existing literature, conducting observations, looking into current information materials and mapping the stakeholders involved. This exploration led to the identification of several areas for further research.

2.1 Research approach

The research question was formulated to position the study within the context, scope, and focus of the project.

RQ. How can **accessible** and **universally applicable** information provision be designed **to support** parents, children and healthcare providers in sickle cell disease care, ensuring **consistency** across all sickle cell centers in the Netherlands?

Based on this question, a combined research approach was chosen (Figure 5), combining literature research with practice-based data collection. More details about how the data was obtained and collected will be provided later.

A literature review was used to determine existing research on sickle cell disease, and the context of information provision in particular. This review examined existing opportunities, proven approaches and recurring challenges to determine where this research could offer meaningful insights. Because user experiences cannot be fully gleaned from literature, observations were conducted. By being present in the care context, it was possible to observe how healthcare providers, parents and children with sickle cell disease communicate with each other, what information is shared, when and in what form. Furthermore, the observations provided insight into the dynamics between healthcare providers and families, including emotional aspects and the practical feasibility of advice in daily life. This contextual knowledge was essential for understanding where information provision in practice does or does not meet the needs of parents and children, and could not be obtained solely from literature. Desk research was also used to analyze existing information material.

In addition, a stakeholder map was created to identify the parties involved in information provision and the stakeholders closest to parents and children with sickle cell disease. On top of that, the healthcare ecosystem was analyzed to gain insight into the influences on various, interrelated levels within care. While the stakeholder map focuses on those closest to parents and children, the healthcare ecosystem shows how policy, guidelines, organizations, systems, and daily care practices influence each other.

This combination of methods enabled informed choices and a coherent picture of the context, needs, and opportunities surrounding information provision for sickle cell disease.

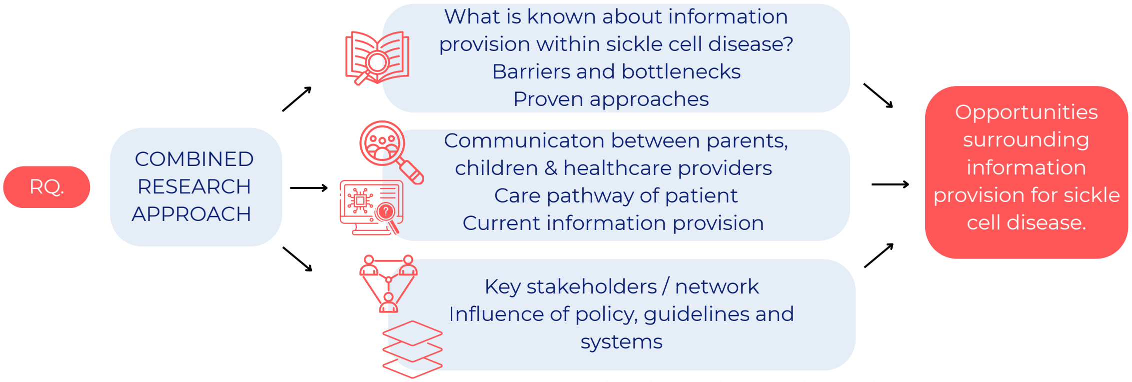


Figure 5: How combined research approach is used

Legend: Research approach

2.2 Literary review

To ensure this literary review was focused, the review is structured around four thematic chapters, based on the scope and focus of this project (see chapter 1.1.2). Chapter 2.2.1 first describes the used method for searching literature. Chapter 2.2.2 addresses information provision and health literacy in sickle cell disease. Chapter 2.2.3 describes the challenges children and parents face with living with sickle cell disease. Chapter 2.2.4 discusses the role of healthcare providers in information exchange. Chapter 2.2.5 focuses on the quality and consistency of information provision across sickle cell care. The aim of this review was to map existing knowledge. Each chapter describes the barriers and bottlenecks surrounding the relevant theme, as well as solutions and facilities that have already been explored to address these problems.

The literature was approached from a broader, general perspective, not exclusively that of the healthcare provider. This allows for a comprehensive overview of existing research on information provision for sickle cell disease. By first providing a broad overview, the literature suggests that opportunities relevant to this project can be identified. In this way, the literature offers insight into both the challenges and experiences of families and the role of healthcare providers, providing a more complete picture of information needs and the context for consistently accessible information provision.

2.2.1 Method

PubMed was used as the primary database for this literature review, supplemented with relevant articles from Erasmus MC and Amsterdam UMC. The search strategy focused on literature on providing information to children and parents of children with sickle cell disease, the role of healthcare providers in information transfer, and promoting consistent communication.

The search strategy was reconstructed based on the included articles and included terms such as "sickle cell disease," "information provision," "patient education," "health literacy," "children," "parents," "healthcare providers," and "consistency."

The following inclusion criteria were applied during the search in the PubMed database: Publication in English or Dutch, publication date from 2009 up to and including 2025 and studies conducted in paediatric healthcare settings. Excluded are studies not focused on children, psychiatric conditions unrelated to sickle cell disease and unavailable full texts. All titles and abstracts were assessed for relevance to the project. Full texts of potentially relevant articles were then evaluated for eligibility. A total of 18 journal articles were included in the review.

2.2.2 Information provision and health literacy in the context of sickle cell disease

Literature shows that current pediatric sickle cell care has some barriers. A significant barrier is the complexity of care processes (Schlenz et al., 2025). Additionally, a recurring problem in pediatric sickle cell care is the provision of information. Studies show that parents often encounter complex and inconsistent information, which directly impacts their experiences with care. Healthcare materials are often written at too high a reading level and do not adequately consider visual needs or cultural context. Illustrations are often inappropriate for the target audience, making it difficult for parents to understand and use the information (Singleton & Krause, 2009). Medical texts also pose a problem. The readability of texts is significantly reduced for laypeople by the frequent use of jargon, abbreviations, and complex sentence structures (Jiang & Xu, 2024).

As noted earlier (see chapter 1.1.2), we are dealing with a group of patients where a large proportion of caregivers have low health literacy. People with limited health literacy lack the necessary skills to find, understand and apply information about health and healthcare (Noordman et al., 2019). Since many parents have low health literacy, complex and inconsistent information provision becomes problematic and therefore poses a risk to healthcare (Nutbeam, 2008) . According to Singleton & Krause (2009) low levels of health literacy, cultural barriers, and limited language skills have been described as threats to effective health communication. Nurses working with patients from an increasingly diverse range of cultural backgrounds witness on a daily basis how these three threats hinder effective care at the system, provider, and patient levels.

These barriers could be countered by various facilitators. Families experience better sickle cell care when it is accessible, flexible and tailored to their needs (Schlenz et al., 2025). Examples include same-day appointments, specialized and shared care structures and better coordination of oral and written communication (Houwing et al., 2021). In addition, improvements in health literacy can lead to a better understanding of sickle cell disease and an increased sense of self-efficacy in parents, which strengthens their ability to care for their child (Houwing et al., 2019).

2.2.3 Challenges in living with sickle cell disease for children and families

To understand the challenges faced by parents and children witch sickle cell disease, its is important to first zoom in on the characteristics of the patient population. As described earlier (see chapter 1.2.2), many families (parents and children) of children with sickle cell disease are situated in middle to low socioeconomic conditions. In Western countries sickle cell disease predominantly affects racial and ethnic minority groups (Houwing et al., 2021). Sickle cell disease is common among Black and Minority Ethnic (BME) groups, within which sociocultural factors play an important role. These groups entails social and cultural complexities, including stigma surrounding heredity. This can make families reluctant to talk about sickle cell disease or seek help (Middleton et al., 2018). In addition, BME groups are more likely to live in poverty and reside in families with a lower family income. As a result, the so-called “hidden costs” of care (for example travel time and missed work hours) form an additional barrier to accessing healthcare (Houwing et al., 2021).

These socioeconomic challenges place pressure not only on access to care, but on the broader impact on family life. Research shows that a chronic illness not only directly impacts the child, but also places a burden on parents and the family as a whole. Parents often experience stress, including the complexity of medical care, frequent hospital visits, the need to be constantly vigilant about risks and worries about the future and the impact of the disease on the child's school and social activities (Cousino & Hazen, 2013). This parenting stress influences how care is utilized and how the child copes with the disease (Johnson et al., 2022). Moody (2021) argues that this directly impact the child’s health: higher levels of parental stress are associated with lower health-related quality of life in children with sickle cell disease.

Given these challenges, improving accessibility of healthcare for parents and children witch sickle cell disease is essential. Accessibility of healthcare concerns the level at which people are able to utilise all healthcare resources they need to sustain or improve their health (Houwing et al., 2021). Enhancing accessibility can help reduce burdens on families. Houwing et al. (2021) describe several best practices aimed at improving healthcare accessibility for this sickle cell disease population: Recommendations focus on reimbursement of invisible costs, clustering and sharing care close to home, improving accessible communication and increasing knowledge and awareness about sickle cell disease.

2.2.4 Healthcare Providers and Information Exchange in Sickle Cell Care

Healthcare providers are responsible for information exchange. However, Noordman et al. (2019) notes that, many healthcare professionals insufficiently check whether patients understand the information they provide, fail to explore what the patient already knows and what information is still needed. Moreover, there is a gap between the involvement that healthcare providers think they provide and the support that parents actually experience (Wijngaarde et al., 2023) A limitation is the lack of exploration of parental or child preferences. Methods such as "teach-back" (communication technique where a healthcare professional explains health information, then asks the patient to repeat it back in their own words to confirm understanding) to check whether information has been properly understood are rarely used (Wijngaarde et al., 2023). In stressful situations this can lead to what is sometimes called a communication trap: a cascade in which minor misunderstandings escalate into greater confusion, mistrust and inadequate decision-making between parents and healthcare providers (Ferretti et al., 2022).

Patients with sickle cell disease (especially children and adolescents) often face barriers to care, including difficulties with relationships with healthcare providers and challenges in self-managing their disease. Results suggest that interactions with healthcare providers that align with the Patient-Centered Communication framework (communication that is tailored to the needs, values, context and health literacy of the patient and their family (Naughton, 2018)) for adolescents with sickle cell disease and their caregivers reduce stress for patients and their families, support disease self-management, facilitate information sharing and treatment decision-making and promote positive and trusting relationships with healthcare providers (Carlson et al., 2022). Furthermore, healthcare providers (particularly nurses) should develop cultural self-awareness and integrate cultural and linguistic competencies into their communication (Singleton & Krause, 2009).

2.2.5 Information Provision Across Sickle Cell Care: Quality and Consistency

According to research by Mussert et al. (2025) both parents and healthcare providers indicated that the current information provision provided varies in quality and completeness. The information must be relevant to the child's clinical picture, severity of the disease, and stage of life. Current sources are often dispersed, outdated, or difficult to assess for reliability. Parents receive different or conflicting messages from various healthcare providers, resulting in uncertainty and frustration (Johnson et al., 2023). There is inadequate coordination between primary care, specialists, and community services, leading to inconsistency in treatment (Obeagu & John, 2025). Inconsistency in information therefore poses a significant barrier (Johnson et al., 2023).

Mussert et al. (2025) states that there is a clear desire for standardized and centralized information, preferably digital and easily accessible. This can be achieved by standardizing which information should always be provided, by offering central and reliable information platforms and by providing tailored care that matches the severity of the illness, the child's life stage and the family's preferences. Research shows that consistent and coordinated communication leads to better knowledge about the disease, greater confidence in managing one's health, improved communication with healthcare providers and sometimes even a reduction in anxiety (Johnson et al., 2023).

2.3 Developing understanding

To gain a better understanding of the current care pathway for children with sickle cell disease, both observations and desk research were conducted.

2.3.1 Observations sickle cell disease outpatient clinic

Several observations were conducted during the sickle cell disease outpatient clinic at the Pediatric Hematology Department of Erasmus MC Sophia Kinderziekenhuis.

During September 2025 I attended the Wednesday afternoon outpatient clinic for sickle cell disease four times. These were non-participatory observations: only observation took place, without any interaction with parents or patients. This approach was chosen to minimize influence on behavior and to gain an objective understanding of real-life situations and interactions as they naturally occur. Sometimes questions were asked afterwards to the healthcare provider to clarify. I also attended the preparatory team meeting before the outpatient clinic. During this meeting all the healthcare providers involved (Figure 6) discuss the medical information of the patients expected at the clinic that day. The goal of these observations was to collect qualitative data by observing what people do and say, and the emotions displayed. The focus was on understanding the dynamics and workflow within the outpatient clinic, with a specific focus on communication and information transfer during consultations.

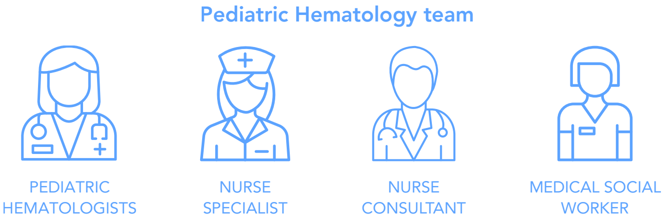


Figure 6: Involved healthcare providers

The observations were recorded in written notes (in Dutch, quotes used in this thesis are translated to English), which factually described what was observed during interactions between caregivers and parents/children, without drawing immediate conclusions. These notes were later reread and striking patterns and recurring elements were identified.

Environment

Patients and parents wait in a waiting room where toys are available for children. A rack with various brochures hangs on the wall. (Appendix A4) They are then called for a consultation in a consulting room. Depending on the situation a consultation with the pediatric hematologist and a consultation with the nurse specialist will take place. If psychosocial issues arise a medical social worker may also be involved. For further explanation or in-depth information an appointment can be made with the nurse consultant, who may also join the consultation with the pediatric hematologist.

Care pathway (Figure 7)

After an abnormal neonatal heel prick screening result a baby is referred to the outpatient clinic, where the diagnosis of sickle cell disease is made. From that point on the child typically has biannual checkups. During consultations a ‘praatplaat’ (Appendix A3) is regularly used to explain the condition. Parents and children are referred to Cyberpoli for additional information (Appendix A2). In the meantime they can ask questions to the care team via the digital platform BeterDichtbij. Consultations usually take place in the presence of both the child and the parent.

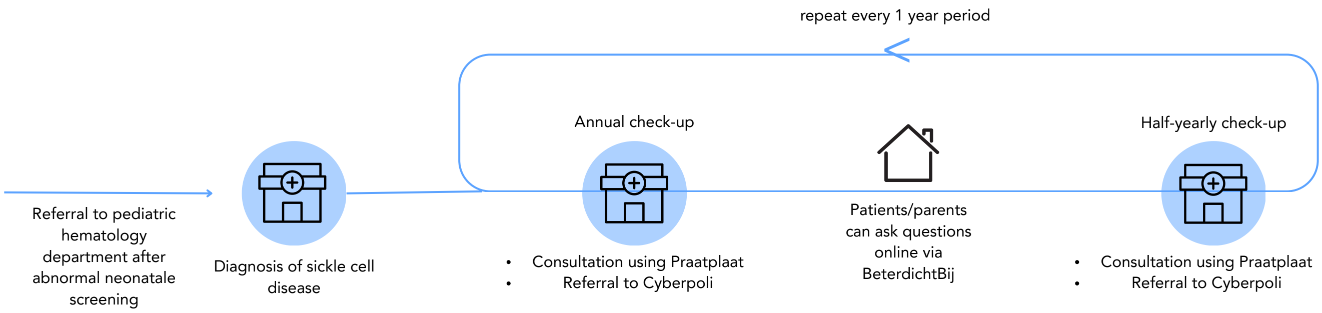


Figure 7: Care pathway that the patient goes through

Healthcare provider

The care team consisting of: pediatric hematologist, nurse specialist, nurse consultant and medical social worker is generally well-informed about the patient's family and home situation. They collaborate multi-disciplinary, sharing information on medical and social aspects. This became evident from quotes such as: "This patient has had a difficult year at home, her parents are divorced"

Parents and patients

Parents and children often adopt a passive attitude during consultations and ask relatively few questions. Many parents and patients have limited knowledge of sickle cell disease. This can be observed in quotations from patients such as: "I'm here for research, but beyond that I don't know" (Quoted by patient of 12 years)

Some parents experience a high emotional burden and stress as a result of caring for a child with sickle cell disease. Quoting parents talking about stress and emotions: "I don't work anymore, I'm at home with burnout" or "I don't understand her iron levels anymore, I don't know what to do with them anymore" (a mother says while she is crying)

The conversation about HSCT in particular evokes a lot of emotions, which becomes clear when a mother of a patient says:"I'd rather not talk about that, it's just too much."

Parents are simultaneously being highly motivated to do the best for their child. As one parent mentioned:"I want the best for my daughter"

Refugees are also among the patients; for this group, health insurance and reimbursements can pose additional complications. This becomes clear when a family who fled from Sierra Leone comes to the outpatient clinic and they discuss the costs they have to incur with the nurse specialist. After the age of twelve, care is sometimes no longer fully reimbursed, which complicates medication use due to the high costs. Furthermore, patients sometimes come to the outpatient clinic without their parents. This became apparent at the moment a 14-year-old girl arrived alone at the outpatient clinic for her appointment.

Approximately 25% of patients fail to attend appointments; according to the pediatric hematologist this mainly occurs when patients experience few symptoms and are therefore less motivated to attend.

Interaction between caregiver and patient

Some parents' limited Dutch knowledge hinders communication and makes it difficult to ensure the information provided is properly understood. Quotes from the nurse consultant about fever like: "I'm not sure now if that mother will call in time"

Therefore, in some cases, the consultation is conducted in English or with an interpreter who can be reached by telephone.

2.3.2 Current information provision

To gain insight into the current information provision regarding sickle cell disease, I investigated which information materials are available and how they are used in healthcare practices. This was done to understand how patients and families are currently informed and to identify potential gaps or inconsistencies in information provision. I contacted multiple sickle cell centers and asked healthcare providers which materials they use, for which purposes, and where these materials can be found.

This research revealed that the information provision is highly fragmented and that there is no central overview of available materials. This fragmentation became apparent for example, during a conversation with a nurse consultant from the Sophia Kinderziekenhuis during the observations, who indicated she had never previously seen materials from the Emma Kinderziekenhuis (which I had obtained). This underscores the fact that centers use their own materials without shared access or coordination.

Furthermore, there is no clear structure for providing information. The timing of the provision of materials varies by healthcare provider and consultation. In some situations, information is provided in detail, while in others, this is omitted, without a clear agreement. Healthcare providers primarily rely on their own judgment and experience in this regard.

The available materials include information used during consultations, materials to give to parents and children and references to digital resources such as the Cyberpoli. An overview of these materials is included in the Appendix A3.

To clarify differences, a comparative table (Figure 8) was created comparing the available material provision between the Sophia Kinderziekenhuis and the Emma Kinderziekenhuis. These centers were selected because they specifically focus on pediatric sickle cell care and have developed a relatively large amount of material.

Finally, the suitability of the materials was assessed using existing assessment frameworks for health information. For this the Suitability Assessment of Materials (Doak et al., 1996) tool was used, which assesses the extent to which information is suitable for patients. Overall, current information materials are insufficiently suitable due to limited accessibility, overly complex language, and inadequate visual support, which may limit understanding for patients and families (Appendix B).

Category / Theme	Sophia Kinderziekenhuis	Emma Kinderziekenhuis
Use during consultation	Use of a “praatplaat” with its own content and visual design	Use of a “praatplaat” with its own content and visual design
Praatplaat – languages	Dutch, English, and French	Dutch
Physical visualizations	Models of red blood cells and sickle cells	Models of red blood cells and sickle cells
Informational leaflets for home use	A4 leaflets on topics such as swimming, traveling, hydroxyurea, pain, fever, and bedwetting	No
Care team contact card	Yes	Yes
Referral card to Cyberpoli	Yes	Yes
Information booklet after diagnosis	No	38-page booklet with comprehensive information
Online information via hospital website	Yes, content and tone vary between centers	Yes, content and tone vary between centers

Figure 8: Comparative table

2.4 Stakeholders

The stakeholder map (Figure 9) was developed by me to gain insight into the network of people involved around parents and a child with sickle cell disease. Parents, along with their child, are central because they form the link between the medical system and their child's daily life. The distance of stakeholders from the center reflects the intensity and frequency of interaction. The closer to the center, the greater the influence on the family's daily life and the more regular the contact. The map is divided into two domains: the clinical domain (blue) and the psychosocial domain (red).

The clinical domain includes healthcare providers such as pediatric hematologists, nurse specialists, and general practitioners, who support parents with medical decisions and treatment. The psychosocial domain includes stakeholders such as the family, school, and medical social worker, who contribute to the family's well-being and social participation.

Parents of a child with sickle cell disease constantly switch between these domains. They must understand and apply medical advice at home, schedule and manage appointments with multiple healthcare providers, communicate their child’s needs and limitations to teachers and school staff, and ensure that their child can participate in social and daily activities while managing the disease. As the child grows older, they gradually take on more responsibility for managing their own care and making health-related decisions.

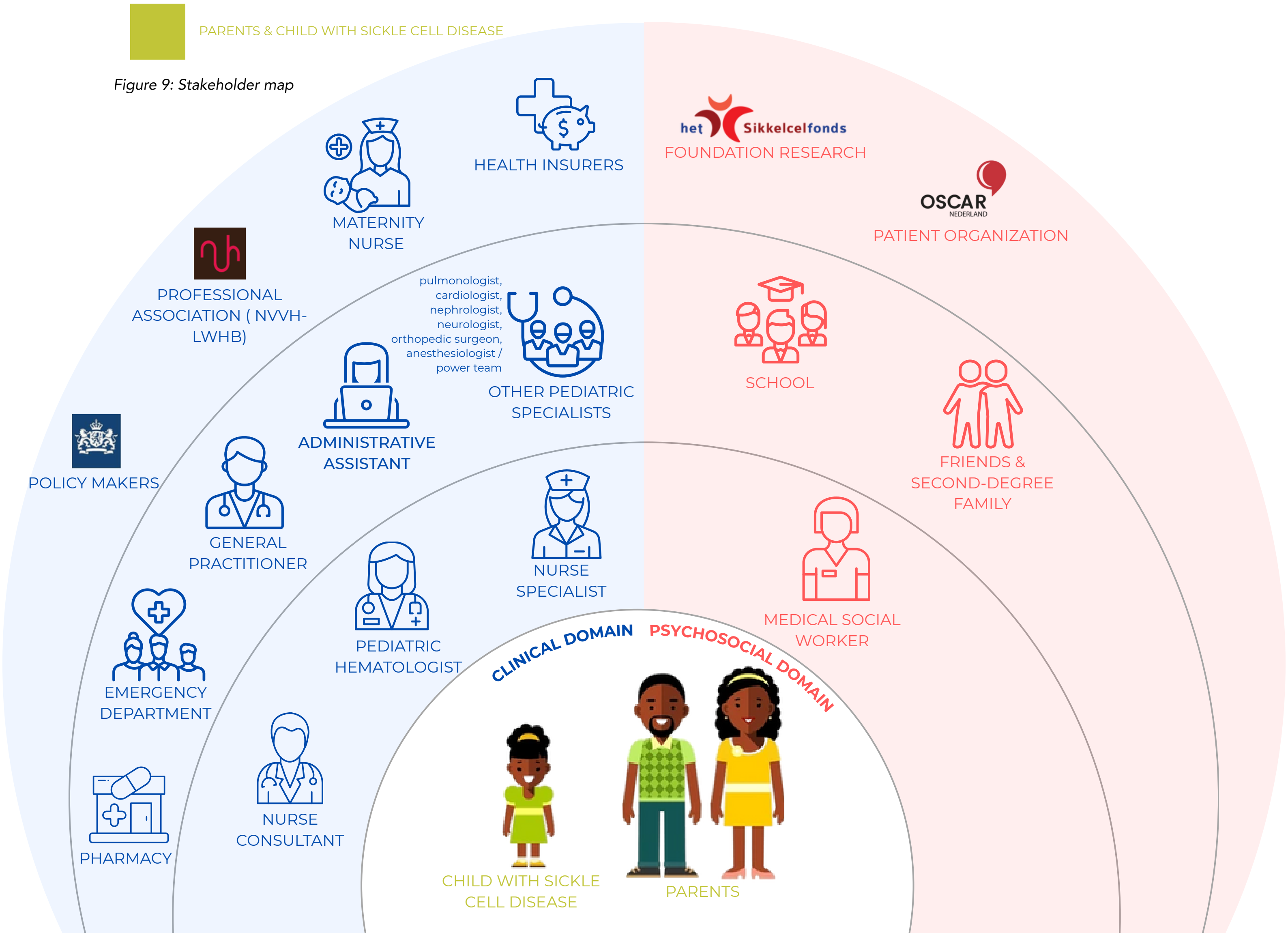
Legend: Stakeholder map

🟦 STAKEHOLDERS IN CLINICAL DOMAIN

🟥 STAKEHOLDERS IN PSYCHOSOCIAL DOMAIN

🟩 PARENTS & CHILD WITH SICKLE CELL DISEASE

Figure 9: Stakeholder map

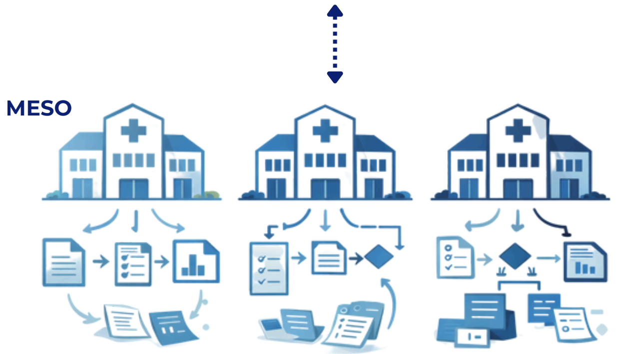


2.5 Healthcare ecosystem

The healthcare ecosystem was analyzed to understand how the various, interrelated levels influence each other and collectively shape the information provision within sickle cell centers (Health Journeys Lab, 2024). At the macro level, policy, guidelines and national quality goals determine how sickle cell care should be organized and the requirements for consistency and accessibility of information. These choices are reflected in the care centers. At the meso level, hospitals and sickle cell centers translate these national goals into concrete work processes, care pathways and task divisions within multidisciplinary teams. Differences in organization and available resources at this level partly explain why information provision can vary from center to center. At the micro level, this converges in the direct interaction between healthcare providers and parents and children with sickle cell disease, where the actual information transfer takes place.

When reasoning from the micro level, it becomes clear how the current fragmentation arises (see chapter 2.3.2) and why information provision is inconsistent. At this level, we see that healthcare providers often determine what information to provide, when and in what form based on their experience or personal assessment of the needs of parents and children. This is a consequence of structures at higher levels of the healthcare ecosystem. At the macro level, national guidelines for sickle cell care stipulate, but offer few concrete instructions regarding sickle cell disease education, which materials should be used, when information should be provided and who is responsible for this (Sikkelcelziekte – MEDonline Publisher, 2024). This vagueness leaves room for interpretation (Lugtenberg et al., 2009). At the meso level, hospitals and centers translate these guidelines into their own work processes. Because there is no shared policy or central coordination, each center develops its own materials stored at internal locations. Figure 10 visualizes the healthcare ecosystem and how inconsistent information provision arises.

Guidelines offer limited direction and clarity.



Guidelines are translated into local, uncoordinated processes.

Information depends on individual provider judgment.

Figure 10: Healthcare ecosystem (This image was created using ChatGPT)

2.6 Areas for further research

The literature review, observations at the Sophia Kinderziekenhuis and desk research into existing materials have collectively provided a broad overview of the current information provision regarding sickle cell disease. Based on these insights several themes emerged that are relevant for further research. These themes fall within the scope of the project and can contribute to improving the information provision for children with sickle cell disease and their families.

2.6.1 Theme's

To create an overview and identify opportunities for improving information provision, a mind map was created clustering insights from the literature review, observations, and desk research (Appendix C). This helped organize the information, identify patterns and relationships, and provide a clear structure for further analysis.

Analysis of the relationships and recurring patterns within the mind map revealed several problems that appeared consistently across multiple sources. These problems include information being perceived as complex, families' needs being insufficiently met, and inconsistencies between different care centers. These recurring problems are directly linked to the research question, as they highlight areas where improvements are necessary: there is a clear need for information provision that is accessible, understandable, and consistent for parents, children, and caregivers. Addressing these issues can help develop a solution that effectively meets families' information needs, enhances caregiver support, and ensures consistency across all sickle cell centers in the Netherlands.

Therefore, I decided to use these themes as areas for further research:

T1. Complexity of information
T2. Unmet needs of families
T3. Lack of consistency across care centers

Figure 11 illustrates how these themes are interconnected and collectively shape the challenges in current information provision. This visualization shows that the themes do not exist in isolation, but reinforce one another, supporting their selection as the key areas for further research.

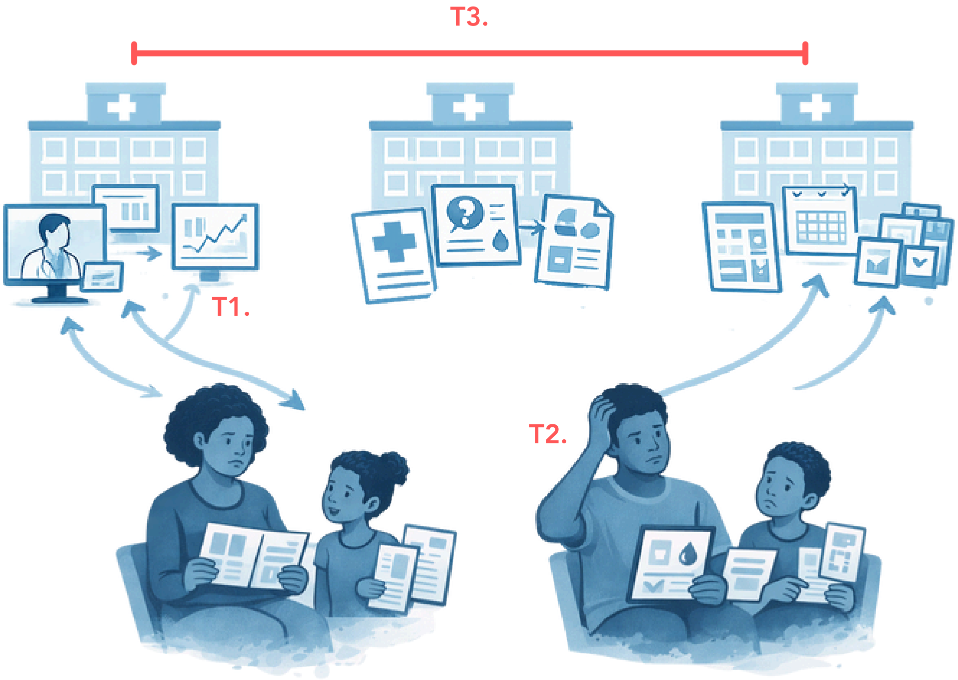


Figure 11: Themes interconnected (This image was created using ChatGPT)

2.6.2 Research questions

To delve deeper into the three themes (areas for further research), additional sub-questions were formulated for each theme:

Complexity of information:
SQ1. What makes medical information about sickle cell disease difficult for parents and children to access?
SQ2. Which communication strategies and visualization techniques can help make complex medical information more accessible?

Unmet needs of families:
SQ3. What information do parents need to effectively perform their care tasks at home?

Lack of consistency across care centers:
SQ4. What are the challenges and advantages of offering uniform information provision across different care centers?
SQ5. How can information provision be integrated into existing hospital care pathways?

To answer the sub-questions (SQ1–SQ5) and and ultimately provide a design direction that can answer the main question (RQ), the following method was used:

Interviews provide direct insights from healthcare providers experiences. By analyzing these using thematic analysis, recurring patterns, bottlenecks and needs can be identified, allowing the substantive subquestions (SQ1–SQ5) to be systematically answered.

Contextual analysis (actor maps, work models, journey maps) places these insights within broader healthcare practice. This clarifies how the identified problems and needs relate to existing work processes, roles and care pathways. This is particularly helpful for questions about uniformity of information provision and integration into care pathways (SQ4 and SQ5), by providing insight into organizational challenges and opportunities.

KEY TAKEAWAYS

- Fragmented information: Sickle cell centers primarily use their own materials; there is no central overview and little coordination.
- Inaccessible material: Information is often too complex, visually obscured, and insufficiently tailored to language level and cultural background.
- Limited health literacy: Emotional stress and low health literacy lead to passivity and forgetting of instructions.
- Subjectivity among healthcare providers: Healthcare providers decide what to say based on their own insights.
- Lack of guidelines: National guidelines do not provide direction for information provision and education.

3 IN-DEPTH RESEARCH

Chapter 2 identified areas for further research. This chapter explores these areas in more depth, based on interviews with healthcare providers and a subsequent thematic analysis.

3.1 Expert interviews

3.1.1 Selecting participants for the interviews

To better understand healthcare providers' perspectives on how to design accessible and universally applicable information provision expert interviews were conducted. These interviews examined which information healthcare providers consider essential how information provision is currently organized and what potential opportunities they see from their perspective.

Participants were selected using purposive sampling: healthcare providers are identified and selected. According to Longhurst (2003), who you interview is more important than how many people you interview. Specifically, how well participants can reflect on their experiences or whether they have anything substantive to say about the topic. Besides knowledge and experience, availability and willingness to participate are also important (Palinkas et al., 2013).

By interviewing healthcare providers from various roles within the pediatric hematology team a broad and nuanced understanding of the current information provision was obtained. Involving a pediatric hematologist, nurse specialist, nurse consultant and medical social worker allows for the exploration of the diverse perspectives and experiences within the team, as each role has specific responsibilities and perspectives on information provision within sickle cell disease.

Because one of the themes is "lack of consistency across care centers," it was decided to also interview healthcare providers from different centers. Each center may have its own routines and information provision. Comparing them can provided insight into differences in working methods and the organization of information between the various centers. Furthermore, involving different centers provides a broader and more reliable picture, ensuring that conclusions are not limited to a single location.

Children/patients ultimately make the transition from pediatric to adult care. That is why it was also decided to interview a healthcare provider from the adult ward, who can reflect on how children enter the adult sickle cell care.

3.1.2 Prepare and conducting the interviews

Participants who were available and willing to participate included healthcare providers from various centers. Two pediatric hematologists, a nurse specialist, a nurse consultant, and a medical social worker from the Sophia Kinderziekenhuis participated. In addition, a nurse specialist from the UMCG and the Amsterdam UMC were interviewed. A pediatric hematologist working at both the Sophia Kinderziekenhuis and LUMC and a nurse specialist from Erasmus MC adult sickle cell care also participated.

This research was conducted in parallel with three other ongoing studies at the Sophia kinderziekenhuis, which also examined the provision of information to patients with sickle cell disease. Because these studies are part of various master's programs that utilize qualitative research methods, such as interviews, the decision was made to conduct the interviews jointly for the Sophia healthcare providers. This also prevented the healthcare provider from having to make multiple appointments and answer duplicate questions. To ensure the studies were well-coordinated, a joint topic guide was developed (Appendix D1). These interviews lasted approximately 1.5 hours and were conducted in Dutch.

The interview included questions about the role and responsibilities of the healthcare provider, communication experience, information transfer, educational materials used, patient fever, pain management, stem cell therapy, medication adherence, and how healthcare providers envision the future of information provision. The interviews with the other centers and the adult ward were relevant to the research on information provision, were removed to make the interview a bit shorter. These interviews lasted approximately 50 minutes and were also conducted in Dutch.

The interviews were audio-recorded with the participants' consent to document the conversation. The recordings were then transcribed. This transcription formed the basis for the thematic analysis (quotes are translated from Dutch to English), which allowed for systematic insight into the perspectives of the healthcare providers involved.

3.1.3 Thematic analysis

A thematic analysis was conducted (Figure 12 and as addition Appendix D2) to analyse the results of interviews with 9 different healthcare providers in sickle cell care. Thematic analysis is a method for identifying, analysing and reporting patterns within qualitative data (Nowell et al., 2017). This method is flexible and allows for rich and detailed insights. To ensure reliability a transparent and systematic analysis process was used (Nowell et al., 2017).

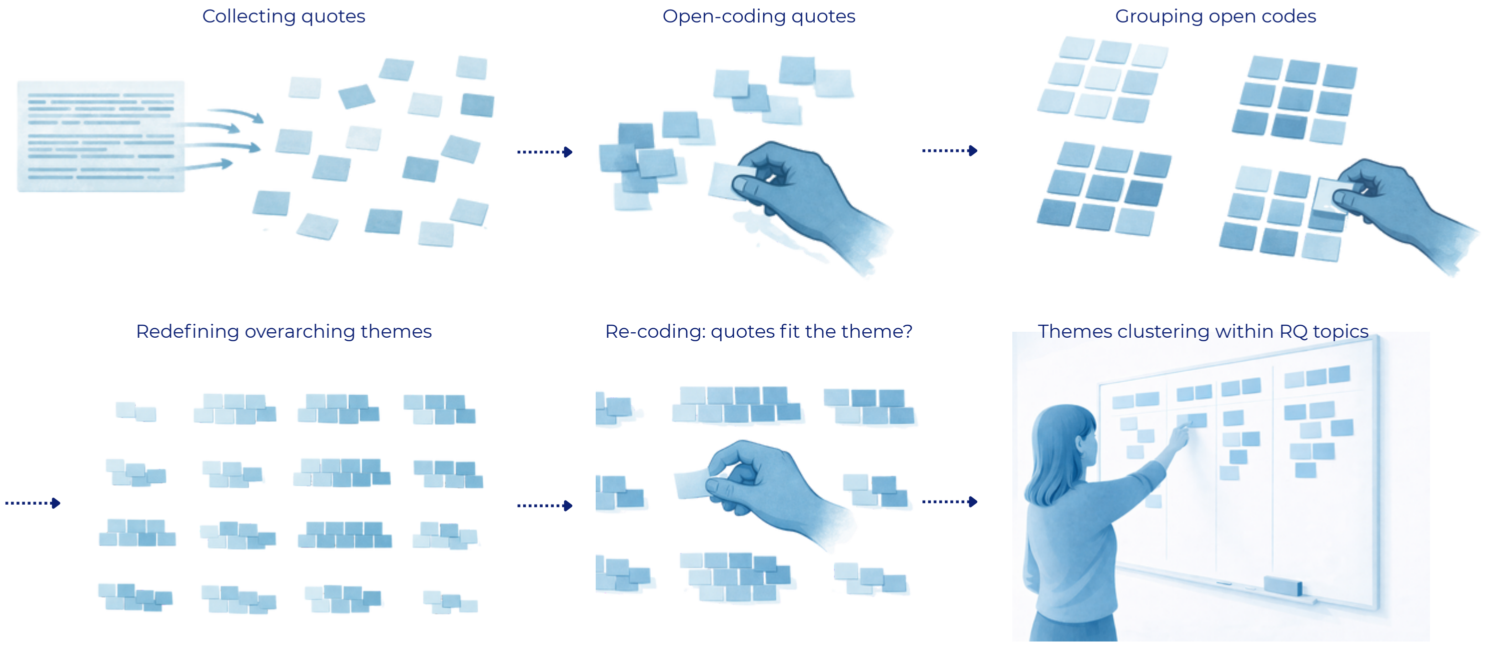


Figure 12: Thematic analysis approach (This image was created using ChatGPT)

The transcripts of the 9 interviews were carefully reviewed multiple times to familiarize myself with the data. During this iterative process, quotes relevant to my research questions were identified and collected, resulting in a total of 168 quotes that formed the basis for the analysis. The selected quotes consisted primarily of paraphrased, interpretive quotes that summarized respondents' observations and experiences. Examples include statements like: "A large group of patients wants to follow advice, but this isn't possible within the daily routines of life," "Information must align with patients' skills" and "The doctor-patient relationship forms the foundation of care." Additionally, quotes were selected that indicated that "knowledge gaps persist despite repeated explanations," that "a supportive tool can also be valuable for nurses," that "sickle cell disease is sometimes considered a side effect," and that "parents don't always believe their child has sickle cell disease."

After selecting the relevant quotes, they were systematically analysed using an iterative coding process. In the first phase, the quotes were open-coded, assigning short, substantive labels that captured the essence of the statement. For example, statements in which respondents indicated that patients want to follow advice, but are limited by daily routines were coded as "daily life”, while statements about the importance of visual support in information provision were coded as "use of visual aids". This open coding allowed me to stay close to the data and avoid imposing predetermined categories.

In the second phase, the open codes were continuously compared and grouped based on similarities in content. For example, codes relating to the failure of information provision to align with skills, the failure to get repeated explanations and the existence of knowledge gaps were grouped together, as they all referred to limitations in information transfer and comprehension. This clustering was based on the argument that the statements described different aspects of the same underlying problem.

In the third phase, these clusters were further analysed and refined into overarching themes. A conscious decision was made to formulate themes at a level of abstraction that allowed sufficient room to maintain variation between statements while safeguarding their content. For example, the cluster of statements concerning the failure to align information with skills, the lack of acceptance of repeated explanations, and the existence of knowledge gaps was abstracted into the theme "Incomprehension," as these fragments all indicated a lack of understanding despite repeated information provision.

Finally, for each theme, it was checked whether the theme title adequately reflected the content of the underlying quotes and whether all quotes logically fit within the theme. Quotes that did not sufficiently connect were recoded or moved. This process ultimately led to the identification of 14 themes, each with corresponding subthemes (see Appendix D2).

To maintain focus and ultimately answer the research question, the 14 identified themes were reorganized in a subsequent step. This step was necessary because, without further structuring, the individual themes did not provide sufficient direction for formulating design directions. Therefore, the themes were clustered within four overarching topics (Accessible, Universally applicable, Consistency, and To support families), which were deductively derived from the research question and served as an analytical framework (Figure 13).

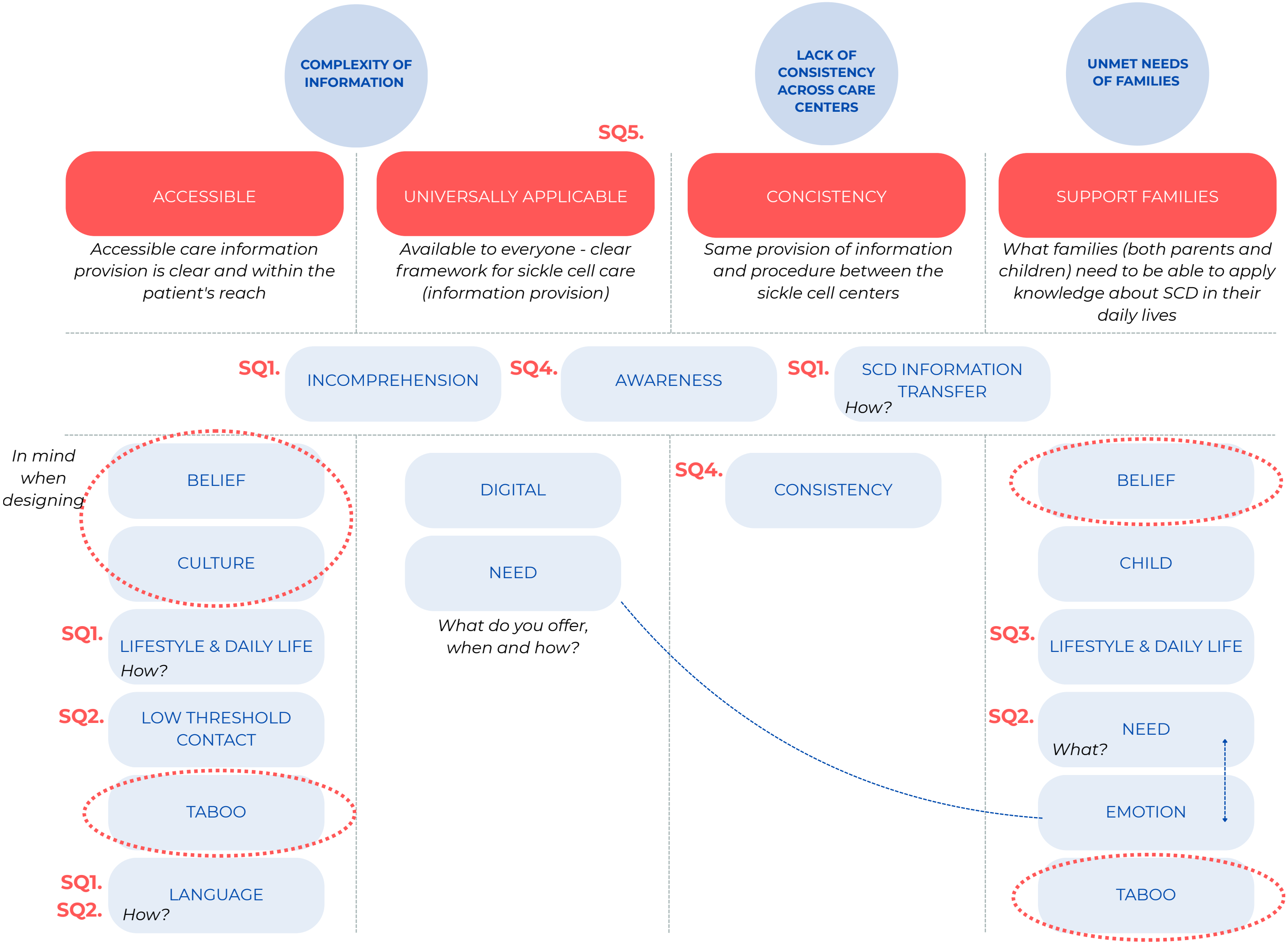


Figure 13: Overview of theme's in RQ topics

The themes were linked to one or more topics based on their content. The choice to allow multiple links was deliberate, as the data showed that aspects of information provision are strongly interrelated. Based on this overview, the sub-research questions questions (see chapter 2.6.2) were again compared to the themes, providing insight into which themes were relevant to answering each sub-question and how they relate to each other.

An overarching reflection question during this process was: "what information is offered, when: at what time, to whom: to which target group, and how: in what form?" By centralizing this question throughout the thematic analysis, the focus remained on information provision regarding sickle cell disease.

To avoid treating themes as abstract labels, each of the 14 themes was further specified in Appendix D3 by explicitly describing what the theme encompasses and by providing two example quotes per theme. This was done to add analytical detail and clarify the meaning of each theme, as theme titles alone provide limited insight into the underlying data.

The themes of beliefs and taboos recurred frequently in the interview data and influenced how information about sickle cell disease was received by parents and children. For example, some parents did not want extended family members to know about their child’s diagnosis due to fear of rejection, others indicated that blood transfusions were not acceptable for religious reasons, and some parents deliberately chose not to give medication to their child based on personal convictions. These examples illustrate the strong influence of deeply held beliefs on decision-making. Because such beliefs and taboos are deeply personal and ethically inappropriate to change directly through design, they were not selected as a primary focus, but treated as contextual factors that need to be acknowledged.

Culture (see Glossary: Definition), by contrast, was included as a focus area because it refers to shared values, norms and communication practices within a group that influence how information is interpreted and decisions are made. Unlike individual beliefs or taboos, cultural factors offer ethically appropriate entry points for design, such as adapting communication styles, framing of information, or modes of engagement, without challenging personal convictions directly.

As shown in Figure 13, needs and emotions were closely related. While emotions such as fear or uncertainty were present, the analysis prioritised identifying the underlying needs of parents and children, as these could be more directly translated into design requirements, with emotional aspects considered as contextual influences.

The manual thematic analysis was supported by an AI-assisted thematic analysis using GPT-5 for comparison and reflection; this confirmed the main themes while showing that the manual analysis provided stronger coherence and deeper connections between themes (Appendix D4).

3.1.4 Conclusions thematic analysis

SQ1. *What makes medical information about sickle cell disease difficult for parents and children to access?*
Accessibility of information about sickle cell disease is hampered by a combination of linguistic, cultural and emotional factors. The language barrier is evident when a nurse consultant says "Language is a challenge; it's difficult to check whether they've really understood it." Parents experience that medical terminology doesn't align with their language level or frame of reference, leading to misunderstandings and uncertainty. This misunderstanding is evident when nurse specialists state that "They sometimes forget to call in case of fever or pain," and, "They don't know what to do in the acute moment." According to a medical social worker this is due to word choice: "You easily resort to your own hospital language, but it's difficult to switch." According to a pediatric hematologist a patient who understands everything is a rarity.

Furthermore, stress and emotional burden following the diagnosis hinder information processing. Socioeconomic circumstances, such as a lack of time and financial pressure, exacerbate these barriers. For example, the medical social worker notes that: "For me conversations are often about money and transportation to get to the hospital."

Quotes such as "We have brochures, but it's difficult language-wise, I think there's a gap there"; "There are knowledge gaps, we repeat, but we also notice that sometimes it just doesn't get through"; "We fill in what they want to talk about. I think we have blind spots that we don't discuss thoroughly enough." This shows that the core of the problem lies not in a lack of information materials, but in the way information is presented and received.

SQ2. *Which communication strategies and visualization techniques can help make complex medical information more accessible?*
Parents and children understand complex information better when it's conveyed in simple language and supported by visual aids such as picture boards, pictograms, or short videos. According to a pediatric hematologist the information should be tailored to skills, and the images should be clear. A personalized, empathetic explanation tailored to cultural backgrounds reinforces this understanding. This is evident when the pediatric hematologist states that "Doctor-patient relationship is important, that is the basis."

According to the interviewed healthcare providers effective communication combines verbal explanations with visual support and presents information in an interactive and repeatable way. A multimodal approach (written, visual, digital, and oral) proves most effective. According to a nurse consultant, it is important that "It should be a reference, not new information. I already heard it in the clinic."

SQ3. *What information do parents need to effectively perform their care tasks at home?*
Parents need clear, practical and emotionally relevant information that aligns with their daily routines. At the same time, interviews reveal that a large group of patients find it difficult to follow advice within the daily routines of life "A large group of patients want to receive advice, but can't manage it within the daily routines of life." A pediatric hematologist described this as follows "Sickness is a side issue in their lives." "Patients only worry when they are in pain or don't have medication at home."

Key topics include symptom recognition, medication use, lifestyle, school, travel and infection prevention. The timing of this information is crucial: parents can only absorb information when they feel safe and emotionally ready.

SQ4. *What are the challenges and advantages of offering uniform information provision across different care centers?*
According to healthcare providers, the lack of uniformity in information provision currently poses a significant challenge. A nurse specialist indicated that each hospital uses its own educational materials and that healthcare providers often provide information based on their own perceived needs "Each hospital has its own information provision; everyone does what they think is needed." Furthermore, there is no clear structure or fixed point in the care pathway at which specific information is provided. As another healthcare provider noted "All the information available, there is no consistency; there is no protocol in the care pathway that states when we provide information."

Implementation within centers also varies. For example, information is sometimes provided as standard at an initial appointment and sometimes not: "In principle we provide things at the initial appointment, but sometimes we don't." This variation contributes to inconsistency and can lead to confusion among parents.

At the same time, healthcare providers see clear advantages in uniform information provision. Uniformity promotes consistency and clarity, strengthens collaboration between care centers and prevents conflicting messages. Therefore, the desire is for a coordinated framework in which the content of information is consistent. One pediatric hematologist put it “You want every center to use the same thing to avoid confusion if, for example, a patient goes from Rotterdam to Amsterdam.”

SQ5. *How can information provision be integrated into existing hospital care pathways?*

Effective information provision requires structural embedding within the care process. Healthcare providers indicate that information should be provided at fixed moments in the care pathway and should align with the information needs at that specific moment. According to the interviews digital platforms are also becoming increasingly important to ensure that information provision is integrated "With information provision we are moving towards digitalisation; old information was in the form of folders, which is deteriorating." An integrated approach promotes continuity of care and prevents information fragmentation. Healthcare providers emphasize the importance of tools that support the care team and strengthen coordination within the team, as reflected in the quotes "A tool that can also support nurses" and "Clear information provision between nurses and doctors." These quotes demonstrate that a clear division of tasks and support for healthcare providers are essential for effective integration of information provision within existing care pathways.

KEY TAKEAWAYS

- Problem with communication: It's not the material itself that's lacking, but the way it's presented; jargon and stress hinder comprehension.
- Lack of uniformity: There's no national standard; hospitals and healthcare providers each communicate in their own way.
- Limited connection to daily life: Medical advice often doesn't connect well with families' realities and routines.
- Need for visual and digital aids: Text alone isn't enough; simple language needs to be supported by visual and digital aids.
- Structural embedding: Information provision must become a permanent part of the care pathway, with fixed moments and supporting tools.

4 CONTEXT ANALYSIS

This chapter describes a context analysis that combines various methods to visualize the context and clarify the interrelationships within sickle cell care. Such a context analysis is needed to understand the complexity of care, make stakeholders, activities, and interdependencies explicit, and support the design of solutions that align with real-life practices (Holtzblatt, 2016). Various methods are used for this purpose, including actor mapping, work models, and journey mapping.

4.1 Actor map

The actor map is a visual representation of the key organizations and individuals within a system. It shows which actors are directly influenced by the system and which actors themselves influence the system (FSG & Schmeer, n.d.).

In this study the actor map was used to understand the complexity of the care system for children with sickle cell disease. The method helps to clarify roles and responsibilities and to identify potential bottlenecks in collaboration and communication between different parties.

Conclusion

The actor map shows (Figure 14) that care for a child with sickle cell disease is a complex and layered system in which medical, social and policy levels intersect. This complexity arises primarily from fragmented responsibilities and poor communication lines between domains.

Key findings and bottlenecks (To make these key points explicit, the most relevant actors and relationships were visually highlighted in Figure 14, while less relevant elements were shown with reduced transparency to maintain overview and focus):

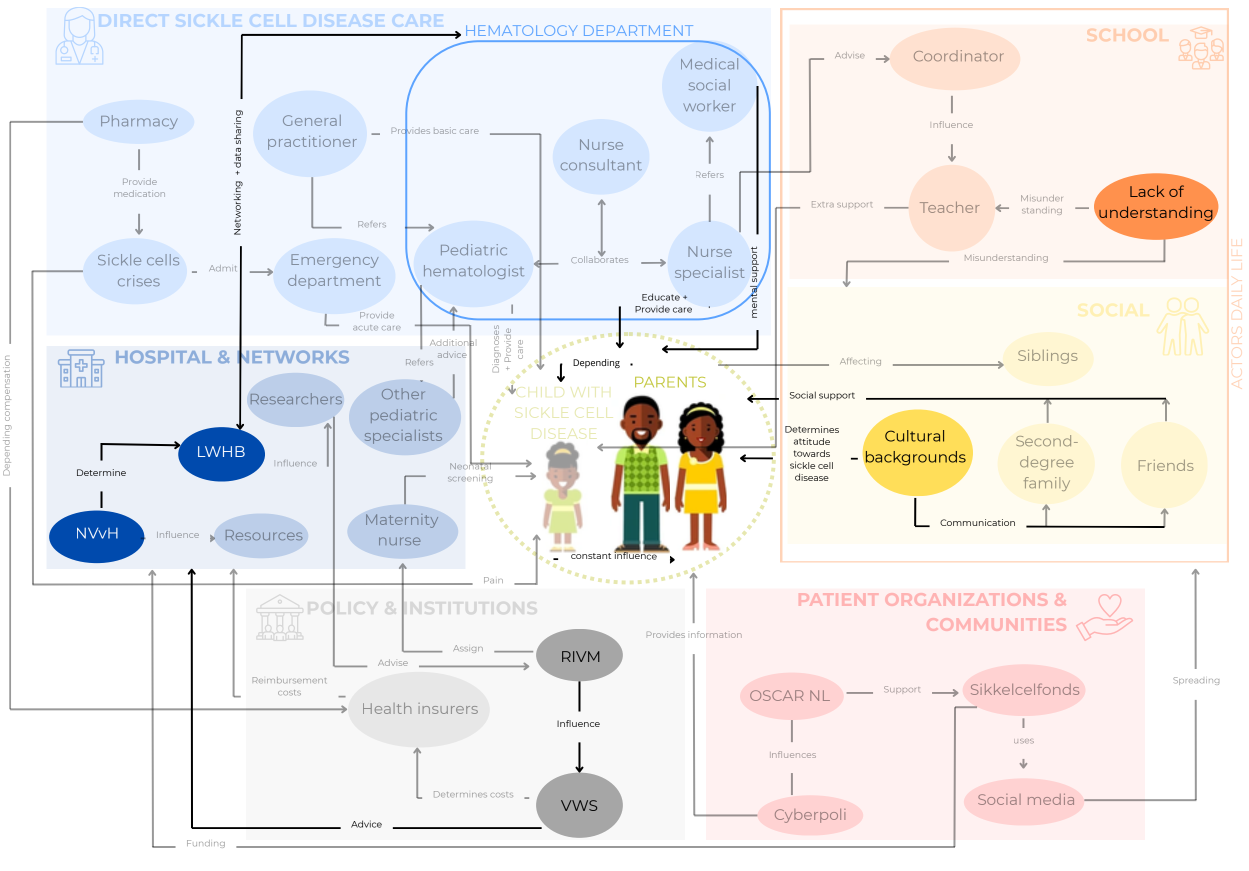


Figure 14: Actor map (See Appendix E for the full version of the actor map)

- There is little feedback between policy institutions (such as the RIVM and VWS) and care practices; the influence is primarily top-down. This top-down influence primarily reflects macro-level decisions impacting meso- and micro-level care practices, with limited upward feedback from daily care to policy.
- There are misunderstandings and a lack of knowledge about sickle cell disease within schools and social settings.
- The cultural background of families influences how they communicate and the extent to which they are open about the disease.
- Parents carry a heavy coordination burden, because they form the link between different domains, such as medical care, school and home situation.

These insights underscore the need for better coordination and clear communication structures within the care network to improve support for families with sickle cell disease.

4.2 Workmodels

To gain insight into how work actually unfolds in practice, work models as defined within Contextual Design were used (Holtzblatt, 2016). In this approach, work models form an overarching concept consisting of several complementary model types, each focusing on a different aspect of work. These models make the underlying structure of work processes, roles, and cultural influences explicit.

One specific type of work model used in this study is the flow model. The flow model was applied to gain insight into the information flows and collaborative relationships between the various actors. This allowed us to understand where inefficiencies arise in the work process that impact the system.

Another specific type of work model is the cultural model. The cultural model was used to map the invisible cultural factors that drive the behavior of actors. This provides insight into which norms and beliefs play a role and where tensions exist between different perspectives. This can reveal why certain working methods persist even when they are not optimal.

4.2.1 Flow model

The core of the care process for sickle cell disease lies in the transfer and translation of medical information. This flow of information relies heavily on parents as intermediaries, which increases the risk of misinterpretation. This emphasizes the need for clear, standardized and accessible communication (Figure 15)

4.2.2 Cultural model

Key tensions:

- Jargon vs. comprehensibility: healthcare providers strive for medical accuracy and completeness, while parents need simplicity and clarity. This leads to information loss and misunderstandings during handover.
- Local flexibility vs. national standardization: tension between daily practice in healthcare centers and national policy guidelines.
- Child vs. parental control: children want to make their own decisions and participate with peers, while parents often out of fear want to remain in control. This creates friction in daily care and affects how information is shared and understood.
- Collaboration and trust: miscommunication between parents and healthcare providers can lead to uncertainty and reduced medication adherence.

The cultural model shows that value conflicts influence the effectiveness of these information flows (Figure 16).

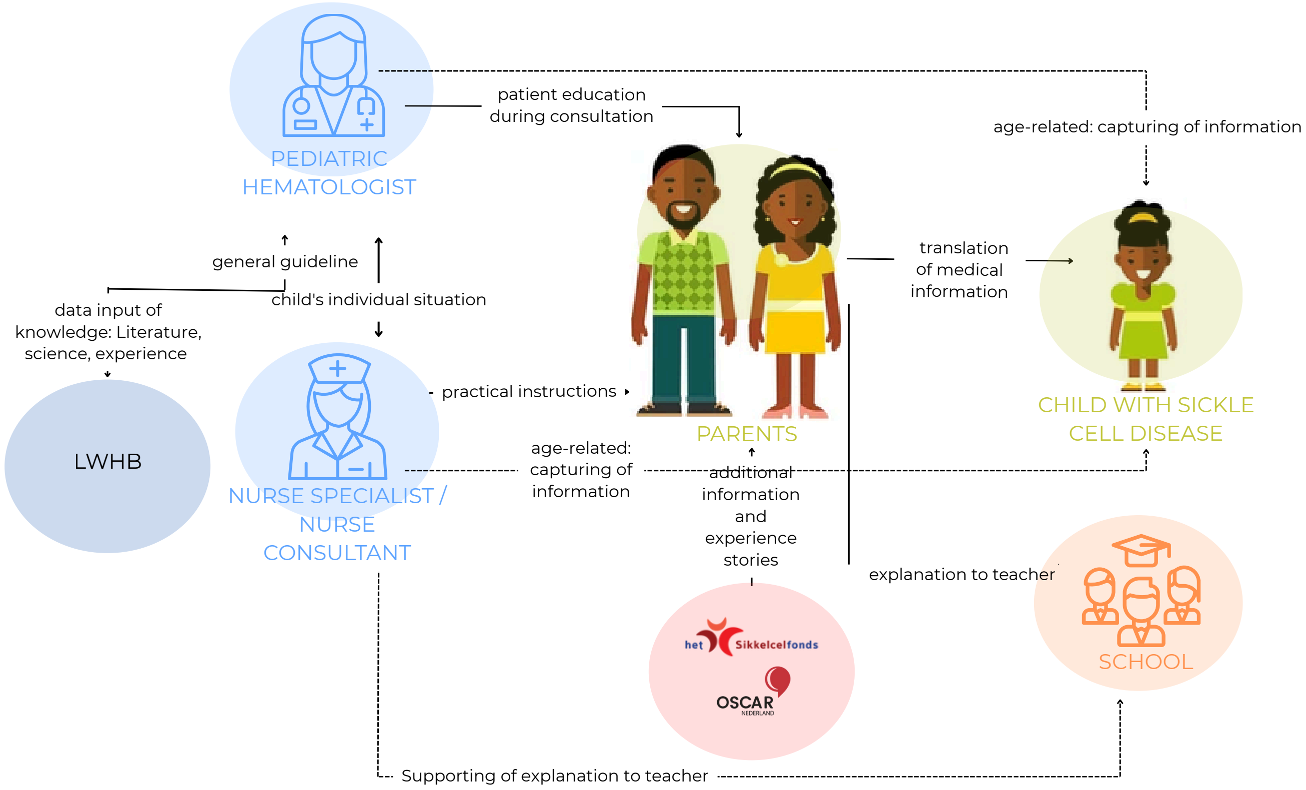


Figure 15: Flow model

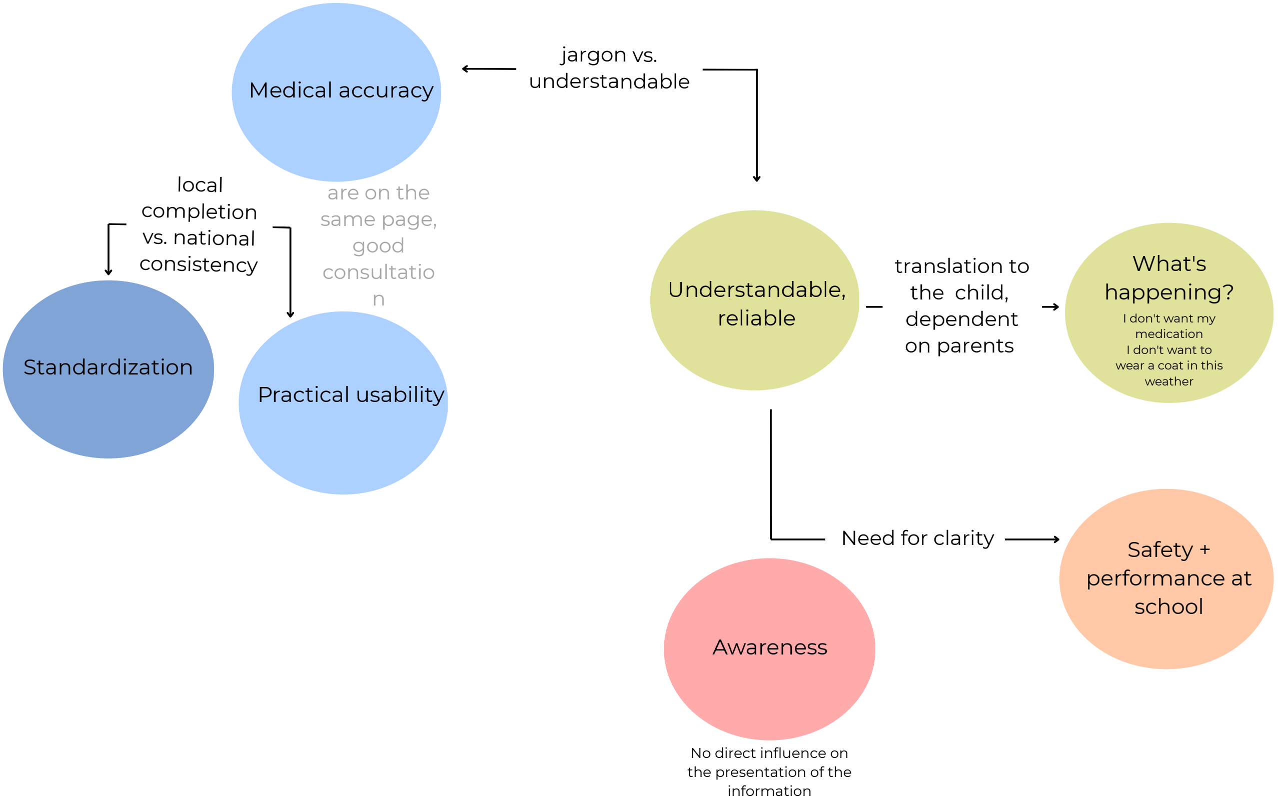


Figure 16: Cultural model

4.3 Journey map

Journey mapping can contribute to patient-centered care and improvements in the healthcare system (Davies et al., 2022). Journey mapping was used to map how parents and children with sickle cell disease navigate the care process. This method allows for analysis of the entire pathway from diagnosis to transition to adult care, understand the interactions in the touchpoints and to identify challenges and opportunities within this process. A comprehensive journey map was developed and is included as an accompanying document; the version presented here is a simplified overview (Figure 17) that highlights only the most relevant moments and insights related to information provision.

4.3.1 Aim and structure journey map

The aim of the journey mapping is to visualize the journey of parents and children with sickle cell disease through care across different phases, with specific attention to moments when information is shared and how this information is processed. The previously defined themes within the project: complexity of information, unmet needs of families and lack of consistency across care centers were used as building blocks for the journey map. The map is structured based on the age and developmental stage of the sickle cell disease patient, consisting of the following phases:

- Heelprick test
- Diagnostics
- First year with sickle cell disease
- Long-term phase (growing up with sickle cell disease)
- Transition

Every child with sickle cell disease in the Netherlands essentially goes through this journey. Children who enter the Dutch healthcare system later (for example, migrants) start with the diagnostic phase, because their first year of life with sickle cell disease has probably already occurred. They then continue the journey directly from the long-term phase.

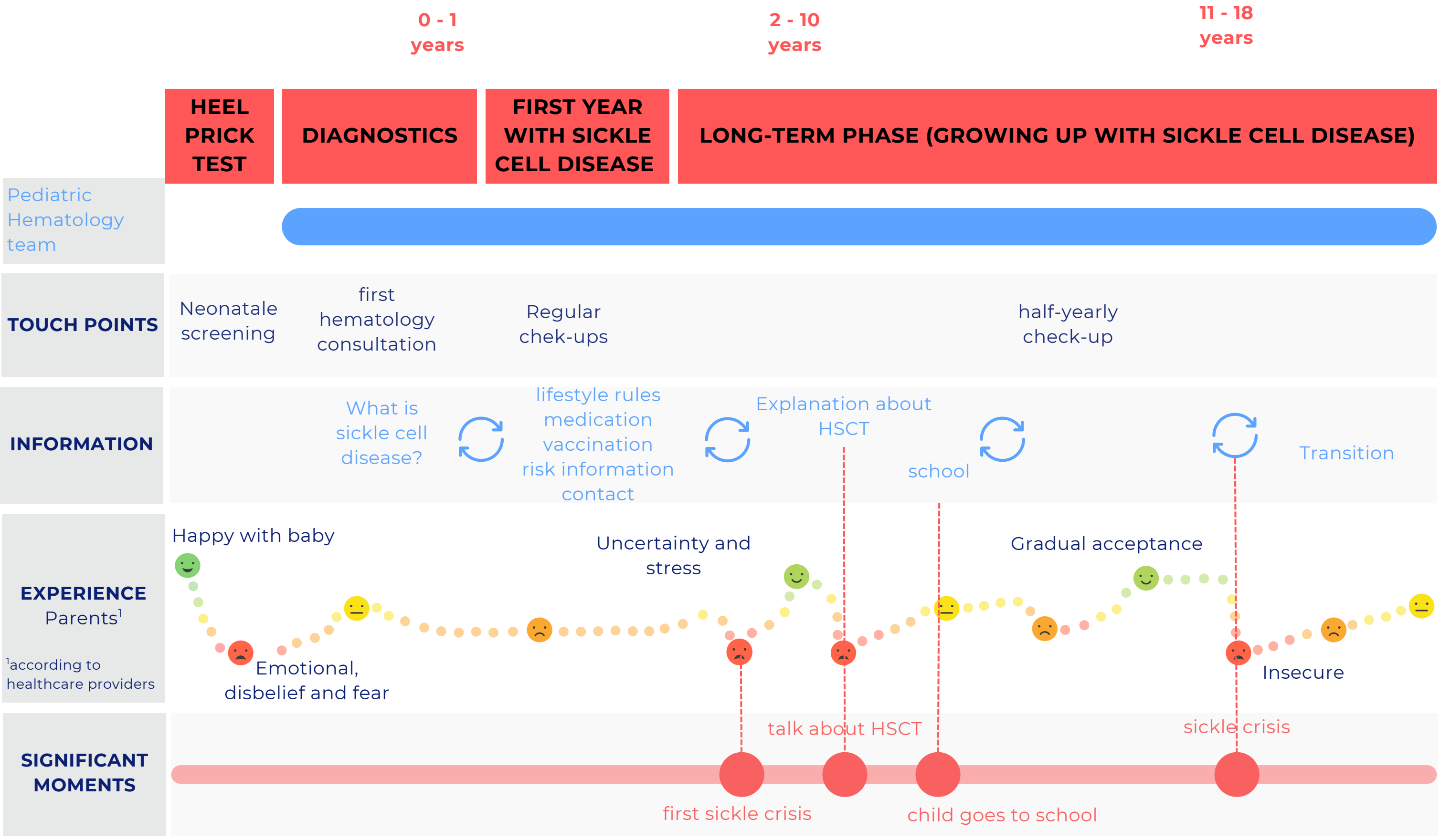


Figure 17: Simplified journey map

Healthcare providers involved

The following healthcare providers are involved in the various phases of the journey:

- Maternity nurse: performs the neonatale screening.
- General practitioner: refers to the pediatric hematologist, but remains involved throughout the entire journey.
- Pediatric hematology team: continuously involved from the diagnostic phase. Within this team there is no clear division regarding information provision; they mainly work together as one interdisciplinary team. Therefore this group is collectively displayed in the journey map.
- Regional pediatrician: involved with families who live far from a sickle cell center. It is often agreed that the patient visits the sickle cell center once a year and a regional hospital once a year.

Touch points

The touch points represent the moments when parents and/or the child come into contact with care related to sickle cell disease. The journey map maps the information exchange during these contact moments. Materials from the Sophia Kinderziekenhuis and the Emma Kinderziekenhuis were used for this, as they developed most of the materials. Other centers, such as UMCG, often use these materials.

Information

By comparing the materials used by the different centers there is investigated whether there are differences in the information provided and the moments at which it is provided. In addition, with regard to SQ3, there is mapped which information materials parents receive at home to support their caregiving responsibilities.

Environment

The environment in the journey map shows the environments in which the life of a child with sickle cell disease unfolds, at home or in the hospital. This provides context for understanding how these environments influence the way information is received, shared and applied in daily life.

Parental Experience

Parents' experiences were mapped to gain insight into their emotions during the various phases of the care pathway. A conscious decision was made to focus on the parent's experience rather than the child's, as young children are not yet very aware of their illness in the early stages. In addition, the extent to which parents' emotions influence the absorption and comprehension of information, particularly in the child's first years, was investigated. The parental experiences in the map are based on observations in the outpatient clinic and interviews with healthcare providers. No parents were directly interviewed, which is recognized as a limitation in the interpretation of the results.

Significant Moments

Significant moments have been defined within the journey: events that can impact the life of a child with sickle cell disease. These moments do not occur for every patient and can occur at different times. A key example is the decision to undergo HSCT treatment. In that case the patient is referred to LUMC, where a new pathway begins. This HSCT trajectory is not included in the current journey map, but in practice it represents an important moment of choice or turning point.

Pediatric Hematology Team Perspective

The pediatric hematology team's perspective is included to explore where the emotions, perceptions, and expectations of healthcare providers may not align with those of parents. This provides insight into differences in communication and the division of responsibilities. The quotes in the map are from the thematic analysis (see chapter 3.1.3).

Challenges and opportunities

This journey map can be used to investigate where in the care pathway communication and information provision are under pressure and when there are opportunities to improve these or better tailor them to the needs of families. The mapping thus forms a basis for identifying challenges and opportunities that can guide further design decisions within this project.

4.3.2 Analysis journey map

The journey map shows that effective care communication is not primarily determined by the amount of information, but by timing, emotional readiness, and context. Especially in the early stages, around diagnosis, parents receive extensive medical information while experiencing an emotionally disruptive situation. The experience layer reveals that parents are stressed during these moments and can only absorb limited information.

The journey map also demonstrates that emotional readiness is essential for understanding. Fear, uncertainty, and disbelief, which recur in several phases (Figure 17), limit the ability to process information. This is corroborated by the perspective of healthcare providers, who doubt whether parents and patients truly understand the severity of the disease.

Furthermore, the journey map shows that repetition of information is necessary rather than a communication deficiency. Central themes such as medication, crisis management, and treatment options recur across different life phases, as the same information gains new meaning in changing contexts. However, the mapping process also revealed that there is no clear or shared structure defining when specific information is provided. Because information delivery is not systematically linked to particular phases or moments in the care pathway, it was difficult to consistently map information provision, highlighting the lack of an overarching framework for structuring repetition in a meaningful way.

It becomes clear that unclear division of responsibilities within the care team leads to confusion in information provision. During the creation of the journey map, it was not always possible to link specific information to a clearly responsible healthcare provider, highlighting the absence of clear agreements on who provides which information.

These insights underscore the importance of a phased approach to care communication, in which information provision is gradually structured to support parents, children, and caregivers throughout the entire care journey.

KEY TAKEAWAYS

- Coordinating role of parents: Parents bear a significant responsibility for coordinating care, school, and home, which increases the risk of misunderstandings.
- Conflicting values: Medical precision and clear communication are under pressure, as are local autonomy and national standardization.
- Importance of timing: Effective communication depends on emotional receptivity; stress hinders information absorption.
- Need for repetition: Information must be repeated and adapted to new life stages and contexts.
- Top-down policy: Policy is often developed without sufficient input from the workplace, leaving practical bottlenecks unresolved.

DEFINE

5 DEFINING DESIGN DIRECTIONS

This chapter concludes the problem space (designing the right thing). All previous research results have been brought together to ensure that the design addresses the right problem. Based on this a design goal and design requirements and wishes have been established that guide the further design process.

5.1 Synthesis

A combination of literature research, observations, desk research, interviews witch healthcare providers, an actor map, work models and journey map reveals that information provision within sickle cell care is hampered by language barriers, cultural differences and limited health literacy. Parents often act as intermediaries, increasing the risk of misunderstandings and their stress (Figure 18).

The core of the problem lies not in a shortage of information materials, but in the way information is presented, timed, and integrated into care. Current materials are inconsistent between center and insufficiently tailored to the emotional and practical realities of families (Figure 19).

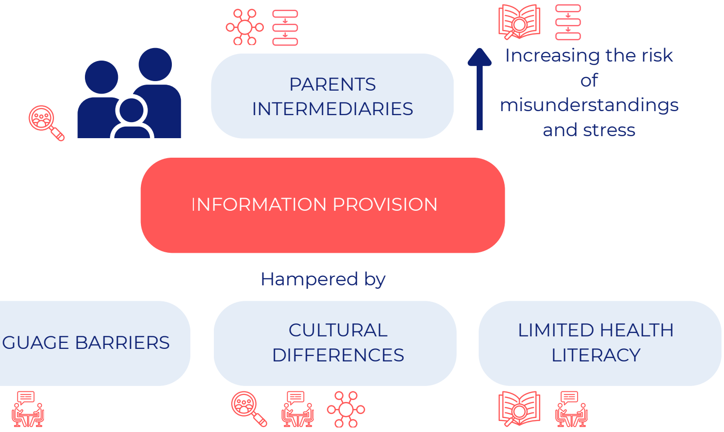


Figure 18: Research combined 1

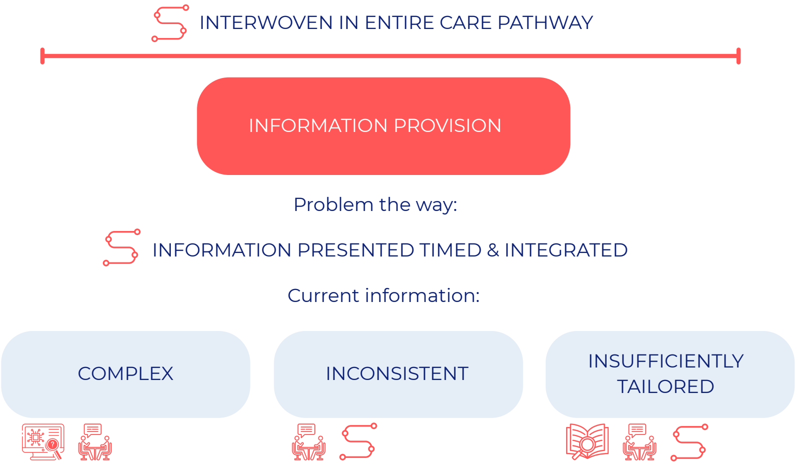
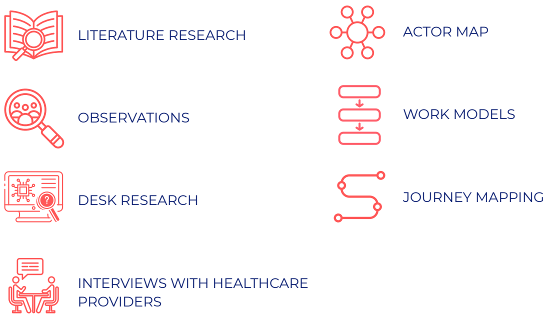


Figure 19: Research combined 2



Legend: Research combined

Interviews with healthcare providers also reveal that a significant bottleneck is the lack of uniformity between sickle cell centers. Information varies in timing, content and approach, meaning families don't always receive a complete and consistent picture of the disease and the care pathway in a timely manner. A concrete example is HSCT treatment, currently the only curative treatment for sickle cell disease. The timing and manner in which HSCT is discussed varies. This can lead to missed opportunities, misunderstandings, additional pain and uncertainty for patients and parents.

The journey map demonstrates that information provision is not a separate event, but an ongoing process interwoven with the entire care pathway. By offering information at fixed, meaningful moments, tailored to the stage of the patient journey, care can be better tailored to the needs of parents and children.

Looking at the healthcare ecosystem as described in chapter 2.5 at the macro level, there are no national guidelines stipulating when and how information should be provided. The journey map shows that information does not have a clearly defined place in the care pathway. Interviews confirm this: care providers indicate that they "do what they think is necessary." The actor map reveals a top-down gap between policy and daily care practice. As a result, at the meso level, information provision often does not fit within existing work processes. Care providers interpret this in their own way. The journey map shows that parents often feel overwhelmed; providing structure can help reduce stress. At emotionally charged moments, it is difficult to convey information effectively, underscoring the importance of correct timing. Interviews show that parents only open up to information when they feel emotionally safe and ready. This translates to the micro-level the information does not always reach the intended target in an understandable way. Not every patient or parent has the same access to or understanding of information.

The research shows that bottlenecks are visible at all levels. There is a gap between policy and practice: national guidelines are insufficiently aligned with the daily reality in hospitals, resulting in the lack of a uniform information provision strategy. Furthermore, the way in which information transfer takes place is not included in existing guidelines (Sikkelcelziekte – MEDonline Publisher, 2024).

Therefore, the design direction focuses on addressing the inconsistency and fragmentation of information between sickle cell centers by developing a uniform, timed information guideline. This design direction constitutes the first step in answering the research question (see chapter 2.1). By initially focusing on developing and providing timed and integrated information materials, a foundation is laid for further improvement of information provision within sickle cell care.

5.2 Design proposition

5.2.1 Design goal

Design a **uniform and central information provision**[1] **strategy**[2] that **supports healthcare providers**[3] in delivering **consistent and timely information**[4] about sickle cell disease, and that serves as the foundation for **accessible**[5] and **consistent**[6] information provision for parents and children within **Dutch sickle cell care**[7].

[1] *A provision that is the same and or organized in one main place (Cambridge dictionary, 2025).*

[2] *A long-range plan for achieving something or reaching a goal (Cambridge dictionary, 2025).*

[3] *A strategy that helps healthcare providers emotionally or in a practical way in providing medical information (Cambridge dictionary, 2025).*

[4] *A strategy that ensures that information is given or available at a suitable moment, and the same everywhere (Cambridge dictionary, 2025).*

[5] *A provision that is able to be reached or easily obtained (Cambridge dictionary, 2025).*

[6] *A Provision that always happening in a similar way (Cambridge dictionary, 2025).*

[7] *See chapter 1.2.3*

5.2.2 Design requirements

Based on the design goal and previous research, the following requirements have been described:

Uniformity & National Applicability

- The design should be suitable for use in all Dutch sickle cell centers.
- The design aims to provide a clear basis for information provision, regardless of location or healthcare provider.
- The design must specify which information about sickle cell disease can be provided.
- The design could be suitable for later inclusion in the sickle cell disease guideline.

Integrated into the Care Process

- Information is provided at fixed, meaningful moments in the care pathway.
- The design must support healthcare providers in determining when information is provided .

Support for Healthcare Providers

- The design promotes clear division of roles and communication within the care team.
- The design provides guidance in clinical practice.
- The design is aligned with existing work processes and attempts to avoid additional workload.

Consistency & Reduced Fragmentation

- The design can contribute to reducing differences in information provision between centers.
- The design can function as a central reference point for information about sickle cell disease.
- The design improves the findability of information materials for healthcare providers.

Accessible for parents and children

- The design should be foundation for accessible information provision for parents and children witch sickle cell disease.

Basis for Further Development

- The design can serve as a foundation for future additions to information provision for sickle cell disease

DESIGN

6 CONCEPT DEVELOPMENT

This chapter builds on the chosen design directions and describes the method used to develop the concept (infographic) and the associated implementation strategy. It explains the concept development process, the steps involved, and how this ultimately led to the final concept. It also outlines the opportunities and possibilities of the concept.

6.1 Method

A step-by-step and participatory method was used to develop this implementable strategy. The ultimate goal was accessible and consistent information provision for sickle cell disease. Information provision regarding sickle cell disease cannot be designed in isolation from healthcare practice. Iterative development and active stakeholder involvement allowed for continuous alignment with user needs and implementation contexts.

Rationale for patient involvement

As previously described the perspective of healthcare providers is central in this project. At the same time an exclusively professional perspective carries the risk of professional bias: healthcare providers use their expertise to determine what information they deem important at specific moments in the care pathway, while this does not always correspond with what patients want or are able to discuss at that same time (Kennedy et al., 2017).

To overcome this bias the decision was made to purposefully involve patients and parents. The aim was not to make patients and parents co-designers, but to test whether healthcare providers' assumptions about the timing, content and form of information actually meet the needs of patients at different stages of the care pathway. Brett et al. (2012) show that Patient and Public Involvement contributes to making implicit assumptions of healthcare professionals explicit and reducing blind spots in healthcare design.

Patient Involvement

During a patient day I explored which topics patients and parents consider important and at what point in the care pathway this information is desirable. The focus was not only on factual information, but also on aspects related to understanding, emotion and uncertainty. This input provided insight into which topics are prioritized by patients and how information can be better aligned with their world.

Co-creation with Healthcare Professionals

Co-creation was used to ensure that the guideline truly aligns with the workflow in clinical practice. Co-creation changes not only what we design, but also how we design: the design is interwoven with social relationships, contexts and the needs of users themselves (Sanders & Stappers, 2008).

Because the goal is to create uniformity between sickle cell centers, healthcare providers from multiple hospitals were involved. Variation in local care processes makes this broad input necessary: differences in working methods provide valuable perspectives, making the guideline widely applicable.

Existing guidelines are often narrative, formulated in general terms and insufficiently integrated into clinical workflows and hospital information systems, making them difficult to use in practice (Heiden & Böckmann, 2013). In addition, passive, top-down implementation often proves ineffective; successful mplementation requires the active involvement of clinicians (Rotter et al., 2019). By consciously applying co-creation, insight was gained into the practical needs of healthcare providers and the likelihood of actual application was increased.

Strategy

Kotter's change model was used to support the intended change. According to Kotter it is essential to clearly communicate why change is necessary, why this moment is appropriate for it and how the change will be achieved (Bedard, 2025).

A strong strategic vision:

- motivates those involved to take action
- coordinates and aligns actions within teams
- provides insight into how the future differs from the past and how this future can be achieved

To make this vision concrete and accessible, two roadmaps were developed. Design roadmapping provides guidance when communicating a design direction or strategic plan (Simonse, 2017):

- Strategic roadmap: describes the desired future and the overarching goal of standardization.
- Tactical roadmap: translates this vision into concrete implementation steps and identifies preconditions for success.

Evaluation and Reflection

Discussions were held with several members of the National Working Group for Hemoglobinopathy Practitioners (LWHB), who are responsible for the national guideline for sickle cell disease, to evaluate both the concept and the proposed implementation approach. The LWHB was deliberately involved because it represents a key stakeholder in the national implementation of changes in sickle cell care. As the body responsible for guideline development and maintenance, the LWHB plays a central role in determining whether and how new strategies can be embedded in existing care structures. The discussions therefore focused on feasibility, alignment with ongoing and future guideline development, and potential sources of resistance, in order to assess the likelihood of successful national implementation.

The roadmaps also serve as a starting point for the student who will conduct follow-up research and develop educational materials. A future research recommendation has been added to support this, addressing:

- how to build on this project
- recommendations for future research.

Finally, the chosen approach was methodologically reflected upon. By critically evaluating whether the methods were appropriate and identifying any limitations, insights emerge that can guide subsequent steps. Methodological reflection contributes to transparency and enhances the quality and usability of design-based research (Peddle, 2021).

This project thus forms a solid foundation for further standardization of educational materials about sickle cell disease.

6.2 Input from parents/patients

During the ‘OSCAR NL’ (patient organization, see chapter 2.4) Symposium on November 15, 2025 (LUMC), parents of children with sickle cell disease and patients themselves were surveyed. The goal was to determine which topics they would like to discuss during consultations at which point in their patient journey. Figure 20 outlines the approach used for the input.

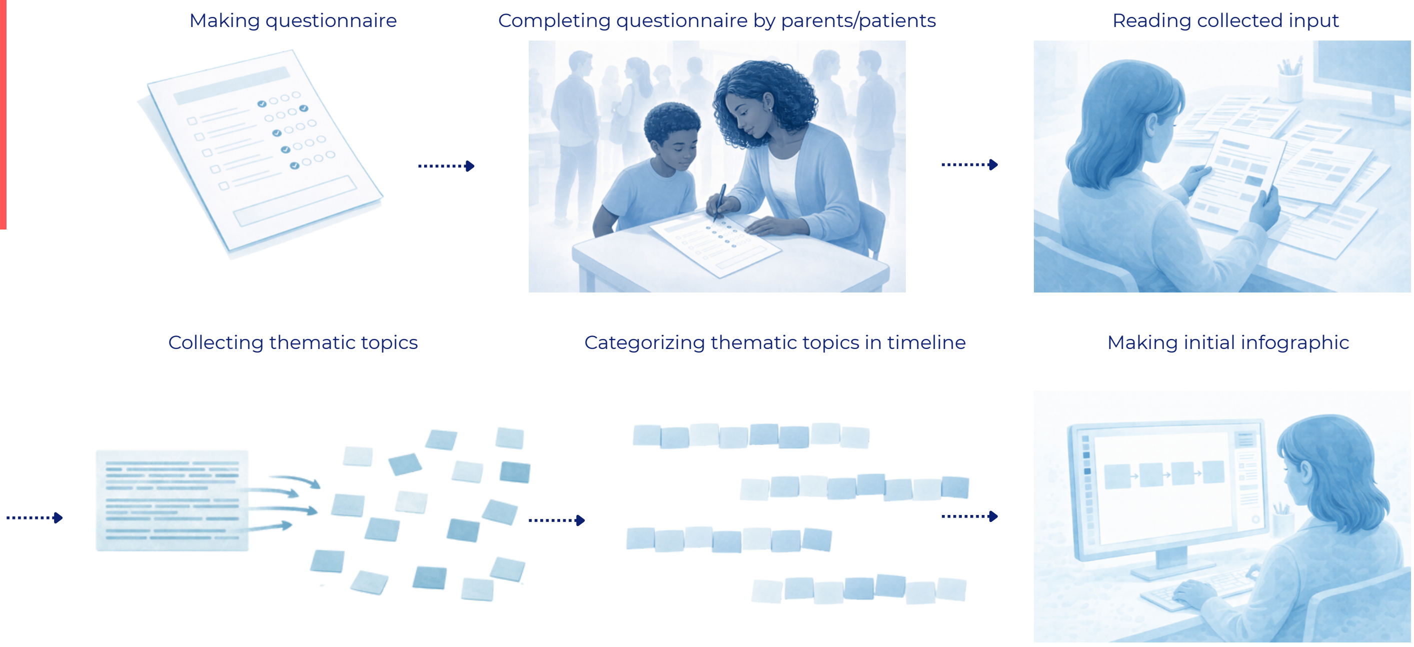


Figure 20: Input parents/patients approach (This image was created using ChatGPT)

During the symposium break, participants were asked to complete a short questionnaire (Appendix F1). The questions were deliberately short and accessible to encourage participation in a busy setting. The questionnaire consisted of a combination of contextual and open-ended reflective questions. First, participants were asked whether they themselves or their child had sickle cell disease, and the age of the participant or child, to place the answers within their care context. Open-ended questions then addressed how participants experienced the current information provision regarding sickle cell disease, whether there were any topics they would have preferred to discuss with their doctor sooner or later and why, and what they would like to discuss with their doctor and when. This design allowed for a short-term understanding of experiences, needs, and preferences regarding the content and timing of information provision.

The collected input from 16 completed forms enabled an initial thematic categorization of topics that should be discussed with patients and parents at specific moments in the sickle cell care journey (Appendix F2) When mapped onto a child-centred timeline, the results showed that information needs vary per phase. Early stages focused on basic disease understanding and acute care, while later stages increasingly addressed daily life, development, and psychosocial aspects. During adolescence and transition, the emphasis shifted toward self-management, lifestyle, and future planning, showing that information needs evolve with the child's developmental stage rather than being delivered all at once.

6.3 Co-creation with Healthcare Providers

6.3.1 Set-up

To make participation as feasible as possible for healthcare providers individual online sessions of 30 minutes were chosen. Longer or joint sessions proved difficult to schedule in their schedules. By offering short one-on-one sessions healthcare providers were able to participate. The Miro program (online collaboration tool that functions as a digital whiteboard where teams can brainstorm in real time) was used during the co-creation sessions (Appendix G1). Figure 21 outlines the approach used for the co-creation.

Based on the themes identified during the OSCAR NL symposium, an initial infographic on sickle cell information provision was developed (Appendix G1) and used as a discussion artefact during the sessions. Healthcare providers were explicitly encouraged to critically reflect on this

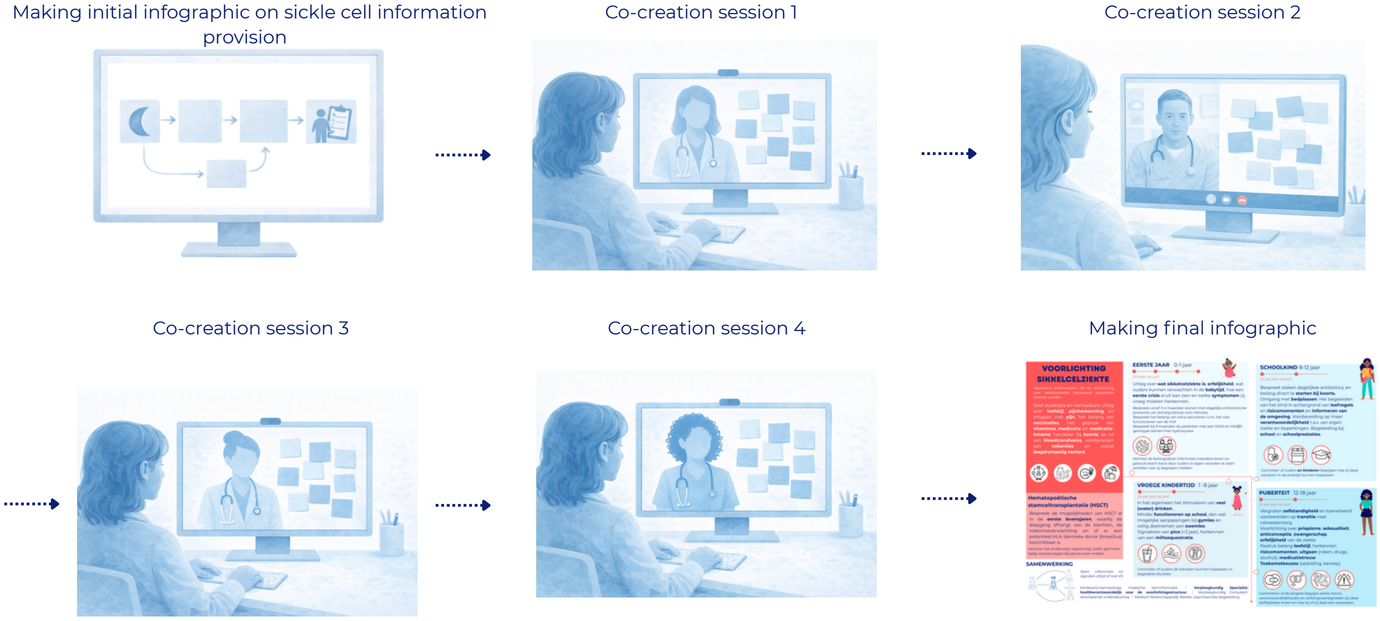


Figure 21: Co-creation approach (This image was created using ChatGPT)

concept and to view it as a starting point rather than a final design. The questions focused on discrepancies between the proposed model and daily practice, responsibilities within the care team, appropriate locations for information availability, clarity of roles in information provision and areas where greater uniformity between centres could have the greatest impact. Participants were invited to freely add comments and suggestions using digital post-its. All input was treated as valuable, and my role as a designer was to synthesise these contributions and translate them into subsequent design iterations.

Feedback from these sessions was systematically incorporated into a revised design, which subsequently formed the basis for a next round of co-creation. This iterative co-creation cycle enabled progressive refinement of the design based on stakeholder input.

Participants

Four healthcare providers from four different sickle cell centers (LUMC, UMCG, Amsterdam UMC, and EMC) participated in the co-creation process: two nurse specialists, one pediatric hematologist and one nurse consultant.

6.3.2 Results

The co-creation confirmed that there is currently no fixed time for healthcare providers to provide information to parents and children. The division of roles within teams regarding information provision is also unclear.

Healthcare providers indicated that uniformity between centers could make a significant difference because it: improves the quality of information, supports small centers with a clear structure, guarantees that every patient receives the same information at the right time, prevents families from hearing different messages when family members are treated in a different center, makes materials easier to find and share, and makes it easier to keep materials up-to-date. The infographic has been adapted based on the practical experiences of healthcare providers (Appendix G2).

6.4 Final concept

This chapter presents the developed concept based on the co-creation sessions. The concept consists of an infographic (Figure 22) that serves as a clear guide for healthcare providers. It visualizes which information is relevant at which point in the

VOORLICHTING SIKKELCELZIEKTE

Algemene onderwerpen die bij voorlichting over sikkelcelziekte standaard besproken moeten worden

Geef duidelijke en herhaalbare uitleg over **leefstijl**, **pijnherkenning** en omgaan met **pijn**, het belang van **vaccinaties**, het gebruik van **vitamines**, **medicatie** en **medicatie-inname**, handelen bij **koorts**, de rol van **bloedtransfusies**, voorbereiden van **vakanties** en vooral **laagdrempelig contact**

Hematopoëtische stamceltransplantatie (HSCT)

Bespreek de mogelijkheden van HSCT al in de **eerste levensjaren**, waarbij de diepgang afhangt van de klachten, de toekomstverwachting en of er een potentieel HLA identieke donor (broer/zus) beschikbaar is.

Herhaal het onderwerp regelmatig zodat gezinnen tijdig weloverwogen keuzes kunnen maken

EERSTE JAAR 0-1 jaar

3/4 keer op poli

Uitleg over **wat sikkelcelziekte is**, **erfelijkheid**, wat ouders kunnen verwachten in de **babytijd**, hoe een **eerste crisis** eruit kan zien en welke **symptomen** zij vroeg moeten herkennen.

Bespreek vanaf 3-4 maanden starten met dagelijks antibiotica ter preventie van (ernstig beloop van) infecties.
Bespreek het belang van extra vaccineren i.v.m. het niet functioneren van de milt
Bespreek bij 9 maanden bij patiënten met een HbSS en HbSβ0 genotype starten met hydroxyurea

Herhaal de belangrijkste informatie meerdere keren en gebruik teach-back door ouders in eigen woorden te laten vertellen wat zij begrepen hebben

VROEGE KINDERTIJD 1 -8 jaar

2x per jaar op poli

In het algemeen het stimuleren van **veel (water) drinken**.
Minder **functioneren op school**, dan wel mogelijke aanpassingen bij **gymles** en veilig deelnemen aan **zwemles**.
Signaleren van **pica** (>2 jaar), herkennen van een **miltsequestratie**.

Controleer of ouders de adviezen kunnen toepassen in dagelijkse situaties.

SCHOOLKIND 8-12 jaar

2x per jaar op poli

Bespreek staken dagelijkse antibiotica, en belang direct te **starten bij koorts.**
Omgang met **bedplassen**. Het begeleiden van het kind in achtergrond van **leefregels** en **risicomomenten** en **informeren van de omgeving**. Voorbereiding op meer **verantwoordelijkheid** t.a.v. van eigen ziekte en beperkingen. Begeleiding bij **school** en **schoolprestaties**.

Controleer of ouders ***en kinderen*** *begrijpen hoe zij deze adviezen in de praktijk kunnen toepassen.*

PUBERTEIT 12-18 jaar

2x per jaar op poli

Vergroten **zelfstandigheid** en toenemend voorbereiden op **transitie** naar volwassenzorg
Voorlichting over **priapisme**, **seksualiteit**, **anticonceptie**, **zwangerschap**, **erfelijkheid** van de ziekte
Nadruk belang **leefstijl**, herkennen **risicomomenten**, **uitgaan** (roken, drugs, alcohol), **medicatietrouw**
Toekomstkeuzes (opleiding, beroep)

Controleren of de jongere begrijpt welke risico's, verantwoordelijkheden en zelfzorgvaardigheden bij deze leeftijdsfase horen en hoe hij of zij deze kan toepassen.

SAMENWERKING

Stem informatie en signalen altijd af met VS

Kinderarts-hematoloog (KH): medische kerninformatie | **Verpleegkundig Specialist (VS): hoofdverantwoordelijk voor de voorlichtingsstructuur** | Verpleegkundig Consulent (VC): doorlopende ondersteuning | Medisch Maatschappelijk Werker (MMW): psychosociale begeleiding

Figure 22: Infographic

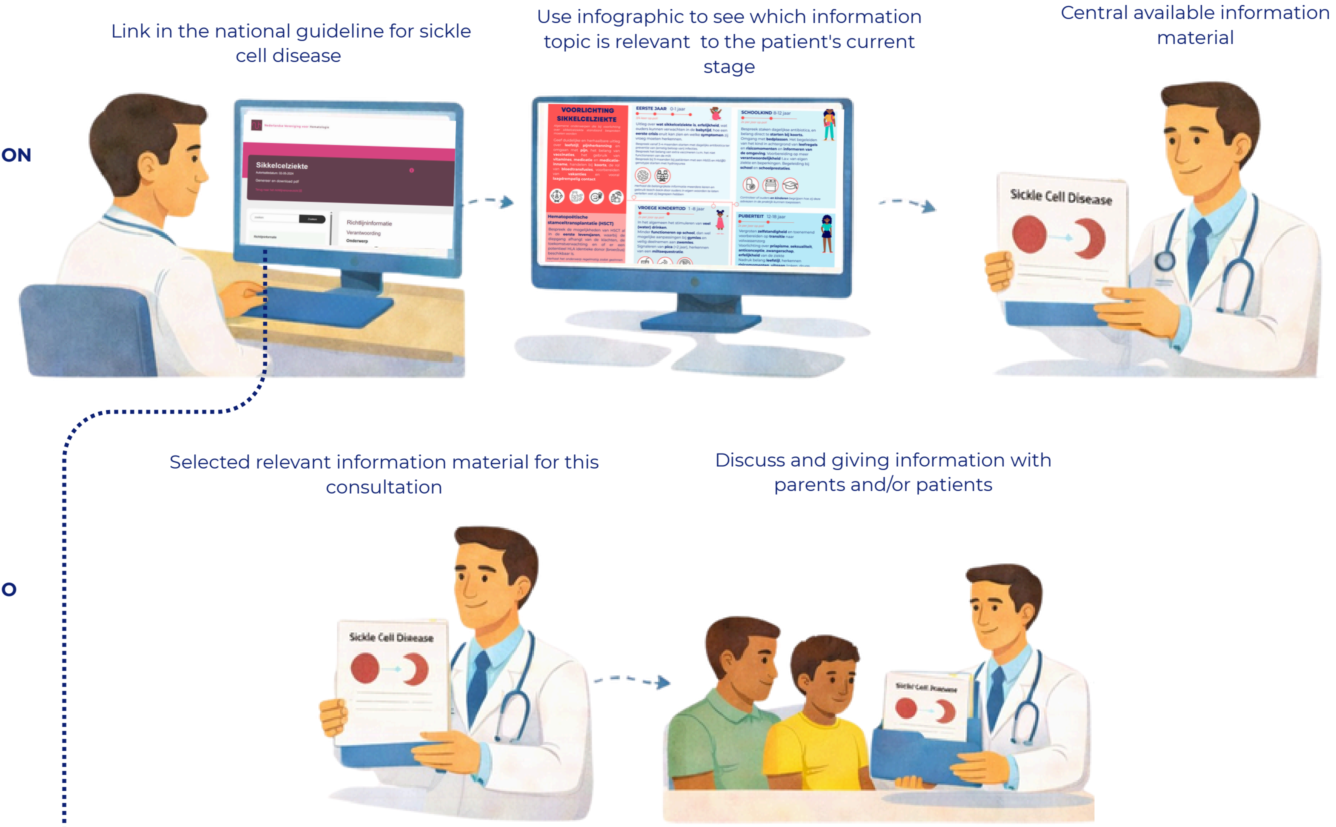
patient journey, which materials are available and who is responsible for communicating this information. The primary goal is to ensure consistent and timely information, minimizing variation between centers and ensuring healthcare providers are adequately supported in their roles. To ultimately ensure that parents and children receive accessible information

6.4.1 National guideline

The national guideline offers a suitable and strategic location for including the infographic, as it serves as a central, reliable, and widely available reference framework for all professional groups involved. The guideline will be distributed digitally to internist-hematologists, pediatric hematologists, clinical geneticists, laboratory specialists, and specialized nurses. An explanatory memorandum will also be published in the Journal of Hematology, and the guideline will be available on the website of the Dutch Society of Hematology (figure). Because the guideline is written in Dutch, the infographic is also deliberately written in Dutch, so that it aligns well with the guideline and is understandable for healthcare providers.

The document was drafted by the LWHB. The LWHB consists of a multidisciplinary and nationally representative working group, comprising hematologists (for both adults and children), transfusion specialists, a laboratory specialist in clinical genetics, nurse specialist, researchers, and a representative of the national patient organization (OSCAR NL). This includes all Dutch centers of expertise and shared care centers for sickle cell disease. The full composition of the working group is included in the national sickle cell disease guideline (Medische Adviesraad en LWHB, n.d.). Because the current guideline does not yet contain specific information on sickle cell disease education, the infographic constitutes a valuable addition as a blueprint for consistent information provision. Inclusion in the guideline guarantees central accessibility and structural integration within existing care processes, enabling national application.

PRIOR TO CONSULTATION



Link in the national guideline for sickle cell disease

Use infographic to see which information topic is relevant to the patient's current stage

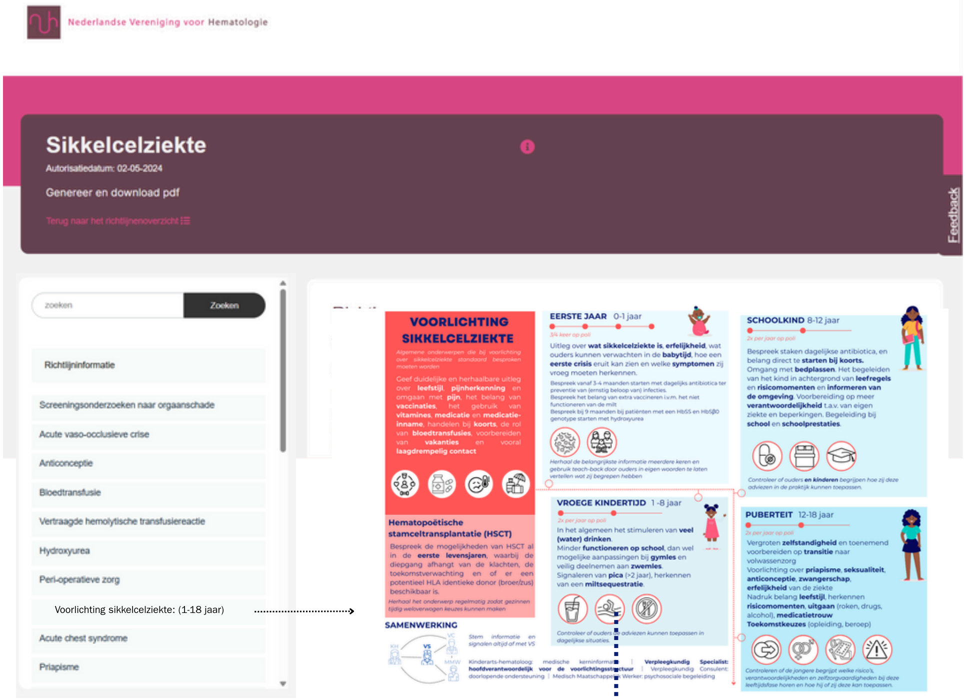
Central available information material

DURING CONSULTATIO N

Selected relevant information material for this consultation

Discuss and giving information with parents and/or patients

Figure 23: User scenario (This image was created using ChatGPT)



Nederlandse Vereniging voor Hematologie

Sikkelcelziekte

Autorisatiedatum: 02-05-2024

Genereer en download pdf

Terug naar het richtlijnenoverzicht

Richtlijninformatie

Screeningsonderzoeken naar orgaanschade

Acute vaso-occlusieve crise

Anticonceptie

Bloedtransfusie

Vertraagde hemolytische transfusiereactie

Hydroxyurea

Peri-operatieve zorg

Voorlichting sikkelcelziekte: (1-18 jaar)

Acute chest syndrome

Priapisme

VOORLICHTING SIKKELCELZIEKTE

Algemene onderwerpen die bij voorlichting over sikkelcelziekte standaard besproken moeten worden

Geef duidelijke en herhaalbare uitleg over **leefstijl**, **pijnherkenning** en omgaan met **pijn**, het belang van **vaccinaties**, het gebruik van **vitamines**, **medicatie** en **medicatie-inname**, handelen bij **koorts**, de rol van **bloedtransfusies**, voorbereiden van **vakanties** en vooral **laagdrempelig contact**

Hematopoëtische stamceltransplantatie (HSCT)

Bespreek de mogelijkheden van HSCT al in de **eerste levensjaren**, waarbij de diepgang afhangt van de klachten, de toekomstverwachting en of er een potentieel HLA identieke donor (broer/zus) beschikbaar is.

Herhaal het onderwerp regelmatig zodat gezinnen tijdig weloverwogen keuzes kunnen maken

EERSTE JAAR 0-1 jaar

3/4 keer op poli

Uitleg over **wat sikkelcelziekte is**, **erfelijkheid**, wat ouders kunnen verwachten in de **babytijd**, hoe een **eerste crisis** eruit kan zien en welke **symptomen** zij vroeg moeten herkennen.

Bespreek vanaf 3-4 maanden starten met dagelijks antibiotica ter preventie van (ernstig beloop van) infecties.
Bespreek het belang van extra vaccineren i.v.m. het niet functioneren van de milt
Bespreek bij 9 maanden bij patiënten met een HbSS en HbSβ0 genotype starten met hydroxyurea

Herhaal de belangrijkste informatie meerdere keren en gebruik teach-back door ouders in eigen woorden te laten vertellen wat zij begrepen hebben

VROEGE KINDERTIJD 1-8 jaar

2x per jaar op poli

In het algemeen het stimuleren van **veel (water) drinken**.
Minder **functioneren op school**, dan wel mogelijke aanpassingen bij **gymles** en veilig deelnemen aan **zwemles**.
Signaleren van **pica** (>2 jaar), herkennen van een **miltsequestratie**.

Controleer of ouders de adviezen kunnen toepassen in dagelijkse situaties.

SCHOOLKIND 8-12 jaar

2x per jaar op poli

Bespreek staken dagelijkse antibiotica, en belang direct te **starten bij koorts.**
Omgang met **bedplassen**. Het begeleiden van het kind in achtergrond van **leefregels** en **risicomomenten** en **informeren van de omgeving**. Voorbereiding op meer **verantwoordelijkheid** t.a.v. van eigen ziekte en beperkingen. Begeleiding bij **school** en **schoolprestaties**.

*Controleer of ouders **en kinderen** begrijpen hoe zij deze adviezen in de praktijk kunnen toepassen.*

PUBERTEIT 12-18 jaar

2x per jaar op poli

Vergroten **zelfstandigheid** en toenemend voorbereiden op **transitie** naar volwassenzorg
Voorlichting over **priapisme**, **seksualiteit**, **anticonceptie**, **zwangerschap**, **erfelijkheid** van de ziekte
Nadruk belang **leefstijl**, herkennen **risicomomenten**, **uitgaan** (roken, drugs, alcohol), **medicatietrouw**
Toekomstkeuzes (opleiding, beroep)

Controleren of de jongere begrijpt welke risico's, verantwoordelijkheden en zelfzorgvaardigheden bij deze leeftijdsfase horen en hoe hij of zij deze kan toepassen.

SAMENWERKING

Stem informatie en signalen altijd af met VS

Kinderarts-hematoloog: medische kerninformatie | **Verpleegkundig Specialist: hoofdverantwoordelijk voor de voorlichtingsstructuur** | Verpleegkundig Consulent: doorlopende ondersteuning | Medisch Maatschappelijk Werker: psychosociale begeleiding

Figure 24: NVvH guideline

When a child is, for example, four years old and swimming lessons are discussed, the healthcare provider can click on the circle with the red outline and swimming icon to access the relevant information materials.

Figure 25: Example of information material swimming (This image was created using ChatGPT)

6.4.2 Conceptual design of the infographic

The infographic (Figure 22) was developed as a conceptual blueprint to support healthcare providers in providing structured information about sickle cell disease. The design combines several objectives: clarity, usability in clinical practice, information consistency and clarity regarding roles and responsibilities.

The infographic's structure follows the logic of the care pathway, with information organized based on when it is relevant to the child and the parents. The age-based structure is a deliberate choice because the information needs, responsibilities, and roles of parents and children change as the child grows older. Age phases correspond to different developmental stages, care moments, and levels of self-management, making the information more relevant to practice and easier to understand and apply at the right time.

General education: This stage provides an ongoing foundation, as core principles remain relevant throughout the patient journey, and repetition is essential for understanding and management.

First year of life: In this stage, parents and baby visit the outpatient clinic more frequently (3 to 4 times) and information can be overwhelming. The infographic structures repeated communication so parents receive essential knowledge in a step-by-step manner without interfering with their focus on the newborn. This emerged as a preference from the patient input received.

Early childhood: In this stage, information focuses on integrating care into daily life, commensurate with the increasing stability of family routines.

School age: This stage supports the transition from parent-led care to shared understanding, where the child is cognitively capable of active involvement.

Adolescence: This stage focuses on preparation for independence and continuity of care, given increasing responsibility and upcoming transition to adult care.

6.4.3 Integration in the workflow

The infographic is designed for healthcare providers within the sickle cell team, including pediatric hematologists, nurse specialists, nurse consultants, and medical social workers. Regional pediatricians can also consult the infographic to ensure consistent information is provided. To illustrate how the infographic can be used in practice, a user scenario was developed and is presented in Figure 23.

Access to the infographic

The infographic is directly accessible via a link in the national guideline for sickle cell disease (Figure 24). In addition, the infographic can be digitally integrated into the electronic patient file, making it part of the daily work environment of healthcare providers. How this should be done exactly is explained in a later chapter.

Preparing consultation

Prior to a consultation the healthcare provider can use the infographic to see which information is relevant to the patient's current stage. The infographic indicates which materials are available by clicking on the circle with the red outline (Figure 25) (e.g. PDFs, brochures, videos) and which topics should be discussed.

During the consultation

The healthcare provider opens the relevant section of the infographic and selects the material that will be handed to the patient or parents during the consultation. If desired the material can be printed immediately or sent digitally via platforms such as Digizorg, depending on the patient's or parents' preference.

Monitoring

After the consultation, the healthcare provider can check off which materials have been provided in the electronic health record. This overview is accessible to the entire sickle cell team, so other team members have insight into what has already been discussed and what still needs to be offered.

Collaboration

In addition, the infographic integrates the roles and responsibilities within the sickle cell team. The nurse specialist acts as case manager and ultimately responsible for information provision. Information and signals (e.g., misunderstanding medication use) are coordinated with the nurse specialist. The pediatric hematologists primarily provide medical content-related information. This clear division of roles supports structured and consistent information transfer.

Bottlenecks

- The diversity of electronic health records in the Netherlands makes standardization complex. Not all electronic health records systems support the same level of integration of digital materials.
- E-health applications such as Digizorg have not yet been implemented everywhere, meaning digital distribution is not possible uniformly.
- Keeping track of which materials have been shared requires a standardized workflow and discipline within the entire team.
- Healthcare providers must be trained in using the infographic and its integration with the electronic health record, to ensure efficient use of the tool and complete registration.

6.4.4 Opportunities

Integrating the infographic into the national guideline offers several advantages:

1. Centralized and broad accessibility: all sickle cell centers and regional hospitals have access to reliable and up-to-date information materials.
2. Uniformity and consistency: information is presented uniformly across all sickle cell patients, minimizing variation between centers.
3. A clear structure for healthcare providers: support with the timing, content, and responsibilities of information provision.
4. Reduced fragmentation and improved findability: all materials are clearly searchable, promoting efficient information provision.
5. Improved accessibility for parents and children: By providing information centrally, structured and in phases, parents and children receive understandable and appropriate information at the right time.

These opportunities contribute to a national, consistent, high-quality information provision that supports healthcare providers and is accessible to parents and children with sickle cell disease.

7 STRATEGY

This chapter describes the implementation strategy. First, the future vision is described. Next, the change logic is explained using Kotter's change model. Finally, it outlines what needs to be done and when, using a strategic and tactical roadmap. The time pacing is explained, and various horizons within the roadmaps are described.

7.1 Developing strategy

7.1.1 Future vision

A future vision is seen as a desired end state or direction that serves as the starting point for planning, innovation and further decisions (Simonse, 2024). To shape the direction for this project, a future vision was formulated:

A nationwide, uniform set of patient information materials for sickle cell disease, offered at meaningful moments throughout the patient journey and sustainably embedded through inclusion in national clinical guidelines (Figure 26).

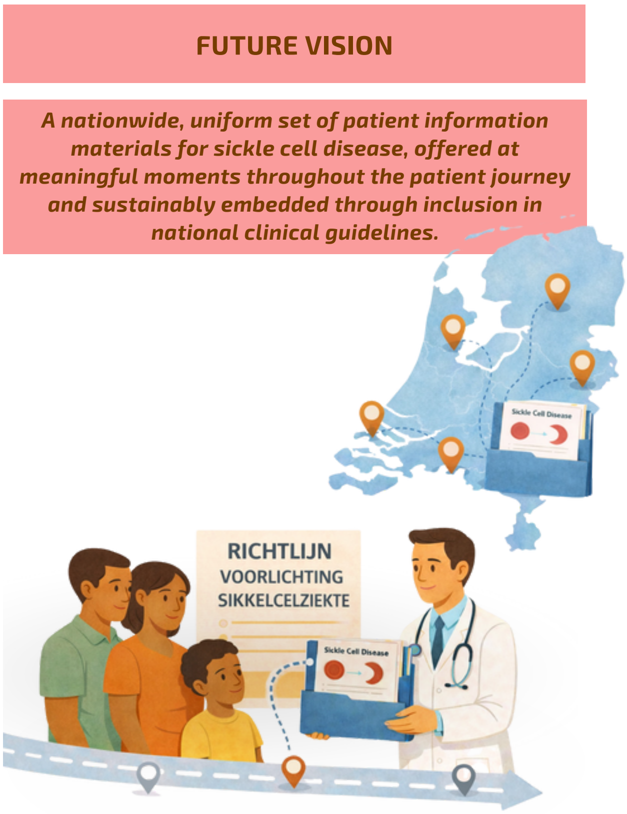


Figure 26: Future vision (This image was created using ChatGPT)

This vision focuses on a national, uniform information provision for sickle cell disease, where patients and families receive the information at fixed and meaningful moments throughout the care pathway. By embedding the infographic and accompanying information materials in the national guideline and linking it to existing care processes, a sustainable tool is created that supports healthcare providers in providing timely and consistent information. This reduces differences between care centers and contributes to the accessibility, quality and continuity of care.

Kotter's change model (Kotter, 1996) was used to explain the change logic (the why and how of change). The implementation (what and when) is then explained with a strategic and tactical roadmap.

7.1.2 Change strategy

To substantiate the strategy behind the formulated future vision and to provide direction for the implementation of the infographic within the sickle cell disease guideline, Kotter's eight-step model for change management was applied (Bedard, 2025):

1. Create a sense of urgency: This step is crucial because change only occurs when the need is recognized. Urgency has been created by highlighting the current fragmentation and disparities in information provision within sickle cell care and demonstrating how this impacts the quality of care. The infographic offers a concrete answer to this problem by integrating uniform and phased information into the guideline, thus clarifying the importance of change.
2. Build a guiding coalition: This step is essential for building support and shared responsibility. Therefore, a multidisciplinary coalition was chosen, including members of the LWHB (see chapter 6.4.1). By involving pediatric

change management was applied (Bedard, 2025):

1. Create a sense of urgency: This step is crucial because change only occurs when the need is recognized. Urgency has been created by highlighting the current fragmentation and disparities in information provision within sickle cell care and demonstrating how this impacts the quality of care. The infographic offers a concrete answer to this problem by integrating uniform and phased information into the guideline, thus clarifying the importance of change.
2. Build a guiding coalition: This step is essential for building support and shared responsibility. Therefore, a multidisciplinary coalition was chosen, including members of the LWHB (see chapter 6.4.1). By involving pediatric hematologists and nurse specialists in particular, who play a central role in providing information, broad support and ownership are created, increasing the likelihood of successful implementation.
3. Form a strategic vision and initiatives: This step is crucial for providing direction and coherence to the change. The strategic vision demonstrates how the future situation differs from the current fragmented practice. The infographic serves as a concrete tool to support healthcare providers. The accompanying initiatives focus on embedding the information in the guideline and making information accessible to parents and children with sickle cell disease.
4. Enlist a volunteer army: Healthcare providers, particularly nurse specialists, are actively involved as co-creators of the information provision. Their involvement encourages broader adoption within teams and centers.
5. Enable action by removing barriers: Potential barriers are identified, such as differences between electronic patient records and lack of clarity regarding responsibilities. These barriers are reduced through clear division of roles and practical instructions.
6. Generate short-term wins: Short-term successes, such as alignment on information provision between all centers, strengthen motivation and confidence in the change process.
7. Sustain acceleration: For this step, it's important to establish who is responsible for updating the infographic and materials as new knowledge or guidelines evolve, ensuring the information remains current. This step is essential because change is only sustainable when progress is secured and improvements can be implemented continuously. By establishing clear responsibilities and evaluation processes, the information provided can evolve with the new insights and needs of parents, children, and caregivers.
8. Institute change: The change is secured by embedding the infographic in the guideline. Through frequent use and a clear link between the new approach and improved information provision, its use becomes part of daily practice.

To translate this change strategy into concrete actions and decision-making, a strategic and tactical roadmap has been developed (Figure 27 & 28).

7.2 Roadmapping

Two types of roadmaps have been developed: a strategic roadmap and a tactical roadmap. The strategic roadmap is a simplified version of the tactical roadmap, designed to communicate the future vision and goal. This roadmap is clear, easy to read, and contains the most important elements. The tactical roadmap delves deeper into the content and describes the concrete actions to be taken and the changes required to achieve the objectives (Simonse, 2017).

In this project, both roadmaps are used to clarify the strategy for achieving the future vision. The strategic roadmap consists of the goal per horizon, supplemented with the most important changes and activities. The tactical roadmap elaborates on this further and consists of the following elements:

Division of work: The required work is broken down into concrete actions and the associated stakeholders. For each action, the stakeholders involved and their responsibilities are clarified.

Value proposition: The change is described per horizon based on: Strategic value: why an activity is important within the broader strategy and how it contributes to the long-term goals. Service proposition: what the service or solution concretely delivers to the user and the value they experience.

Challenges: The main challenges are identified per horizon:

- Regulatory: because the project is embedded in guideline development, it is necessary to consider formal decision-making processes and legal frameworks.
- Technical: differences between electronic health records and digital systems pose implementation challenges.
- Implementational: Practical obstacles may arise during implementation. Identifying these early on can reduce risks.

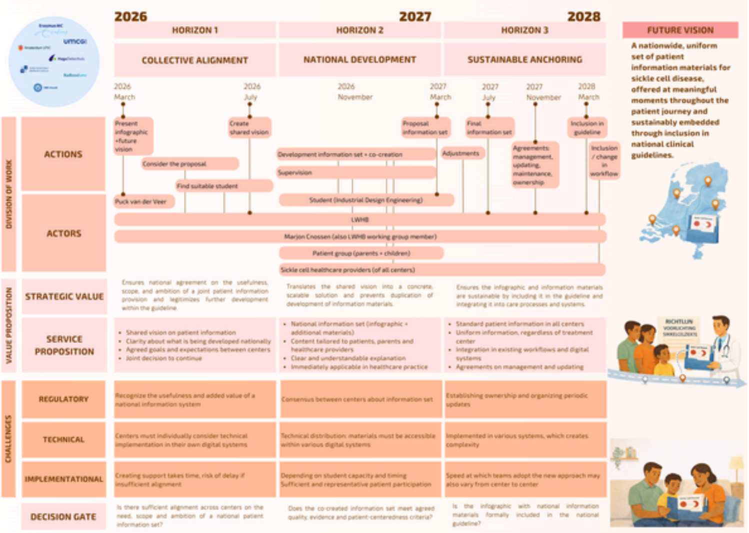
Finally, a decision gate is defined for each horizon: an explicit go/no-go moment. If these conditions are not met it is neither desirable nor feasible to proceed to the next horizon.

	2026 HORIZON 1	2027 HORIZON 2	2028 HORIZON 3
	COLLECTIVE ALIGNMENT	NATIONAL DEVELOPMENT	SUSTAINABLE ANCHORING
GOAL	To build a shared understanding across all sickle cell healthcare centers of the purpose and potential impact of a national patient information initiative. This horizon focuses on creating awareness of the broader benefits of uniform information, fostering commitment to a joint vision, and setting the stage for future collaborative development.	To create a high-quality, patient-focused information set that addresses the needs of patients, families, and healthcare providers. The focus is on ensuring the content is relevant, evidence-based, and adaptable to different care contexts, providing a foundation for standardized and effective patient communication nationwide.	To ensure the national patient information set becomes an enduring component of healthcare for sickle cell disease. This horizon emphasizes the long-term integration of the infographic with standardized information into care processes, supporting continuous access to reliable, understandable, and actionable patient information.
CHANGE	From fragmented, locally developed patient information to a shared national vision and collective commitment.	A transition from a shared vision to a concrete, scalable information solution applicable across healthcare centers.	From a project-based initiative to a structurally embedded and maintained solution.
ACTIVITIES	Creating a shared vision on national patient information Establishing agreement on common goals and expectations between centers Making a joint decision to initiate national development	Co-creating patient information materials with patients and healthcare professionals Aligning content to ensure clarity, consistency, and relevance throughout the patient journey Validating the information set against agreed quality and patient-centeredness criteria	Formally including the information set in national clinical guidelines Integrating the information into existing care processes and workflows Establishing agreements on ownership, maintenance, and updating

FUTURE VISION

A nationwide, uniform set of patient information materials for sickle cell disease, offered at meaningful moments throughout the patient journey and sustainably embedded through inclusion in national clinical guidelines.

Figure 27: Strategic roadmap



	Horizon 1	Horizon 2	Horizon 3
STRATEGIC VALUE	Ensures national agreement on the usefulness, scope, and ambition of a joint patient information provision and legitimizes further development within the guideline.	Translates the shared vision into a concrete, scalable solution and prevents duplication of development of information materials.	Ensures the infographic and information materials are sustainable by including it in the guideline and integrating it into care processes and systems.
SERVICE PROPOSITION	• Shared vision on patient information • Clarity about what is being developed nationally • Agreed goals and expectations between centers • Joint decision to continue	• National information set (infographic + additional materials) • Content tailored to patients, parents and healthcare providers • Clear and understandable explanation • Immediately applicable in healthcare practice	• Standard patient information in all centers • Uniform information, regardless of treatment center • Integration in existing workflows and digital systems • Agreements on management and updating
REGULATORY	Recognize the usefulness and added value of a national information system	Consensus between centers about information set	Establishing ownership and organizing periodic updates
TECHNICAL	Centers must individually consider technical implementation in their own digital systems	Technical distribution: materials must be accessible within various digital systems	Implemented in various systems, which creates complexity
IMPLEMENTATIONAL	Creating support takes time, risk of delay if insufficient alignment	Depending on student capacity and timing Sufficient and representative patient participation	Speed at which teams adopt the new approach may also vary from center to center
DECISION GATE	Is there sufficient alignment across centers on the need, scope and ambition of a national patient information set?	Does the co-created information set meet agreed quality, evidence and patient-centeredness criteria?	Is the infographic with national information materials formally included in the national guideline?

FUTURE VISION

A nationwide, uniform set of patient information materials for sickle cell disease, offered at meaningful moments throughout the patient journey and sustainably embedded through inclusion in national clinical guidelines.

Figure 28: Tactical roadmap

For a larger and more readable version, please refer to the accompanying document.

7.2.1 Time pacing

A time-pacing strategy uses roadmaps structured around a timeline. The required actions are divided across three horizons and executed chronologically. The pace of these actions is decisive, and the various activities influence each other (Simonse, 2017).

When developing a time-pacing strategy for a roadmap, three design cycles are distinguished: value enhancement, value creation, and value proposition. These three cycles run parallel and together create a rhythmic innovation flow (Simonse, 2017).

When these design cycles are linked to Kotter's previously described change model (see chapter 7.1.2), the following results emerge: Value enhancement focuses on incremental improvements that deliver visible results and changes in daily routines. Value creation is made concrete and tangible through initiatives that translate this vision into actionable actions. The value proposition functions as a change vision: a shared vision of the future that guides the roadmap.

The design cycles overlap to ensure continuous innovation.
First horizon: focuses on the initial steps toward collective alignment, developing a shared vision.
Second horizon: focuses on developing information materials that can be deployed nationwide.
Third horizon: focuses on national uniformity and the sustainable embedding of the developed solutions.

Because decision-making and substantive coordination regarding guideline development take place within the LWHB (see chapter 6.4.1), the time pacing is aligned with the rhythm of this working group (Figure 29). The LWHB meets three times a year: in March, July and November.

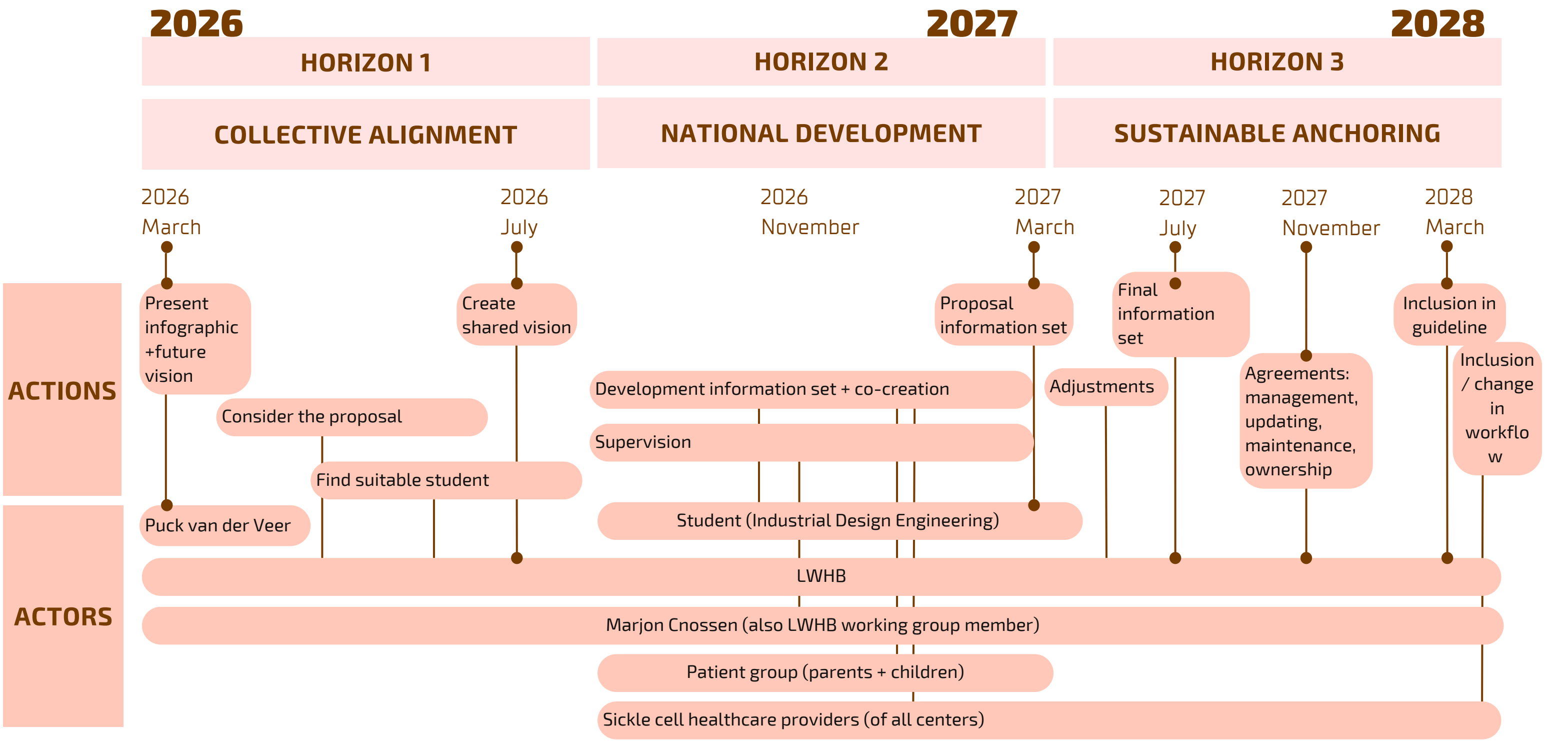


Figure 29: Time pacing strategy

The next meeting will take place in March 2026, where I will present the future vision and establish the basis for further development. The LWHB will then have time to consider the proposal. During the meeting in July 2026 the national vision for information provision from the various centers will be discussed jointly. This shared vision will form the basis for a student project to develop an information set. Consisting of the developed infographic and supplementary materials. The infographic has now been developed, but can be adjusted as needed to optimally align with the materials.

A student can begin the project from this point onward. An Industrial Design student's project has a minimum duration of six months. If the student starts at the beginning of the academic year in September 2026 the first opportunity to present a proposal for the information set will be in March 2027. If the start takes place later the subsequent steps will be postponed accordingly.

Any adjustments will be implemented by the LWHB until July 2027 and the final national information set will be finalized. During the meeting in November 2027 agreements will be made regarding management, updating, maintenance and long-term ownership. In March 2028 the infographic with the developed information materials can be incorporated into the guideline. The centers will then integrate it into their own digital environments and the change will be embedded in the teams' workflow.

Between LWHB meetings stakeholders maintain contact with each other to coordinate matters. These working group meetings serve as formal occasions for ratifying decisions and finalizing agreements.

7.2.2 Roadmap horizons

To clearly describe the roadmap, this chapter is divided into three parts. Each part corresponds to a roadmap horizon and describes how the development unfolds over time.

2026

HORIZON 1

COLLECTIVE ALIGNMENT

From fragmented, locally developed patient information to a shared national vision and collective commitment.

Creating a shared vision on national patient information

Establishing agreement on common goals and expectations between centers

Making a joint decision to initiate national development

Figure 30: Horizon 1 (This image was created using ChatGPT)

Horizon 1: Collective Alignment (Figure 30)

Division of work

As a first step, I presented the infographic and strategy plan to the LWHB, supported by a short explanatory video of approximately two minutes. This video was developed to provide a concise and accessible explanation of the project, its objectives, and the proposed strategy, enabling LWHB members to quickly grasp the core message. This approach supported collective alignment and facilitated discussion within the LWHB.

The LWHB members will evaluate and discuss the proposed direction and the importance of incorporating the infographic and the accompanying information materials into the guideline. By highlighting the current fragmentation and disparities in information provision the LWHB members should recognize the usefulness and added value of a national information system. Furthermore, demonstrating how the future situation differs from the current fragmented practice could ensure a shared vision for uniform patient information materials. Simultaneously Marjon Cnossen, the project supervisor, will work with Delft University of Technology to find a suitable student for the follow-up phase.

Value proposition
In this horizon collaboration between centers is strengthened and a national vision for patient education is created. This reduces variation and fragmentation between centers and forms a foundation for more uniform care.

Challenges
A first challenge is to clarify the usefulness and added value of a national, uniform information system. It is important that the LWHB jointly recognize this, as their support will determine further decision-making and scaling up. This requires explicitly linking information provision to quality improvement, consistency of care, and support for healthcare providers in daily practice.

Furthermore, the technical implementation is a challenge. Healthcare centers will need to individually investigate how the infographic and information materials can be integrated into existing digital patient records and eHealth tools, enabling continuous and practical use.

Decision gate
The prerequisite for moving on to the next horizon is sufficient alignment between the centers on the necessity, scope and ambition of a national patient information facility.

2027

HORIZON 2

NATIONAL DEVELOPMENT

A transition from a shared vision to a concrete, scalable information solution applicable across healthcare centers.

Co-creating patient information materials with patients and healthcare professionals

Aligning content to ensure clarity, consistency, and relevance throughout the patient journey

Validating the information set against agreed quality and patient-centeredness criteria

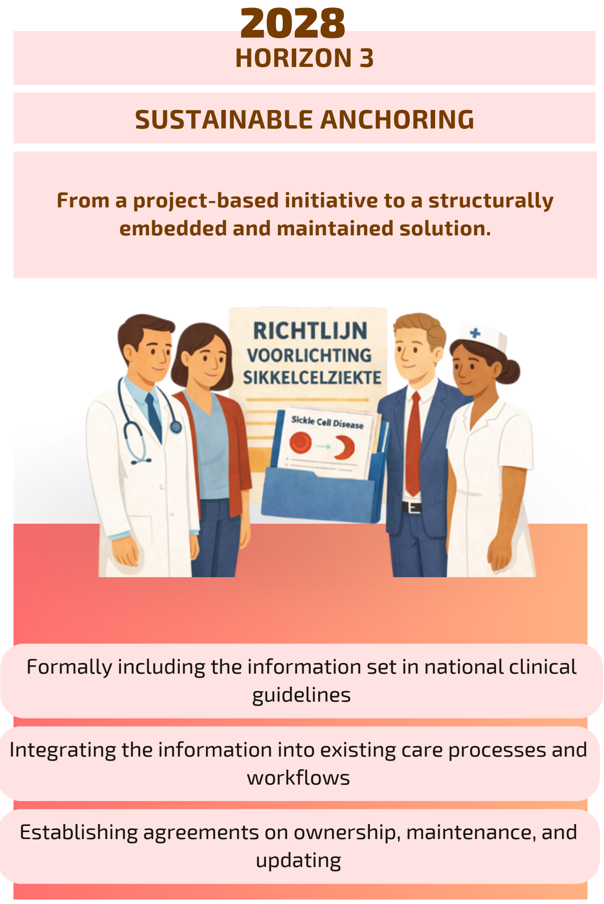
Figure 31: Horizon 2 (This image was created using ChatGPT)

Horizon 2: National Development (Figure 31)
Division of Work
In this horizon the focus is largely on the follow-up student developing the educational materials in co-creation with the sickle cell team and patient groups consisting of parents and children. Marjon Cnossen remains involved as a supervisor. In addition, there is active coordination with members of the LWHB to ensure uniformity and establish joint agreements.

Value proposition
A quality standard for patient information is being developed, leading to more consistent and understandable communication. The materials are better aligned with the needs of patients, parents and healthcare providers. The development of a national set prevents duplication of development within individual centers.

Challenges

Reaching consensus on the information materials poses a significant challenge, as care centers are accustomed to working with their own materials, routines and working methods. Coordinating content and format therefore requires consultation, a willingness to adapt and trust in a collaborative approach. Furthermore, sufficient and representative patient involvement is essential to ensure the materials meet the diverse needs of families with sickle cell disease. Achieving this is complex, however, partly due to research participation within this target group. Furthermore, the project's progress is partly dependent on available student capacity and planning, which impacts the speed and continuity of further development. Finally, technical distribution remains a key concern: the materials must be accessible within various digital systems and care environments to be truly widely used.



2028
HORIZON 3

SUSTAINABLE ANCHORING

From a project-based initiative to a structurally embedded and maintained solution.

Formally including the information set in national clinical guidelines

Integrating the information into existing care processes and workflows

Establishing agreements on ownership, maintenance, and updating

Figure 32: Horizon 3 (This image was created using ChatGPT)

Decision gate

The transition to the next horizon is possible when the information set meets jointly established criteria for quality, evidence-based content and patient-centeredness.

Horizon 3: Sustainable anchoring (Figure 32)

Division of work

In this phase responsibility primarily lies with the LWHB. Agreements are made regarding the updating, maintenance and long-term ownership of the information set. After inclusion in the guideline the sickle cell teams within the individual centers implement the materials into their daily workflows and actively use the infographic and associated information set.

Value proposition

Incorporation into the guideline ensures national uniformity and reduces practice variation. The information set will be permanently integrated into the quality framework and will become a structural component of care processes and digital systems.

Challenges

A bottleneck is establishing ownership and organizing periodic updates in a structured manner. It must be clear who is responsible for updating the materials and ensuring content quality. This is complex because updates must then be implemented across multiple digital systems and care environments. Furthermore the extent and speed at which care teams adopt the new approach can vary from one care center to another, potentially leading to variations in use and implementation.

Decision gate

The formal inclusion of the infographic with the national information materials in the national guideline is essential for realizing the future vision. Only through this anchoring can the infographic contribute to national consistency and sustainable implementation within sickle cell care.

VALIDATE

8 EVALUATION

This chapter provides an overview of the infographic and strategy evaluation. It covers the validation sessions with LWHB and reflects on the design goal and associated requirements.

8.1 Validation session

To determine whether the infographic aligns with the current guideline and whether the strategic and tactical roadmap is realistic and feasible within the existing guideline development framework, validation sessions were planned with members of the LWHB. These sessions assessed the feasibility of the infographic and implementation plan. During these sessions, the infographic, including its use case and the strategic and tactical roadmap, was discussed. The infographic was presented to determine whether it could potentially fit within the existing guideline and whether that would be reasonable. The tactical roadmap was presented, with the question of whether there were any obstacles to implementation and areas for improvement based on practical experience. The strategic roadmap was presented to determine whether it was clear and communicated the future vision effectively. In addition, the validation sessions served to inform the final design by allowing for redesign and refinement of the infographic and roadmap based on feedback. This process aimed to result in a final proposal that can be presented at the LWHB meeting in March, as outlined in Horizon 1 (see chapter 7.2.2), to support collective alignment and decision-making.

8.1.1 Setup

The validation session was held with three members of the LWHB: two pediatric hematologists (Amsterdam UMC and UMC U) and one nurse specialist (Sophia). These participants were deliberately selected because they had not previously been involved in the co-creation process, allowing them to assess the developed material with a fresh and critical perspective. Figure 33 outlines the approach of the validation session. The session lasted approximately 30 minutes and took place during an online meeting. At the beginning of the session, the general aim of the study was explained, along with the purpose of the validation session. I then explained how the infographic was created through co-creation and presented the scenario (see chapter 6.4) to illustrate the intended use. Furthermore, the question was posed whether the infographic could be incorporated into the guideline. Finally, the strategic and tactical roadmaps were presented, and participants were asked if they saw any barriers to implementation, what areas for improvement or critical attention they could identify, and whether any potential risks had been overlooked (Appendix H).

Figure 33: Validation session approach (This image was created using ChatGPT)

8.1.2 Results

The discussion with the LWHB members clearly confirmed the need for standardized information provision. This was evident in quotes such as: "An information set has been planned for years, but never materialized." and "It's a bit of a mess right now. There's no established structure anywhere, we need that." During the validation session, it was confirmed that the guideline is a suitable platform for this standardized information, with central availability of information considered essential. This was explicitly reflected in the statement: “Yes, definitely, in the national guideline.” It was noted that sickle cell centers in large cities such as Amsterdam (Emma Kinderziekenhuis) and Rotterdam (Sophia Kinderziekenhuis) see a relatively large proportion of this patient group, partly due to their demographic composition. At the same time, it was emphasized that it is of great value for smaller healthcare centers to have access to the same information, so that national uniformity can be achieved. In this context, the infographic was seen as a suitable first step towards standardized information provision. The necessity of this was further underscored by the fact that this topic has been on the agenda for some time, but its implementation has been repeatedly postponed. This topic has been discussed several times within the LWHB. In the past, some centers wanted to manage information locally, while others had little or no educational material on sickle cell disease at their disposal. The added value of a uniform set of patient information is now more widely recognized, as evidenced by the quote: "Everyone is just showing off; it would be wonderful if the information were the same, even if you refer a patient to a different center."

Furthermore, it became clear that the nurse specialist is considered the most suitable professional to be responsible for providing information. This was supported by a statement from the nurse specialist herself: "It's good if the nurse specialist is responsible for the main points and monitors the process; we have both the necessary medical and educational knowledge." Healthcare providers also confirmed that they value the infographic being available in Dutch. Building on this, it was suggested that the roadmap should likewise be available in Dutch, ensuring alignment in content and visual language.

Involving parents and patients was considered essential for successful implementation. During the session, it was emphasized that insight into how patients and families interact with information provision at home is necessary, which was expressed in the statement: "We need to gather information from patients: how they use information provision at home." At the same time, one of the pediatric hematologists emphasized that this group of parents and patients must be nationally representative. This poses an additional challenge, as described previously (see chapter 2.3.1), as this patient group sometimes doesn't even show up for appointments, let alone participate in research. Nevertheless, it was concluded that parental and patient involvement is essential to ensure that the information meets their needs and is truly accessible.

Finally, several organisational and practical concerns were raised. A key concern related to how the infographic could be kept up to date after completion of the project and who would be responsible for implementing updates when new materials are developed. In response, the nurse specialist indicated that this responsibility could lie with the group of nurse specialists, as they already operate within a national working group that meets on a quarterly basis. However, it was emphasized that this would only be feasible if there is clarity on how updates should be made and how the information can be systematically kept up to date. It was also noted that clarity is needed regarding where the information materials are digitally available, how they are centrally stored, and how healthcare providers can easily share them with parents and patients. This includes questions about access, distribution, and use in daily care practice. The importance of flexibility and adaptability was emphasized, with the quote: "It must be adaptable, otherwise people will drop out." These considerations make it clear that, in addition to content quality, organizational and digital preconditions also determine the successful and sustainable implementation of standardized information provision and that these aspects require further development.

8.2 Re-Design

Based on the evaluation, it was decided to further develop the design, with specific attention to digital distribution and adaptability. These aspects are essential to ensure the sustainability and future-proofing of the design. Without structured digital distribution, there is a risk of document fragmentation and the use of outdated versions within healthcare practices. Furthermore, an insufficiently adaptable design leads to reduced adoption by healthcare professionals. To promote consistency, the Roadmap has been developed entirely in Dutch, so that its content and visuals align with the infographic, also in Dutch (see accompanying document).

8.2.1 Digital distribution

Healthcare institutions use various electronic patient records (EPDs), while guidelines and supporting documents are often managed locally. This leads to differences in availability, versions, and currency. In this design, digital distribution is conceived as the organization of content, technical infrastructure, and agreements, with the goal of providing a single, centrally managed document that automatically displays the most recent, valid version across different EPD systems, without manual uploads per institution.

The document is positioned as part of the national NVvH guideline. The LWHB acts as the source holder and is responsible for implementing updates and withdrawing outdated versions, in collaboration with the working group of nurse specialists. The guideline consists of a PDF document with associated metadata, including title, version number, date, and target group.

The infographic is offered as a standalone document via a FHIR DocumentReference, in accordance with national healthcare standards. References do not lead directly to other PDF files, but to a central web viewer that always displays the correct underlying guideline documents. This ensures consistent navigation, regardless of the PDF viewer used within the EPD. The document remains centrally stored and is dynamically retrieved by the EPD; when changes are made, the source and metadata are updated, and the previous version is automatically deleted. Figure 34 visualizes the structure of digital information distribution.

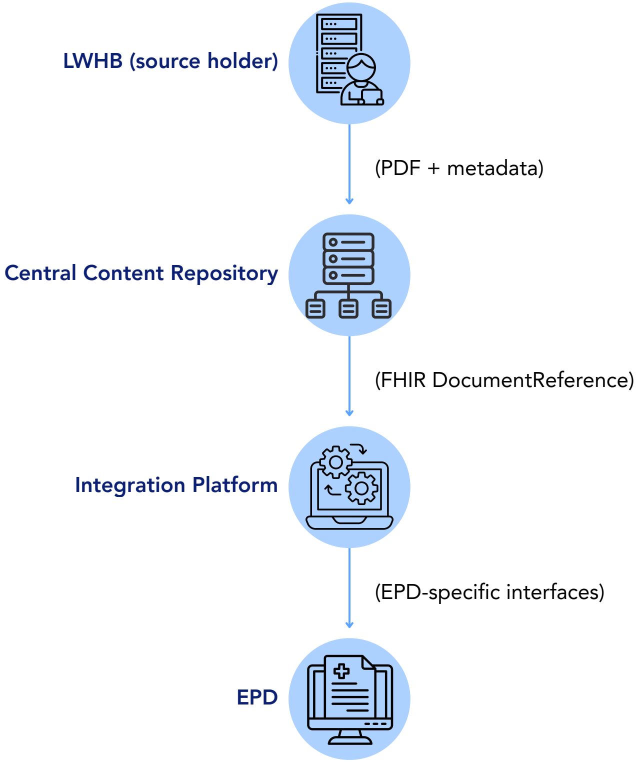


Figure 34: Structure digital distribution

Two access contexts are distinguished: healthcare providers and patients. Healthcare providers consult the document within the EPD and can share it with patients via a secure link, for example, through Digizorg or a patient portal. This method prevents the distribution of static PDF files and ensures that patients always have access to the most up-to-date version.

8.2.2 Adaptability

Adaptability is a prerequisite for sustainable implementation. If the design cannot be easily adapted, the risk of the content becoming outdated and being used less increases. Therefore, the design is structured around a clear decision-making structure, fixed update intervals, and clearly defined roles and responsibilities.

Proposals for adjustments are submitted by the working group of nurse specialists and discussed within the LWHB, where decisions are made. Updates take place at least annually, linked to a new guideline version, with room for interim adjustments if necessary. Adjustments are made in Canva, a user-friendly design tool that does not require any specific design expertise. A step-by-step explanation document has been developed to support this (Appendix I).

After implementation, a new PDF is generated and automatically replaced in the central repository, eliminating outdated versions and making the most current version available via the existing digital link for both EPDs and patient portals. Through established agreements on version management and communication, healthcare providers are informed of updates without having to actively check whether the document has been updated. Figure 35 visualizes the structure of adaptability.

Further recommendations for future research are presented in chapter 9, where the findings of this study are translated into directions for follow-up research.

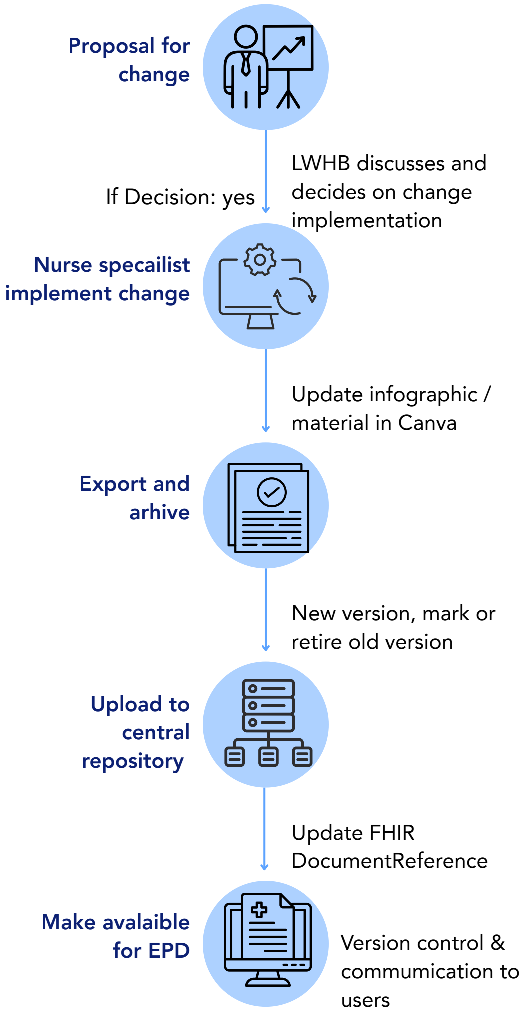


Figure 35: Structure adaptability

8.2 Reflecting on design goal

The design goal and design requirements have been reviewed to ensure that the chosen concept and strategy aligns with the intended objectives. As described in chapter 5.2.1, the design goal is:

Design a uniform and central information provision strategy that supports healthcare providers in delivering consistent and timely information about sickle cell disease, and that serves as the foundation for accessible and consistent information provision for parents and children within Dutch sickle cell care.

Uniformity & National Applicability

The infographic offers a clear basis for information provision, regardless of location or healthcare provider. This was achieved through co-creation with various healthcare providers from different centers, meaning it is not specific to a single center. It describes which information can be provided within the various stages of a child with sickle cell disease. The infographic is designed for use in all Dutch sickle cell centers and even regional hospitals could use the infographic and information materials. The implementation strategy demonstrates that incorporating the infographic with the national information materials into the guideline can achieve uniformity. Validation shows that the infographic is suitable for inclusion in the guideline and that there is indeed a need for it.

Integrated into the Care Process

By dividing the infographic into different age groups and linking relevant information at each stage, information is provided at meaningful moments in the care pathway. This infographic supports healthcare providers in determining when to provide specific information.

Support for Healthcare Providers

Collaboration is explicitly incorporated into the infographic by outlining a clear division of roles, with the nurse specialist primarily responsible for the information structure and coordination within the team. By incorporating it into the guideline the infographic provides guidance for clinical practice. Thanks to co-creation, the infographic aligns with existing work processes. While introducing a new working method and using the information set may initially feel like an additional burden, particularly as the materials become familiar, it is expected that this will no longer result in additional workload after a period of familiarization.

Consistency & Reduced Fragmentation

The strategy of incorporating the infographic into the guideline and thus creating a uniform set of materials, reduces differences in information provision between centers. Each center provides the same information. Because the infographic linking to the information materials is included in the guideline, it serves as a central reference point and is therefore easier to find for healthcare providers. This also reduces fragmentation and duplication of development.

Accessible for parents and children

The strategy provides a basis for accessible information provision for parents and children with sickle cell disease by guiding the development of an information materials tailored to the needs of parents and children, making the information more understandable and accessible.

Basis for Further Development

By including in the strategy how national development should take place the basis for future development is formed. This infographic and implementation plan (strategic and tactical roadmap) is the first step towards accessible information provision for parents and children with sickle cell disease. And offers therefore a basis for future additions.

8.4 Impact on the healthcare ecosystem

The results of this project ensure structural alignment between policy and practice by formally embedding the information strategy within national healthcare structures, rather than leaving it optional. While national guidelines at the macro level previously lacked concrete information on how to provide information, this led in practice to fragmentation and individual interpretation by healthcare providers. This project bridges this gap by making policy directly applicable in daily healthcare practice.

The developed infographic translates abstract policy goals, such as providing adequate information, into a concrete and visual guide for the consultation room. The information is structured by age and developmental stage, making it clear which information should be provided and when. By formally incorporating these materials into the NVvH Guideline, the method is elevated to a national standard, explicitly guiding practice to adhere to the policy.

This approach leads to improvements at multiple levels of the healthcare ecosystem. At the macro and meso levels, uniformity and equality in information provision are created by replacing locally developed materials with a single national standard. This increases efficiency and enables central quality assurance and updating. At the micro level, the strategy aligns with existing care processes and EHR systems, making information a standard part of the consultation. Simultaneously, care becomes more patient-centered, as information is offered proactively and tailored to the child's life stage, strengthening patients' self-reliance.

9 FUTURE RESEARCH

This chapter describes the necessary next steps and the areas requiring further development. This is done to provide insight into how the concept and strategy can be further developed and to ensure they better align with practical application and the needs of all stakeholders involved.

9.1 Next steps

The developed roadmaps serve as a starting point for further research and for a future student project aimed at developing a national information set for sickle cell disease. While this project has established a strategic framework for consistent and universally applicable information provision, additional steps are required to fully address the research question (see chapter 2.1).

This study primarily examined the perspective of healthcare providers. To ensure that the information set becomes truly accessible, future research should more explicitly focus on the experiences and information needs of parents and children. Although an initial step toward patient participation was made, further research is needed to explore these perspectives in greater depth. Based on experience gained during collaboration with OSCAR NL, patient involvement proved challenging in practice, as participants tended to respond passively or provide limited feedback. Future studies are therefore advised to keep participation methods simple, concrete, and low-threshold in order to encourage meaningful engagement.

Further research should examine how parents and children use information at home and how information needs differ across stages of the child's development. In particular, attention is needed for children from around 12 years of age, when self-management increases, as well as for differences between information provision for parents of infants and parents of adolescents.

To ensure that future information provision effectively supports parents, children, and healthcare providers, a co-creation approach is strongly recommended. Based on experience from this project, co-creation helps align information materials with real-world practice, increases relevance, and supports shared ownership. The LWHB is well positioned to function as a sounding board throughout this process, helping to maintain national alignment and commitment across centers.

Findings from the literature review confirm that existing information materials often insufficiently account for visual needs and cultural context, which can hinder comprehension (Singleton & Krause, 2009). The results of the thematic analysis, addressing sub-question 2 (see chapter 2.6.2), provide concrete directions for future development. Healthcare providers emphasized the importance of using simple language supported by visual aids, culturally sensitive and empathetic explanations, and a multimodal approach to information provision.

Future design efforts should account for real-world care contexts, including stress and limited health literacy. Prototype testing is recommended in real-world settings, such as waiting rooms or during consultations, to assess whether materials remain effective within the dynamics and time pressure of outpatient care.

Future projects are encouraged to build upon the existing roadmaps rather than starting from scratch. The infographic and roadmap provide a strategic foundation. The next step is to further structure this into concrete, visual, and accessible information that supports consistent information provision.

10 CONCLUSION

This chapter presents the conclusions of the study and answers the central research question by bringing together the key findings and reflecting on their implications for information provision in sickle cell care.

10.1 Answering the RQ

The central research question is: "How can accessible and universally applicable information be designed to support parents, children, and caregivers in sickle cell care while simultaneously ensuring consistency across all sickle cell centers in the Netherlands?"

This question is answered by an integrated strategy, consisting of a conceptual infographic structurally embedded in the national guideline for sickle cell care.

The information provision is accessible and universally applicable because it is designed as a phased information structure, based on the child's life stage. Instead of presenting a large amount of information at a single moment, information is provided in measured doses at meaningful moments in the patient journey, such as the first year of life, early childhood, school age, and adolescence. The use of visual support and simple language contributes to comprehensibility and reduces barriers related to language skills and health literacy. The infographic serves as a central blueprint that guides all care centers and specifies which topics are covered at which time.

The design supports both healthcare providers and parents and children. For healthcare providers, the infographic offers practical guidance during consultations, indicating which information is relevant and which materials are available for each age group. Furthermore, the strategy clarifies the division of roles within the care team, with the nurse specialist acting as case manager for information provision and the pediatric hematologist remaining responsible for the core medical information. For parents and children, the phased approach means they receive information that meets their current needs, which reduces information overload and promotes understanding and processing.

Consistency between the various sickle cell centers is ensured by the implementation strategy. By incorporating the infographic and accompanying information set into the national NVvH guideline, information provision becomes a formal part of the care process. Additionally, a roadmap has been developed that describes how this strategy will be further developed into definitive materials through national co-creation and sustainably managed by the LWHB.

11 DISCUSSION

The discussion reflects on the methodology, addressing what worked well and what did not. In addition, the limitations of the research are discussed, including constraints related to the participants' capacities. This chapter also reflects on the value of the project by considering what it contributes beyond the immediate research outcomes, as well as on the role and implications of using AI during the project.

11.1 Reflection on method

During this project various research and design methods were applied to understand the context and user experience and to translate these insights into well-founded design choices and an implementation strategy. These methods are being reflected upon to understand how they were used, what I learned from them and what I might do differently in a future project.

Context exploration formed the basis of this project. One of the methods within context exploration was literature research. A systematic approach was lacking here. The search terms were reconstructed based on the included articles. At the time I did not record everything, making this impossible to repeat later. At the beginning of my research I conducted observations to gain an understanding of the current care pathway for children with sickle cell disease. These observations took place exclusively at the Sophia Kinderziekenhuis. In retrospect, it would have been valuable for the research to conduct observations at various sickle cell centers to better understand the differences.

After identifying areas for further interest expert interviews were conducted. During these interviews not all care centers were equally actively involved in the project. Due to the high workload and daily priorities within healthcare it proved difficult to involve everyone involved structurally. Consequently not all centers were interviewed during the interviews. In the current approach I interviewed the people nominated by the Sophia Kinderziekenhuis. Looking back I should have had a better overview of the healthcare providers working for all centers and been able to contact them as well. A thematic analysis was then conducted. This supported the structuring and interpretation of the qualitative data from the interviews. This required critical reflection and interpretation can be subject to subjectivity.

For context analysis actor maps, work models and journey mapping were used. The actor map provided an overview of various stakeholders, their mutual relationships and their influence within the system. During the development of the actor map it became apparent that some relationships and roles were initially unclear, necessitating additional discussions to improve the overview. Using work models, roles and interactions were visualized. Bottlenecks were identified. At the same time abstracting from practice means that not all nuances of daily work are fully captured. Journey mapping was used to chart the user experience over time. This project was conducted from the healthcare provider's perspective. Parents' emotions are also based on that perspective, potentially creating a gap between what healthcare providers believe parents experience and what they actually experience.

Co-creation played a role in the design process. By collaborating with healthcare providers, perspectives emerged and engagement was fostered. The participation in this process presented a challenge: I preferred to collaborate with several partners at the same time and bring multiple centers together, so they could see what everyone else was doing and foster discussion. Due to healthcare providers' busy schedules this wasn't feasible in the short term.

Design roadmapping was used to translate insights and concepts into an implementation plan. This method supports strategic decision-making for both the short and long term, but is partly dependent on assumptions about future developments.

To evaluate the concept and strategy, a validation session was held with members of the LWHB. Organizing this session was challenging, resulting in limited input on the evaluation. In retrospect, contact should have been made earlier in the process to schedule a meeting and to incorporate their perspective on implementation within the guideline. Once the design direction was chosen this group should have been involved to create sufficient time for coordination.

11.2 Project value

The added value of this project manifests itself at three interrelated levels: the collaborative process between centers, the concrete result in the form of a uniform information strategy and design tool, and the creation of a sustainable foundation for implementation and further development.

At the process level, the project contributes to breaking down the existing fragmentation within sickle cell care. Where previously each center used its own materials and methods, healthcare providers from different centers were brought together through interviews and co-creation sessions around a shared vision for information provision. The active involvement of the LWHB, nurse specialists, and pediatric hematologists not only gained insight into mutual differences, but also created support and ownership for a joint, national approach.

The result of this process is a uniform and accessible information strategy, embodied in an infographic that serves as a blueprint for information provision. The strategy structures the care pathway by linking information to fixed, meaningful moments in the patient journey and organizing it by age and developmental stage. This provides healthcare providers with guidance on what needs to be discussed and when, clarifies responsibilities within the care team, and simultaneously lays the foundation for information that meets the needs of parents and children.

Finally, the project provides a solid foundation for future implementation and further development. By incorporating the infographic and accompanying materials into the national sickle cell disease guideline, information provision will become a structural component of the care process. Furthermore, this project established the framework for follow-up research and design: the "what" and "when" have been defined, allowing a graduate student or designer to focus on developing concrete educational materials, already incorporating coordinated input from the involved centers.

11.3 Limitations

In this project there are a few limitations that should be pointed out. First, this project was carried out by me as a single researcher. This means the analysis and conclusions may have been influenced by my own prior experiences and interpretive lens. Furthermore, the insights and interpretations were partly influenced by my perspective and my own prior knowledge of the project. Despite a critical attitude and reflection complete objectivity cannot be guaranteed.

A further limitation is my perspective as a researcher, an outsider to the hospital. While this allowed for a fresh and critical perspective it may also have led to a less thorough understanding of implicit routines, working methods and organizational nuances.

Healthcare is not considered a linear, predictable system, but rather a complex adaptive one. It's a system with many interconnected people, organizations, rules and processes. Change creates unpredictability and uncertainty (Khan et al., 2018). If something changes in one place it has consequences elsewhere. This complexity makes it difficult to fully encompass all relevant dynamics within the scope and duration of this project. Consequently, some effects or bottlenecks remain unseen, even though careful research has been conducted. This is a structural limitation of the healthcare domain.

11.4 The use of AI

During this research, I used generative artificial intelligence (AI), specifically ChatGPT, to support various stages of the research process. The use of AI was aimed at increasing productivity and facilitating creative ideation, while my own critical judgment and substantive decision-making remained paramount. Previous research shows that AI tools like ChatGPT can contribute to more efficient research processes, including by automating repetitive tasks (Zaki et al., 2025).

AI was used as a facilitator during brainstorming sessions and in determining design direction, with the aim of stimulating divergent thinking and exploring alternative perspectives (Urmeneta & Romero, 2025). I also used AI as a reflective tool in thematic analysis, to compare the results of my manual analysis and evaluate its quality and completeness (Appendix D4).

Furthermore, AI was applied as an artifact generator, where I provided initial input through targeted prompts and critically reviewed the generated output, adjusting it where necessary. Finally, I used ChatGPT to support the linguistic finishing of this thesis, specifically for spelling, grammar, and readability. All suggested changes were manually reviewed by me and remained my sole responsibility.

In reflecting on the use of AI within this project, I consider AI to be a valuable and supportive tool that can offer structure, inspiration and efficiency, particularly in a project that is largely conducted independently. At the same time, I regard a critical stance toward AI output as essential. AI-generated content does not replace human judgement, but rather requires careful evaluation, interpretation, and contextualisation. I believe that the considered use of AI has helped elevate the quality of this project in certain aspects, such as linguistic clarity and the development of visual and conceptual ideas, while the responsibility for all substantive decisions remained with me.

Ethical considerations were taken into account throughout the use of AI. These include the risk of algorithmic bias, as AI systems are not neutral but reflect patterns in their training data, potential data privacy concerns when using research-related input, and the risk that overreliance on automation could diminish critical thinking and human judgement (Urmeneta & Romero, 2025).

In summary, AI was used in this research as a productivity-enhancing and creative support tool within the research and design process. Ultimate responsibility for all interpretations, decisions, and outcomes remained with me.

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APPENDIX

The appendix has been added to include additional material relevant to the study.

Appendix A - Sickle cell disease materials

A1. Contact Sophia Kinderziekenhuis

Erasmus MC
Universitair Medisch Centrum Rotterdam

Wie kunt u bellen bij vragen?
Wie belt u bij spoed?

Polikliniek sikkelcelziekte en thalassemie

Kinderhematologie
Erasmus MC Sophia Kinderziekenhuis

Van maandag tot en met vrijdag van 09.00 tot 16.00 uur

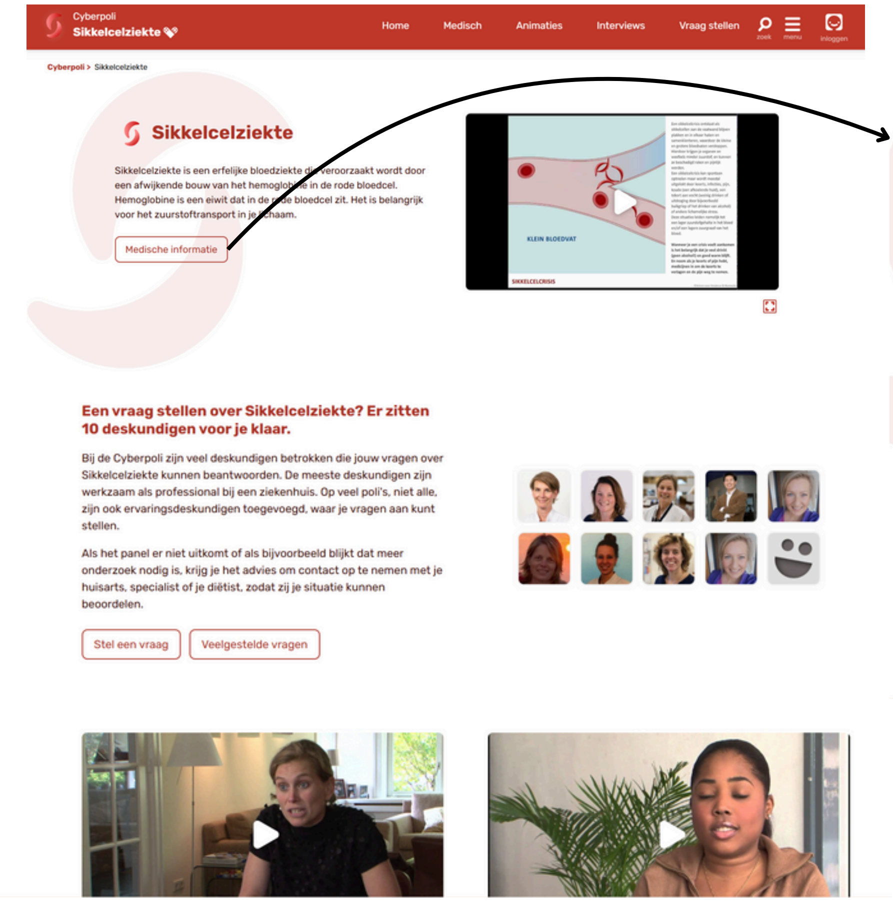
Spoed: Bij pijn, koorts en ziek zijn belt u **06-39012435**
Sikkelcel- en Thalassemie verpleegkundige

Indien de telefoon niet opgenomen wordt belt u
010-703 74 00 Balie afdeling 2 Zuid

Geen spoed: Afspraken maken, verplaatsen en afzeggen, recepten en overige vragen

1. Via de BeterDichtbij app
   BeterDichtbij
2. Of bel 010-703 74 00 Balie afdeling 2 Zuid
3. Of mail naar kindersikkelcel@erasmusmc.nl

A2. Cyberpoli



Sikkelcelziekte

Sikkelcelziekte is een erfelijke bloedziekte die veroorzaakt wordt door een afwijkende bouw van het hemoglobine in de rode bloedcel. Hemoglobine is een eiwit dat in de rode bloedcel zit. Het is belangrijk voor het zuurstoftransport in je lichaam.

Medische informatie

Een vraag stellen over Sikkelcelziekte? Er zitten 10 deskundigen voor je klaar.

Bij de Cyberpoli zijn veel deskundigen betrokken die jouw vragen over Sikkelcelziekte kunnen beantwoorden. De meeste deskundigen zijn werkzaam als professional bij een ziekenhuis. Op veel poli's, niet alle, zijn ook ervaringsdeskundigen toegevoegd, waar je vragen aan kunt stellen.

Als het panel er niet uitkomt of als bijvoorbeeld blijkt dat meer onderzoek nodig is, krijg je het advies om contact op te nemen met je huisarts, specialist of je diëtist, zodat zij je situatie kunnen beoordelen.

Stel een vraag
Veelgestelde vragen

Wat is sikkelcelziekte?

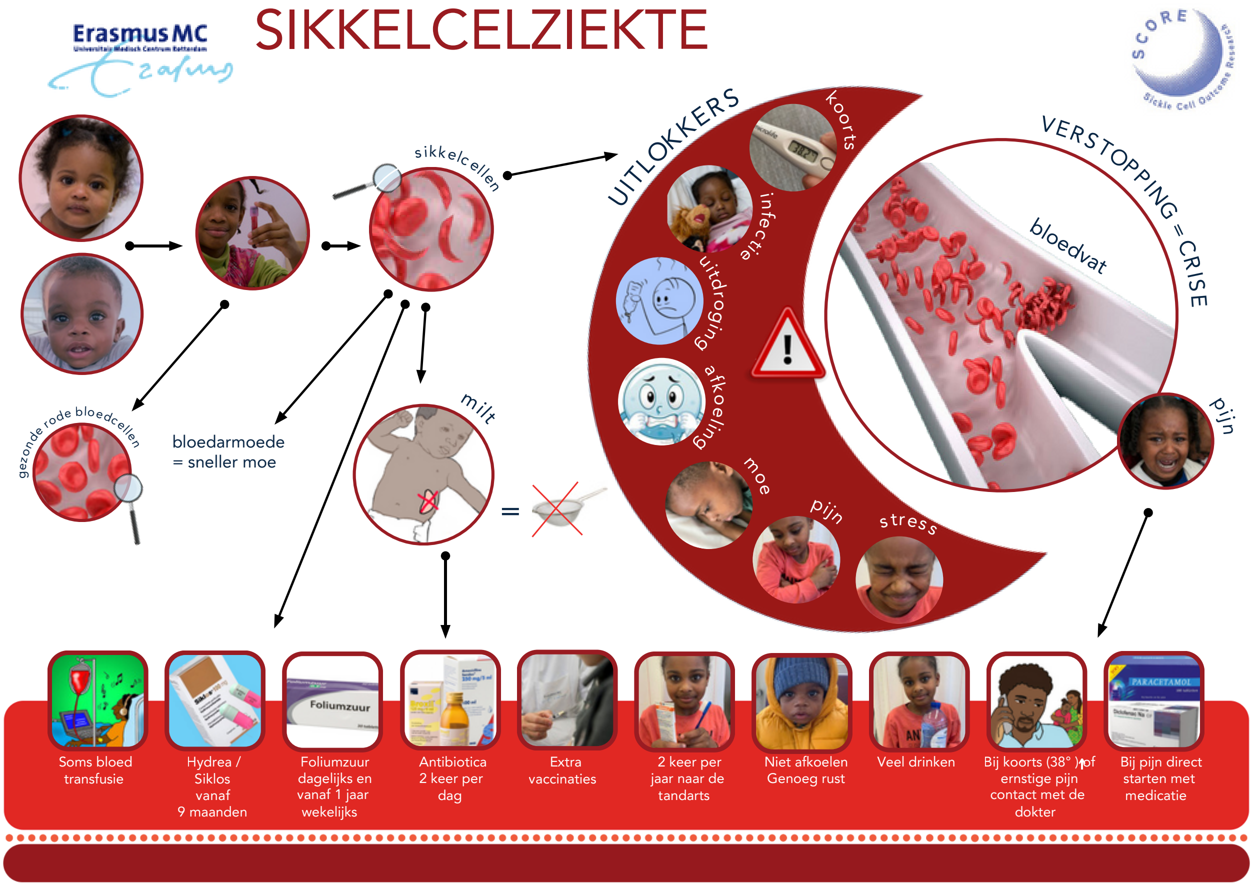
Sikkelcelziekte is een erfelijke bloedziekte die veroorzaakt wordt door een afwijkende bouw van het hemoglobine in de rode bloedcel. Hemoglobine is een eiwit dat in de rode bloedcel zit. Het is belangrijk voor het zuurstoftransport in je lichaam.

Opbouw en rol hemoglobine

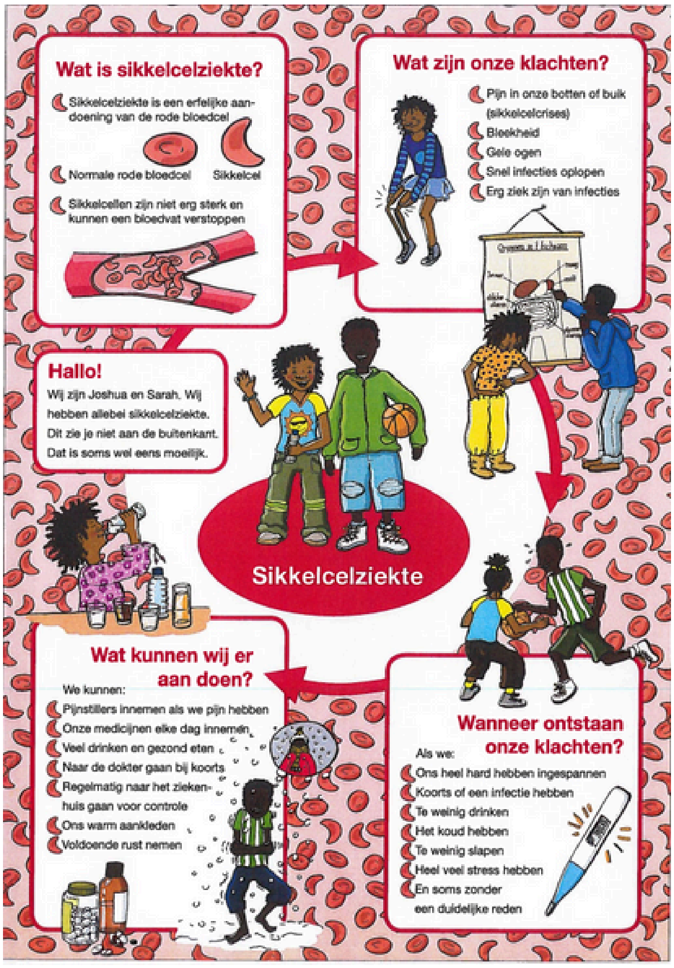
Hemoglobine is het stofje dat er voor zorgt dat de rode bloedcel roodgekleu
In de rode bloedcel zitten een groot aantal hemoglobinemoleculen. Hemogl
is een eiwit dat opgebouwd is uit vier eiwitketens; twee van het alpha globi
en twee van het bèta globine type. Deze vier eiwitketens hebben allemaal e
ion, waaraan zich zuurstof of kooldioxide kan binden. Het hemoglobine kan
vier plaatsen zuurstof of kooldioxide binden en vervoeren via het bloed doo
lichaam. Zuurstof is een heel belangrijke brandstof voor je lichaamscellen.
ademt het via je longen in, waar het wordt opgenomen in het bloed. Daar bi
zich aan het hemoglobine in de rode bloedcel. De rode bloedcellen stromen
het hele lichaam en geven onderweg zuurstof af aan alle lichaamscellen. Z
krijgen je organen zoals de hersenen, nieren, lever of spieren hun energie.

https://www.cyberpoli.nl/sikkelcel/

A3. Current information materials



Praatplaat Sophia Kinderziekenhuis



Wat is sikkelcelziekte?

- Sikkelcelziekte is een erfelijke aandoening van de rode bloedcel
- Normale rode bloedcel Sikkelcel
- Sikkelcellen zijn niet erg sterk en kunnen een bloedvat verstoppen

Wat zijn onze klachten?

- Pijn in onze botten of buik (sikkelcelcrises)
- Bleekheid
- Gele ogen
- Snel infecties oplopen
- Erg ziek zijn van infecties

Hallo!

Wij zijn Joshua en Sarah. Wij hebben allebei sikkelcelziekte. Dit zie je niet aan de buitenkant. Dat is soms wel eens moeilijk.

Sikkelcelziekte

Wat kunnen wij er aan doen?

We kunnen:

- Pijnstillers innemen als we pijn hebben
- Onze medicijnen elke dag innemen
- Veel drinken en gezond eten
- Naar de dokter gaan bij koorts
- Regelmatig naar het ziekenhuis gaan voor controle
- Ons warm aankleden
- Voldoende rust nemen

Wanneer ontstaan onze klachten?

Als we:

- Ons heel hard hebben ingespannen
- Koorts of een infectie hebben
- Te weinig drinken
- Het koud hebben
- Te weinig slapen
- Heel veel stress hebben
- En soms zonder een duidelijke reden

Praatplaat Emma Kinderziekenhuis

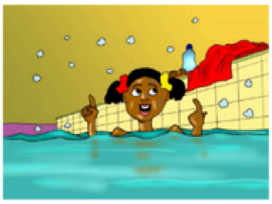
Recurring themes within the information provision

The analysis of the available materials shows that the following themes are addressed repeatedly:

- What is sickle cell disease?
- Development and prevention of complaints
- HSCT
- Bedwetting
- Hydroxyurea
- Fever
- Pain and pain relief
- School
- Vacation
- Heredity
- Pica (eating disorder in which substances that are not food are eaten (e.g., paper, cloth))
- Priapisme (A prolonged and often painful erection that occurs without sexual stimulation)
- Iron-rich food
- Vitamins and supplements

Een leerling met sikkelcelziekte
Informatie en advies voor leraren

Ziezon
landelijk netwerk ziek zijn & onderwijs



Sikkelcelziekte en zwemmen

Voorkom afkoeling, vermoeidheid en uitdroging!

Het is belangrijk dat ieder kind leert zwemmen en dus ook uw kind met sikkelcelziekte. Over het algemeen gaat dit bij de meeste kinderen met sikkelcelziekte goed mits u een aantal maatregelen treft en goed kijkt wat uw eigen kind aan kan.

Als uw kind afkoelt, te moe is of te weinig drinkt kan er makkelijker een crise (verstopping van bloedvat) ontstaan. Met name deze drie 'triggers' of 'uitlokkers' van een crise moeten rondom het zwemmen worden voorkomen.

Belangrijke adviezen en aandachtspunten:

- Licht het zwembad in over de sikkelcelziekte van uw kind en geef de badmeester/juf dit document.
- Niet bloot en nat uit het water op de kant wachten.
- Een dikke badjas en groot badlaken mee en gelijk uit het water onder de warme douche.
- Van te voren, maar ook na het zwemmen extra goed drinken.
- Als het buiten fris is een sjaal/muts op en niet buiten blijven met nat haar.
- Voor en na het zwemmen lekker uitrusten en vroeg naar bed.
- Als een kind al niet lekker of erg moe is, sla de zwemles dan een keer over.
- Wanneer het kind toch steeds tijdens of na het zwemmen pijnklachten heeft of te moe wordt, (hartkloppingen, duizeligheid, hoofdpijn) stel dan het zwemmen een jaar uit. Bespreek dit ook met de arts/ verpleegkundig(e) specialist.
- Eventueel zwemmen in een wetsuit/ surfpak.
- Kijk eventueel of er in de buurt een zwembad is met bepaalde tijden waarop het water extra verwarmd is.

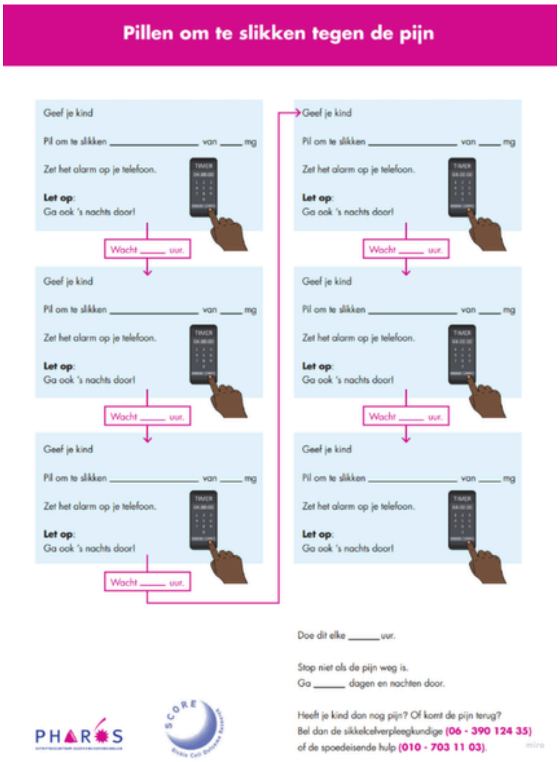
Jaarlijks wordt je bloed onderzocht en worden je lever, nieren en milt op schade gecontroleerd.

Ook wordt 1 à 2 keer per jaar hersenonderzoek gedaan om te kijken of je bloedvaten in de hersenen nog goed doorgankelijk zijn.

Als je ernstige bloedarmoede hebt wordt je hart regelmatig gecontroleerd en ook je ogen. Bij heftige buikpijn wordt gekeken of je galstenen hebt.

Daarnaast wordt uitgelegd wanneer je je moet melden bij medische problemen.

PREVENTIEVE BEHANDELING



Pillen om te slikken tegen de pijn

Geef je kind
Pil om te slikken ____________ van ____ mg
Zet het alarm op je telefoon.
Let op:
Ga ook 's nachts door!

Wacht _____ uur.

Geef je kind
Pil om te slikken ____________ van ____ mg
Zet het alarm op je telefoon.
Let op:
Ga ook 's nachts door!

Wacht _____ uur.

Geef je kind
Pil om te slikken ____________ van ____ mg
Zet het alarm op je telefoon.
Let op:
Ga ook 's nachts door!

Wacht _____ uur.

Geef je kind
Pil om te slikken ____________ van ____ mg
Zet het alarm op je telefoon.
Let op:
Ga ook 's nachts door!

Wacht _____ uur.

Geef je kind
Pil om te slikken ____________ van ____ mg
Zet het alarm op je telefoon.
Let op:
Ga ook 's nachts door!

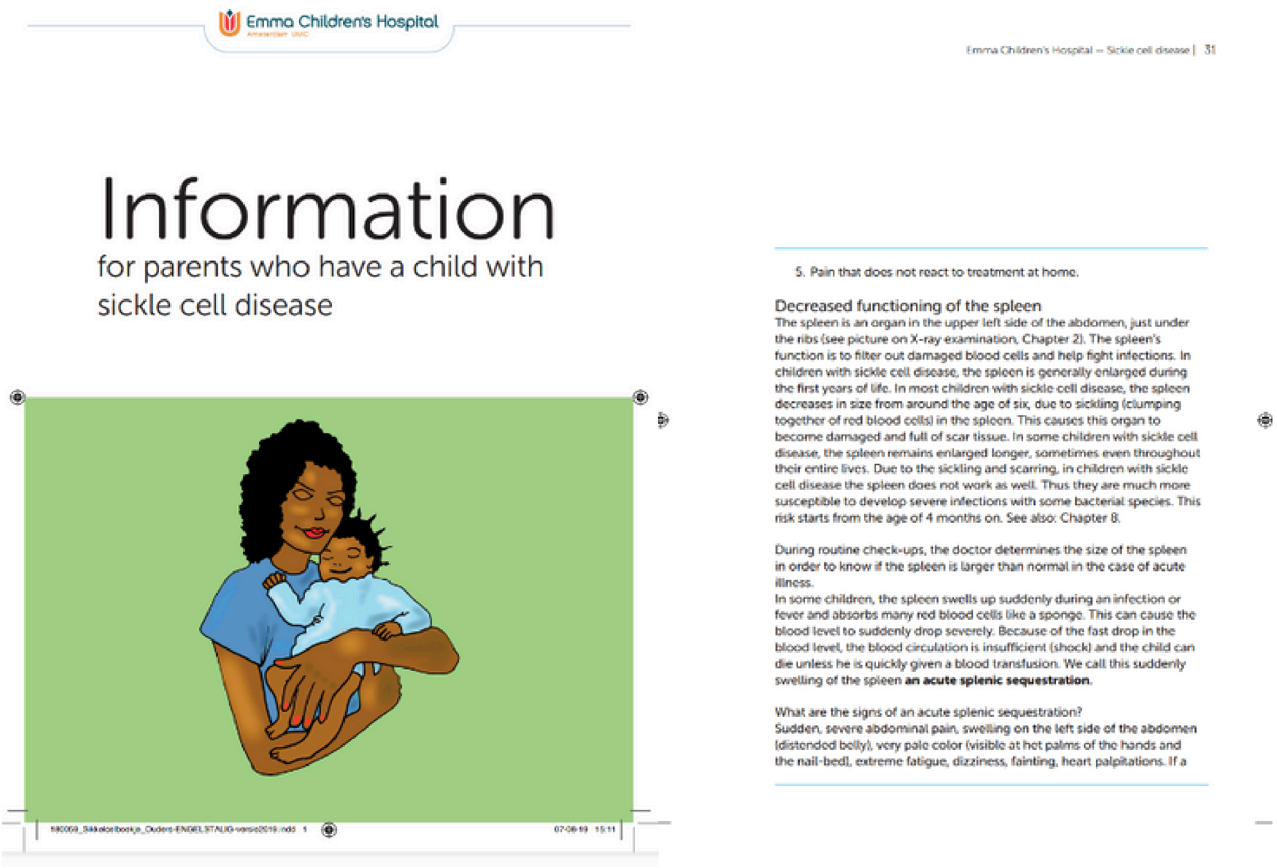
Wacht _____ uur.

Geef je kind
Pil om te slikken ____________ van ____ mg
Zet het alarm op je telefoon.
Let op:
Ga ook 's nachts door!

Doe dit elke ______ uur.

Stop niet als de pijn weg is.
Ga ______ dagen en nachten door.

Heeft je kind dan nog pijn? Of komt de pijn terug?
Bel dan de sikkelcelverpleegkundige **(06 - 390 124 35)**
of de spoedeisende hulp **(010 - 703 11 03)**.



Emma Children's Hospital
Amsterdam UMC

Information
for parents who have a child with
sickle cell disease

180069_Sikkelcelboekje_Ouders-ENGELSTALIG-versie2019.indd 1 07-08-19 15:11

Emma Children's Hospital – Sickle cell disease | 31

5. Pain that does not react to treatment at home.

Decreased functioning of the spleen

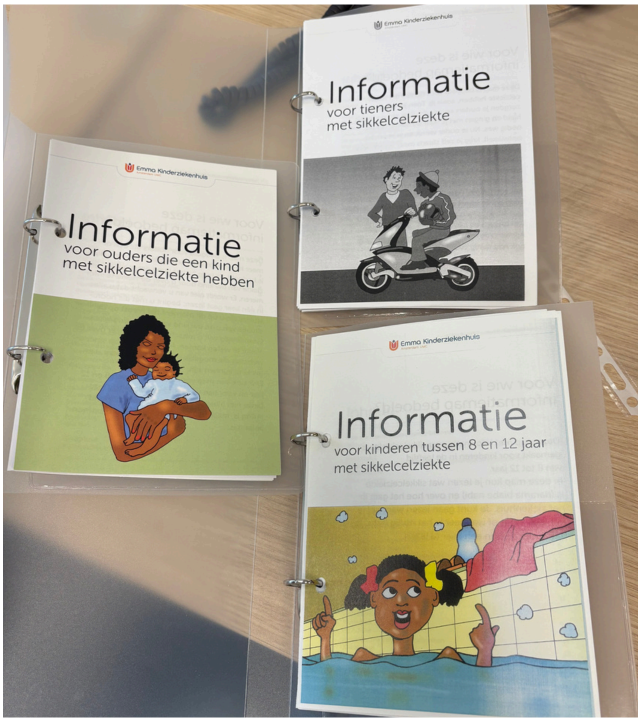
The spleen is an organ in the upper left side of the abdomen, just under the ribs (see picture on X-ray examination, Chapter 2). The spleen's function is to filter out damaged blood cells and help fight infections. In children with sickle cell disease, the spleen is generally enlarged during the first years of life. In most children with sickle cell disease, the spleen decreases in size from around the age of six, due to sickling (clumping together of red blood cells) in the spleen. This causes this organ to become damaged and full of scar tissue. In some children with sickle cell disease, the spleen remains enlarged longer, sometimes even throughout their entire lives. Due to the sickling and scarring, in children with sickle cell disease the spleen does not work as well. Thus they are much more susceptible to develop severe infections with some bacterial species. This risk starts from the age of 4 months on. See also: Chapter 8.

During routine check-ups, the doctor determines the size of the spleen in order to know if the spleen is larger than normal in the case of acute illness.
In some children, the spleen swells up suddenly during an infection or fever and absorbs many red blood cells like a sponge. This can cause the blood level to suddenly drop severely. Because of the fast drop in the blood level, the blood circulation is insufficient (shock) and the child can die unless he is quickly given a blood transfusion. We call this suddenly swelling of the spleen **an acute splenic sequestration**.

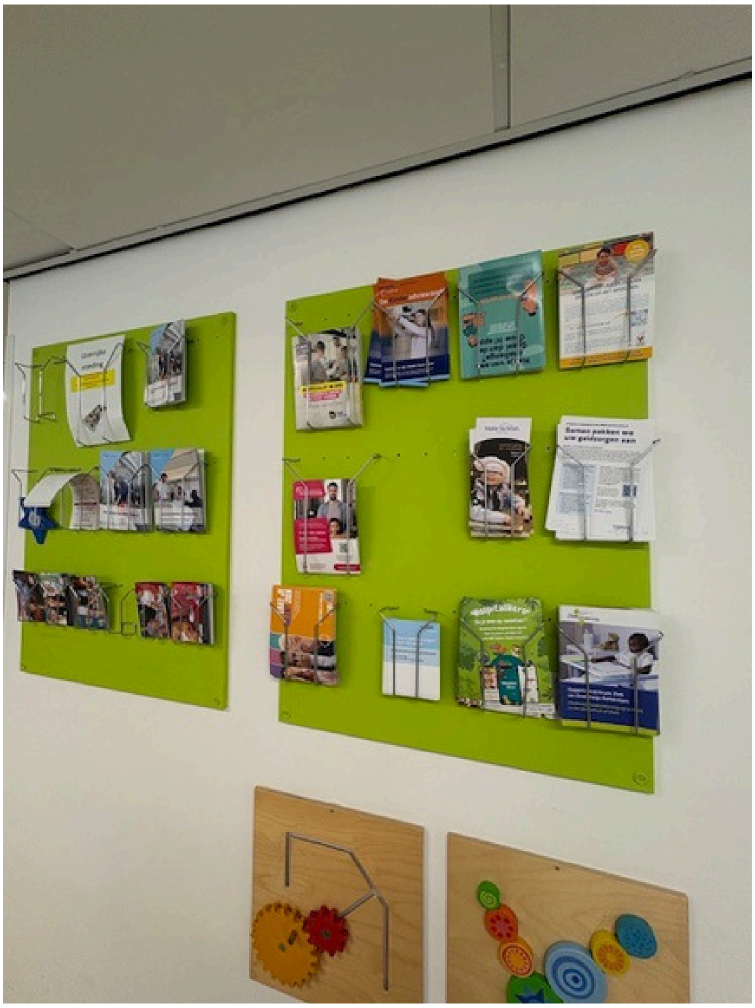
What are the signs of an acute splenic sequestration?
Sudden, severe abdominal pain, swelling on the left side of the abdomen (distended belly), very pale color (visible at hot palms of the hands and the nail-bed), extreme fatigue, dizziness, fainting, heart palpitations. If a

After diagnosis, the Emma Kinderziekenhuis provides a 38-page booklet with comprehensive information about sickle cell disease. This booklet is available in both Dutch and English and can also be accessed digitally. In addition, specific booklets have been developed for children aged 8–12 and for teenagers with sickle cell disease.

Emma Kinderziekenhuis 38-page booklet, in English. Example of page with information.



A4. Environment



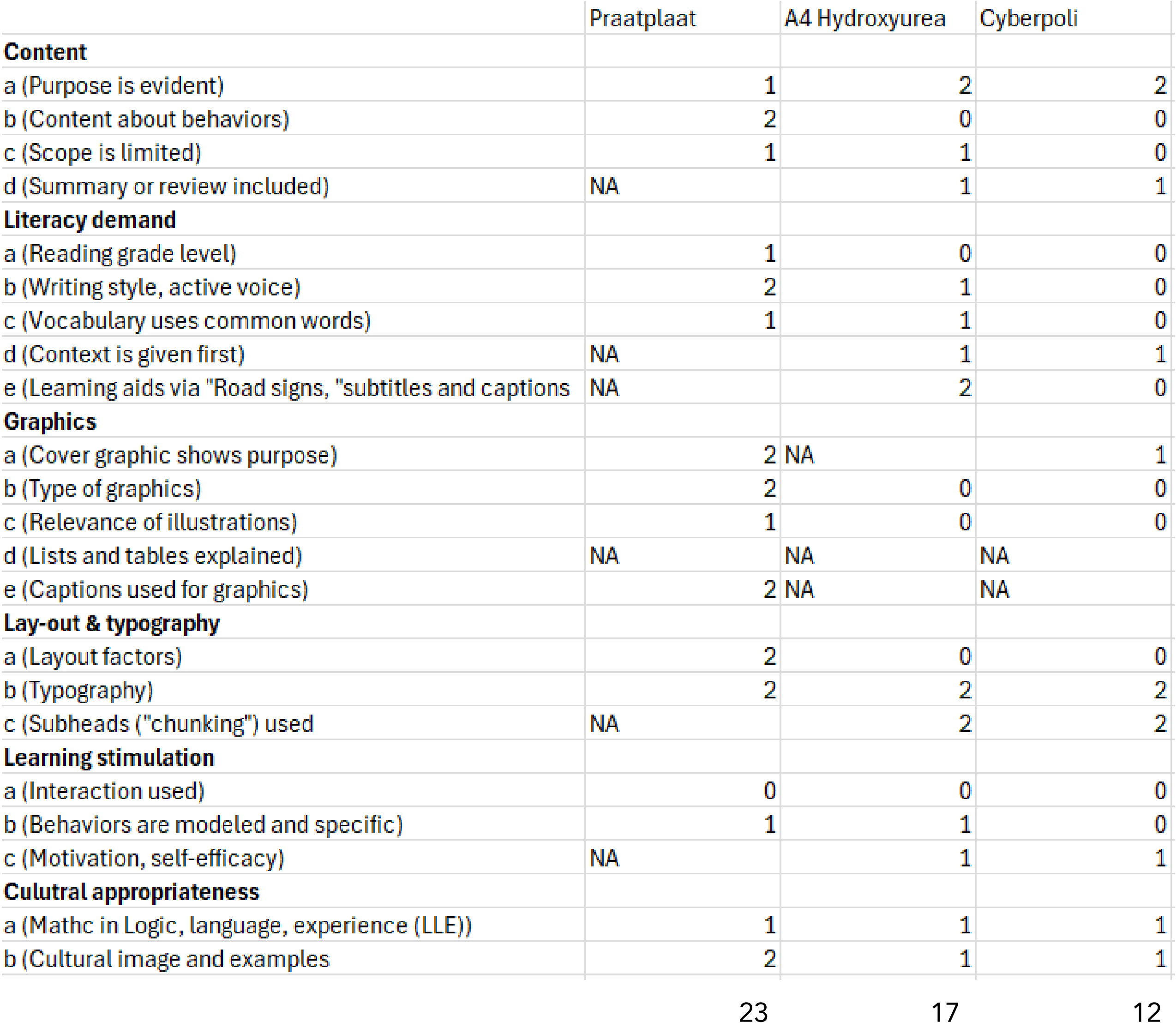
Appendix B - SAM instrument

https://ogg.osu.edu/media/documents/health_lit/HOSAM2006.pdf

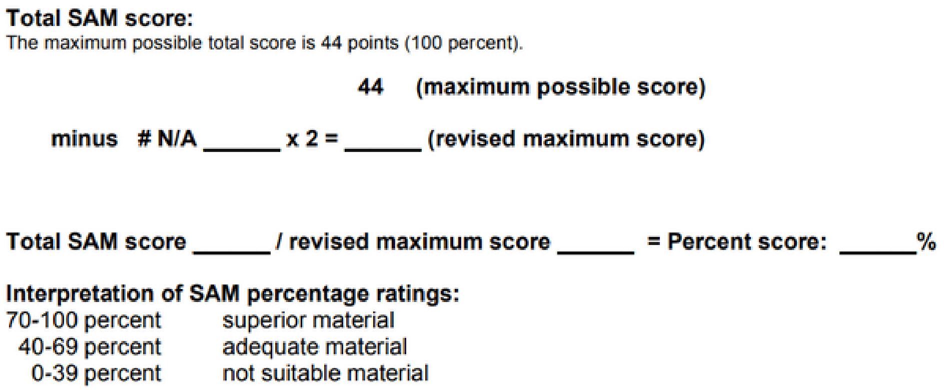
The current level of available information materials was evaluated based on existing assessment frameworks for health information. For this purpose, the Suitability Assessment of Materials (SAM) instrument, developed by Doak et al. (1996), was used. The aim of SAM is to assess the suitability of health information for patients. The instrument takes a broad view of content, language use, visual design and cultural appropriateness, divided into six categories: content, literacy demand, graphics, layout & typography, learning stimulation and cultural appropriateness. See link for full explanation and use of SAM instrument.

Three commonly used materials were assessed for this analysis:

- Praatplaat from the Sophia Kinderziekenhuis: This material is relevant because it is used directly in contact with patients and parents, and thus provides insight into how comprehensible explanations are supported.
- A4 about Hydroxyurea: an information folder that parents receive; the topic is perceived as complex and therefore suitable for analyzing how textual information connects with the language and knowledge level of parents.
- Cyberpoli (section: "What is sickle cell disease?"): an online resource to which many parents and patients are referred. By assessing the first page of text, it can be determined whether accessibility and comprehensibility are sufficient to encourage further use.



	Praatplaat	A4 Hydroxyurea	Cyberpoli
Content			
a (Purpose is evident)	1	2	2
b (Content about behaviors)	2	0	0
c (Scope is limited)	1	1	0
d (Summary or review included)	NA	1	1
Literacy demand			
a (Reading grade level)	1	0	0
b (Writing style, active voice)	2	1	0
c (Vocabulary uses common words)	1	1	0
d (Context is given first)	NA	1	1
e (Leaming aids via "Road signs, "subtitles and captions	NA	2	0
Graphics			
a (Cover graphic shows purpose)	2	NA	1
b (Type of graphics)	2	0	0
c (Relevance of illustrations)	1	0	0
d (Lists and tables explained)	NA	NA	NA
e (Captions used for graphics)	2	NA	NA
Lay-out & typography			
a (Layout factors)	2	0	0
b (Typography)	2	2	2
c (Subheads ("chunking") used	NA	2	2
Learning stimulation			
a (Interaction used)	0	0	0
b (Behaviors are modeled and specific)	1	1	0
c (Motivation, self-efficacy)	NA	1	1
Culutral appropriateness			
a (Mathc in Logic, language, experience (LLE))	1	1	1
b (Cultural image and examples	2	1	1
	23	17	12



Total SAM score:
The maximum possible total score is 44 points (100 percent).

44 (maximum possible score)

minus # N/A ______ x 2 = ______ (revised maximum score)

Total SAM score ______ / revised maximum score ______ = Percent score: ______%

Interpretation of SAM percentage ratings:

70-100 percent	superior material
40-69 percent	adequate material
0-39 percent	not suitable material

Praatplaat: 23/(44-12) = 72%
A4 Hydroxyurea: 17/(44-6) = 45%
Cyberpoli: 12/(44-4) = 30%

The results show that not all current information materials are suitable for the target group. The praatplaat scores relatively well due to its visual and accessible nature.The information brochure about Hydroxyurea is satisfactory; it is informative but not optimally accessible. Cyberpoli's online texts, in particular, contain overly complex language and insufficient visual support.

It is important to emphasize that the assessment contains some subjective interpretation. The analysis was conducted by a student with a high level of education and knowledge of health communication, which could lead to potential bias. Nevertheless, this assessment offers valuable insights into the complexity of the current materials and supports the need to develop clearer, visually supported, and culturally accessible information.

Material	Score (%)	Classification
Praatplaat Sophia Kinderziekenhuis	72%	Superior
A4 Hydroxyrea	45%	Adequate
Cyberpoli (What is sickle cell disease?)	30%	Not suitable

Appendix C - Mind map insights

C1. All insights

theme

project brief

observation

Gesprek eva

bron

Ideaal is 1 filmpje in welke taal zou je dat willen zijn.

Voor wat je mee naar huis kan geven is dat beperkt.

2. Culturele overtuigingen beïnvloeden hoe mensen gezondheidsinformatie interpreteren en erop reageren

parent bad dutch - difficult to communicate

2. Beperkte (Engelse) taalvaardigheid is vaak gekoppeld aan lagere gezondheidsgeletterdheid

Consult: een tolk aansluiten voor mondelingen voorlichting

3. Health literacy als klinisch risico

3. Health literacy als persoonlijke asset

23. 2.4 op schaal van 0-6. -> beperkte gezondheidsvaardigheden bij de meerderheid van de verzorgers

lappen tekst werkt niet

6. ook in goed uitgeruste landen er vaak ongelijkheden zijn; patiënten met SCD hebben vaker te maken met etnische minderheid, lage sociaaleconomische status, taalbarrières etc.

2. begrijpen van medische informatie / beslissing over behandeling (niet vertrouwd met westerse medische concepten)

10. systemische barrières voor deze groep, is het belangrijk dat de zorgverlening specifiek aandacht heeft voor deze context

cultural belief

language barriers

health literacy

easy language

insurance with refugees is difficult

migration background

complex information

20. Medische teksten zijn vaak moeilijk leesbaar voor leken, bijvoorbeeld door jargon, afkortingen, complexe zinsstructuren

20. Andere kenmerken zoals zinslengte en aantal woorden zijn ook relevant

7. Current disease knowledge and information provison regadering haemophilia varies and can be improved

familiar with: family situation

1.patiënt -> sociale determinant-factoren (armoede, vervoersproblemen, zorgen over werk, gezinsverplichtingen)

large household sizes

passive attitude

hereditary blood disorder

lange termijn: digi zorg

17. gebruik van visuele hulpmiddelen kan vooral helpen bij mensen met lagere scholing of wanneer taalbarrières zijn

geen tools om er visueels iets moois van te maken

accessible health care

difficult to remember

9. Wat ouders ervaren als vooral stressveroorzakers: complexiteit van de medische zorg

emotional parents

SCD

6. 4 dimensies van gezondheidszorg toegankelijkheid: fysieke toegankelijkheid, betaalbaarheid, informatie/toegankelijke communicatie en non-discriminatie

17. Vergeten veel: 40-80% van wat gezegd na de consultatie wordt vergeten

8. hogere stress bij de ouder hangt samen met slechtere uitkomsten bij het kind

stress

rare condition

15. ondersteuning voor ouders, mogelijk materiaal / bronnen (folders, digitale tools etc.)

7.centrale, gemakkelijk toegankelijke en betrouwbare (digitaal) informatieplatformen, met updates en visuele ondersteuning

6. Zes thema's met suggesties om toegankelijkheid van zorg te verbeteren

1.zorg toegankelijk is, flexibel en afgestemd op wat families nodig hebben

4. vaker pijn -> hogere ouderlijke stress -> meer gebruik van zorg

7. Overwhelmed by information: Need for strandardized centralized and tailored information

6. Perspectief van zorgprofessionals (mogelijke discrepanties tussen wat professionals denken wat nodig is en wat families ervaren)

12. Communicatie traps verhinderen dat ouders volledig deelnemen aan besluitvorming

4. Parenting stress kan de manier beïnvloeden waarop het kind de ziekte ervaart, hoe zorg gebruikt wordt en de mogelijk ook hun ander functioneren

children: understanding of condition

1.patiënt -> herkennen zorgbehoefte, bereikbaarheid, financiën, engagement

moet visueel en herkenbaar zijn

needs of families

5. Belangrijke tekorten: weinig discussie van alternatieve opties, weinig verkennen van voorkeuren van kind of ouder, weinig 'teach back'of check of de informatie begrepen is

parents: care at home

praatplaat in spreekkamer die werkt wel fijn

10.Vier hoofdthema's wat families belangrijk vinden in communicatie

7.maatwerk: afgestemd op ziekte-ernst, levensfase van kind, persoonlijke voorkeuren

mom wants what is best for her daughters

apply medical information

daily lives of patients and their families

23. verbeteringen in gezondheidsvaardigheden kunnen leiden tot een beter begrip van de ziekte en een verhoogd gevoel van zelfeffectiviteit bij verzorgers

22. Patiënten rapporteren verbeteringen in kennis van hun aandoening, in zelfvertrouwen in het managen van hun gezondheid, betere communicatie met zorgverleners, soms lagere angst

in het acute moment niet meer weten wat te doen

wat te doen bij pijn en koorts?

9.de noodzaak steeds alert te zijn / risico's inschatten, zorgen over de toekomst, impact van ziekte op dagelijkse leven, op school, op sociaal leven van het kind

a4 with text

information leaflets

5. artsen denken vaak dat ze meer betrokkenheid geven dan ouders/patiënten soms ervaren

iedereen doet waarvan die denkt dat de behoefte is

30 min consult

posters aan muur

materialen voor 5 jarige - 16 jarige / ouders hetzelfde

praatplaat (in different languages)

interactie met kinderen is anders

eteren van rmatie en unicatie in versterken pacitéit bij duen en schappen

with less complaints do not care

25% patient not showing

1x in 6 months

hospital environment

Online: beterDichtbij

21. Consistente boodschappen van verschillende zorgverleners, zodat patiënten niet tegenstijdige of verwarrende informatie krijgen

loneliness

lack of understanding (friends)

7. extra ondersteuning door multidisciplinair team en peers (lotgenoten)

6. public awareness - SCD is niet goed bekend bij publiek; stigma; misverstanden over ziekte

Universeel in elk centrum: cyber poli - website

Vaak doorverwijzing -> cyberpoli

network

SCORE - onderzoek

healthcare professionals

7. standaardiseren van wat informatie gegeven moet worden (gestructureerde aanpak)

consistency across care centers

Elk ziekenhuis heeft eigen voorlichting

7. Overwhelmed by information: Need for strandardized centralized and tailored information

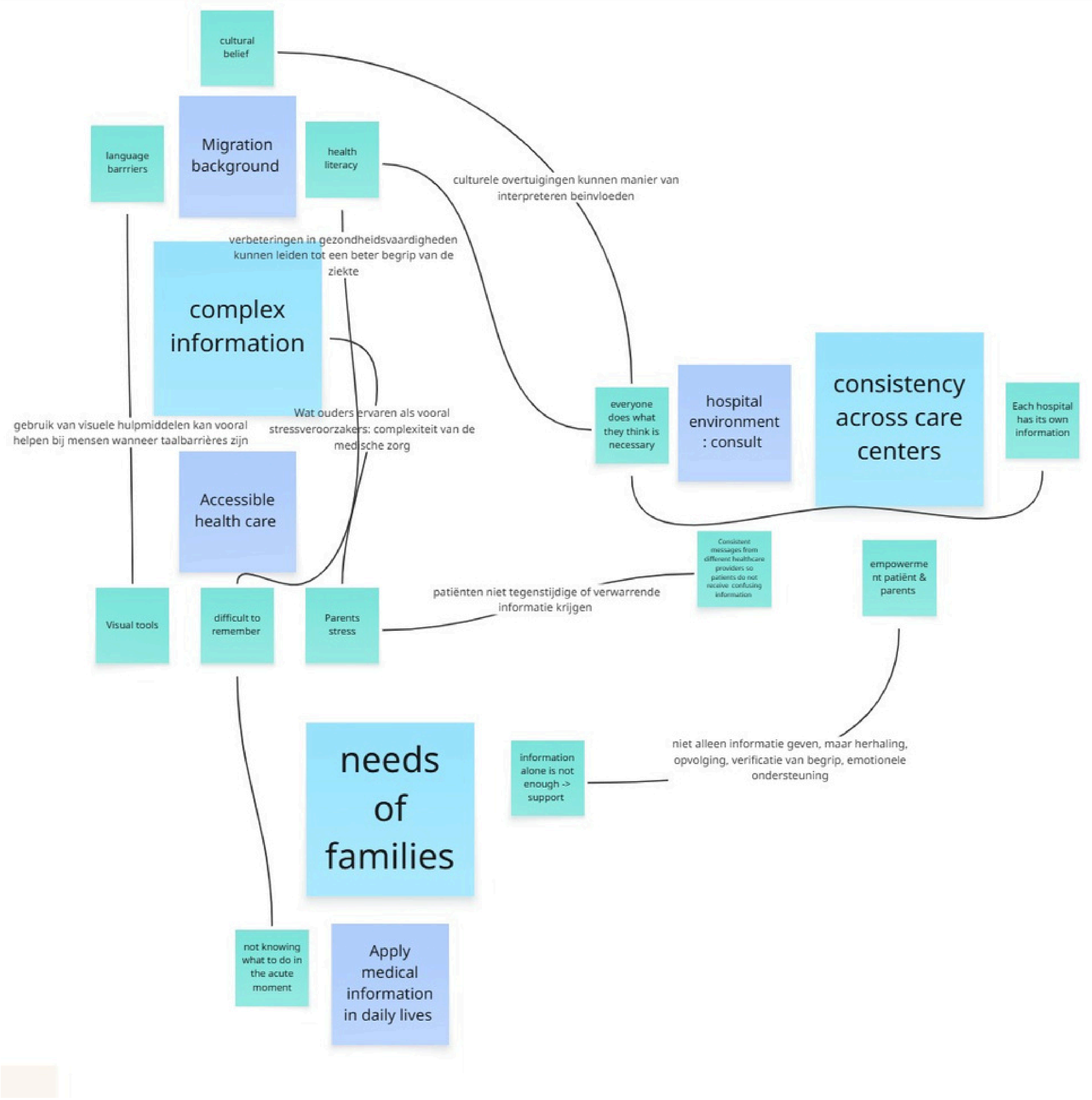
value creation

lumc heeft wel videos van stamceltransplantatie

empowerment

7. ouders meer empowerment krijgen, wat kan leiden tot betere zelfzorg, beter kwaliteit van leven, minder stress/angst en mogelijk betere uitkomsten

C2. Framework (sub-clusters)



culturele overtuigingen kunnen manier van interpreteren beïnvloeden

verbeteringen in gezondheidsvaardigheden kunnen leiden tot een beter begrip van de ziekte

gebruik van visuele hulpmiddelen kan vooral helpen bij mensen wanneer taalbarrières zijn

Wat ouders ervaren als vooral stressveroorzakers: complexiteit van de medische zorg

patiënten niet tegenstijdige of verwarrende informatie krijgen

niet alleen informatie geven, maar herhaling, opvolging, verificatie van begrip, emotionele ondersteuning

Appendix D - Interviews

D1. Interview topic guide

Introductie
Welkom, wij zijn Puck van der Veer, masterstudent Strategic Product Design TU Delft, Charlotte van Kats, masterstudent Integrated Product Design en Esther van Houten, masterstudent Geneeskunde, en doen in het kader van ons masteronderzoek/ afstudeerproject een kwalitatief onderzoek d.m.v. interviews.

Dank voor jouw/ uw deelname aan dit interview dat hieraan bijdraagt. Met onze afstudeerprojecten willen wij de health journey (gezondheidsreis) van patiënten met sikkelcelziekte verder verbeteren. Nu de care pathways (zorgpaden; wat doen we wanneer en waarom?) bij kinderen en volwassenen gereed zijn, zullen we ons nu richten op de patient journey (ervaringen van patiënten/ ouders en verzorgers en hulpverleners met het zorgpad), zodat we kunnen vaststellen wat er goed gaat en wat beter kan.

Tijdens de interviews zullen we kijken wat algemene aspecten zijn waar we rekening mee moeten houden bij communicatie en informatievoorziening bij zowel kinderen als volwassenen met sikkelcelziekte (Puck) en zullen we kijken wat specifiek nodig is om deze communicatie en informatievoorziening te verbeteren, met zowel kinderen en hun ouders/ verzorgers (Esther) met sikkelcelziekte, rondom belangrijke onderwerpen die vaak voorkomen/ besproken worden als je sikkelcelziekte hebt en in een expertisecentrum behandeld wordt. Deze onderwerpen zijn de communicatie/ informatievoorziening bij:
1) Pijn
2) Koorts/ infectie
3) Stamceltransplantatie

Middels de interviews hopen wij inzicht te krijgen in hoe communicatie en informatievoorziening nu ingericht is (huidige materialen en status quo zal ook worden verzameld en besproken), en hopen wij verbeterpunten te identificeren.

Voordat ik begin aan het interview zou ik graag u toestemming willen vragen voor deelname door het invullen van het proefpersonen informatieformulier. Daarnaast willen wij graag het gesprek op te nemen, als u je/ u geen bezwaar hebt. De opname geeft ons/ mij de mogelijkheid om het gesprek goed uit te kunnen werken en te kunnen analyseren. Alle informatie wordt uiteraard anoniem verwerkt.

Graag zou ik willen beginnen met wat 1) algemene vragen over communicatie en informatieoverdracht. Vervolgens wil ik deze aspecten verder in kaart brengen aan de hand van een 2) aantal specifieke onderwerpen. Dit maakt het makkelijker om concrete voorbeelden te geven. Tot slot wil ik oriënteren welke mogelijkheden jullie zien om de zorg in de toekomst te verbeteren.

Kennismaking zorgverlener
- Wat is uw functie binnen de zorg voor kinderen met sikkelcelziekte?
- Hoelang bent u al werkzaam in deze functie?
- Op wat voor momenten heeft u contact met de patiëntengroep?
- Kunt u de patiënten-mix omschrijven (leeftijd, talen)?

Communicatie
- Hoe ervaart u over het algemeen het contact met de patiëntengroep en ouder(s)/verzorger(s)?
- Wat zijn de grootste uitdagingen binnen het contact?
- Wat zijn manieren om deze communicatie te verbeteren in uw ervaring?
- Wat heeft u in de loop der tijd over deze communicatie geleerd?

Informatieoverdracht (algemeen)
- Welke informatie geeft u tijdens een poliklinische afspraak/ klinische opname aan de patiënt en ouder(s)/verzorger(s)?
- Welke momenten tijdens een poliklinische afspraak/ klinische opname vindt u informatie kritisch?
- Hoe reageren ouders meestal wanneer ze de eerste uitleg krijgen na diagnose
- Wat adviseert u patiënten en ouder(s)/verzorger(s) betreffende zelfzorg in de thuissituatie?
o Preventieve maatregelen/ Leefregels
o Monitoring/ follow up van hun gezondheid, belang controle afspraken
o Acties die ondernomen dienen te worden bij klachten
- Welke behandelingsmogelijkheden worden besproken? Zijn er factoren die ertoe leiden dat u bepaalde opties niet bespreekbaar maakt?
Indien nog niet aan bod gekomen: “Zijn er specifieke demografische en/of sociale patiëntkarakteristieken waardoor u besluit een stamceltransplantatie niet te bespreken?”
- Welke situaties vindt u het meest uitdagend in het uitleggen van de ziekte of behandeling?
- Welke vragen of zorgen komen het vaakst terug bij patiënten en ouder(s)/verzorger(s)?
- Hoe wordt informatie aangepast aan de leeftijd van het kind?
- Zijn patiënten en ouder(s)/ verzorger(s) over het algemeen goed op de hoogte van hun ziekte en wat hiervoor belangrijk is? Zijn er kennishiaten? Hoe merkt u dit? Hoe gaat u hiermee om?
- Presenteren patiënten zich later met klachten dan wenselijk is? Welke factoren spelen hierin mee, denk je/ denkt u? Kan hierop worden ingespeeld door de zorgverlener?
- Hoe gaat u om met momenten waarop u merkt dat belangrijke informatie niet is begrepen, maar u zelf weinig tijd heeft om uitgebreid te informeren?
- Hoe zou de communicatie en informatieoverdracht beter kunnen worden ondersteund?

Voorlichtingsmaterialen
- Op welke manier ontvangen patiënten en ouder(s)/verzorger(s) belangrijke informatie over de ziekte/ ziekteproces/ behandeling/ complicaties die gerelateerd zijn aan sikkelcelziekte?
Zijn er ook voorlichtingsmaterialen/ folders of andere manieren van informatie overdragen beschikbaar?
o Zo ja, over welke thema’s is er voorlichtingsmateriaal beschikbaar?
o Zo ja, is er ook voorlichtingsmateriaal voor kinderen in verschillende leeftijdsgroepen?
o Zo ja, zijn deze voorlichtingsmaterialen ook in verschillende talen beschikbaar?
(Huidige materialen meenemen, inscannen en archiveren)
- Zijn er (voorlichtings)materialen die het mondeling consult ondersteunen tijdens het gesprek?
- Waar ziet u dat ouders en kinderen het meeste behoefte aan hebben in de informatievoorziening?

-Heeft u het idee dat de (mondelinge) informatie die u heeft overgebracht aan de patiënt en ouder(s)/verzorger(s) volledig begrepen wordt? Komt het wel eens voor dat u op lange termijn ontdekt dat informatie of begrip mist? Hoe uit zich dat?
-Wat is het niveau van taalbegrip dat u denkt dat nodig is om deze voorlichtingsmaterialen te begrijpen? Zijn deze ook volgens Pharos richtlijnen opgesteld? Heeft u het idee dat de huidige informatievoorziening(en) aansluit bij de gezondheidsvaardigheden en wensen/behoeften van patiënten en ouder(s)/ verzorger(s)?
-Heeft u het idee dat de huidige informatievoorziening(en) aansluit bij de gezondheidsvaardigheden en wensen/behoeften van patiënten en ouder(s)/verzorger(s)?
-(Aan de hand van materialen bespreken: wat is er goed en wat kan er beter m.n. voor verpleegkundigen/ verpleegkundig specialisten)

Koorts
- (Indien nog niet eerder expliciet aan bod gekomen bij de informatievoorziening). Welke instructies geeft u patiënten en ouder(s)/ verzorger(s) mee over koorts?
- In welke mate worden preventieve adviezen (penicilline profylaxe) opgevolgd?
- Wordt wel eens gekozen voor maandelijkse i.m. toediening gekozen bij slechte therapietrouw van de onderhouds/ preventieve antibiotica?
- In welke omstandigheden worden patiënten en ouder(s)/ verzorger(s) geïnstrueerd om contact op te nemen met het ziekenhuis bij koorts? Volgen patiënten en ouder(s)/ verzorger(s) dit ook op? Indien dit niet plaatsvindt, welke factoren liggen hieraan ten grondslag?
- Wordt de voorgeschreven antibiotica adequaat ingenomen bij koorts?

Pijnbestrijding
- Hoe ervaart u de zorg rondom pijnbestrijding?
- (Indien nog niet eerder expliciet aan bod gekomen bij de informatievoorziening). Welke adviezen geeft u omtrent pijnstilling (zowel niet-medicamenteus als medicamenteus) in de thuissituatie?
- Worden deze adviezen adequaat opgevolgd door patiënten en ouder(s)/ verzorger(s)?
- In welke omstandigheden worden patiënten en ouder(s)/ verzorger(s) geïnstrueerd om contact op te nemen met het ziekenhuis bij pijn? Volgen patiënten en ouder(s)/ verzorger(s) dit ook op? Indien dit niet plaatsvindt, welke factoren liggen hieraan ten grondslag?
- Hoe schat u de pijn in tijdens presentatie in het ziekenhuis? Welke pijnschalen worden door u veelal gebruikt?
- Welke adviezen geeft u omtrent pijnstilling (zowel niet-medicamenteus als medicamenteus) in het ziekenhuis?
- Wordt er gebruik gemaakt van een pijnbehandelplan welke individueel is opgesteld voor een patiënt?
- Hoe verloopt de communicatie met patiënt en ouder(s)/verzorger(s) rondom pijnstilling? Wat gaat er goed? Tegen welke moeilijkheden loopt u aan?
- Hoe verloopt de communicatie en samenwerking met andere zorgverleners (expliciet SEH-medewerkers en anesthesie)? Wat gaat er goed? Tegen welke moeilijkheden loopt u aan?

Stamceltherapie
- Hoe ervaart u het verschil in gesprekken over stamceltherapie vergeleken met gesprekken over andere behandelopties (bijvoorbeeld hydroxyureum of bloedtransfusies)?
- Welke emoties (bijvoorbeeld hoop, angst, twijfel) spelen vaak een grote rol bij dit onderwerp, en hoe beïnvloeden die het gesprek?
- Hoe betrekt u kinderen zelf bij dit onderwerp, afhankelijk van leeftijd en ontwikkelingsniveau?

Verschillen tussen patiëntengroepen en interculturele communicatie
- Ervaart u verschillen tussen bepaalde patiëntengroepen? Bijvoorbeeld in de manier waarop zorg geleverd wordt, communicatie of therapietrouw? Dit hoeft niet op basis van ziektebeeld te zijn, maar kunnen ook andere onderscheidende factoren zijn.
- Welke culturele of religieuze overtuigingen komt u tegen in gesprekken over behandelingsopties, en hoe beïnvloeden die het besluitvormingsproces?
- Bent u van mening dat er genoeg aandacht is voor interculturele communicatie? Hoe heeft u deze vaardigheden ontwikkeld? Heeft u bijvoorbeeld speciale trainingen gevolgd om deze vaardigheden te ontwikkelen?
- Wordt u ondersteund en/of heeft u hulpmiddelen bij uitdagingen in interculturele communicatie?
- Merkt u tijdens het leveren van de zorg dat er soms sprake is van een verminderd begrip van medische terminologie, laaggeletterdheid of taalbarrières?
o Hoe beïnvloed dat de zorg die u kunt leveren?
o Hoe navigeert u uitdagingen hierin?

Afspraken en therapietrouw (alleen indien tijd)
- Worden (controle) afspraken in het ziekenhuis goed bezocht door patiënten met sikkelcelziekte en hun ouders/ verzorgers?
- Waarom zijn deze afspraken belangrijk wat u/ jou betreft? Hoe wordt hier doorgaans mee omgegaan?
- Hoe ervaart u de medicatie-trouw onder patiënten?
- Zijn er factoren die het innemen van medicatie kunnen beïnvloeden?
- Wat zijn de mogelijke gevolgen wanneer medicatie niet volgens voorschrift wordt ingenomen? Hoe wordt dit besproken met patiënten en ouder(s)/verzorger(s)?

Toekomst
- Hoe heeft u de zorg voor sikkelcelpatiënten tijdens uw werk zien veranderen?
- Hoe ziet u de zorg voor kinderen met sikkelcelziekte in de toekomst voor zich? Zijn er specifieke thema's die in de toekomst meer prioriteit behoeven?
- Informatievoorziening
o Zou u behoefte hebben aan fysieke en/of digitale voorlichtingsmaterialen? Hoe zou dit in uw dagelijks werk geïntegreerd kunnen worden?
o Zijn er specifieke thema's die uws inziens extra aandacht verdienen bij het ontwerpen van de voorlichtingsmaterialen?
- Praktische toepasbaarheid
o Hoe zou een nieuw informatie-instrument in uw dagelijks werk geïntegreerd kunnen worden?
o Welke randvoorwaarden zijn belangrijk (taal, tijd, vorm, gebruiksgemak)
o Wat zou u als arts/verpleegkundige zelf nodig hebben om dit effectief te gebruiken? Hoe zou dit in uw workflow passen zonder extra werkdruk?
o Wat zijn risico's of valkuilen die we moeten voorkomen?

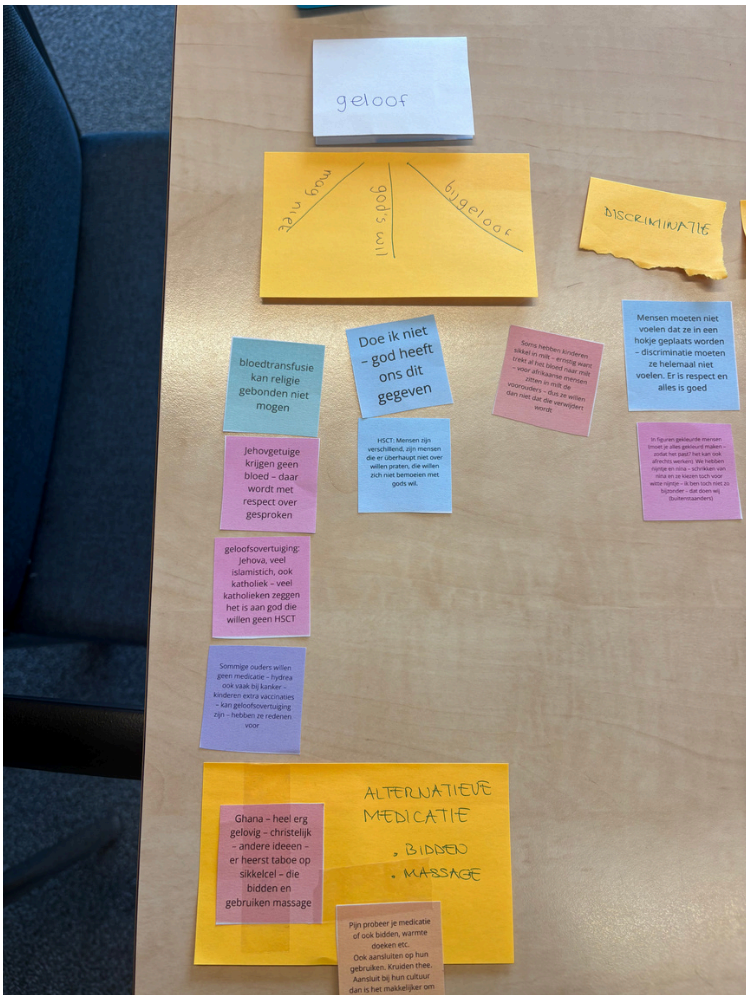
The transcripts and audio recordings are shared and stored within a secure OneDrive environment of Erasmus MC. This environment is accessible only to authorized members of the research team. The storage and sharing of these files are carried out in accordance with the applicable privacy and data security policies of Microsoft OneDrive.

The participants provided prior consent by signing the informed consent form, which explicitly states that the transcripts and audio recordings may be stored and shared in this manner.

D2. Thematic analysis

Performing the thematic analysis by hand witch sticky notes.

Belief, culture, digital, child and awareness



bloedtransfusie kan religie gebonden niet mogen

Doe ik niet – god heeft ons dit gegeven

Soms hebben kinderen sikkel in milt – ernstig want trekt al het bloed naar milt – voor afrikaanse mensen zitten in milt de voorouders – dus ze willen dan niet dat die verwijdert wordt

Mensen moeten niet voelen dat ze in een hokje geplaats worden – discriminatie moeten ze helemaal niet voelen. Er is respect en alles is goed

Jehovgetuige krijgen geen bloed – daar wordt met respect over gesproken

HSCT: Mensen zijn verschillend, zijn mensen die er überhaupt niet over willen praten, die willen zich niet bemoeien met gods wil.

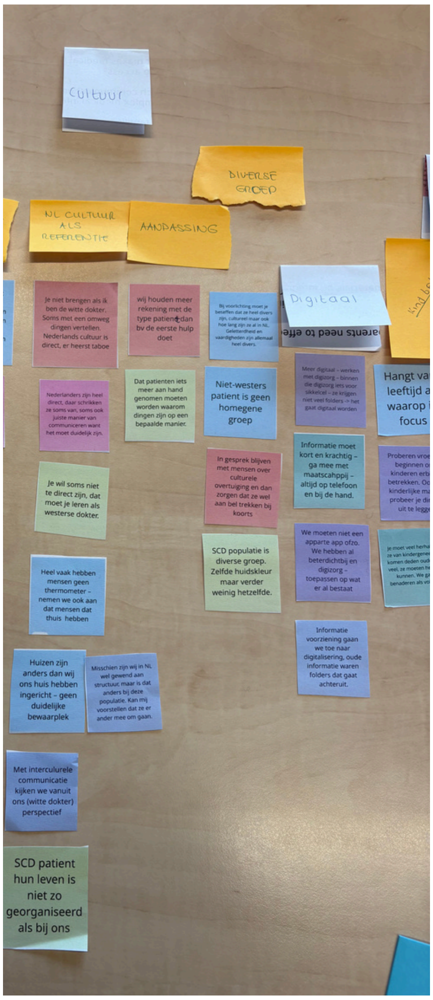
In figuren gekleurde mensen (moet je alles gekleurd maken – zodat het past? het kan ook afrechts werken) We hebben nijntje en nina – schrikken van nina en ze kiezen toch voor witte nijntje – ik ben toch niet zo bijzonder – dat doen wij (buitenstaanders)

geloofsovertuiging: Jehova, veel islamistich, ook katholiek – veel katholieken zeggen het is aan god die willen geen HSCT

Sommige ouders willen geen medicatie – hydrea ook vaak bij kanker – kinderen extra vaccinaties – kan geloofsovertuiging zijn – hebben ze redenen voor

Ghana – heel erg gelovig – christelijk – andere ideeen – er heerst taboe op sikkelcel – die bidden en gebruiken massage

Pijn probeer je medicatie of ook bidden, warmte doeken etc.
Ook aansluiten op hun gebruiken. Kruiden thee. Aansluit bij hun cultuur dan is het makkelijker om



Je niet brengen als ik ben de witte dokter. Soms met een omweg dingen vertellen. Nederlands cultuur is direct, er heerst taboe

wij houden meer rekening met de type patient dan bv de eerste hulp doet

Bij voorlichting moet je beseffen dat ze heel divers zijn, cultureel maar ook hoe lang zijn ze al in NL. Geletterdheid en vaardigheden zijn allemaal heel divers.

Nederlanders zijn heel direct, daar schrikken ze soms van, soms ook juiste manier van communiceren want het moet duidelijk zijn.

Dat patienten iets meer aan hand genomen moeten worden waarom dingen zijn op een bepaalde manier.

Niet-westers patient is geen homegene groep

Meer digitaal – werken met digizorg – binnen die digizorg iets voor sikkelcel – ze krijgen niet veel folders -> het gaat digitaal worden

Je wil soms niet te direct zijn, dat moet je leren als westerse dokter.

In gesprek blijven met mensen over culturele overtuiging en dan zorgen dat ze wel aan bel trekken bij koorts

Informatie moet kort en krachtig – ga mee met maatscahppij – altijd op telefoon en bij de hand.

Heel vaak hebben mensen geen thermometer – nemen we ook aan dat mensen dat thuis hebben

SCD populatie is diverse groep. Zelfde huidskleur maar verder weinig hetzelfde.

We moeten niet een apparte app ofzo. We hebben al beterdichtbij en digizorg – toepassen op wat er al bestaat

Informatie voorziening gaan we toe naar digitalisering, oude informatie waren folders dat gaat achteruit.

Huizen zijn anders dan wij ons huis hebben ingericht – geen duidelijke bewaarplek

Misschien zijn wij in NL wel gewend aan structuur, maar is dat anders bij deze populatie. Kan mij voorstellen dat ze er ander mee om gaan.

Met interculurele communicatie kijken we vanuit ons (witte dokter) perspectief

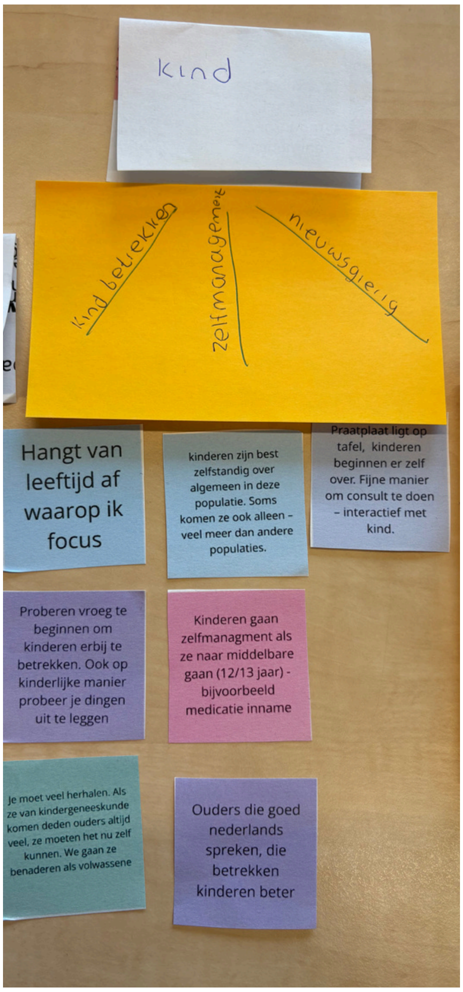
SCD patient hun leven is niet zo georganiseerd als bij ons

Meer digitaal – werken met digizorg – binnen die digizorg iets voor sikkelcel – ze krijgen niet veel folders -> het gaat digitaal worden

Informatie moet kort en krachtig – ga mee met maatscahppij – altijd op telefoon en bij de hand.

We moeten niet een apparte app ofzo. We hebben al beterdichtbij en digizorg – toepassen op wat er al bestaat

Informatie voorziening gaan we toe naar digitalisering, oude informatie waren folders dat gaat achteruit.



Hangt van leeftijd af waarop ik focus

kinderen zijn best zelfstandig over algemeen in deze populatie. Soms komen ze ook alleen – veel meer dan andere populaties.

Praatplaat ligt op tafel, kinderen beginnen er zelf over. Fijne manier om consult te doen – interactief met kind.

Proberen vroeg te beginnen om kinderen erbij te betrekken. Ook op kinderlijke manier probeer je dingen uit te leggen

Kinderen gaan zelfmanagment als ze naar middelbare gaan (12/13 jaar) - bijvoorbeeld medicatie inname

Je moet veel herhalen. Als ze van kindergeneeskunde komen deden ouders altijd veel, ze moeten het nu zelf kunnen. We gaan ze benaderen als volwassene

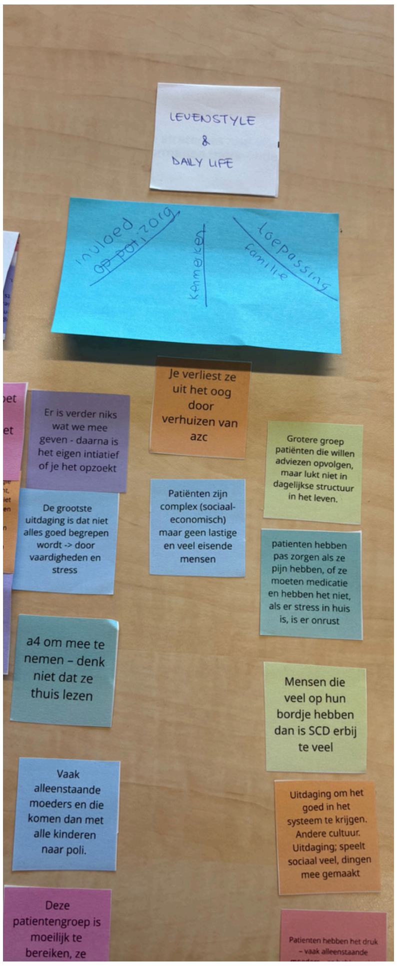
Ouders die goed nederlands spreken, die betrekken kinderen beter

In media moet meer aandacht, het is nog te onbekend

Contrast kinderoncologie zo groot – kwa aandacht, taboe dat mensen het niet mogen weten, die mensen krijgen aandacht en cadeautje en bij SCD kan ik ze niks mee geven terwijl omstandigheden thuis soms slechter zijn

Sommige mensen hebben al gezien bij familie leden – klachten of overleden – dat kan je beeld veranderen

Lifestyle & daily life, consistency, low treshold contact, sickle cell disease information transfer



LEVENSTYLE & DAILY LIFE

invloed op patiënt zorg

kenmerken

toepassing familie

Je verliest ze uit het oog door verhuizen van azc

Er is verder niks wat we mee geven - daarna is het eigen intiatief of je het opzoekt

Grotere groep patiënten die willen adviezen opvolgen, maar lukt niet in dagelijkse structuur in het leven.

De grootste uitdaging is dat niet alles goed begrepen wordt -> door vaardigheden en stress

Patiënten zijn complex (sociaal-economisch) maar geen lastige en veel eisende mensen

patienten hebben pas zorgen als ze pijn hebben, of ze moeten medicatie en hebben het niet, als er stress in huis is, is er onrust

a4 om mee te nemen – denk niet dat ze thuis lezen

Mensen die veel op hun bordje hebben dan is SCD erbij te veel

Vaak alleenstaande moeders en die komen dan met alle kinderen naar poli.

Uitdaging om het goed in het systeem te krijgen. Andere cultuur. Uitdaging; speelt sociaal veel, dingen mee gemaakt

Deze patientengroep is moeilijk te bereiken, ze

Patienten hebben het druk – vaak alleenstaande

Deze patientengroep is moeilijk te bereiken, ze hebben moeite met afspraken

Patienten hebben het druk – vaak alleenstaande moeders – ze hebben niet alle tijd of ruimte om heel boek te lezen- het moet echt makkelijk zijn

naar ziekenhuis komen krijgen ze dan niet georganiseerd, dus dan kan je beter wachten met bellen voordat je adviezen niet opvolgt

Er is altijd een verhaal achter waarom niet therapietrouw.

Dingen mee geven op papier verdwijnt

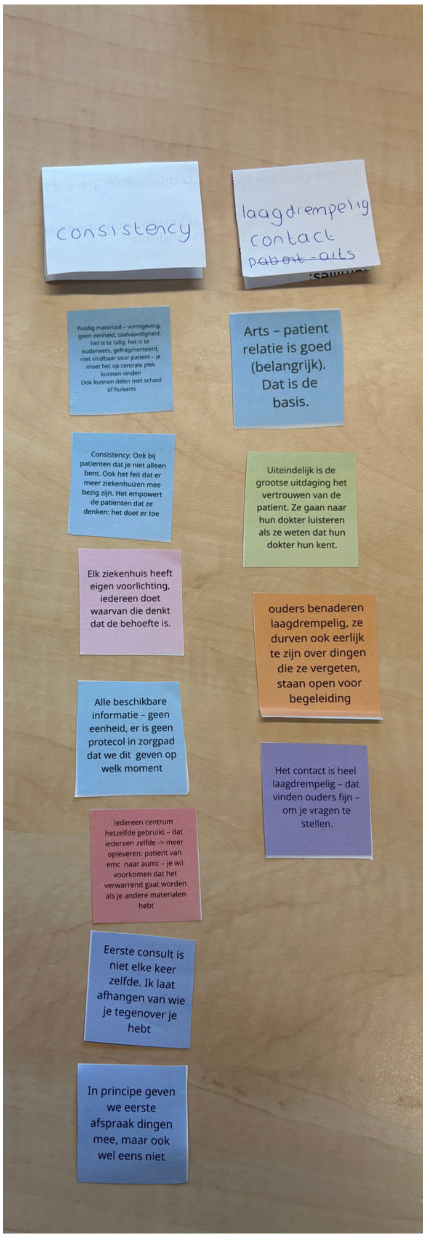
SCD is een bijkomstigheid

Bij mij gaat het heel vaak over geld en vervoer om naar ziekenhuis komen

In het acute moment niet meer weten wat te doen

Sikkelcelzorg is altijd onvoorspelbaar – soms komt de helft

Financiële zorgen – Niet alle medicatie vergoed. Is ook wel eens een reden waarom ze het niet nemen.



consistency

laagdrempelig contact ~~patient~~-arts

huidig materiaal – vormgeving, geen eenheid, taalvaardigheid, het is te talig, het is te ouderwets, gefragmenteerd, niet vindbaar voor patient – je moet het op centrale plek kunnen vinden
Ook kunnen delen met school of huisarts

Arts – patient relatie is goed (belangrijk). Dat is de basis.

Consistency: Ook bij patienten dat je niet alleen bent. Ook het feit dat er meer ziekenhuizen mee bezig zijn. Het empowert de patienten dat ze denken: het doet er toe

Uiteindelijk is de grootse uitdaging het vertrouwen van de patient. Ze gaan naar hun dokter luisteren als ze weten dat hun dokter hun kent.

Elk ziekenhuis heeft eigen voorlichting, iedereen doet waarvan die denkt dat de behoefte is.

ouders benaderen laagdrempelig, ze durven ook eerlijk te zijn over dingen die ze vergeten, staan open voor begeleiding

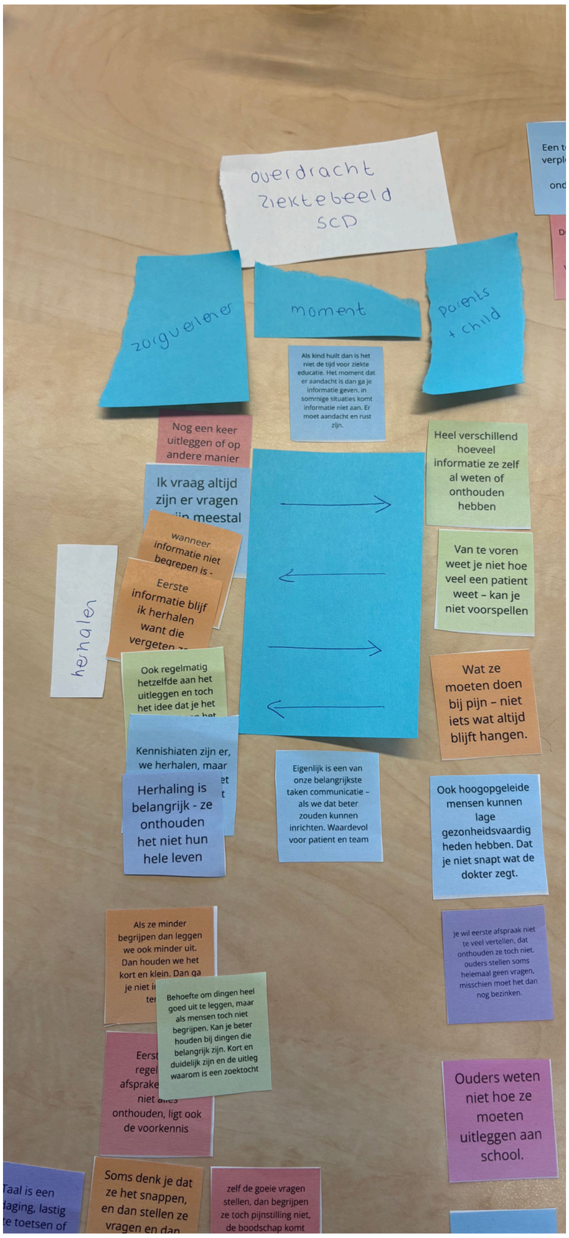
Alle beschikbare informatie – geen eenheid, er is geen protecol in zorgpad dat we dit geven op welk moment

Het contact is heel laagdrempelig – dat vinden ouders fijn – om je vragen te stellen.

Iedereen centrum hetzelfde gebruikt – dat iedereen zelfde -> meer opleveren: patient van emc naar aumc – je wil voorkomen dat het verwarrend gaat worden als je andere materialen hebt

Eerste consult is niet elke keer zelfde. Ik laat afhangen van wie je tegenover je hebt

In principe geven we eerste afspraak dingen mee, maar ook wel eens niet



overdracht ziektebeeld SCD

zorgverlener

moment

parents + child

Als kind huilt dan is het niet de tijd voor ziekte educatie. Het moment dat er aandacht is dan ga je informatie geven. in sommige situaties komt informatie niet aan. Er moet aandacht en rust zijn.

Nog een keer uitleggen of op andere manier

Ik vraag altijd zijn er vragen

wanneer informatie niet begrepen is -

Eerste informatie blijf ik herhalen want die vergeten

herhalen

Heel verschillend hoeveel informatie ze zelf al weten of onthouden hebben

Van te voren weet je niet hoe veel een patient weet – kan je niet voorspellen

Ook regelmatig hetzelfde aan het uitleggen en toch het idee dat je het

Kennishiaten zijn er, we herhalen, maar

Herhaling is belangrijk - ze onthouden het niet hun hele leven

Wat ze moeten doen bij pijn – niet iets wat altijd blijft hangen.

Eigenlijk is een van onze belangrijkste taken communicatie – als we dat beter zouden kunnen inrichten. Waardevol voor patient en team

Ook hoogopgeleide mensen kunnen lage gezonheidsvaardigheden hebben. Dat je niet snapt wat de dokter zegt.

Als ze minder begrijpen dan leggen we ook minder uit. Dan houden we het kort en klein. Dan ga je niet

Behoefte om dingen heel goed uit te leggen, maar als mensen toch niet begrijpen. Kan je beter houden bij dingen die belangrijk zijn. Kort en duidelijk zijn en de uitleg waarom is een zoektocht

Je wil eerste afspraak niet te veel vertellen, dat onthouden ze toch niet. ouders stellen soms helemaal geen vragen, misschien moet het dan nog bezinken.

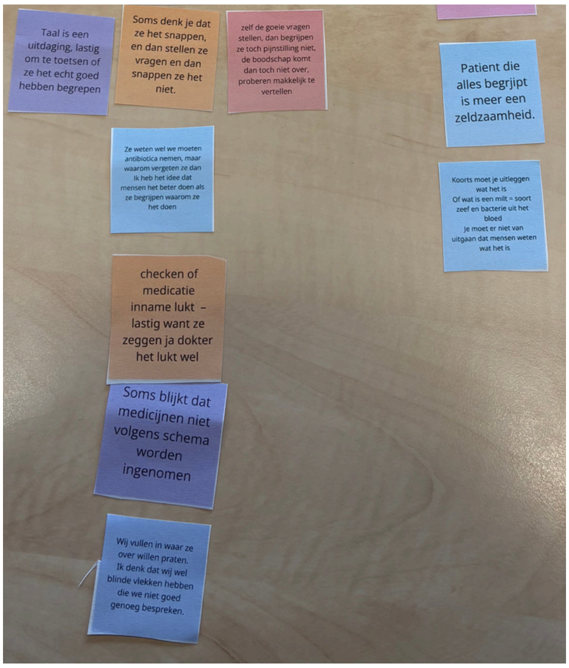
onthouden, ligt ook de voorkennis

Ouders weten niet hoe ze moeten uitleggen aan school.

Taal is een

Soms denk je dat ze het snappen, en dan stellen ze vragen en dan

zelf de goeie vragen stellen, dan begrijpen ze toch pijnstilling niet, de boodschap komt



Taal is een uitdaging, lastig om te toetsen of ze het echt goed hebben begrepen

Soms denk je dat ze het snappen, en dan stellen ze vragen en dan snappen ze het niet.

zelf de goeie vragen stellen, dan begrijpen ze toch pijnstilling niet, de boodschap komt dan toch niet over, proberen makkelijk te vertellen

Patient die alles begrjipt is meer een zeldzaamheid.

Ze weten wel we moeten antibiotica nemen, maar waarom vergeten ze dan
Ik heb het idee dat mensen het beter doen als ze begrijpen waarom ze het doen

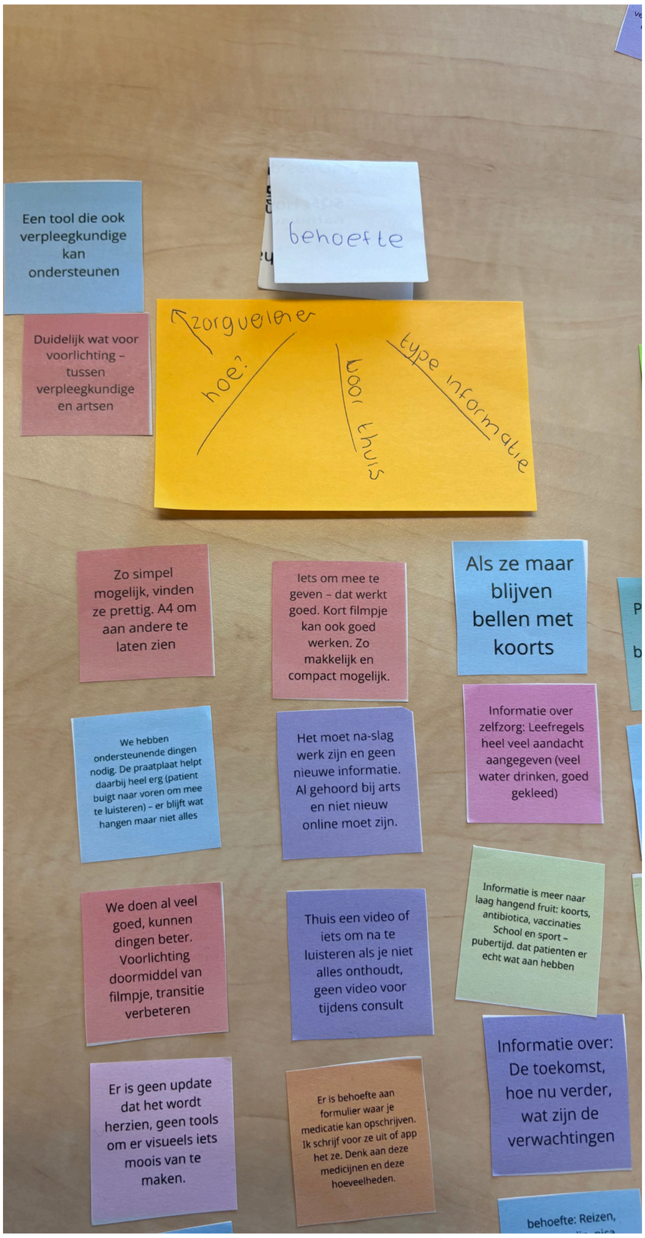
Koorts moet je uitleggen wat het is
Of wat is een milt = soort zeef en bacterie uit het bloed
Je moet er niet van uitgaan dat mensen weten wat het is

checken of medicatie inname lukt – lastig want ze zeggen ja dokter het lukt wel

Soms blijkt dat medicijnen niet volgens schema worden ingenomen

Wij vullen in waar ze over willen praten. Ik denk dat wij wel blinde vlekken hebben die we niet goed genoeg bespreken.

Need, emotion



Een tool die ook verpleegkundige kan ondersteunen

Duidelijk wat voor voorlichting – tussen verpleegkundige en artsen

Zo simpel mogelijk, vinden ze prettig. A4 om aan andere te laten zien

Iets om mee te geven – dat werkt goed. Kort filmpje kan ook goed werken. Zo makkelijk en compact mogelijk.

Als ze maar blijven bellen met koorts

We hebben ondersteunende dingen nodig. De praatplaat helpt daarbij heel erg (patient buigt naar voren om mee te luisteren) – er blijft wat hangen maar niet alles

Het moet na-slag werk zijn en geen nieuwe informatie. Al gehoord bij arts en niet nieuw online moet zijn.

Informatie over zelfzorg: Leefregels heel veel aandacht aangegeven (veel water drinken, goed gekleed)

We doen al veel goed, kunnen dingen beter. Voorlichting doormiddel van filmpje, transitie verbeteren

Thuis een video of iets om na te luisteren als je niet alles onthoudt, geen video voor tijdens consult

Informatie is meer naar laag hangend fruit: koorts, antibiotica, vaccinaties School en sport – pubertijd. dat patienten er echt wat aan hebben

Er is geen update dat het wordt herzien, geen tools om er visueels iets moois van te maken.

Er is behoefte aan formulier waar je medicatie kan opschrijven. Ik schrijf voor ze uit of app het ze. Denk aan deze medicijnen en deze hoeveelheden.

Informatie over: De toekomst, hoe nu verder, wat zijn de verwachtingen

behoefte: Reizen,

VS - UMCG

AUMC

Ilja - verpleegkundig consulent - Sophia

Aida - Medical Social worker - Sophia

Alice -VS - EMC

Gert jan - fellow - LUMC / sophia

Patienten zijn niet op hun best als ze pijn hebben

ouders na diagnose: Emotioneel en geschokt, soms lastig om informatie te laten binnen komen

Ouders vinden HSCT wel echt heftig. Veel angst en onzekereid

Ik vind het een hele heftige ziekte

ouderschap is in begin rozewolk, over het algemeen zijn ouders geschrokken na diagnose

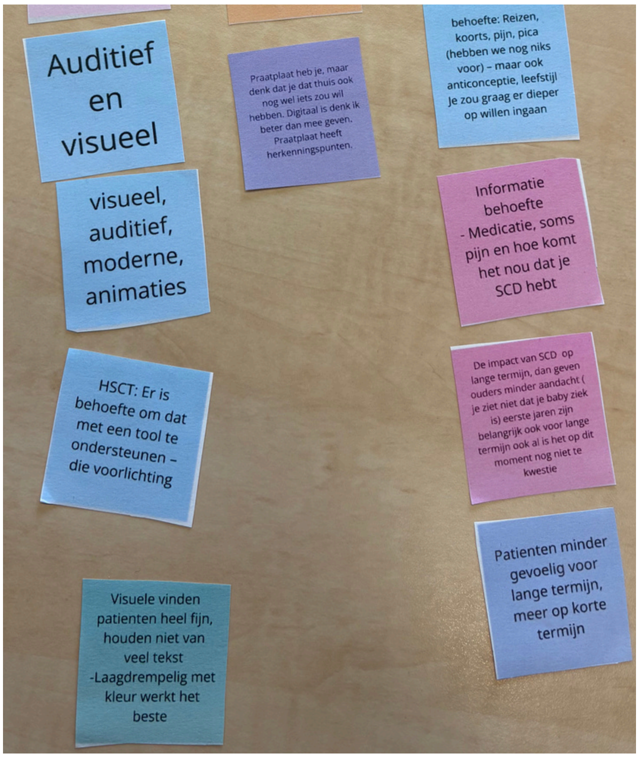
HSCT heftig traject – goed beeld geven. Het is niet zomaar iets, medicijnen zijn toch anders

Soms praat je tegen een dichte deur, momenten dat het minder goed gaat kan je slagen maken in therapie trouw

Ouders zijn verdrietig of ontkennen, in begin zie je niks dus kan onwerkelijk zijn.

Patienten voorbereiden op HSCT, dat is best spannend. Het is een spannende behandeling

HSCT heftig



Auditief en visueel

visueel, auditief, moderne, animaties

HSCT: Er is behoefte om dat met een tool te ondersteunen – die voorlichting

Visuele vinden patienten heel fijn, houden niet van veel tekst -Laagdrempelig met kleur werkt het beste

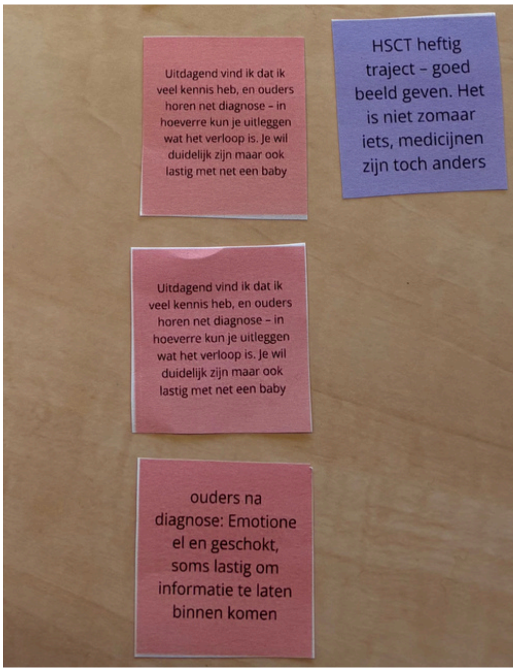
Praatplaat heb je, maar denk dat je dat thuis ook nog wel iets zou wil hebben. Digitaal is denk ik beter dan mee geven. Praatplaat heeft herkenningspunten.

behoefte: Reizen, koorts, pijn, pica (hebben we nog niks voor) – maar ook anticonceptie, leefstijl Je zou graag er dieper op willen ingaan

Informatie behoefte - Medicatie, soms pijn en hoe komt het nou dat je SCD hebt

De impact van SCD op lange termijn, dan geven ouders minder aandacht (je ziet niet dat je baby ziek is) eerste jaren zijn belangrijk ook voor lange termijn ook al is het op dit moment nog niet te kwestie

Patienten minder gevoelig voor lange termijn, meer op korte termijn



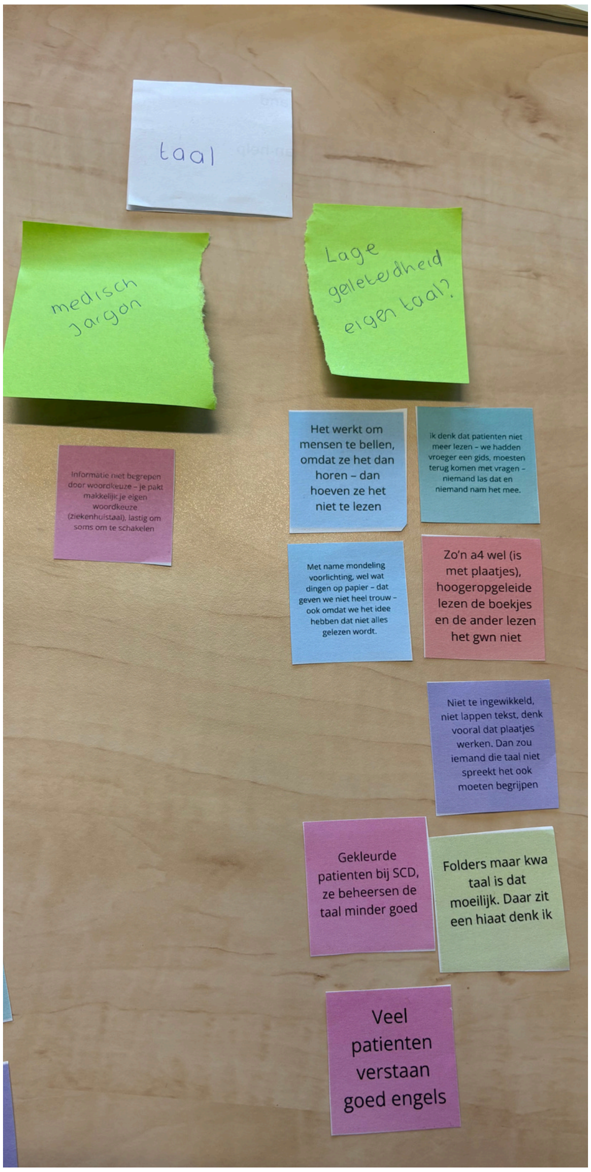
Uitdagend vind ik dat ik veel kennis heb, en ouders horen net diagnose – in hoeverre kun je uitleggen wat het verloop is. Je wil duidelijk zijn maar ook lastig met net een baby

HSCT heftig traject – goed beeld geven. Het is niet zomaar iets, medicijnen zijn toch anders

Uitdagend vind ik dat ik veel kennis heb, en ouders horen net diagnose – in hoeverre kun je uitleggen wat het verloop is. Je wil duidelijk zijn maar ook lastig met net een baby

ouders na diagnose: Emotioneel en geschokt, soms lastig om informatie te laten binnen komen

Language, taboo



taal

medisch jargon

Lage geletterdheid eigen taal?

Informatie niet begrepen door woordkeuze – je pakt makkelijk je eigen woordkeuze (ziekenhuistaal), lastig om soms om te schakelen

Het werkt om mensen te bellen, omdat ze het dan horen – dan hoeven ze het niet te lezen

ik denk dat patienten niet meer lezen – we hadden vroeger een gids, moesten terug komen met vragen – niemand las dat en niemand nam het mee.

Met name mondeling voorlichting, wel wat dingen op papier – dat geven we niet heel trouw – ook omdat we het idee hebben dat niet alles gelezen wordt.

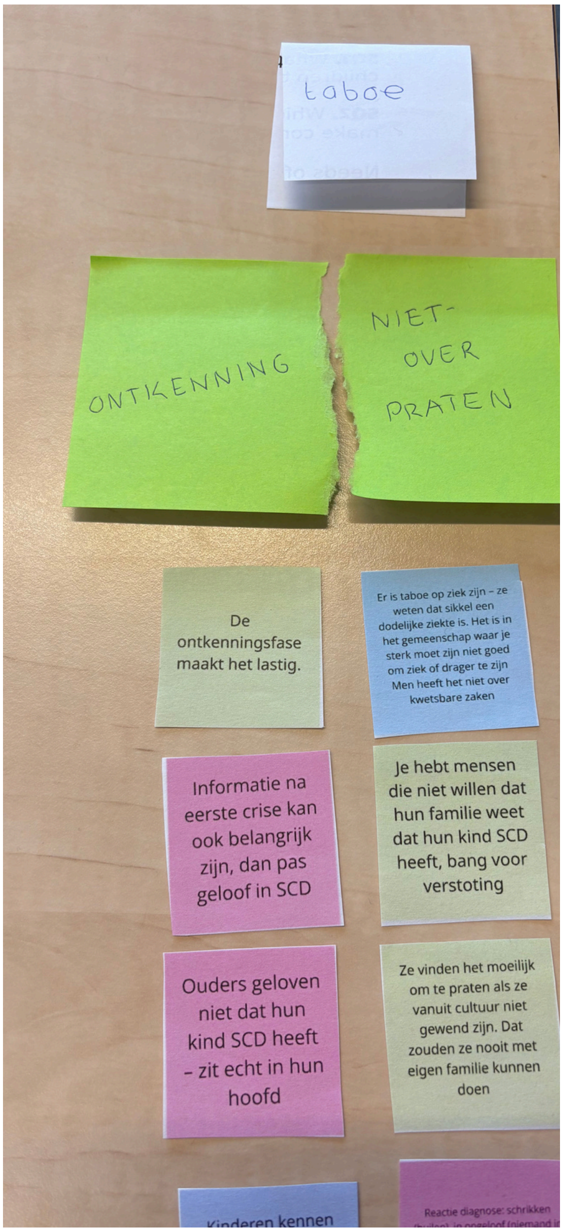
Zo'n a4 wel (is met plaatjes), hoogeropgeleide lezen de boekjes en de ander lezen het gwn niet

Niet te ingewikkeld, niet lappen tekst, denk vooral dat plaatjes werken. Dan zou iemand die taal niet spreekt het ook moeten begrijpen

Gekleurde patienten bij SCD, ze beheersen de taal minder goed

Folders maar kwa taal is dat moeilijk. Daar zit een hiaat denk ik

Veel patienten verstaan goed engels



taboe

ONTKENNING

NIET-OVER PRATEN

De ontkenningsfase maakt het lastig.

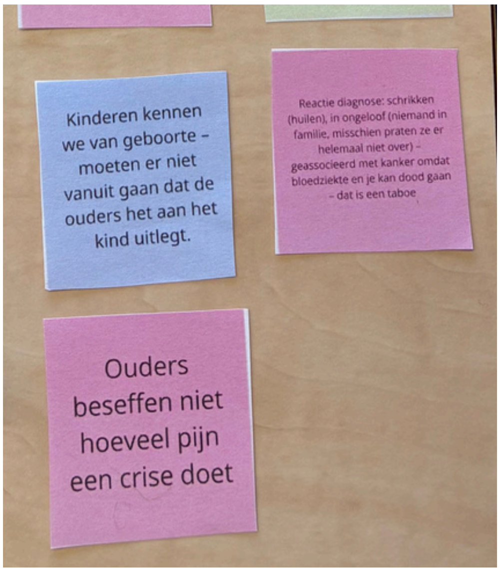
Er is taboe op ziek zijn – ze weten dat sikkel een dodelijke ziekte is. Het is in het gemeenschap waar je sterk moet zijn niet goed om ziek of drager te zijn Men heeft het niet over kwetsbare zaken

Informatie na eerste crise kan ook belangrijk zijn, dan pas geloof in SCD

Je hebt mensen die niet willen dat hun familie weet dat hun kind SCD heeft, bang voor verstoting

Ouders geloven niet dat hun kind SCD heeft – zit echt in hun hoofd

Ze vinden het moeilijk om te praten als ze vanuit cultuur niet gewend zijn. Dat zouden ze nooit met eigen familie kunnen doen

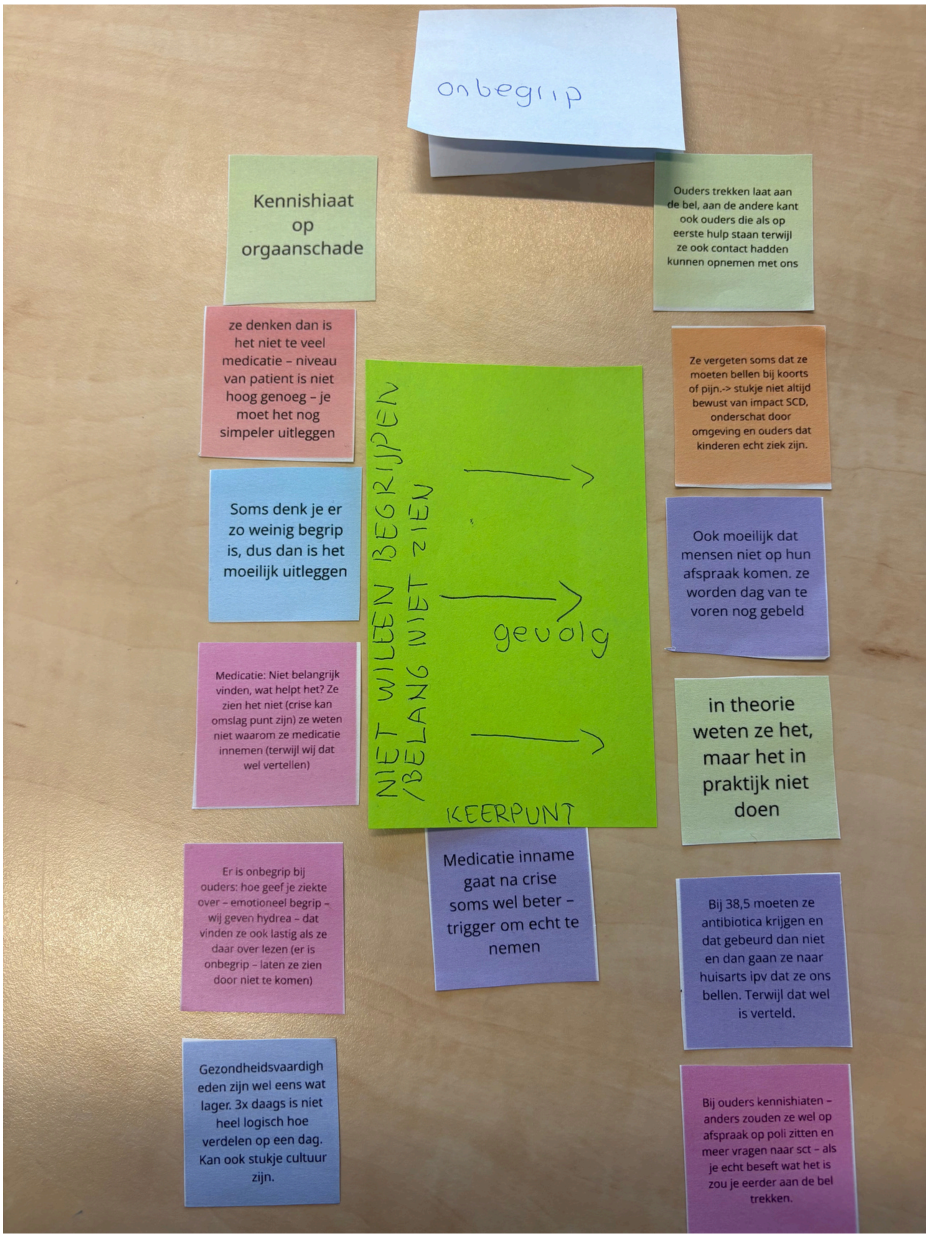


Kinderen kennen we van geboorte – moeten er niet vanuit gaan dat de ouders het aan het kind uitlegt.

Reactie diagnose: schrikken (huilen), in ongeloof (niemand in familie, misschien praten ze er helemaal niet over) – geassocieerd met kanker omdat bloedziekte en je kan dood gaan – dat is een taboe

Ouders beseffen niet hoeveel pijn een crise doet

Incomprehension



onbegrip

Kennishiaat op orgaanschade

ze denken dan is het niet te veel medicatie – niveau van patient is niet hoog genoeg – je moet het nog simpeler uitleggen

Soms denk je er zo weinig begrip is, dus dan is het moeilijk uitleggen

Medicatie: Niet belangrijk vinden, wat helpt het? Ze zien het niet (crise kan omslag punt zijn) ze weten niet waarom ze medicatie innemen (terwijl wij dat wel vertellen)

Er is onbegrip bij ouders: hoe geef je ziekte over – emotioneel begrip – wij geven hydrea – dat vinden ze ook lastig als ze daar over lezen (er is onbegrip – laten ze zien door niet te komen)

Gezondheidsvaardigheden zijn wel eens wat lager. 3x daags is niet heel logisch hoe verdelen op een dag. Kan ook stukje cultuur zijn.

NIET WILLEN BEGRIJPEN /BELANG NIET ZIEN

gevolg

KEERPUNT

Medicatie inname gaat na crise soms wel beter – trigger om echt te nemen

Ouders trekken laat aan de bel, aan de andere kant ook ouders die als op eerste hulp staan terwijl ze ook contact hadden kunnen opnemen met ons

Ze vergeten soms dat ze moeten bellen bij koorts of pijn.-> stukje niet altijd bewust van impact SCD, onderschat door omgeving en ouders dat kinderen echt ziek zijn.

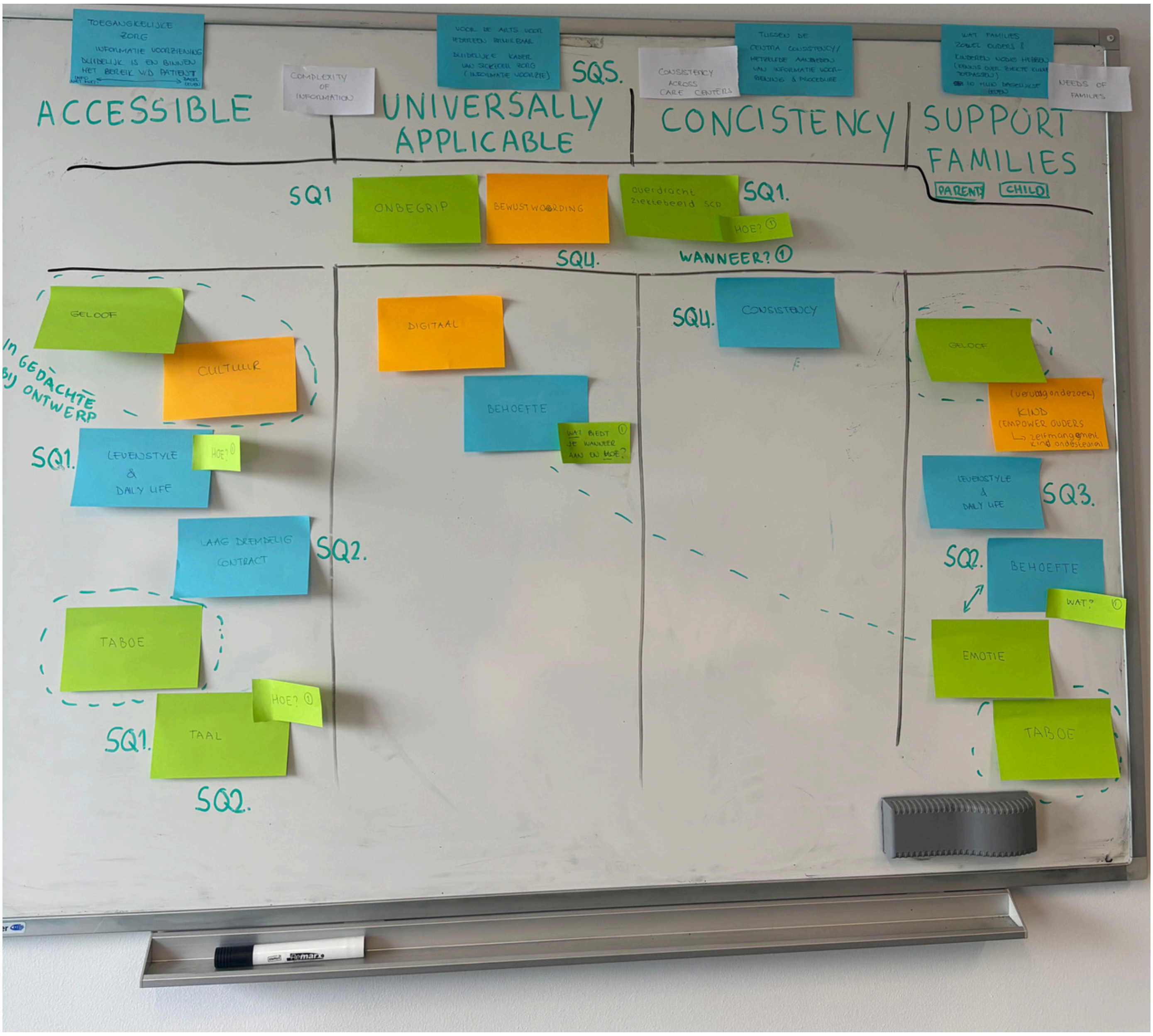
Ook moeilijk dat mensen niet op hun afspraak komen. ze worden dag van te voren nog gebeld

in theorie weten ze het, maar het in praktijk niet doen

Bij 38,5 moeten ze antibiotica krijgen en dat gebeurd dan niet en dan gaan ze naar huisarts ipv dat ze ons bellen. Terwijl dat wel is verteld.

Bij ouders kennishiaten – anders zouden ze wel op afspraak op poli zitten en meer vragen naar sct – als je echt beseft wat het is zou je eerder aan de bel trekken.

Clustering based on the four categories



D3. Explanation theme

Theme	Meaning theme	Example quote (healthcare provider)	Example quote (healthcare provider)
Belief	Religious or life-philosophical convictions that influence medical decision-making, such as refusing medication, blood transfusions, or HSCT, and attributing illness to divine will.	"A blood transfusion may not be allowed because of religious beliefs."	"Some parents do not want their child to take medication for religious reasons."
Culture	Shared values, norms, and communication styles that shape how information is interpreted and how care relationships are formed, including differences between Western medical practice and families' cultural contexts.	"Dutch healthcare communication is very direct, which can be confronting for some families."	"You sometimes need to adapt your communication to their cultural context."
Digital	The use of digital information provision (e.g., DigiZorg) and differences in digital access, skills, and preferences within the SCD population.	"Within DigiZorg, patients no longer receive leaflets; everything is digital."	"Not everyone is able to process digital information in the same way."
Child	Age-dependent approaches to the child, including involvement during consultations, transition to self-management, and child-appropriate explanations.	"My focus depends on the child's age."	"Around the age of 12 or 13, children start taking responsibility for their own medication."
Awareness	Limited societal, institutional, and individual awareness of sickle cell disease and its impact.	"There is still very little attention for sickle cell disease in the media."	"After the initial explanation, families often have to find things out themselves."
Lifestyle & daily life	The influence of daily routines, socio-economic circumstances, and stress on treatment adherence and healthcare use.	"Many patients want to follow advice, but it does not fit into their daily lives."	"People often have so much going on that SCD becomes too much on top of everything else."
Consistency	Variation in information, policies, and educational materials between healthcare professionals and hospitals, leading to confusion for families.	"Each hospital has its own way of providing information."	"Patients should not hear something different every time."
Low-threshold contact	The importance of accessible, trust-based communication between healthcare professionals and families, enabling questions and openness.	"A good doctor–patient relationship is the foundation."	"Low-threshold contact helps parents to be honest and ask questions."
Sickle cell disease information transfer	How information about SCD is communicated, including timing, repetition, and adjustment to stress, crisis situations, and non-acute moments.	"In acute situations, parents often no longer know what to do."	"Information needs to be repeated, otherwise it gets lost."
Need	Concrete informational and support needs of parents and children, such as what to do in case of pain or fever and what to expect in the future.	"Parents mainly want to know what to do when their child is in pain."	"There is a strong need for clarity about what happens next."
Emotion	Emotional responses such as shock, fear, sadness, and uncertainty, particularly around diagnosis, crises, and HSCT, affecting information processing.	"After the diagnosis, parents are often shocked."	"HSCT is experienced as very intense and anxiety-provoking."
Language	Barriers to understanding caused by medical jargon, low language proficiency, low literacy, or the use of a non-native language.	"Hospital terminology is difficult; medical language is not always understood."	"Many information leaflets are too complex in terms of language."
Taboo	Avoidance of discussing sickle cell disease, denial of the diagnosis, and fear of stigma or social exclusion within families or communities.	"Some parents do not want their family to know their child has SCD."	"In some communities, talking about illness is still taboo."
Incomprehension	Persistent lack of understanding despite repeated explanations: information is known in theory but not applied in practice, often due to stress, limited health literacy, or knowledge gaps.	"In theory they understand it, but in practice they do not act on it."	"We keep repeating the information, but it doesn't always land."

D4. Chatgpt thematic analysis

In addition to the thematic analysis performed with post-its, an AI-supported thematic analysis was also conducted. The aim was to compare the results of the AI analysis with the outcomes of my manual thematic analysis, in order to reflect on the quality and completeness of the original manual analysis. The analysis examined whether the identified themes matched and which themes contributed to answering the various sub-questions.

A list of quotes from the interviews was presented to GPT-5 with the instruction to perform a thematic analysis: "Perform a thematic analysis and identify the underlying themes."
→

Thema 1: Taalbarrières en gezondheidsvaardigheden
Kernidee: Communicatie wordt bemoeilijkt door taal, woordkeuze en beperkte gezondheidsvaardigheden.
Typische quotes:
"Gekleurde patiënten bij sickle cell disease, ze beheersen de taal minder goed."
"Taal is een uitdaging, lastig om te toetsen of ze het echt goed hebben begrepen."
"Informatie niet begrepen door woordkeuze – je pakt makkelijk je eigen woordkeuze (ziekenhuistaal)."
"Ook hoogopgeleide mensen kunnen lage gezondheidsvaardigheden hebben."
Subthema's: taalniveau, woordkeuze, culturele interpretatie van medische termen, geletterdheid.
Implicatie: Informatievoorziening moet afgestemd worden op taalniveau en begrijpelijkheid.

Thema 2: Culturele en religieuze overtuigingen
Kernidee: Culturele achtergrond en geloof beïnvloeden de manier waarop patiënten en ouders ziekte, behandeling en communicatie ervaren.
Typische quotes:
"Jehovogetuigen krijgen geen bloed – daar wordt met respect over gesproken."
"Geloofsovertuiging: Jehova, islamitisch, katholiek – veel katholieken zeggen het is aan God die willen geen HSCT."
"Sommige mensen hebben al gezien bij familieleden – dat kan je beeld veranderen."
"Er is taboe op ziek zijn – gemeenschap waar je sterk moet zijn."
Subthema's: taboe, religie, stigma, culturele interpretatie van ziekte.
Implicatie: Voorlichting en begeleiding moeten cultureel sensitief zijn en respect tonen voor geloofsovertuigingen.

Thema 3: Emotionele impact en acceptatie van de diagnose
Kernidee: Ouders en patiënten hebben tijd nodig om de diagnose te begrijpen en te accepteren.
Typische quotes:
- *"Ouders geloven niet dat hun kind sickle cell disease heeft – zit echt in hun hoofd."*
- *"Reactie diagnose: schrikken, huilen, ongeloof."*
- *"Ouders zijn verdrietig of ontkennen, in begin zie je niks dus kan onwerkelijk zijn."*
- *"De ontkenningsfase maakt het lastig."*
- *Subthema's: ontkenning, emotionele verwerking, eerste fase na diagnose.*
- *Implicatie: Timing van informatie is cruciaal; herhaling en empathie zijn essentieel.*

Thema 4: Begrijpelijkheid en vorm van informatie
Kernidee: De vormgeving, taal, en visuele ondersteuning van informatie bepalen of patiënten het begrijpen en toepassen.
Typische quotes:
- *"Visuele dingen vinden patiënten heel fijn, houden niet van veel tekst."*
- *"Niveau voorlichting moet lagere schoolniveau zijn."*
- *"Zo simpel mogelijk, vinden ze prettig."*
- *"Informatie niet te ingewikkeld, niet lappen tekst."*
- *Subthema's: visueel leren, taalniveau, laagdrempeligheid, vormgeving.*
- *Implicatie: Informatie moet visueel, kort, duidelijk en contextueel aansluiten.*

Thema 5: Timing en herhaling van informatie
Kernidee: Patiënten begrijpen of onthouden informatie niet altijd; herhaling op het juiste moment is nodig.
Typische quotes:

- *"Nog een keer uitleggen of op andere manier – blijven herhalen."*
- *"Eerste jaar regelmatig afspraken, je kan niet alles onthouden."*
- *"Informatie na eerste crisis kan ook belangrijk zijn, dan pas geloof in sickle cell disease."*
- *"Herhaling is belangrijk – ze onthouden het niet hun hele leven."*
- *Subthema's: timing bij diagnose, herhaling, crisis als leermoment.*
- *Implicatie: Informatievoorziening moet iteratief en op het juiste moment plaatsvinden.*

Thema 6: Digitale en praktische toegankelijkheid van informatie
Kernidee: Er is behoefte aan makkelijk toegankelijke, digitale en praktische middelen.
Typische quotes:
"We moeten niet een aparte app – toepassen op wat er al bestaat."
"Meer digitaal – werken met digizorg."
"Thuis een video of iets om na te luisteren."
"Praatplaat helpt – digitaal is beter dan meegeven."
Subthema's: digitale tools, herbruikbaarheid, toegankelijkheid.
Implicatie: Informatie moet aansluiten op bestaande digitale zorgkanalen en gebruiksgemak.

Thema 7: Consistentie en samenwerking tussen zorgcentra
Kernidee: Verschillen in informatie en werkwijze tussen centra zorgen voor verwarring.
Typische quotes:
"Elk ziekenhuis heeft eigen voorlichting."
"Iedereen centrum hetzelfde gebruikt – dat iedereen zelfde."
"Er is geen protocol in zorgpad dat we dit geven op welk moment."
Subthema's: standaardisatie, samenwerking, landelijke richtlijnen.
Implicatie: Behoefte aan uniforme en gedeelde informatievoorziening in sickle cell disease-zorg.

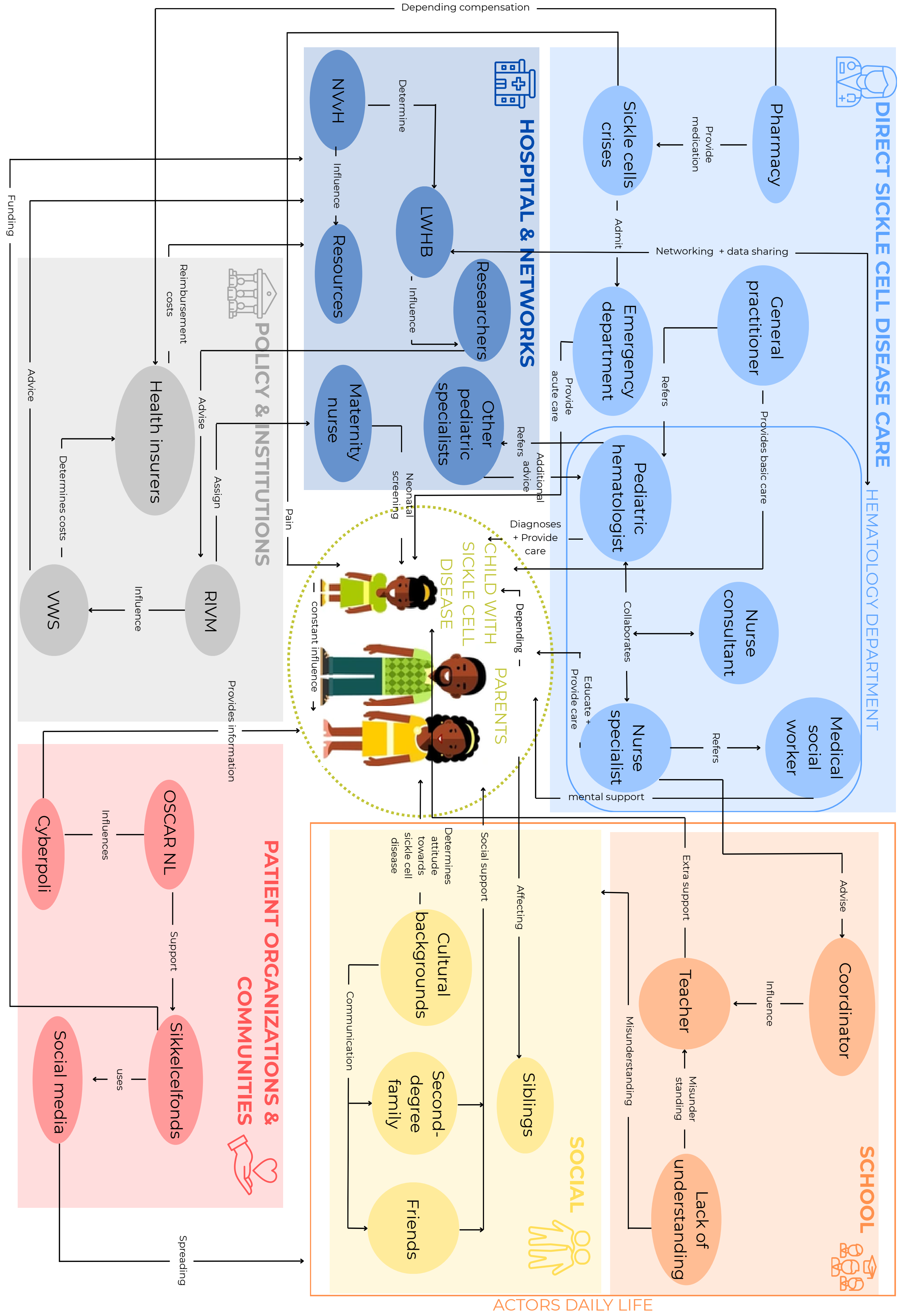
Thema 8: Relatie en communicatie tussen zorgverlener en patiënt
Kernidee: Vertrouwen, empathie en communicatie zijn bepalend voor therapietrouw en begrip.
Typische quotes:
"Arts–patiëntrelatie is goed (belangrijk)."
"Uiteindelijk is de grootste uitdaging het vertrouwen van de patiënt."
"Nederlanders zijn heel direct, daar schrikken ze soms van."
"Als ze minder begrijpen, leggen we ook minder uit."
Subthema's: vertrouwensrelatie, culturele communicatie, toon en empathie.
Implicatie: Relationele communicatie is een voorwaarde voor effectieve voorlichting.

Thema 9: Gezins- en sociaal-economische context
Kernidee: Dagelijkse omstandigheden beïnvloeden hoe informatie wordt verwerkt en opgevolgd.
Typische quotes:
"Vaak alleenstaande moeders – ze hebben niet alle tijd of ruimte."
"Financiële zorgen – niet alle medicatie vergoed."
"Huizen zijn anders ingericht – geen duidelijke bewaarplek."
"Mensen die veel op hun bordje hebben, dan is sickle cell disease erbij te veel."
Subthema's: tijdsdruk, armoede, structuur, stress.
Implicatie: Informatie en ondersteuning moeten rekening houden met leefomstandigheden.

In a next step, GPT-5 was asked to explicitly indicate for each theme which of the five sub-questions (SQ1–SQ5) were answered by that theme, and how.

Theme No.	Theme	Core Idea / Description	SQ1	SQ2	SQ3	SQ4	SQ5
1	**Language Barriers & Health Literacy**	Communication is hindered by language proficiency, medical jargon, and limited health literacy, making information difficult to understand.	☑	☑			
2	**Cultural and Religious Beliefs**	Cultural values, religion, and taboos influence how families interpret illness and medical information.	☑			☑	
3	**Emotional Impact and Acceptance of Diagnosis**	Emotional responses such as denial, shock, and disbelief make it difficult for parents to absorb information immediately after diagnosis.	☑		☑		
4	**Comprehensibility and Format of Information**	Families prefer clear, visual, and simple materials that match their literacy levels and daily needs.		☑	☑		
5	**Timing and Repetition of Information**	Information should be repeated at key moments (e.g., diagnosis, crises, transition) to ensure understanding and retention.			☑		☑
6	**Digital and Practical Accessibility**	Information must be easy to access and integrated into existing digital care systems (e.g., Digizorg).		☑			☑
7	**Consistency and Collaboration Across Care Centers**	Uniform communication and shared materials are needed across hospitals to avoid confusion and ensure continuity.				☑	☑
8	**Care Provider–Patient Relationship and Communication**	Trust, empathy, and cultural sensitivity are key for effective information exchange.	☑	☑	☑		
9	**Family and Socioeconomic Context**	Daily life pressures, financial concerns, and limited time affect families' ability to apply information and follow medical advice.	☑		☑		

Appendix E - Actor map



Appendix F - Parents/patient input

F1. Questionnaire OscarNL symposium

1. Heb jij sikkelcelziekte, of heeft jouw kind dat?

2. Hoe oud ben jij, of hoe oud is jouw kind?

3. Wat vind jij van de informatie die je krijgt over sikkelcelziekte?

4. Over welk onderwerp zou jij graag willen praten met de dokter in deze tijdlijn?

Leeftijd kind	
0 - 1 jaar	DIAGNOSE
	EERSTE JAAR MET SIKKELCELZIEKTE
2 - 10 jaar	VROEGE KINDERTIJD
	SCHOOL
11 - 18 jaar	PUBERTEIT
18+ jaar	TRANSITIE

5. Als je kijkt naar hoe het nu gaat: zijn er dingen die je liever eerder of later met de dokter had besproken? Waarom?

Inspiratie om over te praten met de dokter:

- Wat is sikkelcelziekte
- stamceltransplantatie
- Bedplassen
- koorts
- medicatie
- erfelijkheid
- Pijn / pijnstilling
- school
- vakantie / reizen
- Pica (eetstoornis waarbij niet-eetbare dingen worden gegeten, zoals papier of stof)
- Priapisme (een langdurige en vaak pijnlijke erectie zonder seksuele prikkeling)
- Ijzerrijk voedsel
- Vitamines en supplementen
- vaccinaties
- zwemmen / zwemles
- uitgaan
- sporten
- anticonceptie
- bloedtransfusie
- leefstijl
- nierfalen
- laagdrempelig contact

F2. Thematic categorization of topics

diagnose
wat is sikkelcelziekte
hoe beinvloed het het leven van kind + gezin
wachttijd (op weg naar 1e crise)
erfelijkheid
medicatie
erkenning

eerste jaar
symptomen herkken bij een baby
ook genieten van baby (tijd staat soms stil)
pijn / pijnstilling
bloedtransfusie
koorts
vaccinaties
leefstijl

vroege kindertijd
ontwikkeling (achterstand) motorische ontwikkeling
wat hoort bij scd
medicatie
zwemmen
sporten
bedplassen
pica

school
zwemles
leefstijl
school / hybride onderwijs
pschologische effecten van scd
ziekenhuis opnamen bij een kind
ijzerrijk voedsel, vitamines

puberteit
toekomstpad - school + effect op latere leeftijd → moeten we extra sparen als ouder
uitgaan
sporten
anticonceptie
vakanties

transitie
noodpakket + extra medicatie in huis
zwangerschap
vakanties
leefstijl
vaccinaties
hsct

erkenning

hand-voet syndroom

invloed verzorging kind

leefstijl

vitamines

laagdrempellig contact

hoe weet je of baby crise

leefstijl

wat is sikkelcelziekte

pijn / pijnstilling

vakantie

ijzerrijk voedsel

sporten

gymles

vertellen aan omgeving

ijzserrijk voedsel, vitamines

vakanties

belang leefstijl

belang medicatie (therapietrouw)

sexualiteit

hsct

priapisme

pijn / pijnstilling

stigma

hsct

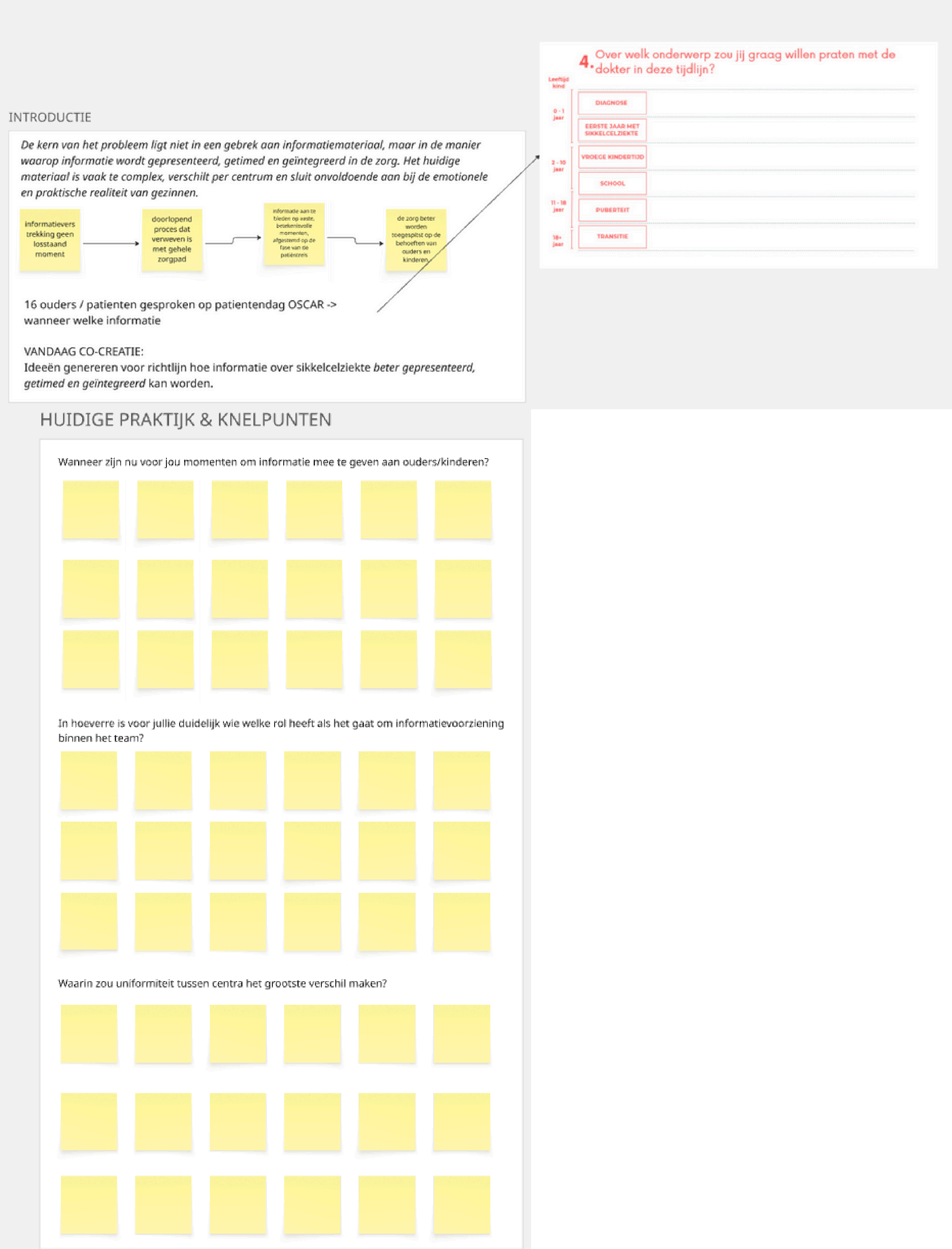
erfelijkheid

zelfstandigheid

psychologische begeleiding

Appendix G - Co-creation healthcare providers

G1. Set-up co-creation



INTRODUCTIE

De kern van het probleem ligt niet in een gebrek aan informatiemateriaal, maar in de manier waarop informatie wordt gepresenteerd, getimed en geïntegreerd in de zorg. Het huidige materiaal is vaak te complex, verschilt per centrum en sluit onvoldoende aan bij de emotionele en praktische realiteit van gezinnen.

informatieverstrekking geen losstaand moment → doorlopend proces dat verweven is met gehele zorgpad → informatie aan te bieden op vaste, betekenisvolle momenten, afgestemd op de fase van de patiëntreis → de zorg beter worden toegespitst op de behoeften van ouders en kinderen

16 ouders / patienten gesproken op patientendag OSCAR -> wanneer welke informatie

VANDAAG CO-CREATIE:
Ideeën genereren voor richtlijn hoe informatie over sikkelcelziekte *beter gepresenteerd, getimed en geïntegreerd* kan worden.

4. Over welk onderwerp zou jij graag willen praten met de dokter in deze tijdlijn?

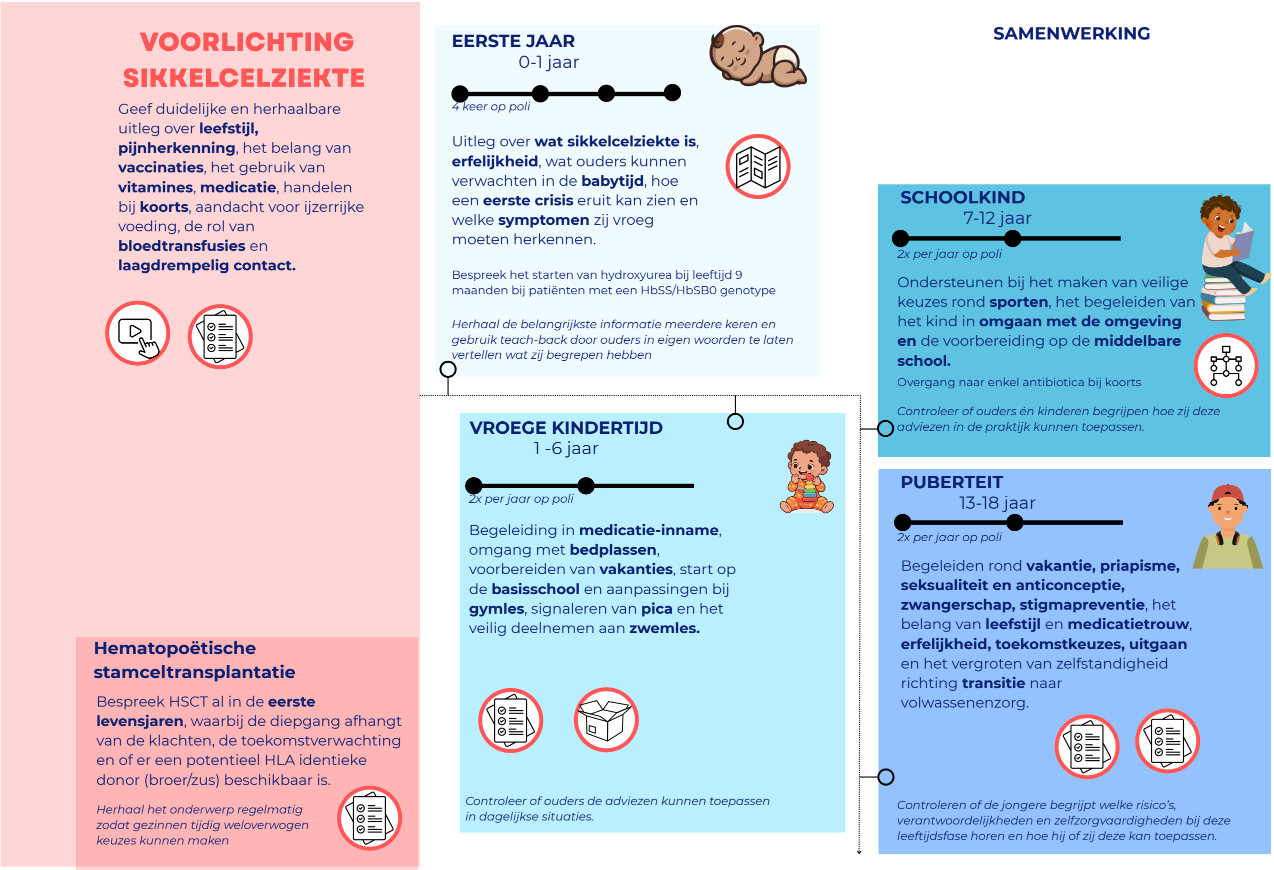
Leeftijd kind	
0 - 1 jaar	DIAGNOSE
	EERSTE JAAR MET SIKKELCELZIEKTE
2 - 10 jaar	VROEGE KINDERTIJD
	SCHOOL
11 - 18 jaar	PUBERTEIT
18+ jaar	TRANSITIE

HUIDIGE PRAKTIJK & KNELPUNTEN

Wanneer zijn nu voor jou momenten om informatie mee te geven aan ouders/kinderen?

In hoeverre is voor jullie duidelijk wie welke rol heeft als het gaat om informatievoorziening binnen het team?

Waarin zou uniformiteit tussen centra het grootste verschil maken?



VOORLICHTING SIKKELCELZIEKTE

Geef duidelijke en herhaalbare uitleg over **leefstijl, pijnherkenning**, het belang van **vaccinaties**, het gebruik van **vitamines**, **medicatie**, handelen bij **koorts**, aandacht voor ijzerrijke voeding, de rol van **bloedtransfusies** en **laagdrempelig contact.**

Hematopoëtische stamceltransplantatie

Bespreek HSCT al in de **eerste levensjaren**, waarbij de diepgang afhangt van de klachten, de toekomstverwachting en of er een potentieel HLA identieke donor (broer/zus) beschikbaar is.

Herhaal het onderwerp regelmatig zodat gezinnen tijdig weloverwogen keuzes kunnen maken

EERSTE JAAR
0-1 jaar

4 keer op poli

Uitleg over **wat sikkelcelziekte is**, **erfelijkheid**, wat ouders kunnen verwachten in de **babytijd**, hoe een **eerste crisis** eruit kan zien en welke **symptomen** zij vroeg moeten herkennen.

Bespreek het starten van hydroxyurea bij leeftijd 9 maanden bij patiënten met een HbSS/HbSB0 genotype

Herhaal de belangrijkste informatie meerdere keren en gebruik teach-back door ouders in eigen woorden te laten vertellen wat zij begrepen hebben

SAMENWERKING

VROEGE KINDERTIJD
1 -6 jaar

2x per jaar op poli

Begeleiding in **medicatie-inname**, omgang met **bedplassen**, voorbereiden van **vakanties**, start op de **basisschool** en aanpassingen bij **gymles**, signaleren van **pica** en het veilig deelnemen aan **zwemles.**

Controleer of ouders de adviezen kunnen toepassen in dagelijkse situaties.

SCHOOLKIND
7-12 jaar

2x per jaar op poli

Ondersteunen bij het maken van veilige keuzes rond **sporten**, het begeleiden van het kind in **omgaan met de omgeving en** de voorbereiding op de **middelbare school.**

Overgang naar enkel antibiotica bij koorts

Controleer of ouders én kinderen begrijpen hoe zij deze adviezen in de praktijk kunnen toepassen.

PUBERTEIT
13-18 jaar

2x per jaar op poli

Begeleiden rond **vakantie, priapisme, seksualiteit en anticonceptie, zwangerschap, stigmapreventie**, het belang van **leefstijl** en **medicatietrouw**, **erfelijkheid, toekomstkeuzes, uitgaan** en het vergroten van zelfstandigheid richting **transitie** naar volwassenenzorg.

Controleren of de jongere begrijpt welke risico's, verantwoordelijkheden en zelfzorgvaardigheden bij deze leeftijdsfase horen en hoe hij of zij deze kan toepassen.

Sleep post-it naar punt in zorgpad waar het om gaat

Wat vind je goed / zou je willen toevoegen / wat werkt minder goed en moet aangepast?

goed

toevoegen

minder goed / aanpassen

Zie je onderdelen die volgens jou anders lopen in de praktijk?"

Hoe zie je voor je wie waarvoor verantwoordelijk zou moeten zijn?

Waar zou dit beschikbaar moeten zijn?

Sleep sterretje naar voorkeur

Ik wil het op mijn tafel hebben liggen

Online bij de richtlijn

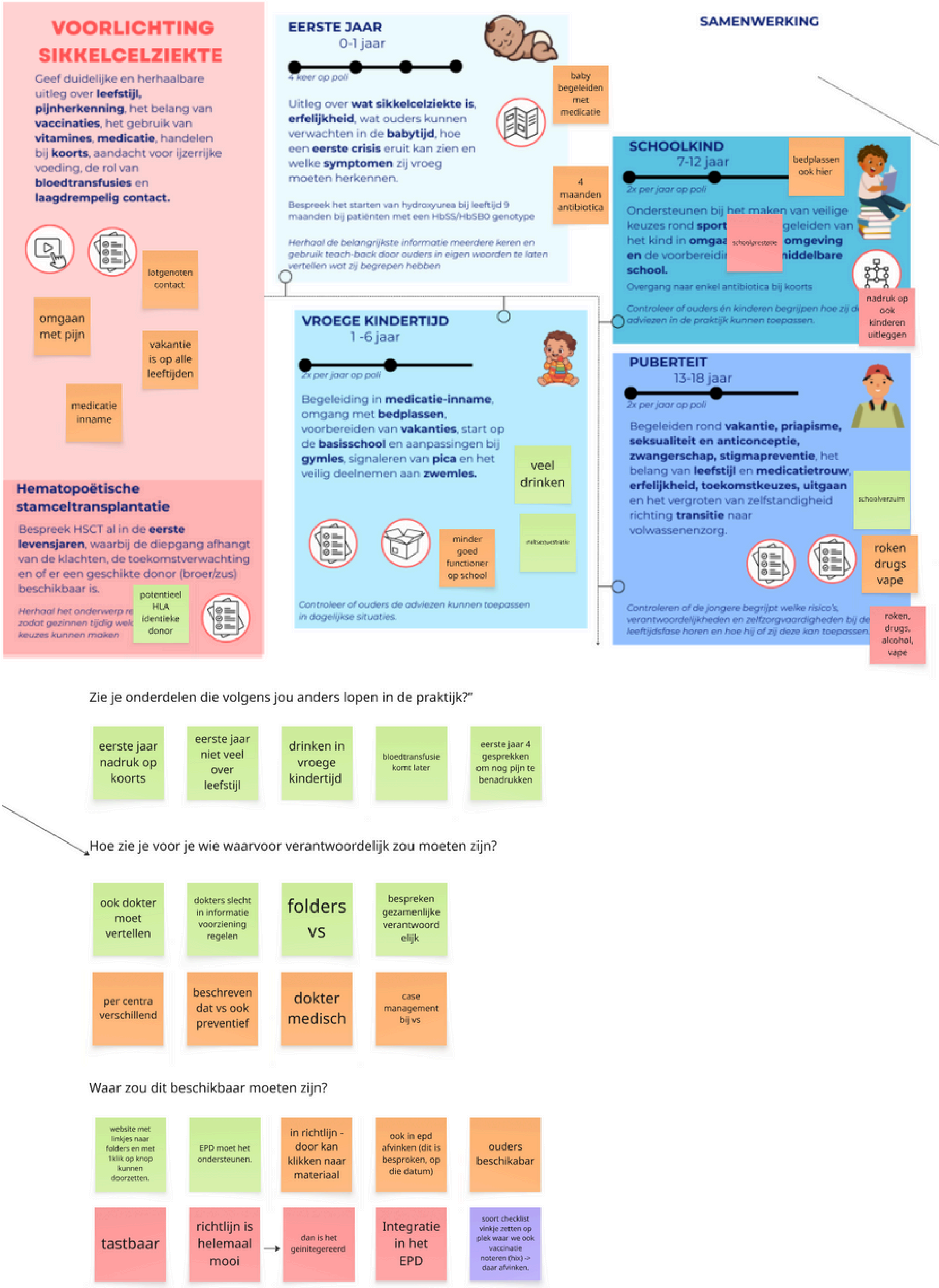
Integratie in het EPD

anders namelijk?

PDF met klikbare onderdelen

Een poster

G2. Co-creation results



VOORLICHTING SIKKELCELZIEKTE

Geef duidelijke en herhaalbare uitleg over **leefstijl, pijnherkenning**, het belang van **vaccinaties**, het gebruik van **vitamines**, **medicatie**, handelen bij **koorts**, aandacht voor ijzerrijke voeding, de rol van **bloedtransfusies** en **laagdrempelig contact.**

lotgenoten contact

omgaan met pijn

vakantie is op alle leeftijden

medicatie inname

Hematopoëtische stamceltransplantatie

Bespreek HSCT al in de **eerste levensjaren**, waarbij de diepgang afhangt van de klachten, de toekomstverwachting en of er een geschikte donor (broer/zus) beschikbaar is.

Herhaal het onderwerp re

zodat gezinnen tijdig wel

keuzes kunnen maken

potentieel HLA identieke donor

EERSTE JAAR

0-1 jaar

4 keer op poli

Uitleg over **wat sikkelcelziekte is**, **erfelijkheid**, wat ouders kunnen verwachten in de **babytijd**, hoe een **eerste crisis** eruit kan zien en welke **symptomen** zij vroeg moeten herkennen.

Bespreek het starten van hydroxyurea bij leeftijd 9 maanden bij patiënten met een HbSS/HbSB0 genotype

Herhaal de belangrijkste informatie meerdere keren en gebruik teach-back door ouders in eigen woorden te laten vertellen wat zij begrepen hebben

baby begeleiden met medicatie

4 maanden antibiotica

SAMENWERKING

VROEGE KINDERTIJD

1 -6 jaar

2x per jaar op poli

Begeleiding in **medicatie-inname**, omgang met **bedplassen**, voorbereiden van **vakanties**, start op de **basisschool** en aanpassingen bij **gymles**, signaleren van **pica** en het veilig deelnemen aan **zwemles.**

veel drinken

minder goed functioner op school

[illegible]

Controleer of ouders de adviezen kunnen toepassen in dagelijkse situaties.

SCHOOLKIND

7-12 jaar

2x per jaar op poli

Ondersteunen bij het maken van veilige keuzes rond **sport** … geleiden van het kind in **omgaa** … **omgeving en** de voorbereidi… **middelbare school.**

Overgang naar enkel antibiotica bij koorts

Controleer of ouders én kinderen begrijpen hoe zij d… adviezen in de praktijk kunnen toepassen.

bedplassen ook hier

schoolprestatie

nadruk op ook kinderen uitleggen

PUBERTEIT

13-18 jaar

2x per jaar op poli

Begeleiden rond **vakantie, priapisme, seksualiteit en anticonceptie, zwangerschap, stigmapreventie**, het belang van **leefstijl** en **medicatietrouw**, **erfelijkheid, toekomstkeuzes, uitgaan** en het vergroten van zelfstandigheid richting **transitie** naar volwassenenzorg.

Controleren of de jongere begrijpt welke risico's, verantwoordelijkheden en zelfzorgvaardigheden bij de leeftijdsfase horen en hoe hij of zij deze kan toepassen.

schoolverzuim

roken drugs vape

roken, drugs, alcohol, vape

Zie je onderdelen die volgens jou anders lopen in de praktijk?"

eerste jaar nadruk op koorts

eerste jaar niet veel over leefstijl

drinken in vroege kindertijd

bloedtransfusie komt later

eerste jaar 4 gesprekken om nog pijn te benadrukken

Hoe zie je voor je wie waarvoor verantwoordelijk zou moeten zijn?

ook dokter moet vertellen

dokters slecht in informatie voorziening regelen

folders vs

bespreken gezamenlijke verantwoord elijk

per centra verschillend

beschreven dat vs ook preventief

dokter medisch

case management bij vs

Waar zou dit beschikbaar moeten zijn?

website met linkjes naar folders en met 1klik op knop kunnen doorzetten.

EPD moet het ondersteunen.

in richtlijn - door kan klikken naar materiaal

ook in epd afvinken (dit is besproken, op die datum)

ouders beschikabar

tastbaar

richtlijn is helemaal mooi → dan is het geinitegereerd

Integratie in het EPD

soort checklist vinkje zetten op plek waar we ook vaccinatie noteren (hix) -> daar afvinken.

Appendix H - Validation session

Topics in validation session

Doel evaluatie: Is het concept voor de infographic en de implementatieaanpak realistisch en uitvoerbaar binnen de bestaande richtlijnontwikkeling?

Probleem niet zozeer ligt in een gebrek aan informatiematerialen, maar in de manier waarop informatie momenteel wordt aangeboden: vaak te complex, inconsistent tussen centra en onvoldoende afgestemd op de praktische en emotionele realiteit van gezinnen.

→ nieuw uitgangspunt waarbij informatie op vaste, relevante momenten wordt aangeboden.

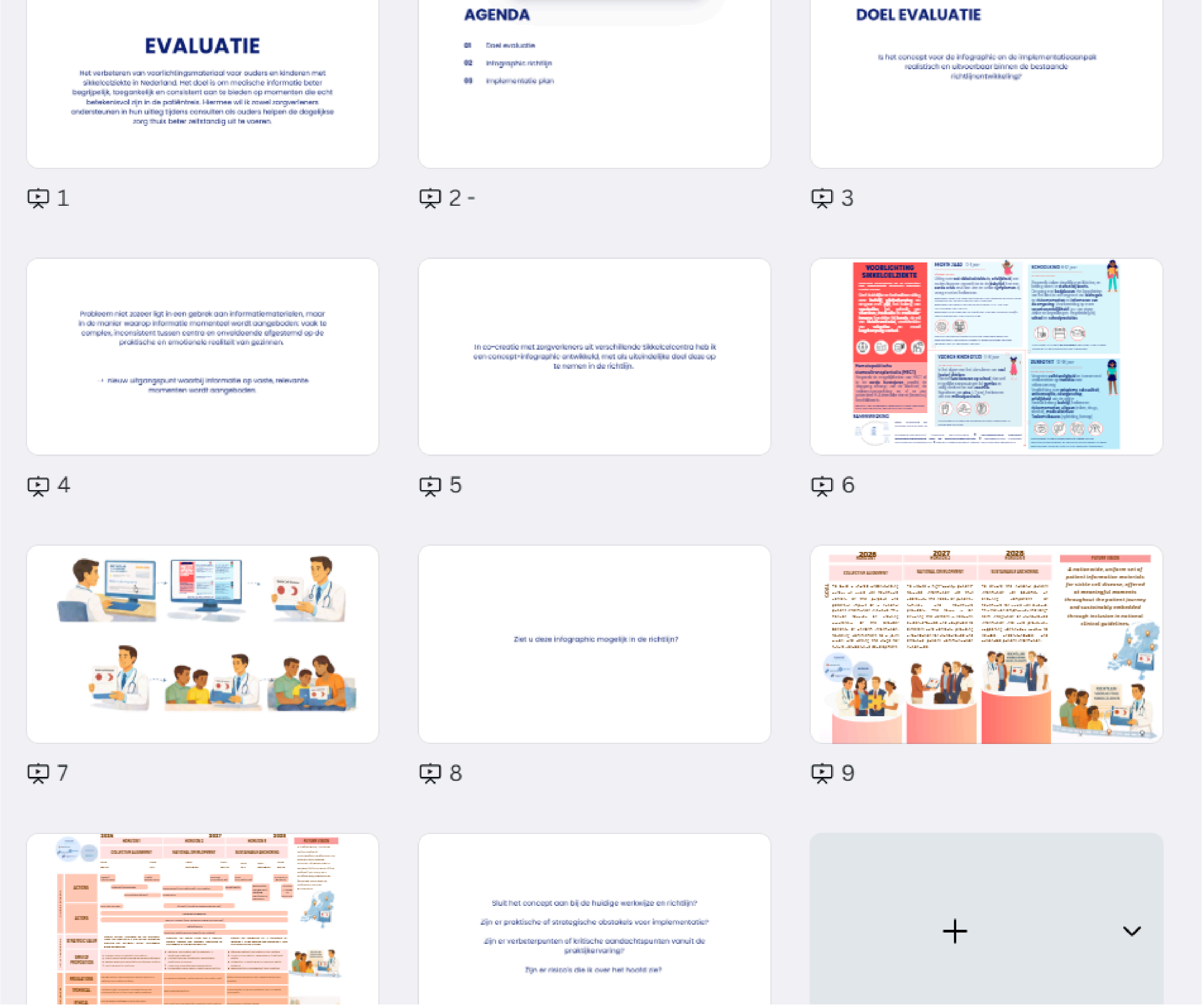
Sluit het concept aan bij de huidige werkwijze en richtlijn?

Zijn er praktische of strategische obstakels voor implementatie?

Zijn er verbeterpunten of kritische aandachtspunten vanuit de praktijkervaring?

Zijn er risico's die ik over het hoofd zie?

Ziet u deze infographic mogelijk in de richtlijn?



EVALUATIE

Het verbeteren van voorlichtingsmateriaal voor ouders en kinderen met sikkelcelziekte in Nederland. Het doel is om medische informatie beter begrijpelijk, toegankelijk en consistent aan te bieden op momenten die echt betekenisvol zijn in de patiëntreis. Hiermee wil ik zowel zorgverleners ondersteunen in hun uitleg tijdens consulten als ouders helpen de dagelijkse zorg thuis beter zelfstandig uit te voeren.

1

AGENDA

01 Doel evaluatie

02 Infographic richtlijn

03 Implementatie plan

2 -

DOEL EVALUATIE

Is het concept voor de infographic en de implementatieaanpak realistisch en uitvoerbaar binnen de bestaande richtlijnontwikkeling?

3

Probleem niet zozeer ligt in een gebrek aan informatiematerialen, maar in de manier waarop informatie momenteel wordt aangeboden: vaak te complex, inconsistent tussen centra en onvoldoende afgestemd op de praktische en emotionele realiteit van gezinnen.

→ nieuw uitgangspunt waarbij informatie op vaste, relevante momenten wordt aangeboden.

4

In co-creatie met zorgverleners uit verschillende sikkelcelcentra heb ik een concept-infographic ontwikkeld, met als uiteindelijke doel deze op te nemen in de richtlijn.

5

6

7

Ziet u deze infographic mogelijk in de richtlijn?

8

9

Sluit het concept aan bij de huidige werkwijze en richtlijn?

Zijn er praktische of strategische obstakels voor implementatie?

Zijn er verbeterpunten of kritische aandachtspunten vanuit de praktijkervaring?

Zijn er risico's die ik over het hoofd zie?

Appendix I - Canva support

Infographic aanpassen in Canva (stap-voor-stap)

Stap 1 – Open het Canva-document

- Ga naar canva.com en log in
- Klik op Projecten
- Open de infographic die je wilt bijwerken → Nu zie je je ontwerp in de bewerkingsomgeving

Stap 2 – Tekst en afbeeldingen aanpassen

Tekst aanpassen

- Klik op een tekstvak
- Bovenin kun je:
  - Lettertype veranderen
  - Tekst groter of kleiner maken
  - Kleur aanpassen
  - Tekst uitlijnen (links, midden, rechts)
  - Effecten toevoegen (bijv. schaduw of vetgedrukt)

Afbeeldingen aanpassen

- Klik op een afbeelding om:
  - De grootte te veranderen (hoeken slepen)
  - De afbeelding te vervangen (sleep een nieuwe afbeelding erop)
  - Kleuren of helderheid aan te passen via Bewerken

VOORLICHTING SIKKELCELZIEKTE

Algemene onderwerpen die bij voorlichting over sikkelcelziekte standaard besproken moeten worden

Geef duidelijke en herhaalbare uitleg over **leefstijl**, **pijnherkenning** en omgaan met **pijn**, het belang va **vaccinaties**, het gebruik **vitamines**, **medicatie** en **medica** **inname**, handelen bij **koorts**, de ro van **bloedtransfusies**, voorbereiden van **vakanties** en vooral **laagdrempelig contact**

Hematopoëtische stamceltransplantatie (HSCT)

Bespreek de mogelijkheden van HSCT al in de **eerste levensjaren**, waarbij de diepgang afhangt van de klachten, de toekomstverwachting en of er een potentieel HLA identieke donor (broer/zus) beschikbaar is.

Herhaal het onderwerp regelmatig zodat gezinnen tijdig weloverwogen keuzes kunnen maken

SAMENWERKING

Stem informatie en signalen altijd af met VS

Kinderarts-hematoloog: medische kerninformatie | **Verpleegkundig Specialist: hoofdverantwoordelijk voor de voorlichtingsstructuur** | Verpleegkundig Consulent: doorlopende ondersteuning | Medisch Maatschappelijk Werker: psychosociale begeleiding

EERSTE JAAR 0-1 jaar

3/4 keer op poli

itleg over **wat sikkelcelziekte is**, **erfelijkheid**, wat uders kunnen verwachten in de **babytijd**, hoe een erste crisis eruit kan zien en welke **symptomen** zij roeg moeten herkennen.

Bespreek vanaf 3-4 maanden starten met dagelijks antibiotica ter preventie van (ernstig beloop van) infecties.

Herhaal de belangrijkste informatie meerdere keren en gebruik teach-back door ouders in eigen woorden te laten vertellen wat zij begrepen hebben

VROEGE KINDERTIJD 1 -8 jaar

2x per jaar op poli

In het algemeen het stimuleren van **veel (water) drinken**.
Minder **functioneren op school**, dan wel mogelijke aanpassingen bij **gymles** en veilig deelnemen aan **zwemles**.
Signaleren van **pica** (>2 jaar), herkennen van een **miltsequestratie**.

Controleer of ouders de adviezen kunnen toepassen in dagelijkse situaties.

SCHOOLKIND 8-12 jaar

2x er op poli

Be ek staken dagelijkse antibiotica, en belang direct te **starten bij koorts.**
Om g met **bedplassen**. Het begeleiden va kind in achtergrond van **leefregels** en **risicomomenten** en **informeren van** **omgeving**. Voorbereiding op meer **twoordelijkheid** t.a.v. van eigen en beperkingen. Begeleiding bij **ool** en **schoolprestaties**.

Controleer of ouders ***en kinderen*** *begrijpen hoe zij deze adviezen in de praktijk kunnen toepassen.*

PUBERTEIT 12-18 jaar

2x per jaar op poli

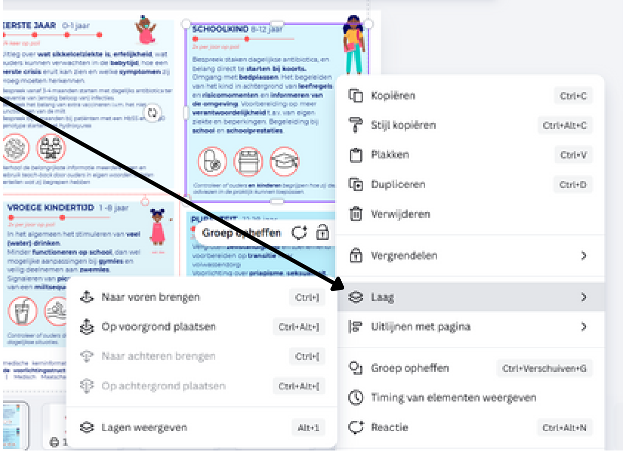
Vergroten **zelfstandigheid** en toenemend voorbereiden op **transitie** naar volwassenzorg
Voorlichting over **priapisme**, **seksualiteit**, **anticonceptie**, **zwangerschap**, **erfelijkheid** van de ziekte
Nadruk belang **leefstijl**, herkennen **risicomomenten**, **uitgaan** (roken, drugs, alcohol), **medicatietrouw**
Toekomstkeuzes (opleiding, beroep)

Controleren of de jongere begrijpt welke risico's, verantwoordelijkheden en zelfzorgvaardigheden bij deze leeftijdsfase horen en hoe hij of zij deze kan toepassen.

Stap 3 – Ordenen en lagen gebruiken

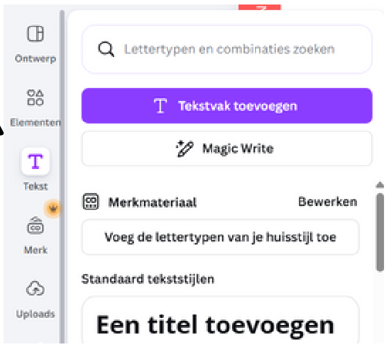
Als onderdelen over elkaar vallen:

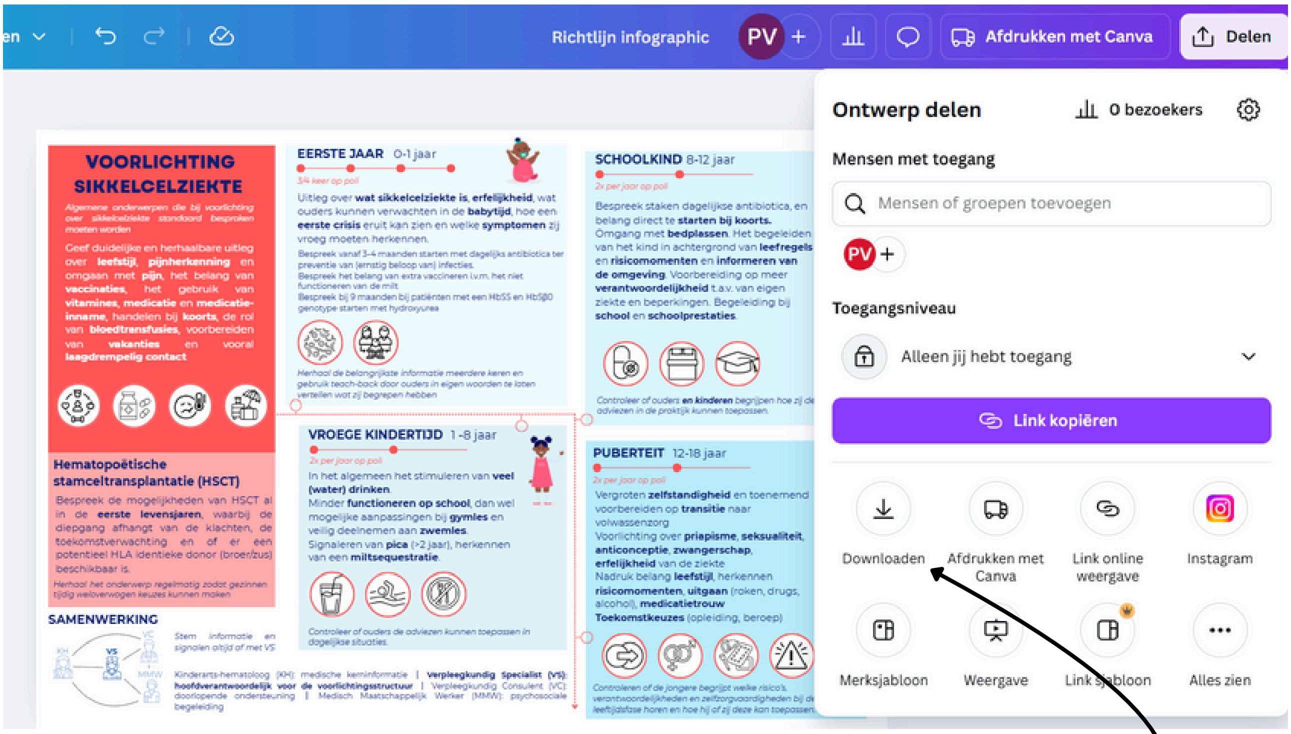
- Klik op het element
- Kies Positie: Naar voren / naar achteren
- Gebruik Uitlijnen om alles netjes recht te zetten
- Selecteer meerdere onderdelen → Groeperen → Zo blijven ze samen bewegen



Stap 4 – Nieuwe informatie toevoegen

- Klik links op Tekst of Elementen
- Voeg nieuwe titels, cijfers, iconen of grafieken toe
- Zorg dat:
  - Lettertypes consistent blijven
  - Kleuren passen bij de rest van de infographic
  - De informatie kort en overzichtelijk is





VOORLICHTING SIKKELCELZIEKTE

Algemene onderwerpen die bij voorlichting over sikkelcelziekte standaard besproken moeten worden

Geef duidelijke en herhaalbare uitleg over **leefstijl**, **pijnherkenning** en omgaan met **pijn**, het belang van **vaccinaties**, het gebruik van **vitamines**, **medicatie** en **medicatie-inname**, handelen bij **koorts**, de rol van **bloedtransfusies**, voorbereiden van **vakanties** en vooral **laagdrempelig contact**

Hematopoëtische stamceltransplantatie (HSCT)

Bespreek de mogelijkheden van HSCT al in de **eerste levensjaren**, waarbij de diepgang afhangt van de klachten, de toekomstverwachting en of er een potentieel HLA identieke donor (broer/zus) beschikbaar is.

Herhaal het onderwerp regelmatig zodat gezinnen tijdig weloverwogen keuzes kunnen maken

SAMENWERKING

Stem informatie en signalen altijd af met VS

Kinderarts-hematoloog (KH): medische kerninformatie | **Verpleegkundig Specialist (VS): hoofdverantwoordelijk voor de voorlichtingsstructuur** | Verpleegkundig Consulent (VC): doorlopende ondersteuning | Medisch Maatschappelijk Werker (MMW): psychosociale begeleiding

EERSTE JAAR 0-1 jaar

3/4 keer op poli

Uitleg over **wat sikkelcelziekte is**, **erfelijkheid**, wat ouders kunnen verwachten in de **babytijd**, hoe een **eerste crisis** eruit kan zien en welke **symptomen** zij vroeg moeten herkennen.

Bespreek vanaf 3-4 maanden starten met dagelijks antibiotica ter preventie van (ernstig beloop van) infecties.

Bespreek het belang van extra vaccineren i.v.m. het niet functioneren van de milt

Bespreek bij 9 maanden bij patiënten met een HbSS en HbSβ0 genotype starten met hydroxyurea

Herhaal de belangrijkste informatie meerdere keren en gebruik teach-back door ouders in eigen woorden te laten vertellen wat zij begrepen hebben

VROEGE KINDERTIJD 1-8 jaar

2x per jaar op poli

In het algemeen het stimuleren van **veel (water) drinken**.

Minder **functioneren op school**, dan wel mogelijke aanpassingen bij **gymles** en veilig deelnemen aan **zwemles**.

Signaleren van **pica** (>2 jaar), herkennen van een **miltsequestratie**.

Controleer of ouders de adviezen kunnen toepassen in dagelijkse situaties.

SCHOOLKIND 8-12 jaar

2x per jaar op poli

Bespreek staken dagelijkse antibiotica, en belang direct te **starten bij koorts.** Omgang met **bedplassen**. Het begeleiden van het kind in achtergrond van **leefregels** en **risicomomenten** en **informeren van de omgeving**. Voorbereiding op meer **verantwoordelijkheid** t.a.v. van eigen ziekte en beperkingen. Begeleiding bij **school** en **schoolprestaties**.

*Controleer of ouders **en kinderen** begrijpen hoe zij de adviezen in de praktijk kunnen toepassen.*

PUBERTEIT 12-18 jaar

2x per jaar op poli

Vergroten **zelfstandigheid** en toenemend voorbereiden op **transitie** naar volwassenzorg

Voorlichting over **priapisme**, **seksualiteit**, **anticonceptie**, **zwangerschap**, **erfelijkheid** van de ziekte

Nadruk belang **leefstijl**, herkennen **risicomomenten**, **uitgaan** (roken, drugs, alcohol), **medicatietrouw**

Toekomstkeuzes (opleiding, beroep)

Controleren of de jongere begrijpt welke risico's, verantwoordelijkheden en zelfzorgvaardigheden bij de leeftijdsfase horen en hoe hij of zij deze kan toepassen.

Stap 5 - Opslaan, downloaden en delen

Canva slaat je werk automatisch op. Je hoeft niets extra's te doen.

Downloaden

Klik op Delen → Downloaden en kies het juiste formaat:

PNG / JPG voor afbeeldingen

PDF voor documenten of printen

MP4 / GIF voor video of animatie

Controleer of je de juiste pagina's selecteert.

Model E1E2.
Informatiebrief Niet WMO-plichtig onderzoek, inclusief toestemmingsformulier

05-07-2024,versie 1.0

Informatie voor deelname aan onderzoek

Partitura studies; het verbeteren van het gezondheidstraject voor patiënten met een zeldzame aandoening

1. Inleiding

Geachte meneer/ mevrouw,

In deze informatiebrief vragen wij u om mee te doen aan (medisch-) wetenschappelijk onderzoek. Meedoen is vrijwillig. U ontvangt deze brief omdat u een zorgverlener bent betrokken bij de zorg voor kinderen en/of jong volwassene met een zeldzame aandoening.

U leest in deze brief waar het onderzoek over gaat. Ook leest u wat het voor u betekent als u aan het onderzoek deelneemt.

Heeft u belangstelling?
- Lees deze informatiebrief dan aandachtig door.
- Stel vragen aan de onderzoeker/ onderzoeksmedewerker die u deze informatie geeft.

Wilt u meedoen?
- Vul dan het toestemmingsformulier (bijlage B) in, onderteken en dateer deze.

2. Algemene informatie

Het onderzoek is opgezet door de afdeling Kinderhematologie van het Erasmus MC Sophia Kinderziekenhuis. Het onderzoek wordt uitgevoerd door artsen en onderzoekers van het Erasmus MC.

De Niet WMO Toetsingscommissie Erasmus MC heeft beoordeeld dat dit onderzoek niet onder de reikwijdte van de Wet Medisch-Wetenschappelijk Onderzoek met Mensen (WMO) valt, maar heeft het onderzoek inhoudelijk beoordeeld.

3. Wat is het doel van het onderzoek?

Het doel van deze studies is om de zorg te evalueren. Dit doen we door het maken van zorgpaden en het in kaart brengen van patiëntervaringen voor verschillende ziekten. Een zorgpad laat zien hoe de zorg geregeld is, bijvoorbeeld wanneer er contact is tussen de patiënt en zorg-professionals en wie er op welk moment verantwoordelijk is. Dit is belangrijk omdat eerder onderzoek heeft laten zien dat het in kaart brengen van zorgpaden ervoor kan zorgen dat patiënten uitkomsten, de kwaliteit van de zorg en communicatie verbeterd kunnen worden. Daarnaast zorgt het ervoor dat het zorgproces, en de voordelen en kosten ervan, inzichtelijk worden en richtlijnen verbeterd kunnen worden. De continue terugkoppeling vanuit patiënten over hun ervaringen en behoeften leidt ook tot terugkoppeling aan zorgverleners waar de zorg verbeterd zou kunnen worden.

4. Hoe verloopt het onderzoek en wat betekent dat voor u?

Kinderen en volwassenen met een zeldzame ziekte, ouders/ verzorgers en zorg-professionals kunnen meedoen aan dit onderzoek.

Groepsgesprek en co-creatie sessies.
Hetonderzoekbestaat uitverschillendedelen:

1. **Deelname aan een groepsgesprek voor het in kaart brengen van ervaringen en behoeften**
   Het groepsgesprek vindt plaats inhetErasmus MC.Een groepsgesprekduurt ongeveer 120 minuten en zal gaan over uw ervaringen en behoeften als zorg-professional rondom de zorg. Het gesprek zal geleid worden door een van de onderzoekers van de studie. Tijdens het groepsgesprek zullen wij opnames maken. U leest in paragraaf 8 wat wij met deze opnames willen doen.
2. **Deelname aan een co-creatie sessie voor het opstellen van het zorgpad**
   De co-creatie sessie vindt plaats in het Erasmus MC of online via Teams. De co-creatie sessie duurt ongeveer 120 minuten. Tijdens de co-creatie sessie zal het zorgpad voor het behandelcentrum waar u werkzaam bent in kaart worden gebracht, door bijvoorbeeld te kijken naar wanneer welke zorg plaatsvindt, wanneer er contactmomenten zijn tussen de patiënt en de zorgprofessional en wie er op elk moment van het zorgtraject verantwoordelijk is. Ook wordt u gevraagd naar mogelijke verbeterpunten binnen het zorgproces. Het gesprek zal geleid worden door een van de onderzoekers van de studie. Tijdens de co-creatie sessie zullen wij opnames maken. U leest in paragraaf 7 en 8 wat wij met uw gegevens en de opnames willen doen.
3. **Validatie van het opgestelde zorgpad**
   De co-creatie sessies zullen op een iteratieve manier worden uitgevoerd totdat er een consensus is bereikt over het geïdentificeerde en gevisualiseerde zorgtraject. Hiervoor zullen we deskundige zorgprofessionals werkzaam in zeldzame aandoeningen en werkzaam bij het Erasmus MC Sophia kinderziekenhuis, Erasmus MC of een ander geassocieerd expertise centrum benaderen.

5. Wat zijn de voordelen en de nadelen als u meedoet aan het onderzoek?

Het onderzoek kan nuttige informatie opleveren over hoe het zorgproces voor kinderen en jong volwassenen met een zeldzame aandoening eruit ziet. En hoe het zorgproces verbeterd zou kunnen worden. U heeft zelf geen direct voordeel van deelname aan dit onderzoek.

De nadelen van deelname zijn dat het u enige tijd kost en dat wij u vragen actief na te denken wat er in uw ogen verbeterd kan worden aan het zorgproces.

6. Als u niet mee wilt doen of wilt stoppenmet het onderzoek

Deelname aan het onderzoek is geheel vrijwillig. Alleen indien u wilt meedoen, ondertekent u het toestemmingsformulier (Bijlage B).

Ukunt altijd stoppen met het onderzoek. Wij vragen u wel dit zo snel mogelijk aan de onderzoeker te melden. U hoeft daarbij niet te zeggen *waarom* u stopt.

Degegevens die tot dat moment zijn verzameld, worden wel gebruikt voor het onderzoek.

7. Welke gegevens en opnames verzamelen wij?

Bestaande gegevens
Webewarenpersoonlijke gegevens van u, zoals uw naam en uw specialisme.

Nieuwe gegevens
Naastde bestaande gegevens zullen wij tijdens het interview of groepsgesprek door middel van een opname onderzoeksgegevens verzamelen over uw ervaring rondom de zorg.

8. Wat doen we met uw gegevens, en opnames?

Waarom verzamelen,gebruiken en bewaren we uw gegevensen opnames?
We verzamelen, gebruiken en bewaren de gegevens van u, om de vragen van dit onderzoek te kunnen beantwoorden.

Wij willen de resultaten van het onderzoek publiceren.

Hoe beschermenwijuw privacy?
Om uw privacy te beschermen geven wij de gegevens een code. Op alle gegevens zetten we alleen deze code.

De gegevens die direct naar u verwijzen worden dan niet meer gebruikt. De sleutel van de code bewaren we op een beveiligde plek in het Erasmus MC. Alleen de onderzoeker en leden van het onderzoeksteam weten welke code u heeft. Als we uw gegevens verwerken of delen, gebruiken we steeds alleen die code. In rapporten en publicaties over het onderzoek kan niemand terughalen dat het over u ging.

Hoe lang bewarenwe uw gegevens?
We bewaren uw onderzoeksgegevens 10 jaar in het Erasmus MC.

Watdoenwemetbeeld-engeluidsopnames?
Indien u op de opname herkenbaar bent (bijvoorbeeld als deze is opgenomen via Microsoft Teams), zal na afloop van het interview of groepsgesprek het beeld van de geluidsopname afgehaald worden. De geluidsopname van het interview of groepsgesprek zal met professionele apparatuur (met *encrypted* opslag van de opnames) uitgetypt worden. Hierna zal de geluidsopname verwijderd worden. De uitgetypte tekst zal opgeslagen worden.

Kunt u uw toestemming voorhet gebruik van uw gegevens weerintrekken?
Ukunt uw toestemming voor het gebruik van uw gegevens op ieder moment intrekken. Dit geldt voor hetgebruik in dit onderzoek en voor het gebruik in ander onderzoek. Als u uw toestemming intrekt en deanalyse van de verzamelde gegevens is nog niet gedaan, dan zullen we uw gegevens niet gebruiken. Als de analyse al wel gedaan is, dan zijn uw gegevens niet meer te achterhalen en kunnen weuw gegevens niet meer terugtrekken uit de analyse.

Mogen wij una dit onderzoekopnieuw benaderen vooreen vervolgonderzoek?
Wanneer dit onderzoek is afgelopen, doen we misschien een vervolgonderzoek. We willen u dan graag benaderen met de vraag of u weer deel wilt nemen. Op het toestemmingsformulier kunt u aangeven of u ons toestemming geeft u opnieuw te benaderen.

Wilt u meerweten overuw privacy?
Wilt u meer weten over uw rechten bij de verwerking van persoonsgegevens? Kijk dan op https://www.autoriteitpersoonsgegevens.nl/nl/over-privacy/persoonsgegevens.
Als u vragen of klachten heeft over uw privacy, raden we u aan om deze eerst te bespreken met het onderzoeksteam. U kunt ook naar de Functionaris Gegevensbescherming van het Erasmus MC gaan. Of u dient een klacht in bij de Autoriteit Persoonsgegevens.

9. Krijgt u een vergoeding voor meedoen?

Voor deelname aan dit onderzoekontvangt u geen vergoeding.

10. Heeft u vragen?

Bij vragen over dit onderzoek kunt u contact opnemen met de uitvoerende onderzoeker Drs. Caroline Mussert of hoofdonderzoeker Prof. dr. M.H. Cnossen.
De contactgegevens vindt u in bijlage A.

Met vriendelijke groet,

Het onderzoeksteam

Bijlage A: Contactgegevens

Hoofdonderzoeker:
Prof. dr. M.H. Cnossen, kinderarts-hematoloog, bereikbaar via telefoonnummer 010-7036691 (secretaresse)

Uitvoerende onderzoekers:
Drs. Caroline Mussert
c.mussert@erasmusmc.nl

Klachten:
Digitaal klachtenformulier via https://www.erasmusmc.nl/nl-nl/patientenzorg/klachtenopvang-en-klachtenbemiddeling

Functionaris voor de Gegevensbescherming van de instelling:
De Functionaris voor de Gegevensbescherming van het Erasmus MC is bereikbaar via het secretariaat van de afdeling Juridische Zaken. E-mail:
functionaris.gegevensbescherming@erasmusmc.nl
Tel: 010-703 4986

Voor meer informatie over uw rechten:
Voor meer informatie of bij vragen over uw rechten kunt u contact opnemen met de functionaris voor de Gegevensbescherming of met de Autoriteit Persoonsgegevens.

Bijlage B: Toestemmingsformulier deelnemer

Partitura studies; het verbeteren van het gezondheidstraject voor patiënten met een zeldzame aandoening

- Ik heb de informatiebrief gelezen. Ook kon ik vragen stellen. Mijn vragen zijn voldoende beantwoord. Ik had genoeg tijd om te beslissen of ik meedoe.
- Ik weet dat meedoen vrijwillig is. Ook weet ik dat ik op ieder moment kan beslissen om toch niet mee te doen of te stoppen met het onderzoek. Daarvoor hoef ik geen reden te geven.
- Ik geef toestemming voor het verzamelen en gebruiken van mijn gegevens op de manier en voor de doelen die in de informatiebrief staan.
- Ik geef toestemming om mijn gegevens nog 10 jaar na dit onderzoek te bewaren binnen Erasmus MC.
-

We verzoeken u in de tabel hieronder ja of nee aan te kruisen:

Ik geef toestemming om mijn gegevens te bewaren om deze te gebruiken voor ander onderzoek, zoals in de informatiebrief staat.	Ja ☐	Nee ☐
Ik geef toestemming om mijn gegevens nog 10 jaar na dit onderzoek te bewaren binnen het Erasmus MC.	Ja ☐	Nee ☐
Ik geef toestemming om mij eventueel na dit onderzoek te vragen of ik wil meedoen met een vervolgonderzoek.	Ja ☐	Nee ☐
Ik geef toestemming voor het verzamelen en gebruiken van filmopnames/geluidsopnames. Deze opnames zullen nadat zij zijn uitgeschreven worden vernietigd.	Ja ☐	Nee ☐

- Ik wil meedoen aan dit onderzoek.

Mijn naam is (deelnemer):

Handtekening: Datum : __ / __ / __

Ik verklaar dat ik deze deelnemer volledig heb geïnformeerd over het genoemde onderzoek.

Als er tijdens het onderzoek informatie bekend wordt die de toestemming van de deelnemer zou kunnen beïnvloeden, dan breng ik hem/haar daarvan tijdig op de hoogte.

Naam onderzoeker:

Handtekening: Datum: __ / __ / __

De deelnemer krijgt een volledige informatiebrief mee, samen met een kopie van het getekende toestemmingsformulier.

Appendix K - Projectbrief

Personal Project Brief – IDE Master Graduation Project

Name student Puck van der Veer **Student number** 5071410

PROJECTTITLE,INTRODUCTION,PROBLEMDEFINITIONandASSIGNMENT
Complete all fields, keep information clear, specific and concise

Project title Designing accessible information materials for parents and children with sickle cell disease

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

Introduction

Describe the context of your project here; What is the domain in which your project takes place? Who are the main stakeholders and what interests are at stake? Describe the opportunities (and limitations) in this domain to better serve the stakeholder interests. (max 250 words)

Sickle cell disease (sickle cell disease) is a chronic hereditary blood disorder that affects the daily lives of patients and their families. In the Netherlands, approximately 2000 people live with the disease, about 50% are children (Sikkelcelfonds.nl, 2025). Most of the patients have a migration background. At the Sophia Children's Hospital, the pediatric hematology outpatient clinic treats a diverse group of children with sickle cell disease (Figure 1). Families often face additional challenges such as cultural and language barriers, large household sizes, and varying levels of health literacy, which make it harder to access, process, and apply medical information (Singleton & Krause, 2009).

Currently, information is mostly provided in hospitals through conversations with doctors and nurses, sometimes supported by leaflets. This information is often complex, difficult to remember, and not sufficiently tailored to the needs of families. While healthcare professionals are available in the hospital, parents are responsible for most care at home. In this context, accessible and lasting information becomes essential.

This project therefore focuses on developing generically applicable information materials that can be used by parents and children with sickle cell disease. The goal is to create accessible resources that remain relevant beyond the hospital setting. A key ambition is to ensure that the same information can be offered across all sickle cell centers in the Netherlands, supporting consistency, recognition, and empowerment for families.

Sikkelcelfonds.nl. (2025, August 11). Help je mee sikkelcelziekte te genezen? - Het Sikkelcelfonds. https://hetsikkelcelfonds.nl/
Singleton, K., & Krause, E. M. S. (2009). Understanding cultural and linguistic barriers to health literacy. OJIN the Online Journal of Issues in Nursing, 14(3). https://doi.org/10.3912/ojin.vol14no03man04

➔ *space available for images / Figures on next page*

Personal Project Brief – IDE Master Graduation Project

Problem Definition

What problem do you want to solve in the context described in the introduction, and within the available time frame of 100 working days? (= Master Graduation Project of 30 EC). What opportunities do you see to create added value for the described stakeholders? Substantiate your choice.
(max 200 words)

Families with children who suffer from sickle cell disease are often confronted with a large amount of complex medical information. This information is not always accessible, is difficult to remember, and is often not adapted to the needs of families. Parents, who take on the majority of care at home, can feel overwhelmed, while children have limited opportunities to gradually build understanding of their condition. As a result, important knowledge does not always translate into effective daily care.
This project will focus on developing information materials that translates complex medical knowledge into accessible, clear, and lasting support for families. By identifying key themes together with health care specialists, and by drawing on the experiences of parents and children, opportunities will arise to create information that remains relevant both in the hospital and at home.

The added value lies in reducing the burden on families, strengthening their ability to manage care in daily life, and supporting children in stepwise learning about their disease. For healthcare professionals the goal is offering a consistent tool in all sickle cell centers in the Netherlands, to improve communication and ensure that essential knowledge is understood and remembered.

Assignment

This is the most important part of the project brief because it will give a clear direction of what you are heading for. Formulate an assignment to yourself regarding what you expect to deliver as result at the end of your project. (1 sentence) As you graduate as an industrial design engineer, your assignment will start with a verb (Design/Investigate/Validate/Create), and you may use the green text format*:*

Design information materials that improves the accessibility and understanding of sickle cell disease for children and their families, supports parents in their care responsibilities at home, and assists healthcare professionals in providing consistent and empowering information across all sickle cell centers in the Netherlands.

Then explain your project approach to carrying out your graduation project and what research and design methods you plan to use to generate your design solution (max 150 words)

This project follows a human centered design approach to develop accessible information materials for parents and children with sickle cell disease.

First, literature research is conducted to understand existing knowledge on health communication and sickle cell disease education. Context analysis (expert interviews, observations) with healthcare professionals clarify essential information and current practices. Context mapping provides insights into the daily experiences and needs of parents and children. Using journey mapping, the experience of parents and children from diagnosis onward is tracked to identify key moments for information delivery. In co-creation sessions (joint value creation) healthcare staff collaborate to generate and refine ideas. Throughout the process, value tensions such as balancing detailed medical information with emotional support are explored. Promising concepts will be prototyped and validated. Finally, the project will also explore how the new materials can best be implemented in the existing care path to ensure effective use.

Project planning and key moments

Tomake visible how you plan to spend your time, you must make a planning for the full project. You are advised to use a Gantt chart format to show the different phases of your project, deliverables you have in mind, meetings and in-between deadlines. Keep in mind that all activities should fit within the given run time of 100 working days. Your planning should include a ***kick-off meeting***, ***mid-term evaluation meeting***, ***green light meeting*** *and* ***graduation ceremony***. *Please indicate periods of part-time activities and/or periods of not spending time on your graduation project, if any (for instance because of holidays or parallel course activities).*

Make sure to attach the full plan to this project brief.
The four key moment dates must be filled in below

Kick off meeting 11 September 2025

Mid-term evaluation 6 Nov 2025

Green light meeting 15 Jan 2026

Graduation ceremony 12 Feb 2026

In exceptional cases (part of) the Graduation Project may need to be scheduled part-time. Indicate here if such applies to your project

Part of project scheduled part-time	☐
For how many project weeks	
Number of project days per week	

Comments:

Motivation and personal ambitions

Explainwhyyou wishtostartthisproject, what competencies you want to prove or develop (e.g. competencies acquired in your MSc programme, electives, extra-curricular activities or other).

Optionally, describe whether you have some personal learning ambitions which you explicitly want to address in this project, on top of the learning objectives of the Graduation Project itself. You might think of e.g. acquiring in depth knowledge on a specific subject, broadening your competencies or experimenting with a specific tool or methodology. Personal learning ambitions are limited to a maximum number of five.
(200 words max)

This project strongly aligns with my personal drive to create meaningful impact through design, especially in emotionally complex contexts such as healthcare. I am motivated by the opportunity to support families during a vulnerable time by improving how information is shared and understood.

I want to apply and further develop my competencies in human centered design, systems thinking, and communication design. In particular, I aim to strengthen my ability to conduct qualitative research (user and expert interviews, context mapping) and translate insights into a feasible, validated design solution that fits a real clinical setting.