MASTER THESIS

Bridging the Knowledge Gap:

Improving Information Provision for Hemophilia Patients

Tjaisha Eekelaar

Strategic Product Design, TU Delft
September 2023

SAMEN SPRAAK:
A tool to improve the information provision for hemophilia patients during outpatient clinic visits.

Tjaisha Eekelaar

MASTER GRADUATION PROJECT 2023
T.M. Eekelaar

Master Strategic Product Design
Faculty of Industrial Design Engineering
Delft University of Technology
September 2023

Supervisory Team
Chair Dr. Ir. A. Albayrak
Mentor MSc. S.R. Dehli

In collaboration with
Erasmus MC/ Drs. C.M.A. Mussert
Partitura MSc. E.S. van Doorn

ACKNOWLEDGEMENTS

As a student at the Faculty of Industrial Design Engineering, it is great to have the opportunity to do assignments within courses for a wide range of companies and organizations. In this way, you get better insight into the sectors where your interests lie. During an elective course for Partitura, I discovered that my passion lies with human-centered design. That is why I continued for this client during my graduation project - the last stop of my student career.

First, I thank my supervisors, Armagan and Silje, for their involvement and guidance in this project. I found it exciting and sometimes challenging to complete such a large project, but your guidance helped me a lot and often showed me that it would work out. Thank you for your valuable feedback, tips, and always pleasant meetings.

Second, I would also like to thank Caroline for the guidance as a mentor from Erasmus MC. I have benefited greatly from your knowledge within the healthcare sector. Because of you, entering a completely new environment felt like a warm bath. You were always there for me to think along or name the right contacts I could approach. I also want to thank Shannon. As an 'extra' supervisor, you have been very involved in my project. Your insight has kept me sharp while writing my thesis.

In addition, I would like to thank all the hemophilia treatment center healthcare professionals in the Sophia Children's Hospital for their enthusiasm, thinking, and involvement in your team. Of course, I also want to thank all parents, children, and stakeholders for their time and sharing their experiences; with your insights, I achieved the result as it is now.

Finally, I thank my family and friends for their unconditional support and help during this project.

Tjaisha
Rotterdam, September 2023

ABSTRACT

Hemophilia, a bleeding disorder, is divided into types A and B, resulting from coagulation factors VIII and IX deficiencies. The levels of these clotting factors in the body determine the severity of hemophilia. The classification includes severe, moderate, and mild hemophilia. Managing hemophilia involves options like on-demand and prophylactic treatment. A key part of managing this condition involves Hemophilia Treatment Centers (HTCs) as the primary healthcare providers for patients.

The HTC at Erasmus MC is one of the six centers in the Netherlands. It offers comprehensive care for adults and children with hemophilia and other rare bleeding disorders. In the pediatric department of Erasmus MC's HTC, children with hemophilia attend multiple outpatient clinic visits annually. During these visits, patients and their caregivers receive education about the bleeding disorder, its treatment, and potential consequences. However, grasping the information during these visits can be challenging, especially as most of it is conveyed verbally. This poses a particular difficulty for patients and caregivers with lower literacy levels.

To enhance the information provided to hemophilia patients and caregivers, HTCs must offer comprehensive support to ensure patients understand the information communicated during outpatient clinic visits. Improving information provision in these contexts aims to make significant progress towards a future where patient information and education are improved, resulting in better outcomes for those living with hemophilia.

This graduation project involved conducting research through literature reviews, analyzing materials, observing HTC's operations, and interviewing healthcare professionals, patients and their caregivers, and relevant stakeholders. The findings revealed several pain points regarding the current information provision. These areas include the information exchanged during outpatient clinic visits and the accessibility of provided information outside of these visits. Consequently, two solutions were developed: an information tool named "Samen Spraak," designed to enhance information exchange between healthcare professionals and parents by introducing interactivity and structure during consultations. This tool is then detailed in a strategy outlining a digital solution's implementation roadmap.

Based on this developed tool and strategy, it is advisable to classify it under the Dutch Association for Hemophilia Patients (NVHP) for further implementation and testing. Future research could explore expanding the approach to other blood clotting disorders across all age groups.

TABLE OF CONTENTS

LIST OF ABBREVIATIONS

HCP	Healthcare Professional
HJHS	Hemophilia Joint Health Score
HTC	Hemophilia Treatment Center
MC	Medical Center
METC	Medisch Ethische Toetsings Commissie
NVHP	Nederlandse Vereniging van Hemofilie-Patiënten (Dutch Association of Hemophilia Patients)
NVHV	Nederlandse Vereniging van Hemofilie-Verpleegkundigen (Dutch association of hemophilia nurses)
PHE	Personal Health Environment
PFCC	Patient- and Family centered care

GLOSSARY

Coagulation	Coagulation is the process by which blood forms clots to prevent excessive bleeding.
eHealth literacy	is defined as "a set of skills and knowledge that are essential for productive interactions with technology-based health tools" (Chan & Kaufman, 2011).
Electronic patient record	Digital system that stores and manages comprehensive medical information about a patient, making it easily accessible to healthcare professionals for diagnosis, treatment, and care coordination.
Health literacy	is defined as "people's knowledge, motivation, and competencies to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention, and health promotion" (Sørensen et al., 2012).
Hemophilia Joint Health Score	Assessment used to evaluate the condition of joints in individuals with hemophilia, measuring the extent of damage and functional impairment caused by repeated bleeding episodes
Outpatient clinic	Medical facility where patients receive healthcare services and treatment without being admitted to a hospital, usually for less severe conditions or routine check-ups.

INTRODUCTION

01

1.0 Project Introduction

This chapter explains the scope and objectives of the project assignment. It clarifies the rationale behind this graduation project, outlines the subject, formulates the core problem statement, and articulates the project's overarching aim. Furthermore, it offers insight into the various research questions and presents the project approach employed to address these questions.

1.1 PROJECT ASSIGNMENT

This project is part of the Partitura research program initiated by participants of the SYMPHONY consortium. SYMPHONY aims to improve treatments for patients with inherited bleeding disorders, impacting patient care and cost-efficiency (Symphony Consortium, n.d.). Within this consortium, Partitura is focused on improving the care of patients with hemophilia and other inherited bleeding disorders by structuring the care pathway and mapping the patient journey to better the communication between healthcare professionals (HCPs), patients, and their families and to improve the quality of care. Over 180.000 children and adults in the Netherlands are affected by an inherited bleeding disorder (Symphony Consortium, n.d.); 1600 have hemophilia (Cyberpoli, n.d.-b). For this graduation project, the focus is on hemophilia, a bleeding disorder that causes blood not to clot (properly).

Previous research by Partitura into the experiences of patients and their patient journey has revealed various points for improvement, one of which is that the information provision for children with hemophilia and their parents needs improvement. That is why this graduation project aims at mapping the experiences of the information provision for hemophilia patients and thereby identifying points for improvement to improve the information provision for parents of children with hemophilia.

In this graduation project, research will be conducted on what information provision is currently provided for hemophilia patients and how HCPs, patients, and their family experience this. Existing patient journeys and the care pathway will be used to build upon during this research. The results will lead to a tool design to improve the information provision in the short term, followed by a strategy to elaborate on this tool, enhancing the information provision in the long term.

This research is conducted within the Erasmus MC, meaning the data is collected from HCPs and patients from the Erasmus MC. The demarcation is for parents of children with hemophilia aged 0-10 years, regardless of the type or severity of hemophilia.

See Appendix A1 for the project brief of this thesis.

Main Question

How to improve the information provision for caregivers of hemophilia patients between 0-10 years old?

Research Questions

This study aims to provide an answer to the following subquestions:

1. What is information provision and which aspects are important to consider?
2. What sources of information provision are currently offered at the Erasmus MC – Sophia's Children's Hospital?
3. How do caregivers of patients with hemophilia experience the information provision of the hospital?
4. What are the key moments of information provision?
5. What are the (unmet) needs of caregivers of patients with hemophilia regarding information provision by the hospital?
6. How do HCPs working in the field of hemophilia experience the information provision for caregivers of patients with hemophilia? Moreover, how do they use the information provision to educate patients and caregivers?
7. How do stakeholders relevant to this topic experience providing information in their work?
8. What are the pain points, and improvement opportunities within the information provision for caregivers of patients with hemophilia?

1.2 PROJECT APPROACH

This project requires a thorough understanding of healthcare systems' complexities and the needs and expectations of various stakeholders. The goal is to create innovative and sustainable solutions that improve human health. Given the disparities in the backgrounds and interests of the stakeholders involved, a holistic approach is required to ensure health and well-being. A human-centered and contextual design approach is typically used to address challenges in healthcare systems (van Boeijen et al., 2020).

As previously stated, this project aims to create a tool to improve patient information for caregivers of patients with hemophilia aged 0-10. Furthermore, the goal is to develop a strategy to elaborate on the tool for enhancing information provision for these young patients and their caregivers in the long term. To achieve this goal, extensive research will be conducted to understand the current interactions between HCPs, patients, and caregivers. Their experiences, needs, and desires regarding information provision will be examined. This analysis will ensure that the developed tool and strategy are desirable, feasible, and viable, contributing to successful implementation.
Figure 1 shows that the project employs the double diamond design method (Design Council, n.d.). The model employed is a commonly utilized framework at the Faculty of Industrial Design Engineering at TU Delft that embodies an extensive design process characterized by the principles of divergence and convergence.

The initial stages of the design process, known as the "Discover and Define" phases, primarily focus on conducting research, engaging in exploration, determining the project's scope, and establishing the direction for the design. Throughout these stages, a series of interviews and user observations will be carried out alongside generative methodologies such as sensitizing booklets and a comprehensive literature review. The "Develop and Deliver" phases encompass the processes of generating ideas and executing them. Brainstorming and rapid prototyping techniques are commonly employed in ideation and idea validation. The complete procedure involves a series of iterative loops, wherein each phase delivers valuable insights that contribute to enhancing the ultimate design. Incorporating feedback is a crucial component of this process as it facilitates the development and improvement of ideas.

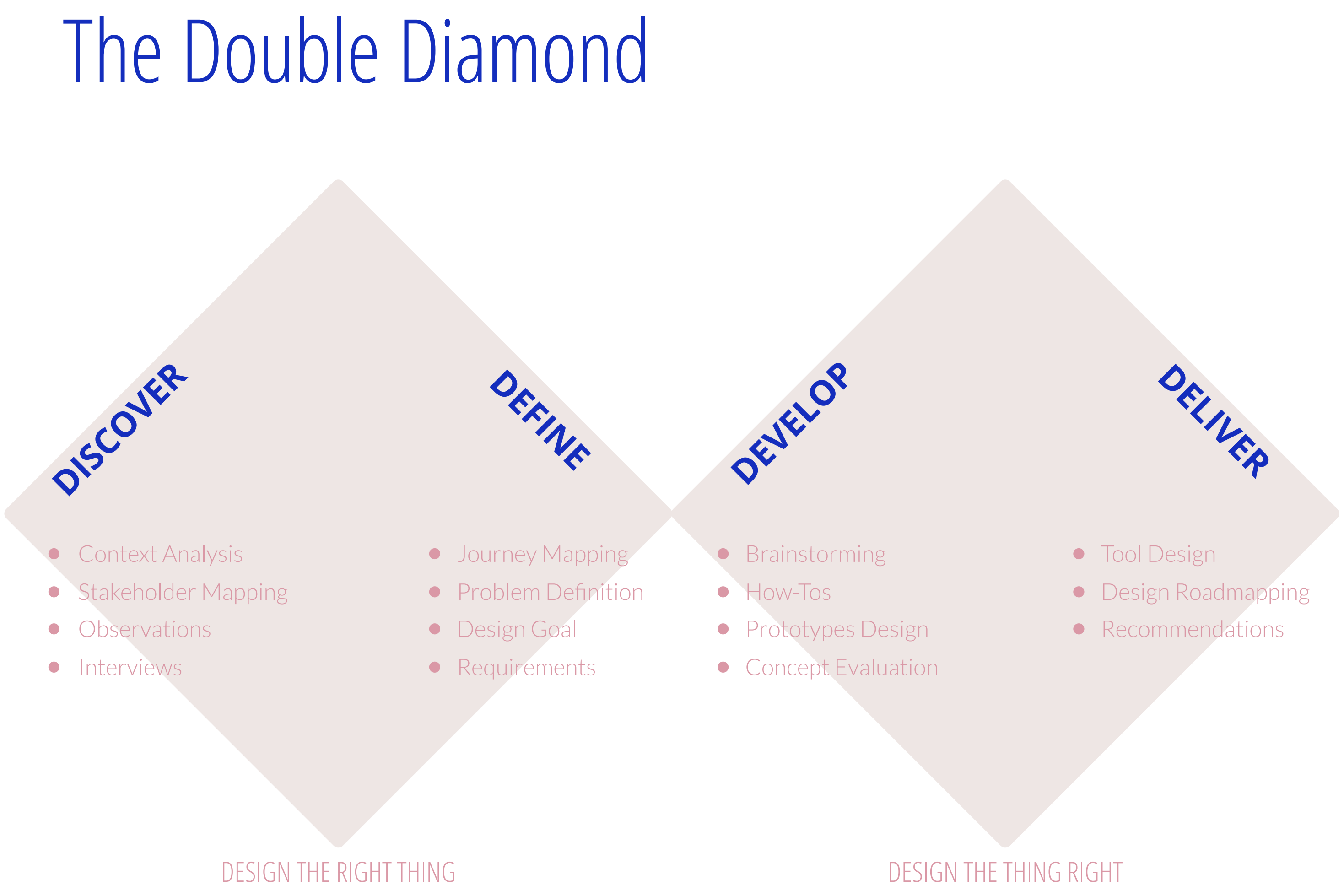


Figure 1: The Double Diamond model

DISCOVER

02

2.0 Background Information

This chapter provides an understanding of the topic of this thesis, namely hemophilia, and an exploration of the contextual background within which the project is situated, specifically the Erasmus MC, see Appendix B1 for the initial analysis. The chapter provides an overview of the project assignment, including its objectives and the research questions it seeks to address. In conclusion, a detailed overview of the approach in the design project is provided.

2.1 HEMOPHILIA

Hemophilia is an X-linked genetic bleeding condition caused by a deficiency of coagulation factor VIII (8) or factor IX (9). The condition of hemophilia encompasses two primary categories: hemophilia A, which results from a lack of factor VIII, and hemophilia B, which occurs due to a deficiency in factor IX. Hemophilia A is more common than hemophilia B [85:15] (Dolan et al., 2018). The primary symptom of this bleeding disorder is bleeding into joints and muscles. Without appropriate intervention, hemophilia can lead to profound joint deterioration and consequential loss of mobility (Chai-Adisaksopha et al., 2021).

Hemophilia patients are likely to experience bleeding, bruising, and bleeding after surgery (NVHP, 2015). Furthermore, it is notable that hemophilia is more prevalent among men than women since it is an X-linked genetic bleeding disorder. Therefore, the condition phenotypically manifests in men, whereas women typically serve as carriers. Nevertheless, it is worth acknowledging that women, despite being carriers, might also exhibit lower clotting levels, potentially giving rise to related concerns and symptoms.

The severity of hemophilia is classified based on the residual levels of the respective clotting factors, as illustrated in Figure 2. *Severe hemophilia* is defined as FVIII/FIX <1%, *moderate hemophilia* as FVIII/FIX 1-5%, and *mild hemophilia* as FVIII/FIX >5% (Konkle & Fletcher, 2022). The symptoms experienced by individuals with hemophilia vary depending on the severity. Those with severe hemophilia may have frequent and abnormal bleeding after minor injuries, surgeries, or tooth extractions and can experience spontaneous bleeding. In contrast, individuals with moderate hemophilia experience bleeding episodes less frequently and rarely spontaneously, and those with mild hemophilia only bleed heavily after trauma or invasive procedures (Konkle & Fletcher, 2022).

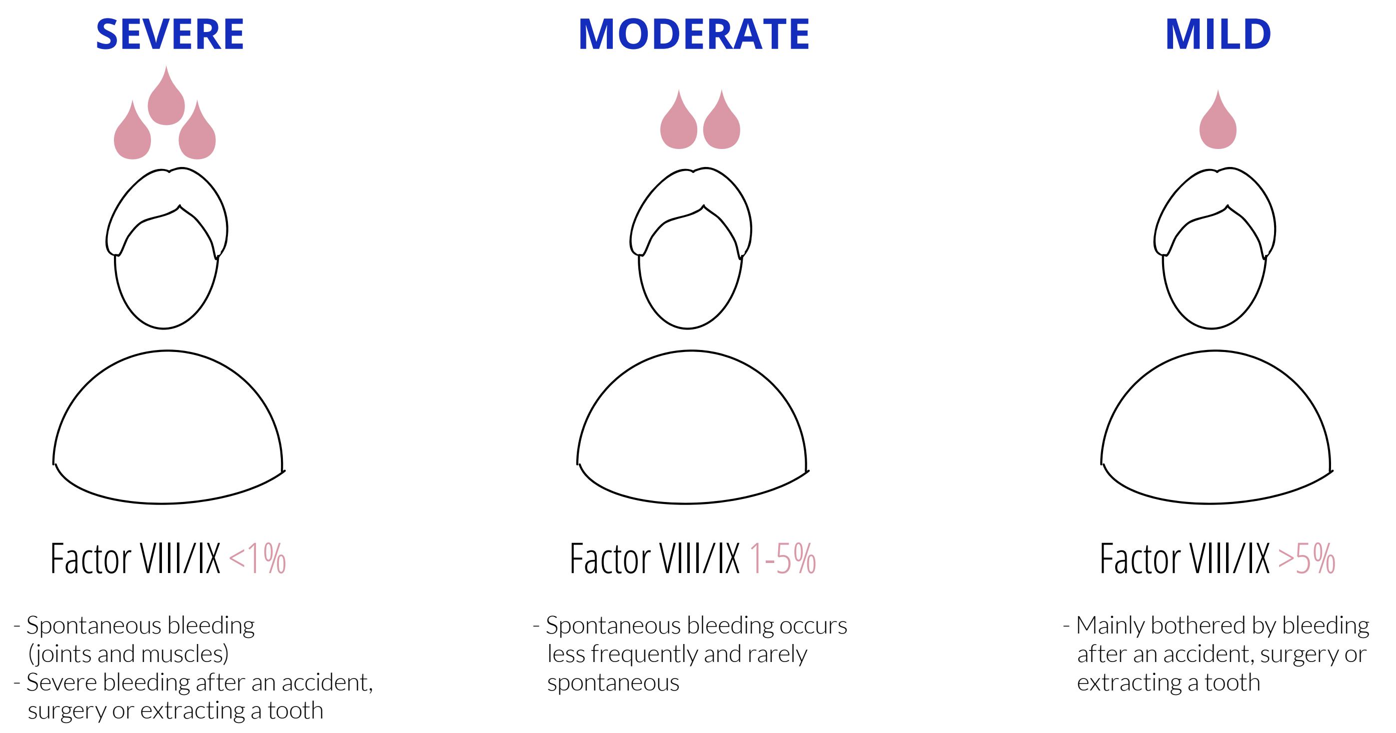


Figure 2: Types of hemophilia

Key Takeaways

- Hemophilia is an X-linked genetic bleeding disorder
- Hemophilia phenotypically manifests in men; women are carriers but can experience symptoms too
- Hemophilia is classified into severe, moderate, and mild hemophilia based on the residual levels of clotting factors
- The symptoms are (spontaneous) bleeding, bruising, and bleeding after surgery
- Treatment options are prophylactic treatment (preventive) or on-demand treatment (only when needed)
- Prophylactic treatment is given regularly, and eventually at home by parents themselves

Treatment options for hemophilia include on-demand treatment and prophylactic treatment. Prophylactic treatment involves regular intravenous injections with factor concentrates to prevent spontaneous bleeding and minimize joint damage in the long term. It is typically used 2-3 times weekly for individuals with severe or moderate hemophilia (Chai-Adisaksopha et al., 2021). However, the severity of bleeding can vary among individuals, making personalized treatment plans necessary. Emicizumab, a subcutaneous treatment, is an alternative to intravenous therapy and is only suitable for hemophilia A patients. However, it has to be administered once per 1-4 weeks only, offering more convenience, for example, for children with a fear of needles (Konkle & Fletcher, 2022). For acute bleeding or surgical procedures, on-demand factor replacement may be administered in both prophylactic and non-prophylactic treated patients.

Hemophilia can significantly impact the lives of children with the condition and their caregivers, depending on the severity and intensity of treatment. Additionally, there may be differences in the quality of life between individuals with hemophilia A and hemophilia B due to variations in disease characteristics, treatment options, and patient experiences (Dolan et al., 2018). Caregivers might have to take extra precautions to prevent bleeding in children with hemophilia, and these children might have to be more cautious in their activities to avoid injury and bleeding. As a result, their quality of life may be affected, as they may not be able to participate in certain activities like their peers (Konkle & Fletcher, 2022). For mild and moderate hemophilia patients, it is possible that this impact on their quality of life may be less compared to those with severe hemophilia. Nonetheless, a hospital's importance as any hemophilia patient's healthcare provider cannot be overstated. The team of HCPs plays an essential role in a hemophilia patient's life, not only in training for home infusion and injection procedures but mainly in supporting the patient and their family (Konkle & Fletcher, 2022).

The treatment of hemophilia has been continuously improved over the past years. Where blood products were used decades ago, causing hemophilia patients the risk of getting HIV-infected blood products, the medication is now plasma-derived. Also, the new subcutaneous treatment reduces the frequency of injections for patients with hemophilia A. Moreover, several studies are held upon fascinating potential future therapies, of which recently, gene therapy has officially succeeded as an establishment for sustained factor IX activity, thereby protecting patients with hemophilia B against bleeding without burdensome factor IX replacement (Pipe et al., 2023). The dynamic nature of hemophilia treatment calls for frequent adjustments to the provision of information.

2.2 ERASMUS MC - SOPHIA CHILDREN'S HOSPITAL

The Erasmus Medical Center (MC) in Rotterdam is an academic hospital and a medical research facility. It is one of Europe's largest and most technologically advanced hospitals. Domestic and international patients receive excellent care from the hospital's specialized departments and clinics. The hospital manages most areas of specialization.

Erasmus MC prioritizes research, education, and clinical care (Erasmus MC, n.d.-b). Many cutting-edge medical research centers and laboratories are housed at the hospital. Erasmus MC works with Erasmus University Rotterdam and other world-class research institutions to advance medical science and develop new treatments. For example, Erasmus University Rotterdam, Erasmus MC, and the Delft University of Technology have joined forces to implement research and education strategies centered on social issues (Atie Bruggeling & Tessa Govers, 2023). In addition, the Erasmus MC is a medical school. Clinical education is provided to doctors, nurses, and other healthcare professionals. Erasmus MC is well-known for its healthcare innovations, patient care, and international collaborations. The hospital strives to advance medicine and improve healthcare around the world.

Sophia Children's Hospital

Sophia Children's Hospital is Netherlands' largest academic pediatric hospital. This 160-year-old institution houses a wide range of specialized disciplines. Its specialty is pediatric complex medical conditions.

The hospital's **core values** are, as shown in Figure 3:

- *Samen* (Together)
- *Gastvrij* (Welcoming)
- *Durf* (Dare)
- *Persoonlijk* (Personal)
- *Waardevol* (Valuable)

These core values are integrated throughout the organization and guide how to interact with one another. It establishes a common language of communication. The unwavering commitment to putting children and their families at the forefront of its care structure is central to its ethos (Figure 4). As a result, patient-centeredness is seamlessly woven into the foundation of the hospital's mission, with a broad strategy driven by a dedication to patient care, research, and education. The hospital emphasizes shared care with the child and its family as equal partners and one team based on the patient- and family-centered care principles (PFCC) (Atie Bruggeling & Tessa Govers, 2023).

Interdisciplinary teams of physicians and nurses at Sophia Children's Hospital deliver holistic and integrated care. The hospital's proactive approach begins before birth, including prenatal and sometimes preconception. This comprehensive continuum of care continues into young adulthood, demonstrating the hospital's commitment to supporting all phases of growth.

Figure 3: Sophia Children's Hospital's core values

Figure 4: Samenzorg concept

Hemophilia Treatment Center

The Hemophilia Treatment Center (HTC) is one of Erasmus' specialties, and it specializes in treating and supervising adults and children with hemophilia and other rare clotting diseases. Due to its hereditary origin, individuals with hemophilia require lifelong therapy and monitoring at all ages. This demands the cooperation of two separate treatment teams of professionals in different locations. One team is responsible for pediatric patients at Sophia Children's Hospital, while the other is responsible for adult patients at Erasmus MC's Center location. HCPs at the HTC's pediatric department encounter patients with hemophilia multiple times a year for outpatient clinic visits (Erasmus MC, n.d.-a). 3-4 times a year for severe patients and 1-2 times a year for mild and moderate patients, depending on individual needs. Individual treatment plans are modified once a year based on pharmacokinetic profiles obtained by blood and any bleeding that occurred. During consultations, patients and caregivers are educated and informed about the bleeding disease, its treatment, and its consequences. To keep the patients from bleeding, life rules are discussed. Patients receiving prophylactic treatment are asked to keep track of their medicine consumption using a particular app: the HemoNED Vaste Prik app. This will be explained more in Chapter 5.1.

3.0 Literature Review

This chapter provides a comprehensive examination of research on the relevant subject matter to this project. Firstly, this chapter overviews health literacy and its relevance in information provision. Furthermore, the chapter explores the value of effective communication and collaboration within the healthcare sector. Finally, this chapter contributes to understanding information processing and the constraints on an individual's capacity to retrieve it. Appendix B2 shows an overview of the literature review analysis

Answering research question

① What is information provision and which aspects are important to consider?

3.1 BUT FIRST...

As previously stated in Chapter 1.1, prior research conducted by Partitura has indicated an opportunity for enhancing the information provision. Furthermore, a study conducted by SYMPHONY reveals the necessity for enhancing the information provision, particularly among parents of the patients. In this study, some patients have indicated that improving the way health information is shared could make up for the sometimes poor exchanges between healthcare professionals. This was considered crucial to make coordination better (Brands et al., 2023).

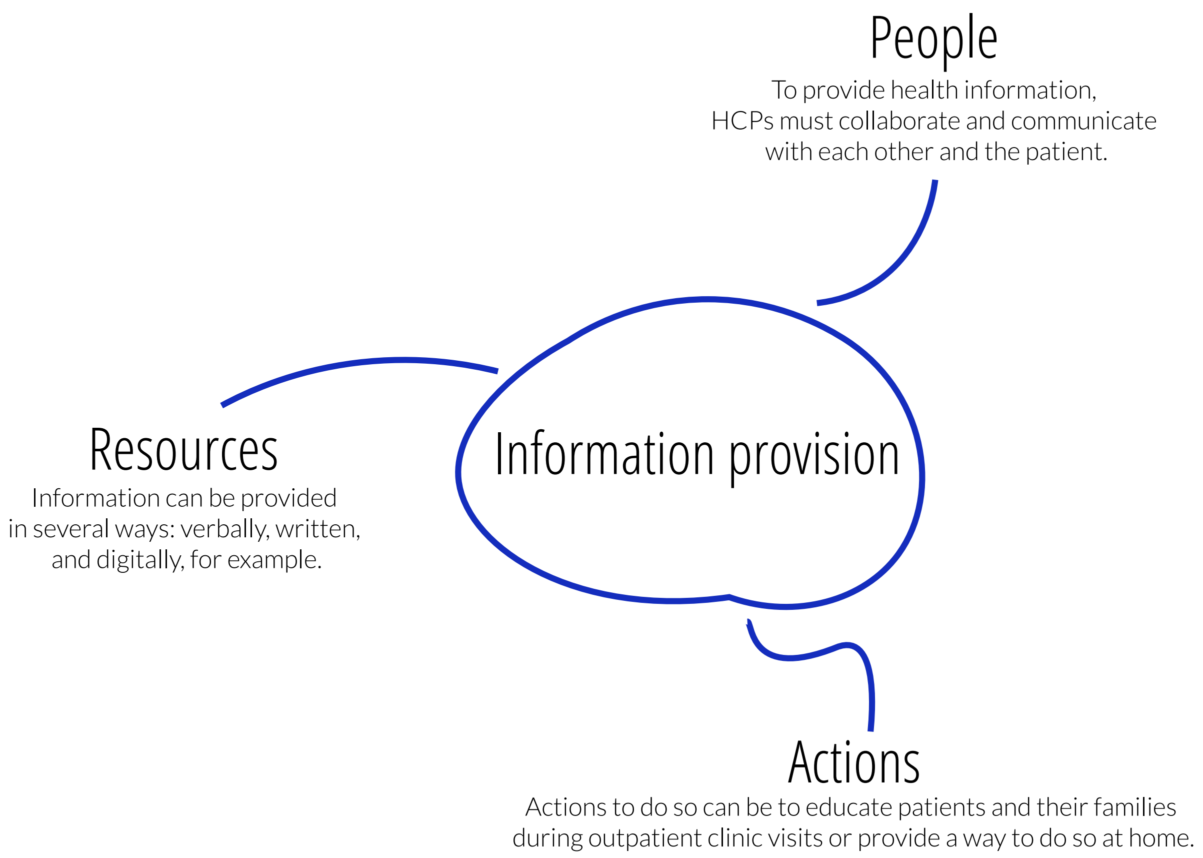
BUT WHAT IS INFORMATION PROVISION?

According to Wikipedia, "the information provision of an organization is the whole of people, resources, and actions aimed at the information needs of that organization" ("Informatievoorziening," 2022).

In the case of this project, it is not necessarily the information provision of an organization, but the information provision for hemophilia patients, provided by the healthcare institutions. Therefore, I would give this definition my own interpretation:

"Information provision in healthcare is the whole of people, resources, and actions aimed at the information needs of the patient."

The figure below shows the envisioned aspects of information provision.



To provide health information, HCPs must collaborate and communicate with each other and the patient.

Information can be provided in several ways: verbally, written, and digitally, for example.

Actions to do so can be to educate patients and their families during outpatient clinic visits or provide a way to do so at home.

Figure 5: Information provision

The literature review initiates by examining the need for HCPs to collaborate and communicate effectively. This examination aims to get insight into the human aspect of information exchange. The research subsequently emphasizes how information is processed, which is crucial in educating and informing patients and their families. Lastly, health literacy is vital in understanding what to consider when creating information resources. This necessitates a comprehensive examination of academic research on individuals' acquisition of health-related knowledge.

3.2 COMMUNICATION AND COLLABORATION IN HEALTHCARE

Efficient communication and collaboration are vital in the healthcare sector, benefiting both individual HCPs and the delivery of health services. These factors contribute to improved patient care quality and positive outcomes. However, a study analyzing 14,000 hospitalizations identified insufficient teamwork and communication techniques as the primary cause of avoidable clinical errors (Wu et al., 2012).

Communication failures can be attributed to two factors: a failure to communicate effectively with all key team members and inconsistent, incomplete, and inaccurate communication content (Dingley et al., 2008). In response to these inefficiencies, healthcare organizations have started implementing new communication technologies, such as eHealth services, to address the challenges.

Nevertheless, the introduction of new systems brings its own set of obstacles. The health sector is complex and unpredictable, comprising professionals from various disciplines, each with their own perspective on patient requirements. Disparities in education and training among these professions result in different communication styles and strategies. Unfortunately, many healthcare education programs focus on individual technical skills while neglecting teamwork and communication skills (Dingley et al., 2008).

To address these issues, fostering stronger interprofessional relationships through an appropriate communication system and good information sharing is crucial. Such a system should facilitate the communication and distribution of vast amounts of patient data to the right person at the right time. Moreover, it should empower patients by giving them more control over their medical information, fostering equality between patients and physicians, and improving patient-centered care (Wu et al., 2012). Developing new strategies requires integrative thinking and theorizing, considering the fragmented nature of technology's role in healthcare communication.

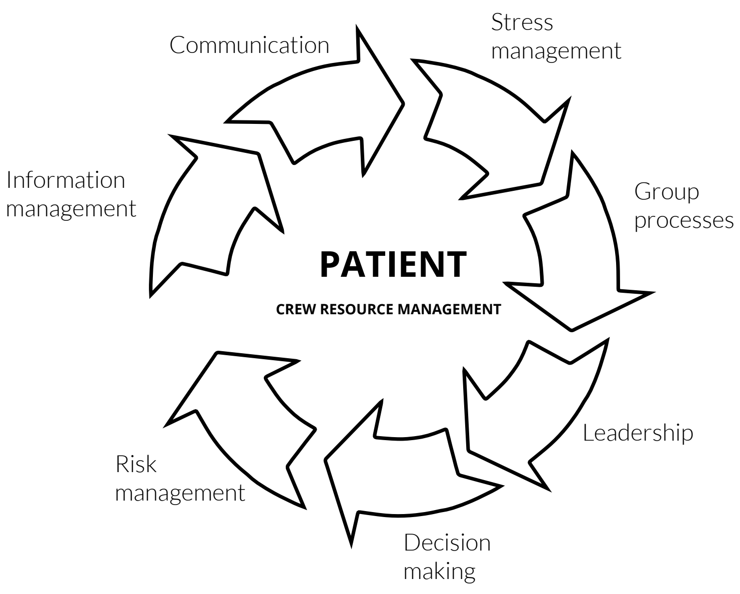


Figure 6: Crew Resource Management training

Key Takeaways

- The main reasons behind preventable medical mistakes are inadequate teamwork and communication methods
- Developing better relationships between HCPs through a suitable communication system and effective information sharing is extremely important
- To guarantee that all HCPss engaged in patient care have complete information and to establish a common language among different types of HCPs, a strong strategy for communication and collaboration is necessary
- Successfully implementing new approaches relies on education, support from stakeholders, and seamless integration with current systems

Interestingly, collaboration and communication concepts from the aviation industry have proven applicable to healthcare. Good communication and collaboration are essential for safety in the aviation sector. Mistakes in communication or collaboration can lead to catastrophic consequences. Shared aspects are Teamwork and Collaboration, Standardized Procedures, Clear Communication, Error Reporting and Learning Culture, and Simulation and Training. By drawing from these shared aspects, healthcare can learn from the aviation industry's safety practices and improve collaboration, communication, and patient care. Adapting aviation concepts in healthcare has shown promising results in reducing errors, improving patient outcomes, and enhancing overall safety culture. Therefore, ideas and practices from aviation are being implemented in healthcare settings (Dingley et al., 2008). For instance, the introduction presentation of Sophia Children's Hospital for new employees showed that the hospital has already started providing CRM training, as seen in Figure 6, modeled after aviation industry methods (Atie Bruggeling & Tessa Govers, 2023).

A robust communication and collaboration strategy should ensure that HCPs involved in patient care are fully informed and establish a standard interprofessional language across diverse HCPs. The successful adoption of innovative strategies or technologies in the healthcare system depends on providing adequate education and securing the support of stakeholders and end users. In addition, it is essential to recognize that the information may overlap with that contained in an electronic patient record, necessitating seamless integration (Wu et al., 2012).

In conclusion, adequate communication and collaboration are essential to improving patient care and outcomes. Addressing communication inefficiencies requires implementing new technologies and fostering stronger interprofessional relationships. Drawing on concepts from the aviation industry can also provide valuable insights. Ultimately, the successful adoption of innovative strategies depends on education, stakeholder support, and seamless integration with existing systems.

3.3 INFORMATION PROCESSING

Effective medical information processing and retrieval during hospital consultations are crucial for patients to improve comprehension and healthcare outcomes. This chapter explores the factors influencing information processing and recall abilities in-hospital consultations.

The initial stage of information processing is attending to the information presented during consultations. Active patient participation, questioning, and focused attention are essential. Research indicates that patients typically retain only 20% to 60% of the medical information HCPs provide (Visser et al., 2017). Factors such as using complex medical terminology by HCPs, the mode of information delivery (spoken or written), and patients' educational backgrounds or specific expectations can contribute to information recall failures (Kessels, 2003). External distractions and psychological stress can also reduce attentional capacity and hinder effective information processing. Encoding converts incoming information into cognitive representations that can be stored in memory. Patients must engage in active cognitive processing and understanding of the medical information communicated by HCPs. This involves relating new information to prior knowledge, making connections, and assigning personal importance.

Working memory serves as a temporary information store and cognitive processor. During consultations, patients rely on working memory to retain and process the discussed information. This is also illustrated in the crew resource management training as the first phase 'information management', see Figure 7. Due to its limited capacity, patients may need to engage in active rehearsal or use external aids, such as note-taking, to mitigate the risk of forgetting important information. Effective communication between HCPs and patients significantly facilitates information processing. Clear and concise explanations, visual aids, and simple language can enhance patient comprehension. Encouraging patients to seek explanations about their medical conditions and treatment plans and providing written materials for future reference can also aid understanding.

Emotional states have been found to influence information processing and recall abilities. Anxiety, stress, or emotional distress can interfere with the retention and retrieval of information. Research suggests that patients receiving negative medical diagnoses or prognoses, resulting in significant emotional stress, tend to have poorer overall information recall (Visser et al., 2017). HCPs should create an environment that addresses emotional barriers to optimize patients' ability to recall medical information.

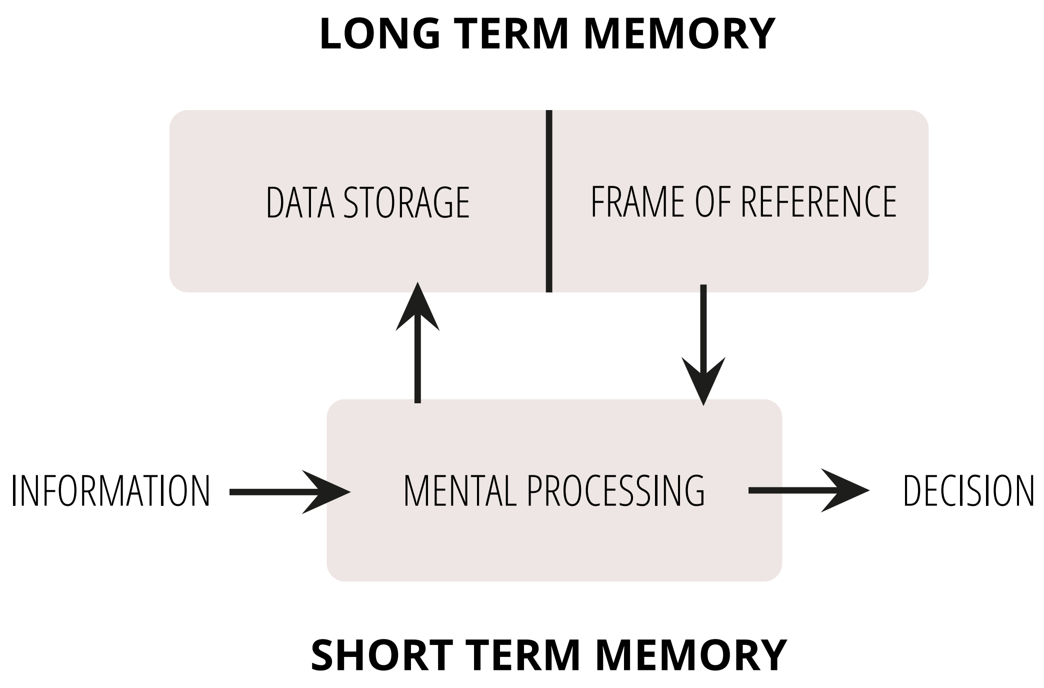


Figure 7: Information management of the CRM training

Key Takeaways

- Efficiently processing and retrieving medical information during hospital consultations holds immense importance in enhancing patient understanding and overall healthcare results
- Patients remember only 20-60% of the information they receive
- Several factors play a role in the failure of recalling information, including the use of intricate medical jargon, how the information is conveyed, and the patient's educational background or specific assumptions
- Feelings of anxiety or emotional distress can also disrupt the ability to retain and retrieve information
- Enhancing patient comprehension can be achieved through clear and succinct explanations, visual aids, and using plain language

Assessing patients' recall and retention of information following consultations is crucial. Information overload can occur when individuals' processing capacity is overwhelmed. Patients can become overwhelmed with traditional health education and self-management, and the abundance of online health information has further exacerbated the problem of information overload (Khaleel et al., 2020). Summarizing key points, reviewing written materials, and discussing with caregivers or family members can enhance memory consolidation and long-term retention. Health literacy plays a vital role in information processing and retention. HCPs should adapt communication styles, use simple language, and assess patient comprehension to facilitate effective information processing. To increase joint attention and improve understanding of shared ideas, it is effective to use visual aids, especially for people with limited reading ability. In addition, the use of visual aids improves memory through the 'pictorial superiority effect'. This phenomenon is enhanced by the combination of auditory and visual learning channels, which allows people to store verbal and visual representations more efficiently in their working memory, thereby increasing their recall capacity (Mbanda et al., 2021).

Understanding the complexities of information processing and recall capabilities following hospital consultations is crucial for improving patient comprehension and healthcare outcomes. Attention, encoding, working memory, communication strategies, emotional influences, and health literacy play significant roles. By considering these factors, HCPs can enhance patient comprehension and promote more efficient patient care.

3.4 HEALTH LITERACY

Health literacy refers to an individual's ability to obtain, understand, and utilize health information to make informed decisions about their health and well-being (Sørensen et al., 2012). It involves reading and comprehension skills and the capacity to evaluate information and apply it to real-life situations critically. Health literacy is crucial in enabling patients to navigate the complex healthcare system, understand medical instructions, make informed choices, and actively participate in their care, see Figure 8.

Adequate information provision is essential for patients with different health literacy levels. Clear, concise, and easily understandable health information helps patients comprehend their medical condition, treatment options, and preventive measures. It empowers them to communicate effectively with HCPs, ask relevant questions, and actively engage in shared decision-making.

With the rise of digitalization, there has been increased adoption of eHealth services in healthcare. EHealth refers to using digital technologies, such as websites, web-based apps, and mobile apps, to deliver health-related information and services. Individuals need sufficient health literacy within eHealth (Kim & Xie, 2017).

Low health literacy contributes to health inequities and unequal access to healthcare resources. Individuals with low health literacy face difficulties using and interacting with eHealth effectively. As a result, they may utilize eHealth and preventative services less, which can harm their health and increase morbidity, mortality, and hospitalization rates. Vulnerable populations, such as the elderly (65+), patients with low literacy or language proficiency (such as non-Dutch speakers and people with less education), and those with limited education or socioeconomic status, are particularly at risk (Kim & Xie, 2017).

Figure 8: Barriers of low health literacy (PublicHealth, n.d.)

Key Takeaways

- Health literacy plays a pivotal role in empowering patients to navigate the intricate healthcare system, comprehend medical directions, make educated decisions, and play an active role in their own well-being
- Limited health literacy significantly contributes to disparities in health and uneven access to healthcare resources
- Individuals with low health literacy encounter challenges in effectively using and engaging with eHealth tools
- Research indicates that a substantial portion of health-related content online is written at a level that surpasses appropriate reading capacities.
- Health literacy stands as a fundamental factor in furnishing patients with adequate information, both in traditional healthcare settings and the domain of eHealth

Notably, low-literacy and high-literacy patients may lack confidence in their ability to find reliable online health information due to the abundance of available information (Ghaddar et al., 2012). Research also indicates that much health-related content online is written beyond an appropriate reading level. Therefore, improving the readability of online health information and ensuring its reliability are important considerations.

In addition to readability, usability is crucial for eHealth services to provide appropriate access to and use of online health information. Design principles and recommendations have been proposed in the article of Kim & Xie to enhance the usability of eHealth services, which can aid in improving health literacy and user experience.

Efforts should be made to improve individual health literacy through educational programs (Kim & Xie, 2017) while ensuring that eHealth services are readily available and accessible to people with low literacy levels. Mobile apps, in particular, provide interactive health services specifically designed for individuals with limited health literacy (Leroy & Miller, 2010).

In conclusion, health literacy is a critical factor in adequate patient information provision, both in traditional healthcare settings and within the realm of eHealth. By improving health literacy and tailoring information to meet the diverse needs of patients, HCPs can empower individuals to make informed decisions, actively manage their health, and ultimately improve healthcare outcomes. Ensuring the readability and usability of eHealth services is essential to enable individuals to access and utilize online health information effectively.

4.0 Methods

This chapter provides a detailed overview of the methodologies used to contextualize the existing workflow and information resources. This entailed a series of observations and an examination of relevant materials, including existing care pathways and patient journeys derived from Partitura's prior research. Furthermore, this chapter explains how to use human-centered design methodologies to understand better the experiences around the current information provision. Qualitative research was carried out using the context mapping method to accomplish this.

The relevant stakeholders were identified and classified into three distinct groups. The first group comprises caregivers for hemophilia patients, while the second group comprises HCPs who work in the field of hemophilia. The third group includes stakeholders who are involved in the process of providing information to hemophilia patients.

4.1 PROTOCOL

Before this project could start, a non-WMO research protocol had to be written to get approval to interview caregivers of patients of the Erasmus MC, HCPs, and stakeholders, all materials created to submit this protocol can be found in Appendix B3. In this research protocol, the project setup and procedure needed to be explained for the Medisch Ethische Toetsings Commissie (Medical Ethics Review Committee; METC) to check. Here, the different stakeholder groups were identified and explained.

It was aimed to interview all the HCPs that are part of the team working in the pediatric department of the Erasmus MC 's HTC, at least one representative per relevant stakeholder in the information provision. Lastly, at least seven caregivers of hemophilia patients since 6-7 interviews will capture the majority of themes in a homogeneous group, and six interviews will give 80% of data saturation (Guest et al., 2020). The group of caregivers is homogeneous in that they are all caregivers of hemophilia patients but heterogeneous in the type of hemophilia since there will be no distinction in severity classification or type A and B, whereby maximum variation sampling will be used to gather information from a variety of ages in the range of 0-10 years old and various treatments (intravenous-, subcutaneous prophylactic- and on-demand treatment) to get the broadest possible overview of their journey and experiences.

4.2 METHOD OVERVIEW

Material Analysis

In order to establish an initial grasp of the workflow within the pediatric division of the HTC and to formulate interview guides for subsequent semi-structured interviews (Appendix B7), a thorough analysis of both the care pathway and the patient journeys created in previous research of Partitura was conducted. These materials, together with the insights gained from observations and interviews, provided a comprehensive overview of the current information resources in use.

Observations

Caregiver, patient, and HCP interactions were observed in an outpatient clinic. Such observations provided a comprehensive understanding of these cohorts and the critical factors that affect outpatient clinic visits. This approach not only allows for a more in-depth understanding of the interactions but it also aids in defining the trajectory of information provision, which includes the flow of information as well as the tools, resources, and techniques used to provide information.

Context Mapping

Context mapping is a user-centered research method commonly used in design and innovation processes to gain a deeper understanding of users' needs, experiences, and behaviors in their natural environments. The method involves engaging directly with users to explore their daily lives, activities, and challenges, with the aim of uncovering valuable insights that can inform the development of new products, services, or solutions (van Boeijen et al., 2020).

Sensitizing Cards

Sensitizing cards were sent in advance for the interviews with caregivers, see Appendix B4. It was a set of 8 double-sided cards with parent and child assignments (Figure 9). If old enough, the child could do their own assignments. The parents would do this for their child otherwise. This way, the parents were prepared to address the interview topics and were able to think about them in advance (sensitizing). The filled-in cards were sent back, making me more prepared.

Interviews

The interviews were semi-structured, with tailored interview guides developed for each participant group. This allowed for flexibility regarding follow-up questions based on the responses provided. The interviews were conducted in person as well as online. Before each interview, participants were asked to read and sign a consent form. The stakeholder interviews were lightly transcribed, whereas the HCP and caregiver interviews were fully transcribed (Appendix B8).

Statement Cards

For the interviews with HCPs and caregivers, a method involving creating statement cards was used for data analysis (Appendix B9). These statement cards include direct quotes from the interview data, a contextual interpretation, and a title (Figure 10). Following that, the statement cards were clustered, allowing the identification and clustering of common themes that spanned multiple cards. This method aided in the extraction of overarching insights from the interview data.

Journey/Experience Mapping

Using the identified themes, a workflow was developed, elucidating the current operational dynamics of the HCPs. In addition, an information journey map was created, focusing on the insights gained from the caregiver data. This was useful in mapping out the experiences and perspectives surrounding information provision for hemophilia patients. Furthermore, it served as a framework for identifying critical pain points in the current information provision.

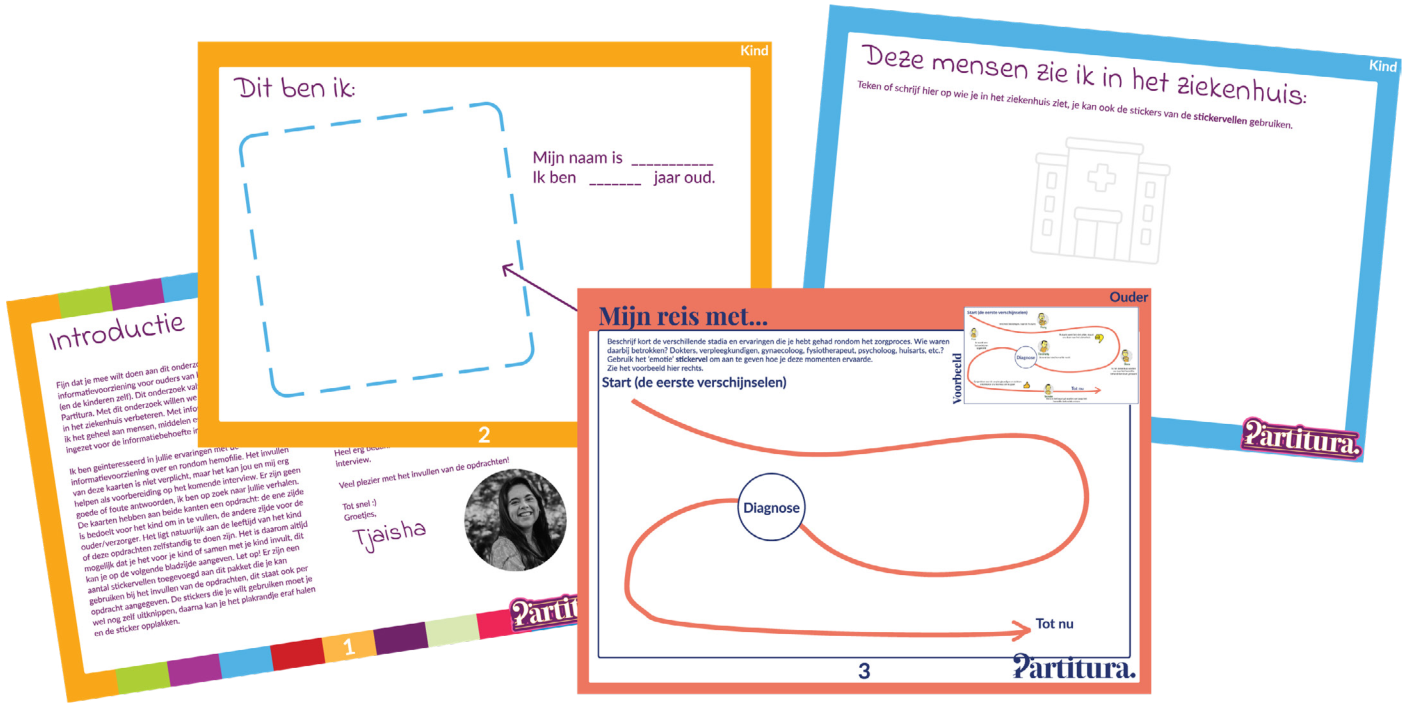
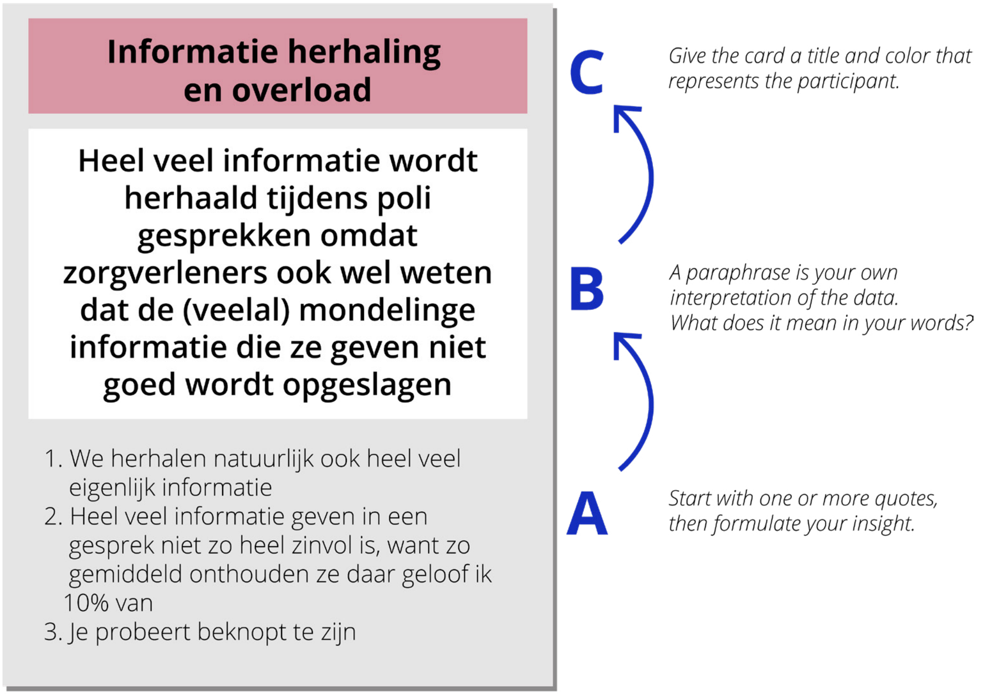


Figure 9: Representation of the statement cards



Informatie herhaling en overload

Heel veel informatie wordt herhaald tijdens poli gesprekken omdat zorgverleners ook wel weten dat de (veelal) mondelinge informatie die ze geven niet goed wordt opgeslagen

1. We herhalen natuurlijk ook heel veel eigenlijk informatie
2. Heel veel informatie geven in een gesprek niet zo heel zinvol is, want zo gemiddeld onthouden ze daar geloof ik 10% van
3. Je probeert beknopt te zijn

Give the card a title and color that represents the participant.

A paraphrase is your own interpretation of the data. What does it mean in your words?

Start with one or more quotes, then formulate your insight.

Figure 10: Example of a statement card

4.3 MATERIAL ANALYSIS

A more elaborate understanding of the current care trajectory within the HTC was cultivated through an analysis of materials developed in previous Partitura projects, most notably the care pathway specific to the pediatric department of Erasmus MC's Hemophilia Treatment Center (HTC) and multiple patient journeys. This resulted in creating an initial workflow, depicted visually in Figure 11.

Individuals are referred to Erasmus MC if they are suspected of having hemophilia. Adult patients or newborns are tested for hemophilia to determine a definitive diagnosis. If diagnosed with hemophilia, they become official patients of Erasmus MC's HTC. In the case of an adult pregnancy, the child can be tested either during or after birth and also becomes a patient at the pediatric department of the HTC if diagnosed.

Following diagnosis, an initial consultation is held, during which preliminary information is given primarily through verbal communication and brochures. The clinical nuances of hemophilia are discussed during this initial consultation, including details about the diagnosed type and severity. Furthermore, parents are instructed on when to contact the HTC and are given information about their child's expected treatment regimen.

Following this initial consultation, periodic consultations are held, with the frequency dependent on the type of hemophilia. These follow-up consultations reinforce previously shared information and impart age- or context-relevant information.

Prophylactic treatment is typically initiated on the HTC premises before transitioning to home-based administration via home care services or parental administration after being educated on the procedure. In the event of a bleeding episode, each patient requires consultation to determine whether to initiate on-demand treatment. This can happen at the HTC, if possible at home, or, if necessary, at the emergency department (ED), particularly after regular business hours.

During the consultations, a substantial amount of information is shared to educate patients and their families about essential lifestyle considerations. This includes advice on effectively managing life with a hemophilic child and disseminating relevant information to schools, family members, and sports organizations. Parents' compliance with these directives within their domestic and social environments is essential.

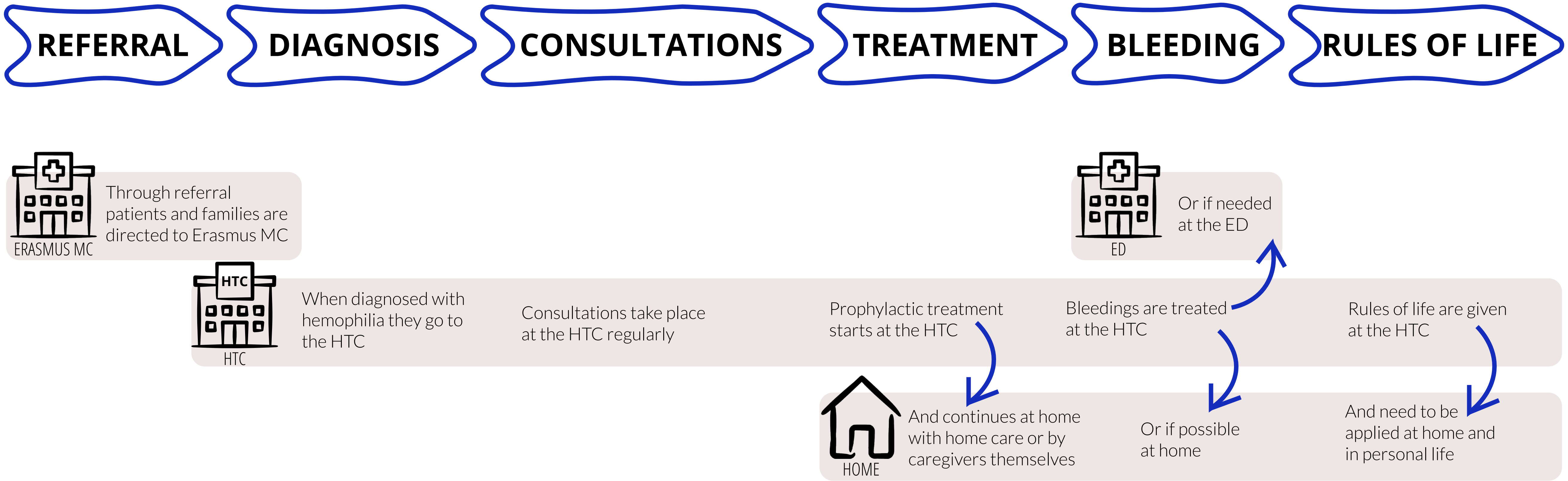


Figure 11: Initial workflow

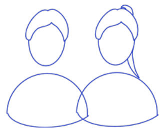
Figure 12: Material analysis

Partitura's previously created care pathways, patient journeys, and the conducted literature review were also used to develop interview questions (Figure 12). The questions were organized into themes and participant groups, resulting in interview guides for each participant group.

5.0 Stakeholder Analysis

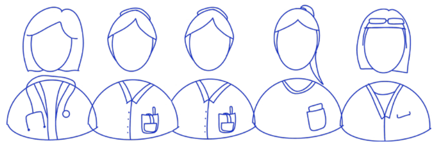
This chapter examines the key stakeholders in the information provision for children with hemophilia in the Netherlands. As previously stated, these stakeholders can be distinguished into three participant groups for the interviews. In this context, the roles and significance of each participant group will be explained and shown through the stakeholder map.

5.1 EXPLORING STAKEHOLDER GROUPS



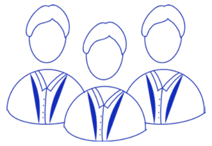
Caregivers of pediatric patients with hemophilia

As stated in the preceding chapter's initial workflow, parents are responsible for adhering to important lifestyle guidelines, knowing when to contact the HTC, passing down information obtained from the HTC, and, in cases of prophylactic treatment, eventually administering medication to their child. This requires effective processing of the information provided for the successful execution of these parental responsibilities. According to the literature review, this ability to process information is influenced by a variety of factors, with health literacy standing out as a significant determinant. The level of familiarity that parents have with hemophilia can vary greatly depending on their family history with the condition and the extent to which they are aware of it. It is worth noting that until a child is capable of managing their condition on their own, the competence of parents in dealing with hemophilia remains vital. Therefore, it is essential to interview caregivers as one of the participant groups to understand their experiences with the current information provision and identify pain points and needs.



Healthcare professionals

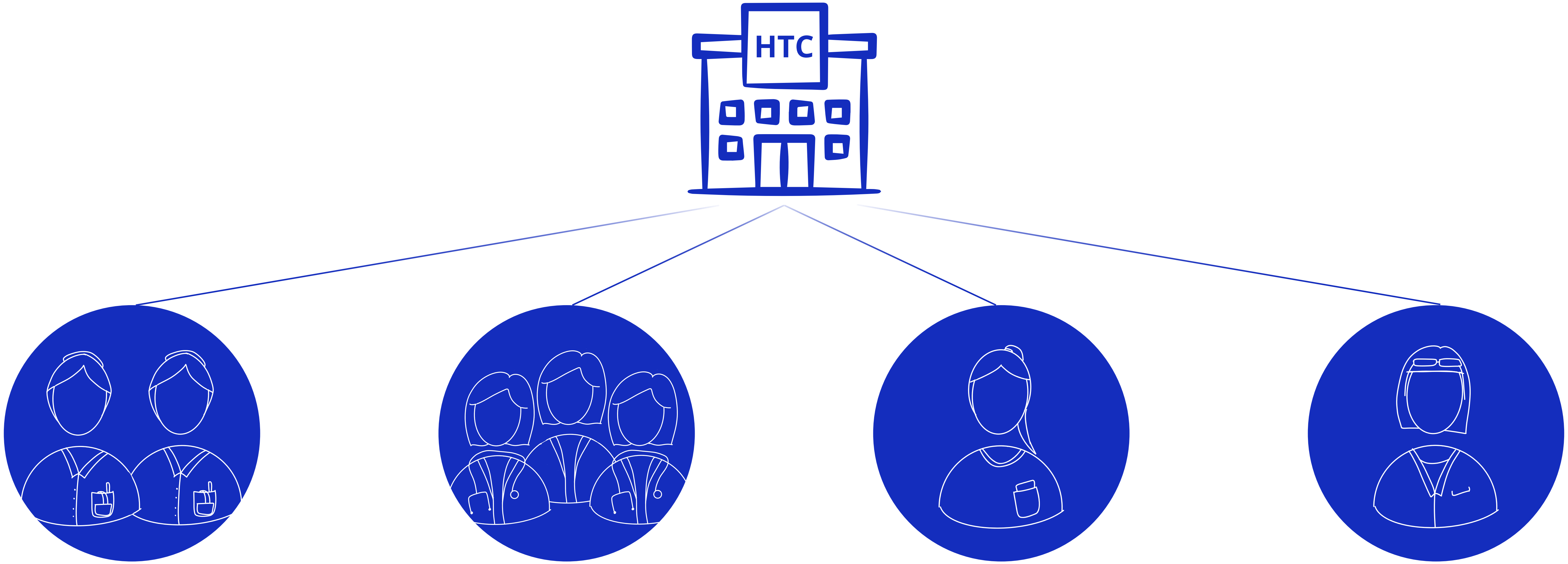
In Chapter 2.2, an introduction is given to Erasmus MC's HTC, which serves as a dedicated facility for treating patients with hemophilia and various other bleeding disorders. To attain a comprehensive understanding of the workflow, engaging in interviews with all members of the pediatric department of the HTC team is imperative. This approach enables a holistic comprehension of the workflow and crucially incorporates the perspectives of HCPs. Given that the tool and strategy that will be designed are aligned with their workflow and incorporate their aspirations for enhancement, including their insights is important.



Relevant stakeholders

The Netherlands is home to six HTCs, which include Erasmus MC, Amsterdam UMC, UMC Groningen, Leiden UMC, Radboud UMC, and UMC Utrecht (NVHP, n.d.-a). Nevertheless, due to the distinctive communication and information provision approaches adopted by each HTC, it becomes key to gather stakeholders involved in providing patient information at a national level, irrespective of the HTC where patients are treated. These key stakeholders encompass the Nederlandse Vereniging van Hemofilie-Patiënten (NVHP), Cyberpoli, and HemoNED. Additionally, for a more comprehensive grasp of the creation of patient information materials within Erasmus MC, the communication department of the EMC is included as another pertinent stakeholder. Representatives from these four stakeholders are interviewed to gain insights into their experiences with information provision for individuals with hereditary bleeding disorders such as hemophilia. The interviews are designed to uncover any perceived (unmet) needs, elucidate the objectives underpinning their information provisioning efforts, and offer this project a multi-faceted perspective on the information process.

Healthcare Professionals



NURSE SPECIALIST AND NURSE CONSULTANT

The hemophilia nurses play a pivotal role in information provision and patient education. This dominant position is due to their role as primary contact persons for questions that arise outside of outpatient clinic appointments. Furthermore, they are the designated individuals who answer phone calls to the HTC line. The distinction between the nurse specialist and the nurse consultant lies in the nurse specialist's intensified education and, consequently, a more significant level of authority.

PEDIATRIC HEMATOLOGISTS AND FELLOW

Pediatric hematologists are pediatricians who have specialized in hematology. The hematologists of the HTC team are particularly focused on bleeding disorders such as hemophilia. These pediatric hematologists actively participate in outpatient clinic visits, addressing medical concerns with patients and their parents. They take anamnesis and perform physical examinations if needed, taking on a pivotal role as a medical practitioner. The pediatricians develop comprehensive treatment plans to guide patient care after each outpatient consultation. The two pediatric hematologists alternate the weekly outpatient clinic with the pediatric hematologist in training (fellow).

PEDIATRIC PHYSICAL THERAPIST

The pediatric physical therapist conducts annual assessments on patients with severe hemophilia to preserve their joint health. This assessment, known as the Hemophilia Joint Health Score (HJHS), entails practical exercises to evaluate muscles and joints. Furthermore, the pediatric physical therapist is available to provide guidance and recommendations to all patients in cases of bleeding.

MEDICAL SOCIAL WORKER

The medical social worker also plays an important role on the team. Parents are welcome to meet with the medical social worker to discuss their situation. Given that a child's illness can have a significant impact on their lives, the medical social worker's assistance becomes invaluable. When parents or children face difficulties as a result of the illness, the medical social worker is skilled at providing support and guidance.

Relevant Stakeholders

DUTCH ASSOCIATION OF HEMOPHILIA PATIENTS (NVHP)

The Nederlandse Vereniging van Hemofilie-Patiënten (Dutch Association of Hemophilia Patients; NVHP) is a voluntary organization founded in 1971 with about 1250 members. The association is there for hemophilia and everyone with an inborn bleeding disorder. The organizational structure consists of day-to-day management by a cooperative board and working groups focusing on various focus groups oriented on the goals of the association (NVHP, n.d.-b).

The association's **goals** are:

- **Advocacy:** working for everyone with a bleeding disorder by maintaining close contact with the HTCs in the Netherlands and other relevant organizations.
- **Peer contact:** organizing activities and meetings for the various target groups to meet fellow sufferers.
- **Information and communication:** via the website, in the newsletter called Faktueel, in their magazine: Faktor, and on social media, the association shares what is happening in the medical world and provides information about various topics related to living with a bleeding disorder. The main aim is to provide the correct information to the patients.

CYBERPOLI

Cyberpoli is an internet outpatient clinic and gathering place for young people with disabilities or chronic conditions aged 13 to 26. Through texts, animations, and interviews with patients, parents, and specialists, Cyberpoli provides credible information for patients and parents to watch or read at home. This allows them to learn more about the condition. Furthermore, HCPs can be questioned, and the experiences of others can be found. Cyberpoli is also open to parents. Currently, there are 31 distinct outpatient clinics. The Cyberpoli receives over 100,000 visitors per month and is linked to 194 professionals who have created over 330 medical animations and interview videos (Cyberpoli, n.d.-a).

The **goals** of Cyberpoli (Cyberpoli, n.d.-c) are:

- To **increase** young people's **knowledge** about their condition. The more they know, the better they can learn to cope with their condition and the more relevant questions they can ask about their treatment.
- **Increasing** young people's **self-confidence** to cope better in everyday life.

DUTCH HEMOPHILIA REGISTRY (HEMONED)

The Dutch Hemophilia Registry (HemoNED) is managed by the HemoNED Foundation, a joint initiative of the Nederlandse Vereniging voor Hemofiliebehandelaars (Dutch Association of Hemophilia Practitioners;NVHB) and the NVHP (Stichting HemoNED, n.d.-b). A national registry is essential for mapping treatments, registering side effects, evaluating results, and improving therapy.

The **goal** of the registry (Stichting HemoNED, n.d.-a) is:

- To **improve the quality of care** for individuals with hemophilia and related conditions by **registering, merging, and comparing data** about their disease, treatment, and treatment outcomes.

Patients with home treatment register their medication and bleeding in a digital logbook application called 'Vaste Prik'. The information from the digital record is forwarded to the registry. Healthcare professionals in the field of hemophilia can view and discuss this information with their patients during an outpatient clinic visit.

After anonymization, the data in the registry can be used for various purposes:

- Providing insight into the total number of people with hemophilia and other bleeding disorders, their diagnosis, clotting factor use, bleeding, treatment outcomes, and side effects.
- Comparing the quality of care between HTCs in the Netherlands and between countries.
- Reporting side effects of medication.
- Making information available for reports, scientific research, and safety studies of (new) medication.

COMMUNICATION DEPARTMENT OF THE ERASMUS MC

The communication department of EMC consists of 40 employees, three of whom are engaged in the following tasks:

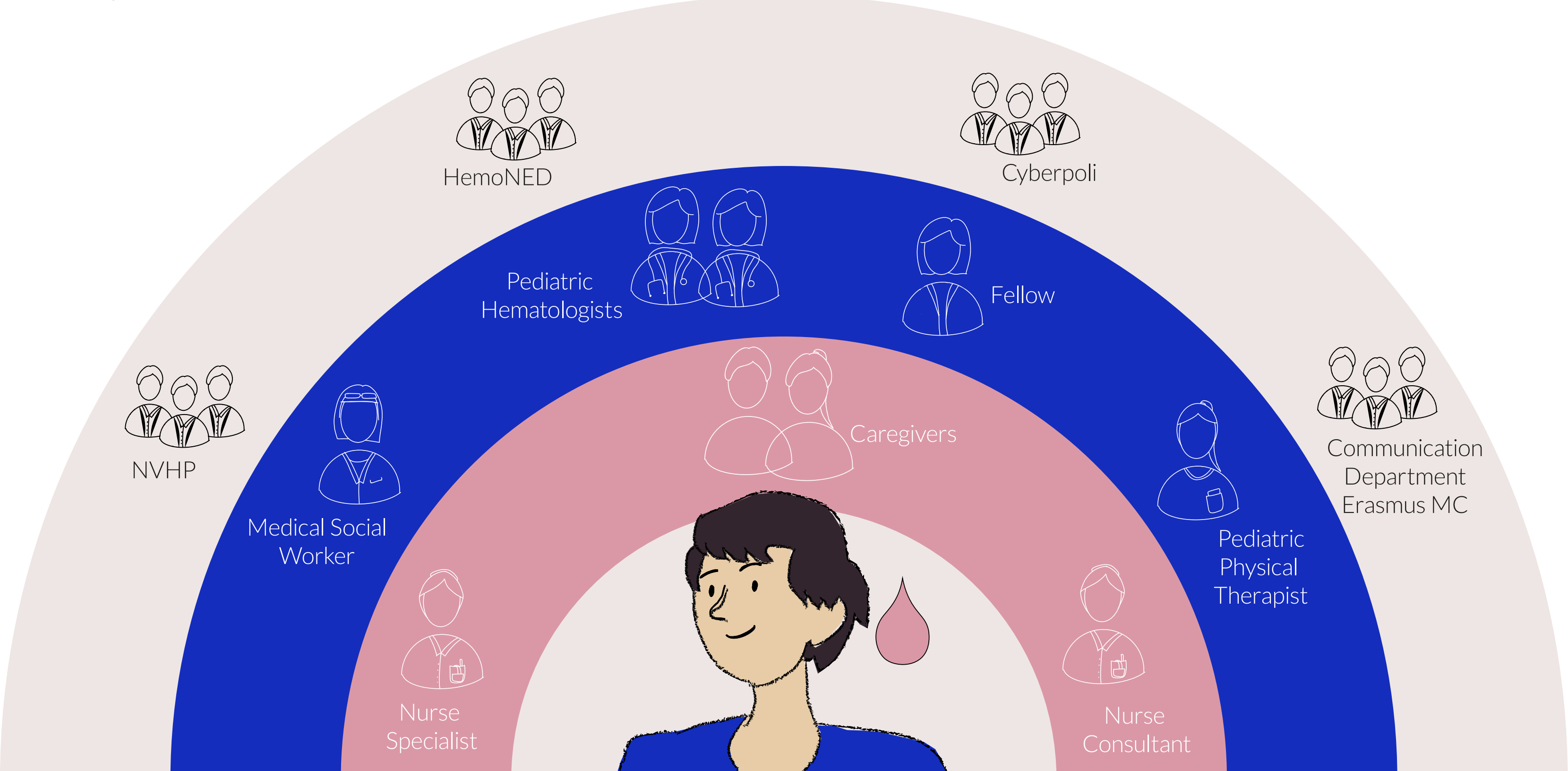
- The administrator project
- Setting up patient brochures/material
- An advisory role at DigiZorg

The department's **goal** is to provide information that patients need to **understand their condition** and what it entails or **know what to do before a procedure and what will happen** during one. If patients are aware of this information, this could also lower their anxiety. Furthermore, only a tiny amount of information is retained from the conversations during consultations. Therefore, it is necessary to be able to reread the information at home.

5.2 STAKEHOLDER MAP

Figure 13 shows the stakeholder map, including the different stakeholders per identified group. The information provision occurs during outpatient clinic visits and is conducted by HCPs, with nurses being the primary point of contact for patients and their caregivers. Nurses play an essential role in delivering information and education. The rest of the medical team is mapped on the second circle. Where the pediatric physical therapist and the social worker have a smaller role in the patient's care pathway, they are a part of the team. Like the rest, they are always present at the weekly preliminary discussion before the coagulation outpatient clinics on Thursdays. The relevant stakeholders are mapped on the outer circle as providers of information.

Figure 13: Stakeholder map



6.0 Field Analysis

This chapter explains the observations conducted at the outpatient clinic and discusses the insights derived from these observations. Subsequently, the current information provision is examined, drawing upon material analysis and observations.

6.1 OBSERVATIONS

I attended the coagulation outpatient clinic's visits every Thursday for several weeks (Figure 16). To be able to take notes during the observations, a template was used to fill in and can be found in Appendix B5. Children with hemophilia and other bleeding disorders attend their scheduled outpatient appointments at the outpatient clinic regularly. The map shown in Figure 14 on the next page depicts the physical layout and structure of the pediatric HTC. Upon entering the premises, one is greeted by a service desk where registration is completed and then takes place in the waiting room. A preliminary discussion is held in a designated conference room prior to the start of the outpatient clinic. All HCPs are present: nurses, the physical therapist, the medical social worker, and a pediatric hematologist or fellow. This meeting allows for discussing any pertinent medical history or unresolved issues of the patients and families scheduled for an appointment that day. A printed summary is available from the electronic medical record in this regard. While the physical therapist and medical social worker are not required to interact directly with every patient, their consistent presence during preliminary discussions ensures that they remain informed about their conditions and allows them to determine their involvement in specific situations.

The observations served as a valuable assessment of the operational dynamics within an outpatient clinic after thoroughly examining the care pathway and devising the initial workflow. I had the opportunity to shadow both the pediatric hematologist and the nurse consultant. In addition, I had the opportunity to observe a HJHS performed by the physical therapist. I gained insights into the dynamics of conversations and improved my understanding of communication patterns and work processes as a result of this observation. It is worth noting that most medical students are at the outpatient clinic undergoing their internship phase. Typically, a student of this type traverses the path several times, with a different person taking on the role on subsequent occasions. It occurs rarely that the HCPs do not have an intern shadowing them, meaning they have to guide them about upcoming events or discussions with the patient and their family. In addition, the outpatient clinic was occasionally conducted by a physician's assistant rather than the pediatric hematologist or fellow. This factor could play a significant role in the inconsistency, and potential ambiguity patients and their families feel.

The outpatient clinic is equipped with three consultation rooms. The nurse consultant works in consulting room four and always has a trolley with various folders and materials that may be needed during a consultation. It is noteworthy that HCps exclusively use the materials present on this trolley despite the existence of two additional locations where informational materials can be accessed: the folder rack in the hallway and the cupboard in the injection room.

The pediatric hematologist is located in consulting room number six. During the pediatric hematologist's observation, it was discovered that recurring themes are typically addressed. This is an anamnesis of the patient's current condition. Personal well-being, occurrences of bleeding or bruising, academic progress, potential surgical or dental interventions, familiarity with SOS bands or chains and card, and any questions the patient or parent may have will be addressed. Furthermore, there is a consistent supply of explanations for hemophilia. The pediatric hematologist completes this task by retrieving a sheet of paper from the printer and drawing a blood vessel and its constituent particles with a pen. Also, the process of x-linked transfer is frequently explained using traditional methods like pen and paper (see Figure 15).

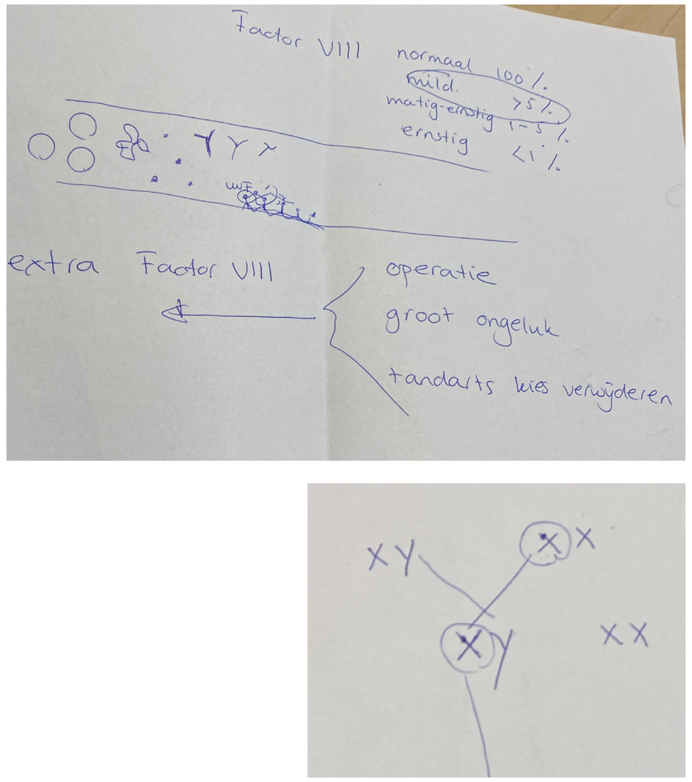


Figure 15: Handdrawn visualization

The nurse consultant can be consulted when patients and parents seek additional clarification from the pediatric hematologist. Examples of these supplementary inquiries include questions about a child's fear of needles, the feasibility of a child participating in specific athletic activities, the best ways to inform schools or teachers, and strategies for adequately preparing for a vacation. Occasionally, the nurse consultant will join the pediatric hematologist in the discussion. Furthermore, the nurse specialist may be intermittently available, devoting time away from her other responsibilities to provide her presence, and it is critical to dedicate time to specific patients.

It is worth noting that the discussions usually involve both the child and the parents. However, in cases where the child is significantly older, the HCPs may request the child to attend the consultation room alone at first.

During the observation process, a discernible distinction in parental behavior emerges. Given the HCP's concerted efforts to engage in extensive communication with the child rather than interacting solely with the parent, it is worth noting that there are two distinct parental approaches. On the one hand, some parents prefer to act as their child's spokesperson, while on the other hand, there are parents who encourage their child to communicate and interact with HCPs independently. In this context, a distinction can be seen in the child's cognitive awareness. Compared to those who do not receive such support, there appears to be a link between children who receive proactive support and increased awareness and knowledge about their disease.

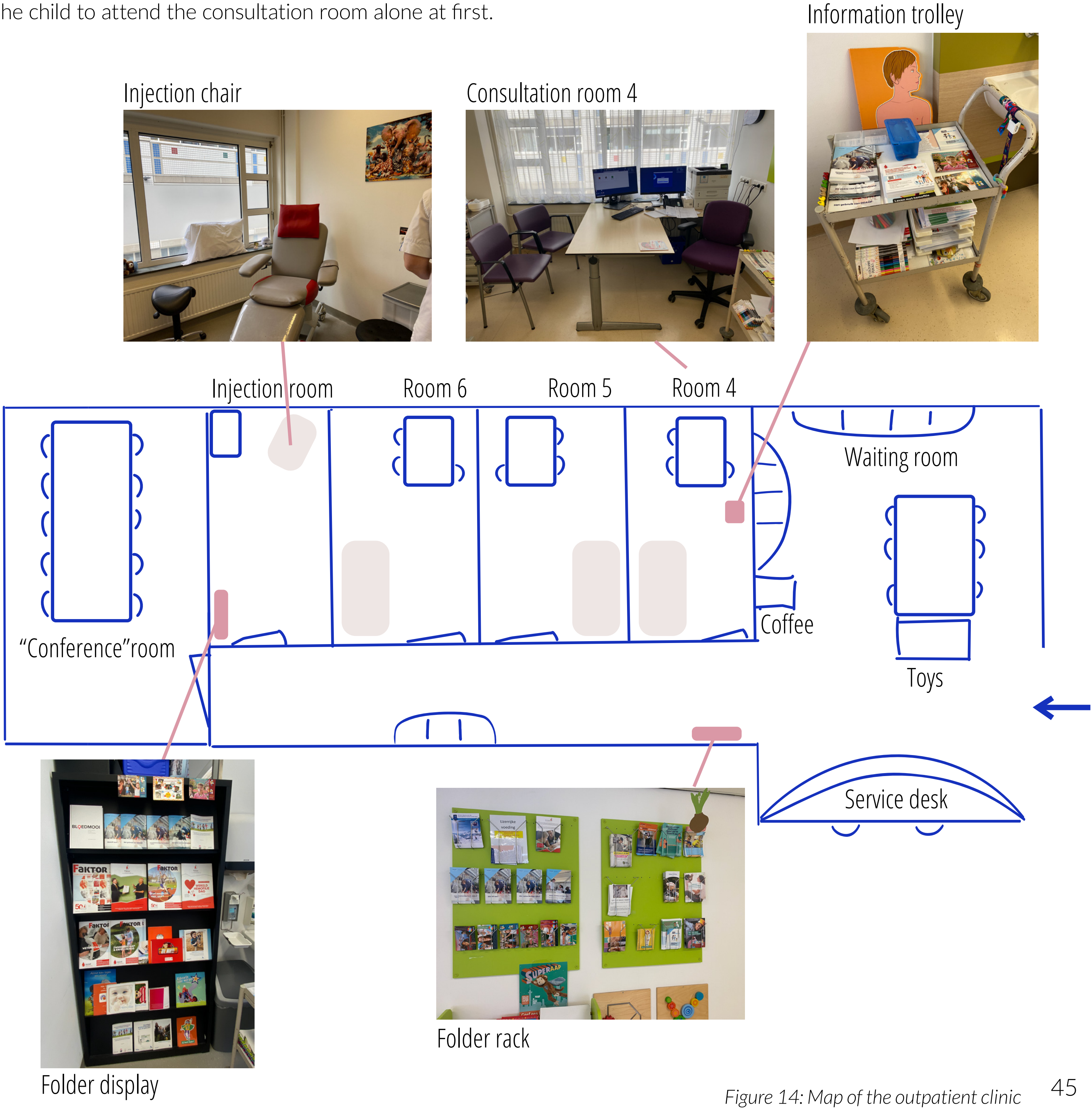


Figure 14: Map of the outpatient clinic

It may be necessary to collect a blood sample in order to update the treatment plan. Depending on the level of busyness at the outpatient clinic, this is accomplished by nurses in the injection room at the outpatient clinic or the laboratory in a different department. Furthermore, the injection room treats patients who receive prophylactic treatment. It also follows that these actions must be carried out during the outpatient clinic, in addition to the standard clinic appointments.

I also took part in a telephone consultation. The original plan was to conduct the consultation digitally via the electronic medical record system. However, due to the limited use of this technology, it was determined that a telephone consultation would be more convenient. The child's absence was due to the parent's lack of knowledge about the event's specific purpose and the parent's uncertainty about whether it was intended to replace the regular physical appointment. This finding suggests there is potential for improving the quality of outpatient invitation letters, particularly when physical presence is not required.

In conclusion, outpatient clinic visits have a somehow structured way of discussing the same topics during the conversation regardless of the type of bleeding disorder. However, the outpatient clinic is strongly influenced by different factors that can cause chaoticness or a shortage of time, like patients who cancel their visit last-minute or do not show up at all or acute cases that interfere with the outpatient clinic schedule. Besides that, it is an essential insight that the expectations surrounding an outpatient clinic visit can be better managed so that it is clear what such a visit entails and how parents and patients can best prepare.

Figure 16: In uniform to attend the outpatient clinic

6.2 CURRENT INFORMATION PROVISION

Answering research question

② What sources of information provision are currently offered at the Erasmus MC – Sophia's Children's Hospital?

The care pathway created by Partitura showed that several information brochures are usually provided per phase. Different stakeholders, like the communication department of Erasmus MC and the NVHP, make these brochures. They also refer to the websites of the NVHP and Cyberpoli for more information about hemophilia and living with hemophilia. Notable is that the brochures displayed at the outpatient clinic are not all mentioned in the care pathway. As discussed in the previous chapter, brochures are displayed in the hallway of the outpatient clinic, on a trolley in the consultation room, and on display in the injection room for injections. An inventory was conducted to document all brochures located within the HTC and referenced in the care pathway, see Figure 17. An overview of this analysis can be found in Appendix B6. It is intriguing to observe that the number of brochures at the HTC exceeds what was specified in the care pathway. However, the nurses also indicate that many of these brochures need to be updated. On display in the injection room, you mostly see the NVHP magazine Faktor alongside a collection of books. The brochures present on the cart are primarily distributed to patients.

Brochure name	**Provided by**	**Physically present**	**Mentioned in care pathway**
Kind met hemofilie	NVHP		x
Zuigelingen informatie / creche	?		x
Neusbloeding	Erasmus MC	x	x
Cyberpoli	Cyberpoli	x	x
NVHP	NVHP	x	x
School (een leerling met hemofilie?)	Ziezon		x
Sociale omgeving	?		x
Emicizumab	?		x
DDAVP test	Erasmus MC	x	x
Het gebruik van DDAVP	Erasmus MC	x	x
Reisgids voor mensen met hemofilie	NVHP		x
Leven met hemofilie	NVHP	x	
Hemofiliebehandelcentrum Erasmus	Erasmus MC	x	
Vaste Prik app	HemoNED	x	x
Travel guide app	Travelguide	x	

Figure 17: Overview of the current brochures provided

7.0 Interview outcomes

This chapter discusses the interview outcomes of the three distinct participant groups. An information journey map has been created to describe the stages that caregivers and their children go through. This subchapter also goes into the themes that emerged from the data analysis. The initial workflow from Chapter 4.3 was supplemented by integrating the themes from the data analysis of the interviews with HCPs. The subsequent chapter goes into the findings of the various stakeholder interviews. Finally, this chapter ends by giving the overarching conclusions from these interviews.

7.1 CAREGIVERS OF PATIENTS

Answering research question

3 How do caregivers of patients with hemophilia experience the information provision of the hospital?

4 What are the key moments of information provision?

5 What are the (unmet) needs of caregivers of patients with hemophilia regarding information provision by the hospital?

For the interviews with caregivers of hemophilia patients, no distinction was made based on type or severity of hemophilia. The following interviews were held:

	Age child	Type of hemophilia	Treatment type	Location interview	Interviewees	Duration
1	8	Severe hemophilia A	Subcutaneous	At home	Mother and child	01:30 h
2	4	Severe hemophilia A	Subcutaneous	At home	Mother	01:10 h
3	10	Mild hemophilia A	On-demand	At outpatient clinic	Mother, father, child	01:05 h
4	5	Mild hemophilia A	On-demand	At home	Mother, father	01:05 h
5	2	Severe hemophilia B	Intravenous	At outpatient clinic	Mother	00:45 h
6	4 & 6	Mild hemophilia A	On-demand	At home	Mother	01:05 h
7	8	Moderate hemophilia A	On-demand	Online	Mother	00:55 h

Information Journey Map

The data, obtained from the caregivers' interviews, has been visually represented in an information journey map, as depicted in Figure 18 and 19. This map comprehensively elucidates the distinct phases of the caregivers' experiences and arranges them in a quasi-chronological sequence. Additionally, the map incorporates the themes that were found after clustering the statement cards, selectively aligning them with their corresponding phases. Alongside this, the map illustrates the various touch points and experience curve involved in the process. Finally, it identifies and outlines any encountered pain points and potential areas for improvement in each phase, as deemed applicable.

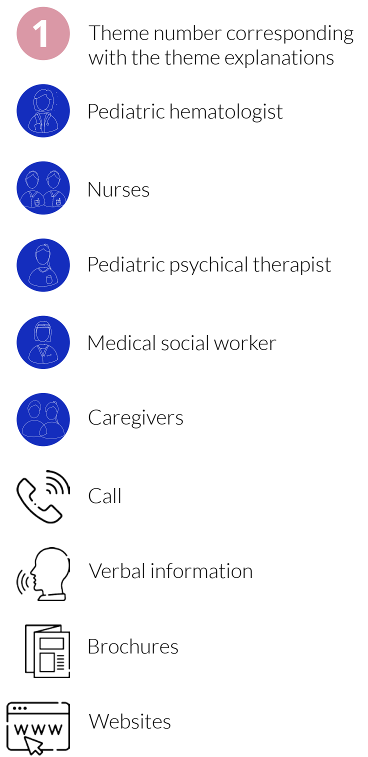
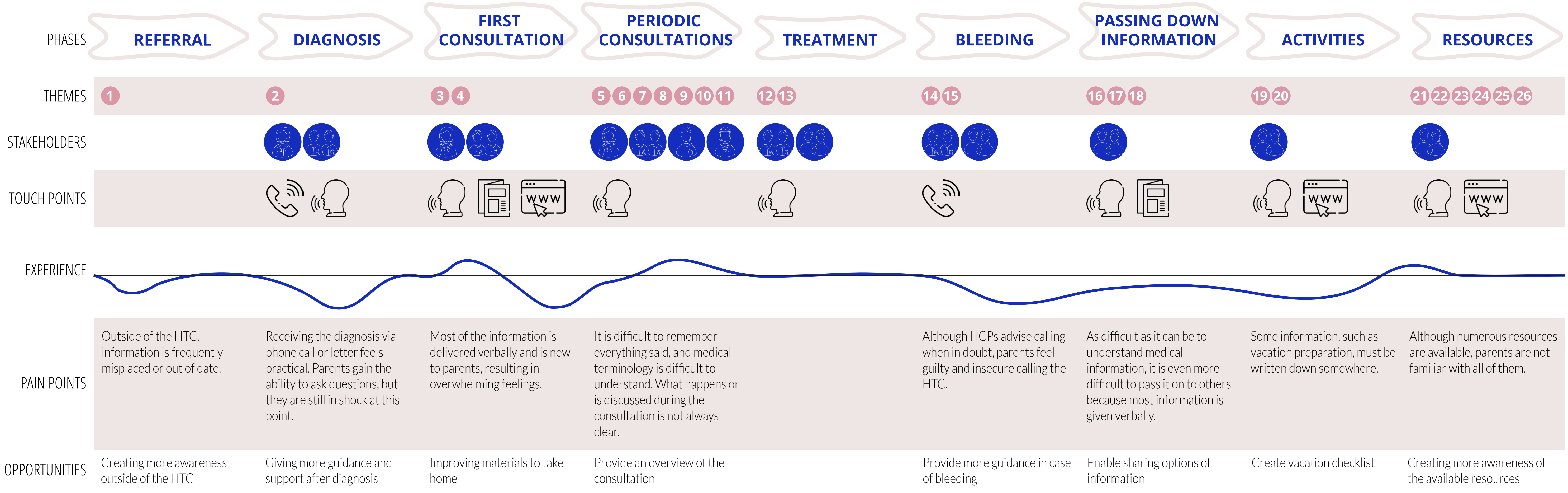


Figure 19: Legend of the information journey map



PHASES	REFERRAL	DIAGNOSIS	FIRST CONSULTATION	PERIODIC CONSULTATIONS	TREATMENT	BLEEDING	PASSING DOWN INFORMATION	ACTIVITIES	RESOURCES
THEMES	1	2	3 4	5 6 7 8 9 10 11	12 13	14 15	16 17 18	19 20	21 22 23 24 25 26
STAKEHOLDERS									
TOUCH POINTS									
PAIN POINTS	Outside of the HTC, information is frequently misplaced or out of date.	Receiving the diagnosis via phone call or letter feels practical. Parents gain the ability to ask questions, but they are still in shock at this point.	Most of the information is delivered verbally and is new to parents, resulting in overwhelming feelings.	It is difficult to remember everything said, and medical terminology is difficult to understand. What happens or is discussed during the consultation is not always clear.		Although HCPs advise calling when in doubt, parents feel guilty and insecure calling the HTC.	As difficult as it can be to understand medical information, it is even more difficult to pass it on to others because most information is given verbally.	Some information, such as vacation preparation, must be written down somewhere.	Although numerous resources are available, parents are not familiar with all of them.
OPPORTUNITIES	Creating more awareness outside of the HTC	Giving more guidance and support after diagnosis	Improving materials to take home	Provide an overview of the consultation		Provide more guidance in case of bleeding	Enable sharing options of information	Create vacation checklist	Creating more awareness of the available resources

Figure 18: Information journey map

Themes

The themes that were found by clustering the statement cards will be explained per phase of the information journey map.

REFERRAL

① *Referral outside HTC*

Some parents have their first consultation about hemophilia outside of the HTC at a regional hospital. Information outside the HTC is generally perceived as poor because misinformation is provided, causing enormous despair and anxiety among parents. Furthermore, because hemophilia is so unfamiliar, alarm bells do not always sound among HCPs outside the HTC when there are symptoms of hemophilia.

DIAGNOSIS

② *Diagnosis*

The moment of diagnosis is determined by when they enter the HTC. If the diagnosis was made during pregnancy, medical examinations are performed immediately after birth to confirm the diagnosis. If it is discovered (some time) after birth, it is through a blood test performed outside of the HTC or within the HTC after referral. The diagnosis was announced businesslike to some parents via phone or letter, even though this is emotionally charged news for parents. A period of uncertainty and the need for more information may occur between the diagnosis result after birth and the first outpatient clinic visit. The parents were overwhelmed and had much to process after such a traumatic event. They require some information safety net to keep them going until the first consultation.

FIRST CONSULTATION

③ *The very first consultation*

During the initial consultation, extensive information is provided about hemophilia and what life with this condition would be like today. The conversation, led by the nurses and pediatric hematologist, covers important topics such as calling immediately in case of a head injury and the risk of long-term muscle and joint damage due to bleeding. All of this information was communicated verbally. One parent stated that they had a multidisciplinary consultation during which all healthcare team members introduced themselves and explained their specific roles. It was emphasized that the HCPs could always be contacted if there was any doubt. The nurses play an essential role in informing and reassuring the parents.

④ *Start of the journey*

There is much uncertainty following a hemophilia diagnosis. Although HCPs provide much information initially, not everything sticks, and it is difficult to comprehend the full impact on daily life. The realization of the consequences arises only when something occurs and they are in the middle of it. Understanding medical terms like factor 8, prophylaxis, and on-demand can be difficult. Parents initially struggled to understand the meaning of these terms, but they became more familiar over time. Initially, the emphasis was primarily on treatment, and parents emphasized the importance of providing information during the first year. They expressed a desire for more assistance in comprehending the treatment and its impact on daily life. Parents gradually better understood hemophilia and how to treat it but still found it challenging to manage. More information and guidance were required to deal with the situation more effectively. Parents understand that you cannot fully prepare for life with a hemophilia child, but you can learn and experience it along the way.

PERIODIC CONSULTATIONS

⑤ *Blood clotting system*

HCPs often draw pictures of a blood vessel to explain how the blood works and what happens in hemophilia. Parents appreciated this visual support as it helped them understand the complex medical aspects more clearly. There is, therefore, a need to have something like this available at home to provide this explanation to the school, social environment, etc.

⑥ *Information provision for caregivers*

Parents report that most of the information they receive is verbal and that they were given several brochures or booklets to take home for information. (Information for the GP, information packages, brochures from the Vaste Prik app and Beter Dichtbij) Because of all the separatepieces of information, this provides a less structured overview. In general, parents are at ease asking questions if they are missing information, and they do receive the answers they require. However, more structured and framed information is required to provide a clear overview of all aspects of hemophilia, treatment, and care focused on their child's situation. Parents decided to create their own care plan or curated map to address this issue. This was a kind of 'manual' in which all critical information about their child's treatment and care was recorded as clearly as possible. Although parents value repetition in verbal communication, they prefer a more central and organized method of receiving information.

⑦ *Periodic consultations*

Consultations are initially regarded as necessary, but they become more of a formality as the child ages. Depending on the type of hemophilia, the frequency of periodic consultations varies. These regular consultations are crucial for mild patients to be informed and reminded about the consequences of hemophilia since they visit less frequently and may experience less impact on life. That is why parents believe it is critical to keep these appointments and to attend them physically. Furthermore, a periodic consultation may be overlooked if the child already attends the outpatient clinic regularly to learn how to inject. Parents emphasize that consultations could be more transparent, with more information about whom they will see, what will happen during the consultation, whether a blood sample will be taken, how much time is allotted for the consultation, and when they will receive test results. As the child ages, new issues arise, such as self-managing their condition.

⑧ *Frequently Asked Questions*

When asked where parents needed more information, the following topics emerged:

- Pregnancy: Parents had questions about a possible desire for another pregnancy and were unsure where to seek advice and information. Some patients were referred to a clinical geneticist for additional guidance and advice.
- Support: Some parents reported a greater need for psychosocial support, indicating that hemophilia poses physical and emotional challenges.
- Adjustments: Parents needed clarification about what modifications were required in their child's daily life due to hemophilia. They had concerns about how to handle specific situations.
- Sports and activities: There needs to be more clarity about which sports and activities are safe for children with hemophilia and how to handle them.
- Medical breakthroughs and gene therapy: Parents are interested in the latest medical developments and breakthroughs, particularly gene therapy and other innovative treatments.

⑨ *Conducting their own research*

Some parents seek information on their own, including scientific articles. These parents believe in-depth and detailed information is required to understand hemophilia and its treatments better. Because of their background, they may be more confident in comprehending scientific literature and, as a result, can expand their knowledge.

⑩ *Satisfaction with HCPs*

Some parents appreciate that each change in treatment is accompanied by a thorough explanation of what it entails and why it is being implemented. However, some parents report disagreements between HCPs, leading to disappointment and confusion. The ability to communicate with HCPs quickly and efficiently is something that parents value. The nurses' low-threshold contact contributes to a sense of continuity and trust. The nurses are a familiar face, which gives parents peace of mind.

⑪ *Child involvement*

Making the child with hemophilia aware of his condition is crucial. Some parents involve their children in the process, bringing books to school and telling classmates about them. This helps the child understand their hemophilia and what it entails. Others are still looking for the best way to explain it to their children. Several booklets for children of various ages explain hemophilia in children's language. (Arno kan tegen een stootje, Jeroen heeft hemofilie, De pelikaan, Strip boek over bloed)

TREATMENT

⑫ *Learn to inject*

Parents of younger children report receiving only verbal information about teaching their children how to inject. In contrast, a parent of an older child reported receiving an extensive booklet about home treatment techniques at the time. Although some parents suggested that some theoretical background information would be helpful, the practical exercise was ultimately the most important.

⑬ *Fear of needles*

Some children are afraid of needles. Several people may be required to hold the child during the procedure. A 'medical pedagogical care provider' assisted a child in overcoming this fear. This HCP has created a step-by-step plan for the child, illustrating what will happen during the injection with icons. The step-by-step plan gives the child a sense of control and predictability, which can alleviate anxiety.

BLEEDING

⑭ *Bleeding procedure*

Although they know what to do in an emergency, they hesitate to call directly. When parents call in the event of a trauma, they believe it is too late. When parents call, they are always asked to provide detailed information about the fall, such as how the child fell, from what height the child fell, where the child fell, and the impact of the fall. This can be hard to answer, especially if parents were absent or no one else witnessed the fall. They should rely on the child's reaction or story in that case. Parents desire more information on what constitutes severe and non-serious cases of bleeding. For example, knowing that bleeding in the head is uncommon can be reassuring.

⑮ *The emergency department*

Parents have had bad experiences in the emergency department. When injecting is difficult, it can lead to a fear of needles. Another issue parents have encountered in the emergency room is that they are frequently required to indicate that the child requires medication before further examination. Not all medical professionals know the specific treatment needs of children with hemophilia.

PASSING DOWN INFORMATION

⑯ *Informing the school*

Parents believe the school must be fully informed about what to do if their child falls. Parents must share this information repeatedly so that it is remembered. A parent-created care plan may apply, but it is also important to have a conversation with the teachers, clearly stating who to call in the event of a fall that necessitates direct contact with the parents. Parents want their children to be safe at school by adequately informing the school with the necessary information. However, this could be improved so that teachers and school staff respond quickly and appropriately if a medical emergency arises.

⑰ *Digital vs. Paper*

In general, people prefer to have or look up information digitally. When parents have questions or want to look something up, they find it convenient and quick to consult digital sources. This facilitates the quick discovery and sharing of information with others. Some parents stated that they search Google for hemophilia information, which can be dangerous regarding misinformation. However, some parents feel the need to retain the option of having the information available digitally and receiving a physical brochure, for example, at first. This would make it easier for them to demonstrate this in a social setting.

⑱ *Telling the class*

Some parents take the initiative to educate their children about hemophilia. These children have explained themselves in class by, for example, giving a school lecture. These children were also present during the interviews and were well aware that if they fell, they would face different consequences than other children.

ACTIVITIES

⑲ *Going on vacation*

Parents of children with hemophilia must be well-prepared for a holiday. One of the parents stated that they go on vacation, but they check ahead to see if there is an HTC near their vacation destination. One parent stated that it was unclear how much medication they needed to take with them at first and that they did not realize that sometimes one extra clotting treatment was not enough for bleeding, but that after bleeding can also occur, which means that they must give extra clotting for a more extended period. The parents said they needed a checklist to help them prepare thoroughly before going on vacation. A checklist like this would help them ensure that they have enough medication, the right resources, and know what to do if they experience bleeding while traveling.

⑳ *Connecting with others*

Contact with other parents who have had similar experiences is important to parents. They have had positive experiences with information meetings at Erasmus MC that welcome parents and family members. They received information from doctors and discussed the most recent medical developments. Another worthwhile initiative is the "hemophilia school", in which children spend a day in the hospital with other children with hemophilia. They visit the laboratory, where they are given information about their blood and play games with the physical therapist. The hemophilia camp also plays an important role. The Facebook group with other parents is the most valuable to parents. It allows parents to ask questions, share experiences, and learn from one another's approaches. This fosters a sense of belonging and support. Reading about other parents' experiences makes them feel they are not alone in their hemophilia journey. It provides hope and inspiration to see how others have found a way to care for their hemophilia child.

RESOURCES

㉑ *Anxiety*

Pregnancy is usually a time of great joy and happiness for parents, but for those who discovered their child had hemophilia, the joy quickly turned to distress and fear. Some parents panicked in the early stages of their child's diagnosis. For example, learning about spontaneous bleeding kept them constantly alert and concerned. Parents felt compelled to examine their surroundings and preferred playdates at home because they felt safer than with other parents. Traveling became a stressful experience, and long-distance vacations were deemed dangerous. However, it all turned out to be less concerning than initially thought. Although the fear and anxiety have subsided over time, feelings of guilt and anxiety continue to play a role in parents at various stages of the child's development. Some parents may need to speak with a psychologist or social worker about their feelings and guilt. More transparency regarding the normalization of discussing anxiety with HCPS may aid in lowering the barrier to speaking with the medical social worker.

㉒ *Beter Dichtbij app*

For parents, using the Beter Dichtbij app to ask questions and send photos is a valuable and enjoyable experience. The app provides an easy way to communicate with the nurses. Parents may be embarrassed to call with questions or concerns, but they can use the app to send a message quickly and easily.

㉓ *NVHP*

If parents are NVHP members, they will receive a package containing brochures to help them learn more about the condition. Magazines with stories are also distributed regularly. Although some parents initially used the website and brochures extensively, this use has declined over time. They stated that while current brochures name and explain the various types of hemophilia, they would find it more helpful if information tailored to an individual's situation was available. Misconceptions or unnecessary panic in the social environment can thus be avoided. Meetings are also held, such as those for women with coagulation issues. However, not all parents are NVHP members.

㉔ *Vaste Prik app*

Some issues have arisen with the Vaste Prik app, such as crashing, difficulties sharing the log between father and mother on different phones, stock disappearing, or problems scanning the QR code. Some parents believe it necessitates more actions than the traditional paper logbook. One specific issue mentioned was notifications arriving on the wrong days, most likely due to incorrect settings. As a result, it was suggested that more information about how the app works and how to optimize the settings be provided during a consultation with the HCP. Despite these issues, another parent reported that the app works appropriately after getting used to it. The feature that indicates how much stock is left and when it needs to be reordered is handy.

㉕ *Cyberpoli*

HCPs distribute a promotional card that includes a link to the website. Some parents visit the website to learn more about hemophilia and watch the videos. However, as parents become more familiar with hemophilia, they find the website less useful. Others claim they have not done much with it. Parents rate the website's information as good but point out that it primarily contains basic information. They claim no distinction is made between mild and severe hemophilia, which could be improved. A child used the website for his presentation. The visit to the website was in response to a nurse's referral, so parents knew the information was trustworthy. Finally, the interviews demonstrate that not everyone is aware of Cyberpoli.

㉖ *Symptoms with females*

Some mothers, unaware of their carrier status or the accompanying symptoms, recall specific complaints more clearly. For example, they suffer from heavy menstrual blood loss, leakage, and fainting. The GP then advised starting the contraceptive pill to reduce blood loss. After being diagnosed as a carrier of hemophilia, mothers may be subjected to medical tests, such as DDAVP testing and its use in blood loss control procedures. This again demonstrates HCPs' lack of knowledge outside of HTCs.

7.2 HEALTHCARE PROFESSIONALS

For the interviews with healthcare professionals of the pediatric part of Erasmus MC's HTC, all members of the team were interviewed. All these interviews were held physically at the hospital. The following interviews were held:

	Interviewee	Duration
1	Nurse consultant	01:25 h
2	Pediatric hematologist	00:55 h
3	Pediatric physical therapist	00:55 h
4	Nurse specialist	01:05 h
5	Fellow	00:50 h
6	Pediatric hematologist	01:00 h
7	Social worker	00:40 h

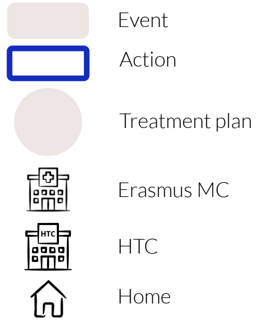


Figure 21: Legend workflow map

Answering research question

⑥ How do HCPs working in the field of hemophilia experience the information provision for caregivers of patients with hemophilia? Moreover, how do they use the information provision to educate patients and caregivers?

Workflow map

From the interview data of HCPs, the workflow of the multidisciplinary team at the HTC of the Erasmus MC - Sophia Children's Hospital was mapped out in a workflow overview, as you can see in Figure 20 and 21. In this workflow map, the themes found in the interview data of the HCPs are included to show where the themes are mapped in the workflow. The themes will be further explained later in this Chapter.

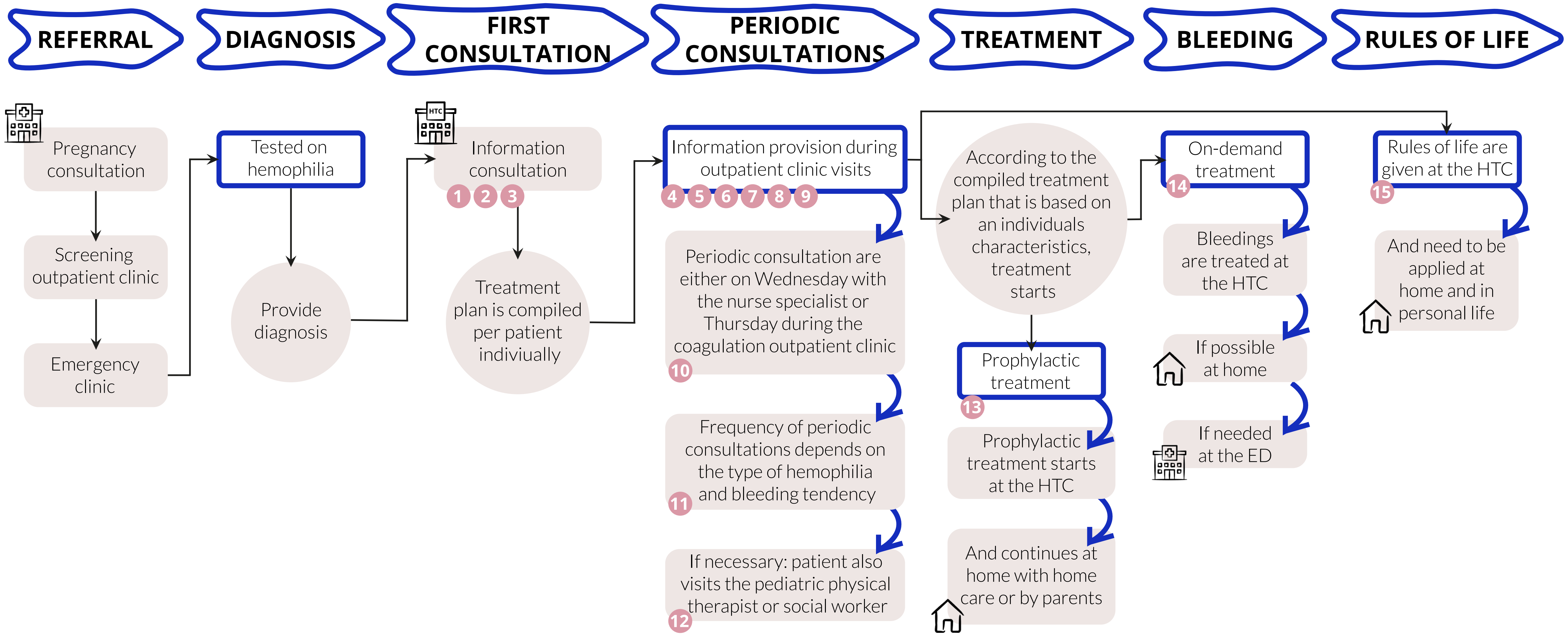


Figure 20: Workflow map

Themes

The themes that were found by clustering the statement cards will be explained per phase of workflow map.

FIRST CONSULTATION

① *Differences in prior knowledge with Hemophilia*

HCPs strive to standardize the information they provide, regardless of whether the parents are familiar with hemophilia. Because hemophilia care has drastically improved in recent years, people with this prior knowledge must know what life with hemophilia can look like. HCPs see a lot of doubt and uncertainty at first when parents are utterly unfamiliar with hemophilia. However, they also see that experience and knowledge of hemophilia grows with all parents as the child ages, which has a positive effect.

② *Information roles within the HTC team*

The nurses and pediatric hematologists coordinate what has and has yet to be discussed, but the nurses are primarily in charge of providing information and education. This makes it more difficult for the pediatric hematologists to intervene if they are only called in when the situation is critical and have missed the preliminary phase. To reduce this, before each coagulation outpatient clinic, a team meeting is held in which every member of the HTC treatment team is present, and the patients who come in that day are discussed. Patients with severe hemophilia are seen by a pediatric physical therapist annually. She also sees patients who are experiencing severe bleeding. The medical social worker is available to assist parents and families needing psychosocial support. Although the social worker and physical therapist play a smaller role in the team, the patient and parents must understand that they can be reached if there are any problems or questions.

③ *Consultation after diagnosis*

If the child's hemophilia is discovered during pregnancy, the first point of contact will be at birth, when HCPs will come to meet them. Because of the amount of information provided, the first consultation after diagnosis often lasts longer than a periodic consultation. A pediatric hematologist and the nursing consultant usually conduct these consultations. Because HCPs are aware that information is frequently not obtained during the initial consultation, they may offer the option of scheduling an additional consultation. HCPs recommend visiting the NVHP and Cyberpoli websites for more information. The initial consultation covers the following topics: hemophilia, where it comes from, and an introduction to the HTC team. The physical therapist also arrives to meet a new patient with severe hemophilia, which is uncommon among the other types.

PERIODIC CONSULTATIONS

④ *Assumptions of HCPs on caregivers*

HCPs are constantly attempting to assess the needs of patients and parents. In their experience, this goes typically well since they have much expertise, can assess people's level of knowledge a bit, and attempt to ask questions back to see if people have comprehended. However, this can be a risk at times because it might be difficult to accurately assess someone's level of understanding. Most parents generally have no detailed questions; only a few cases explore themselves and have particular questions.

⑤ *Information on blood clotting systems*

Because medical information on the functioning of the blood coagulation system is pretty complicated, HCPs frequently draw this explanation on a blank piece of paper to better understand the blood blood vessel and its contents.

⑥ *Verbal information and its retention*

Most information is provided verbally; HCPs know that patients and parents only recall a small fraction of it, which is why it is frequently given. Because it is primarily recalled from memory, there is a desire to have a checklist of what must be declared. Brochures are also issued on occasion as a reference for the information discussed.

⑦ *Questions and Answers*

Commonly asked questions include school, sports, vacation, and medication, as well as what to do in the event of bleeding and how to manage prophylactic treatment. There are also genetics-related considerations, such as how the problem may influence other family members. On a psychosocial level, the part about coping with it is also frequently emphasized.

⑧ *Age-related information*

Part of the information is age-related; for example, new information can be discussed in daycare or school, and the danger of bleeding grows as the child begins to walk.

⑨ *The involvement of children*

Children can participate in the conversation as soon as they can communicate and understand. This is frequently tough for them, but it allows the HCP to establish whether the child is aware of his hemophilia and gradually enhances his understanding. At a certain age, it is vital that kids know everything and know what to do.

⑩ *Periodic consultations*

The standard topics are discussed and repeated during the periodic consultations, and parents can ask questions. Periodic consultations with the pediatric hematologist and nurse consultant are held on alternate Thursdays during the coagulation outpatient clinic or on Wednesdays during the nurse specialist's outpatient clinic. Patients must come in for regular check-ups because forgetting increases the risks of hemophilia. That is why general information is so frequently repeated. The general information is standard topics covered during a consultation. This is frequently done by memory, but there is now a list in the electronic patient record. The narrative may sometimes be inconsistent because information is primarily shared verbally, and an unambiguous format is desired. During Corona, outpatient clinic visits were frequently digital; however, HCPs prefer physical visits to talk with the patient and parents more efficiently, build and maintain a better relationship with them, see the patient himself, and recognize whether everything is okay by their walk.

⑪ *Different types of hemophilia*

Many available information materials are often focused on severe hemophilia, which is understandable given that prophylactic treatment significantly impacts daily life. However, HCPs frequently observe that most severe patients are well-versed in the clinical picture. Hence, information materials on the clinical picture would be more beneficial to mild patients. This is because they have fewer contact moments with the HTC, resulting in less influence by the HCPs in improving these patients' understanding of the disease. This can lead to uncertainty about when and when not to act. Furthermore, mild patients can forget about their medical condition.

⑫ *Parents' characteristics*

A social worker can assist if one parent is overly protective or nervous about their child, which may impair the child's growth; the other parent is too relaxed and needs to be reminded more of the potential consequences of acting inadequately. In this regard, it is always necessary to strike a balance with parents.

TREATMENT

⑬ *Learn how to administer medication*

There is frequent interaction with the HTC, mainly with the nurses, while learning to administer prophylactic treatment. There was formerly a handbook and a website where people could learn how to inject. This brochure is no longer in print, nor is the website accessible. The nursing specialist is a member of a working group within the Dutch Association of Nurses (NVHV) to solve this, but it does not get off the ground due to a lack of time.

BLEEDING

⑭ *Crucial information*

The most crucial factor is that patients understand when to contact the HTC, can spot bleeding, and contact if they are unsure about bleeding. Patients, for example, should call in the event of a planned procedure in which suitable medication must be supplied at the appropriate time. Even inside Erasmus MC, this frequently does not go smoothly, which is why it is critical. HCPs outside the field of hemophilia must also grasp what hemophilia is, what is and is not possible with hemophilia, and the potential consequences.

RULES OF LIFE

⑮ *The social environment and the rules of life*

Parents and patients must comprehend the condition and its effects to communicate this to their social environment. Much can be accomplished in sports through collaborative decision-making; it is underlined that exercise is beneficial for children with hemophilia in order to build resistance in joints and muscles. Only kickboxing, diving, and trampoline jumping are strictly discouraged. As "life rules," many recommendations are made to allow the kid to develop as normally as possible with as few constraints as possible. Consider how vaccinations are given, wearing an SOS bracelet, and preparing for a vacation.

7.3 RELEVANT STAKEHOLDERS

Answering research question

7 How do stakeholders relevant to this topic experience providing information in their work?

Interviews were conducted with (a) representative(s) of the relevant stakeholders involved in the information provision process. All of the interviews were conducted remotely via teams. The following interviews were held:

	Interviewees	Stakeholder	Duration
1	Board member of the medical portfolio and a former board member	NVHP	00:55 h
2	Board member of the communication and information portfolio and a communication employee of the NVHP	NVHP	01:00 h
3	Project leader	Cyberpoli	01:00 h
4	Project coordinator & data manager	HemoNED	00:55 h
5	Two employees of the three working on patient information brochures	Communication department Erasmus MC	00:55 h

In the following subchapters, the interview outcomes per stakeholder will be discussed.

Dutch Association of Hemophilia Patients (NVHP)

The NVHP is supported by a devoted team of volunteers who donate their time and effort to the organization. However, the association has one paid employee who performs all communication-related responsibilities. This person is in charge of overseeing the publication of the magazine Faktor, generating the newsletter Faktueel, managing the website, and handling all social media interactions.

One of the key goals of the NVHP is to provide patients with reliable information to assist them in understanding their bleeding disorder. General practitioners and other HCPs are commonly unaware of these conditions, which leads to underdiagnosis. To address this problem, the NVHP aims to raise awareness among patients and the general public. Women's underdiagnosis, in particular, is an important cause of concern. Unfortunately, despite being carriers and experiencing symptoms, women are frequently neglected by HCPs.
Mothers who pass on the bleeding disorder may feel guilty. As a result, it is vital to provide information that addresses these difficulties. Furthermore, a thorough understanding of the bleeding disorder can help prevent exclusion from specific activities in school and social groups. Children with bleeding disorders can still actively participate in all aspects of life by boosting awareness and removing unnecessary anxieties.
The NVHP publishes brochures to provide patients with information on bleeding disorders. Individualized information is challenging to supply because each patient's condition is unique. The NVHP is updating its website to improve information accessibility. Figure 22 shows that they built a media bank where patients can find digital brochures, webinars, and videos. Users can also filter on the website by age range and specific topics such as treatment, carriers, gene therapy, and hemophilia. Women carriers were recently selected as a target group since they require further attention.

Furthermore, the organization has received funds to focus on providing information to patients aged 15 to 25. This period is essential since children transition from childhood to adulthood and must self-manage their condition. Furthermore, the NVHP has established podcasts on Spotify where patients discuss bleeding disorders and share their experiences.

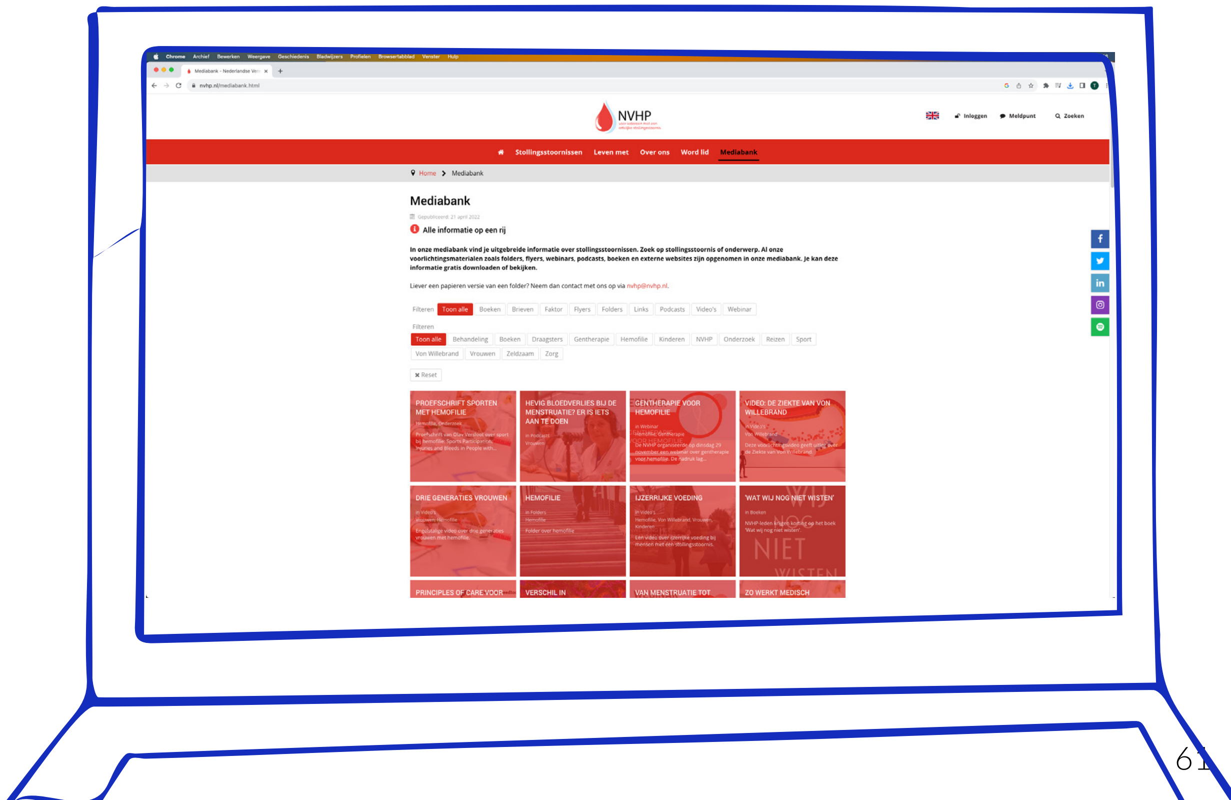
The NVHP has recently revised the brochure on living with hemophilia, updating the content, treatment information, and visual layout to fit its current corporate identity. Furthermore, they made the text more reader-friendly by removing jargon and ensuring readability at a B1 level in Dutch. The media bank also offers brochures for general practitioners, dentists, daycare providers, and schools. However, several of these brochures are over ten years old and must be updated. Given the lengthy duration of this procedure, the NVHP decided which brochures would be revised first.

The NVHP manages a Facebook community where patients can interact with others to facilitate peer assistance. In these gatherings, parents of patients frequently ask questions, and the NVHP monitors the topics covered to provide pertinent information. Furthermore, the NVHP conducts activities to bring patients together. Guest speakers at these events include either HCPs or patients.

The NVHP meets with the HTCs annually to discuss the need for information materials. These sessions discuss various issues and give the opportunity to provide HTCs brochures and an invitation card to join the NVHP. Despite the abundance of digital information on the NVHP website, many people prefer physical materials. However, the website is accessible to both members and non-members. Unfortunately, membership in the NVHP has been declining. To encourage membership, the NVHP provides a welcome information packet to new members aged 0 to 8.

The NVHP actively participates in different initiatives as a conversation partner, giving their experience. They feel that embedding their corporate brand as a separate entity in new efforts will prevent it from being used only within a single HTC. In identifying areas for improvement, the NVHP emphasizes the importance of addressing the fear of needles. Furthermore, they believe providing information about parental anxiety when a child with a bleeding disorder begins walking, cycling, and participating in sports is critical. These areas must be prioritized to help patients and their families better.

Figure 22: Mediabank of the NVHP website



Mediabank

Gepubliceerd: 21 april 2022

Alle informatie op een rij

In onze mediabank vind je uitgebreide informatie over stollingsstoornissen. Zoek op stollingsstoornis of onderwerp. Al onze voorlichtingsmaterialen zoals folders, flyers, webinars, podcasts, boeken en externe websites zijn opgenomen in onze mediabank. Je kan deze informatie gratis downloaden of bekijken.

Liever een papieren versie van een folder? Neem dan contact met ons op via nvhp@nvhp.nl.

PROEFSCHRIFT SPORTEN MET HEMOFILIE
Hemofilie, Onderzoek
Proefschrift van Olav Versloot over sport bij hemofilie: Sports Participation, Injuries and Bleeds in People with...

HEVIG BLOEDVERLIES BIJ DE MENSTRUATIE? ER IS IETS AAN TE DOEN
in Podcasts
Vrouwen

GENTHERAPIE VOOR HEMOFILIE
in Webinar
Hemofilie, Gentherapie
De NVHP organiseerde op dinsdag 29 november een webinar over gentherapie voor hemofilie. De nadruk lag...

VIDEO: DE ZIEKTE VAN VON WILLEBRAND
in Video's
Von Willebrand
Deze voorlichtingsvideo geeft uitleg over de Ziekte van Von Willebrand.

DRIE GENERATIES VROUWEN
in Video's
Vrouwen, Hemofilie
Engelstalige video over drie generaties vrouwen met hemofilie.

HEMOFILIE
in Folders
Hemofilie
Folder over hemofilie

IJZERRIJKE VOEDING
in Video's
Hemofilie, Von Willebrand, Vrouwen, Kinderen
Een video over ijzerrijke voeding bij mensen met een stollingsstoornis.

'WAT WIJ NOG NIET WISTEN'
in Boeken
NVHP-leden krijgen korting op het boek 'Wat wij nog niet wisten'.

PRINCIPLES OF CARE VOOR

VERSCHIL IN

VAN MENSTRUATIE TOT

ZO WERKT MEDISCH

Cyberpoli

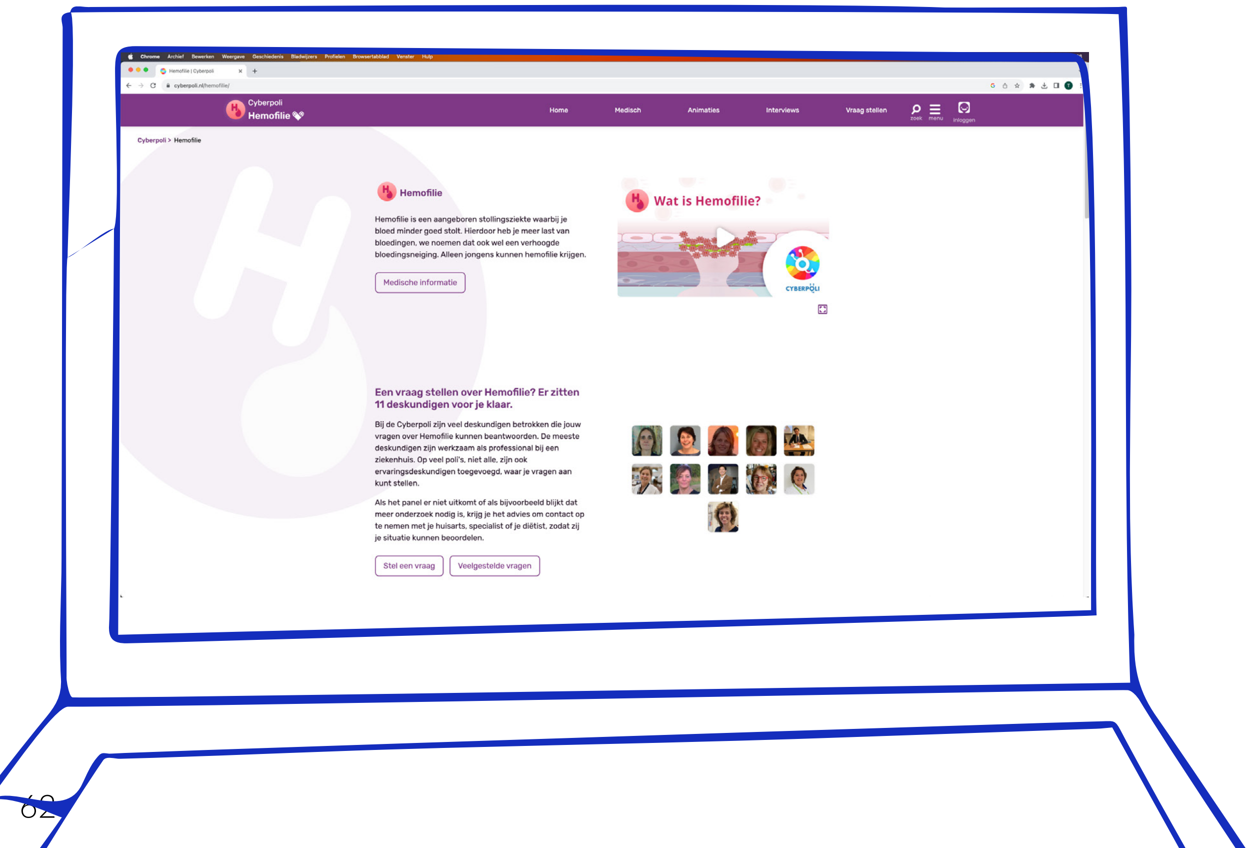
The Cyberpoli team, formed by panel members from the Stichting Artsen voor Kinderen (Foundation Doctors for Children), works with various HCPs and BioMedia to improve information provision. The interviewed project leader handles practical issues, a manager is in charge of content implementation, and a pediatrician writes texts. Each Cyberpoli is constructed with the assistance of HCPs. BioMedia contributes to the website's technical structure and animations.

Figure 23 depicts how the Cyberpoli platform delivers disorder information in multiple formats. The medical content includes thorough information regarding various disorder-related issues. A separate part provides answers to frequently asked questions. Recognizing that children and adolescents prefer visual knowledge, the animations explain how the body works. These animations can be found on Cyberpoli's website and YouTube channel. Children, adolescents, parents living with chronic diseases, and HCPs seeking extra information are the primary target audience.

The Cyberpoli platform highlights the necessity of displaying real-life experiences in addition to medical facts. Interviews with children, parents, and HCPs give insight into the condition's effects and the most recent breakthroughs. To transmit information, text, photos, and personal tales are employed. The information is designed to be aesthetically appealing and recalled. HCPs distribute promotional materials to parents to raise awareness of the Cyberpoli platform.

The impact of the Cyberpoli platform appears in children's and parents' greater understanding and confidence about their diseases. This leads to increased acceptance of the disease, better adherence to therapy, and, eventually, improved quality of life. The Cyberpoli team intends to expand its clinics beyond particular conditions to encompass general pediatrics. The VriendenLoterij has provided funding to facilitate this growth. Furthermore, in the future, they aim to achieve inclusion by presenting information in an easily understood way while giving in-depth content to those needing it. The organization also intends to broaden its foreign support, now available in the Netherlands, Belgium, the Netherlands Antilles, and Suriname. In addition, they are working to give information in English on diseases widespread in Africa, such as Sickle cell disease, to guarantee that these populations have consistent access.

Figure 23: The hemophilia cyberpoli



Hemofilie

Hemofilie is een aangeboren stollingsziekte waarbij je bloed minder goed stolt. Hierdoor heb je meer last van bloedingen, we noemen dat ook wel een verhoogde bloedingsneiging. Alleen jongens kunnen hemofilie krijgen.

Een vraag stellen over Hemofilie? Er zitten 11 deskundigen voor je klaar.

Bij de Cyberpoli zijn veel deskundigen betrokken die jouw vragen over Hemofilie 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.

Dutch Hemophilia Registry (HemoNED)

The HemoNED registry is led by three board members and a steering committee composed of doctors and NVHP representatives. They also have a patient panel for the 'Vaste Prik' application to see if any new issues or problems arise.

Patients used to keep a paper record of their medicine and bleeding. Because of current technology's capabilities, the demand for an application increased, see Figure 24. Using an application provides a better insight for the patient and allows the HCP to have a dashboard overview prior to an outpatient clinic visit. HCPs mainly market the Vaste Prik app to patients receiving prophylactic treatment. Nurses are often in charge of informing patients about the app and how to utilize it. Furthermore, videos demonstrating how to use the Vaste Prik app are accessible on the HemoNED website and YouTube channel. Also, a webinar was recently performed to fully explain the use and answer queries. As it turns out, there are a lot of issues regarding how to utilize technology and what abilities are required, which can be problematic for older individuals. They attempt to obtain this by creating videos and instructions. The text in these was also tested at the Dutch B1 level.

The registry uses data from registered patients to identify what the medicine does and how it connects to the type of medication used. HemoNED plans to study this further in the future using quality-of-life questionnaires. Furthermore, in the event of bleeding, patients should be able to dial the appropriate phone number directly from the app. It would also be advantageous if medication obtained from a pharmacy were automatically added to the app's supply. This may already be achievable with the new personal health environment being developed, in which everything is centralized in an app. Finally, they want to know how to encourage and support the shift from parents registering to children registering everything for themselves.

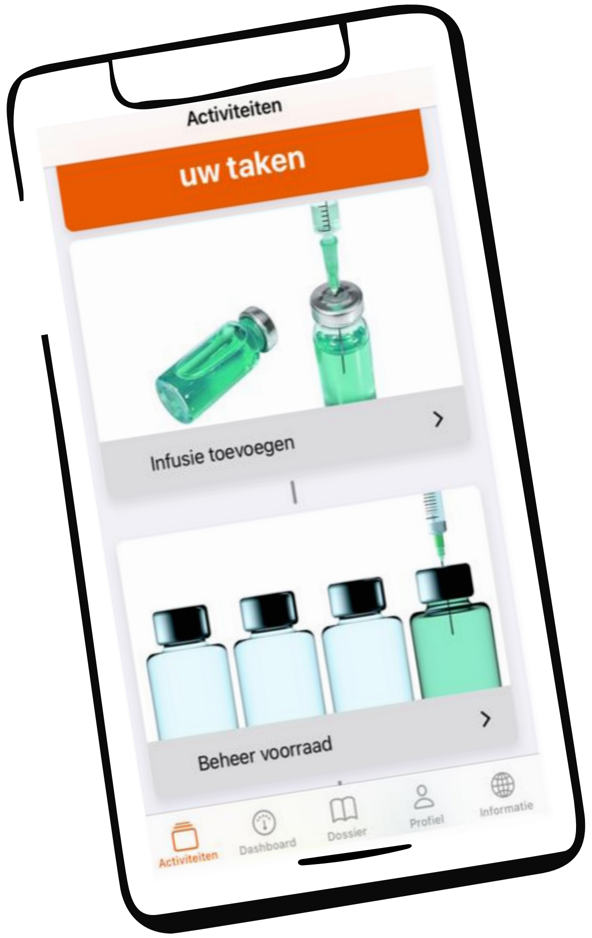


Figure 24: Vaste Prik application

Communication department Erasmus MC

The administrator project manages patient brochure information materials and their integration into the public website. Assigning responsibility for each brochure to ensure proper entry into the system is critical. Furthermore, incorporating information resources on the website is an important aspect. Brochures have a two-year expiration date, after which they should be examined for sustainability and modified as needed. However, due to insufficient maintenance in the past, allocating responsibility for all brochures within Erasmus MC is difficult.

The work of developing brochures entails inserting texts into the system, checking understanding, and converting the language level to Dutch B1. The Dutch language levels vary from C2 (the most difficult) to A1 (the easiest). HCPs initiate brochure creation and provide text. Templates with subheadings are provided here to help with formatting. Most texts offered by HCPs are at the C1 level, which only 15% of individuals understand. The department aims to reach B1 so that 80% of the public understands it, see Figure 25. As a result, the department intends to translate the texts to B1 level for improved comprehension. To preserve readability for people with higher literacy, they avoid utilizing levels lower than B1. The texamen.nl tool is used to test and simplify the language level. The HCP then reviews the amended text to verify medical correctness. Reactions to the altered text vary, with some satisfied and others questioning the degree of the changes, often unaware of the population's varying language levels.

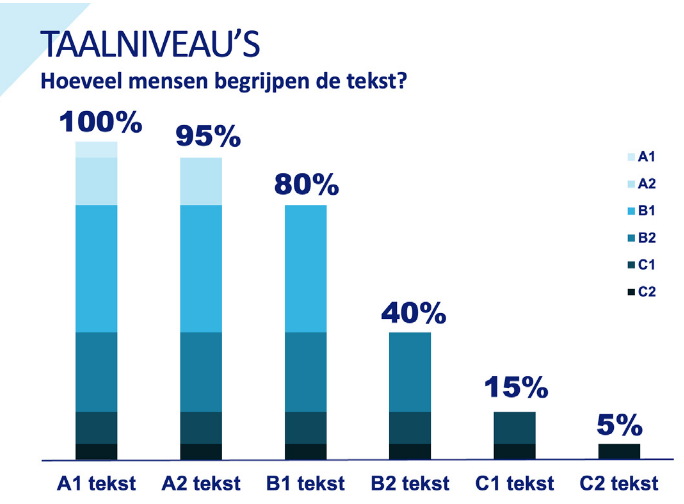


Figure 25: Language levels and the percentage of people that understand it (Eline Bakker et al., n.d.)

The department is not informed of all the available information within the hospital and the number of patients who have benefited from various brochures. Collecting this information would be perfect for designing a communication strategy, but it would necessitate more capacity.

Brochures are initially created digitally in A4 format. Patients receive them online or through the patient portal, and HCPs or patients can print them. However, printing A4 brochures and stapling them appears amateurish when given to patients. Departments requiring A5 brochures must make their own arrangements, which frequently results in just decreasing A4 to A5, making the text too small for specific target groups. The interviewees believe that paper brochures will continue to be used for information and hope that hybrid options will be preserved. Personalized information may benefit from dividing brochures by disease or therapy subtype if excessive brochure expansion is avoided. A future consideration would be investigating how HCPs can verify the type, subtype, and treatment to generate automatic information.

In addition, the team aids the Digizorg team by monitoring app content and pushes for the use of existing brochures to avoid duplication of materials. Digizorg is a patient-focused app that provides access to medical data. It also facilitates communication with the hospital and HCPs. While videos are becoming more popular as a source of information, interviewees saw more drawbacks than advantages. Videos lack targeted information access, necessitate active viewing, and are more difficult to update than brochures.

According to the interviewees, a sizable proportion of the Dutch population is illiterate, resulting in low health literacy and difficulties reading information or packaging leaflets, which can lead to health concerns. Previous research by the interviewees demonstrated that patients prefer textual information when dealing with extensive content. Patients can be categorized into two groups: those looking for specific information and those looking for a broad understanding. It can be challenging for most patients to understand medical terms, but repetition and abbreviations can help. People with low literacy have difficulty scanning material. Thus, utilizing headings helps them recognize key information. Finally, it is critical to prioritize critical information.

7.4 CONCLUSIONS

After bringing together all the available data, a series of conclusions can be deduced.

The need for a central location with all relevant information
Parents of children with hemophilia need organized, accessible, and reliable sources of information. It shows the necessity for a central platform for parents to communicate and locate information. Understanding the medical terms and complex treatments is essential to help parents feel more confident and provide their children the best care and support. Parents of hemophilia patients can feel more supported by a holistic strategy that addresses medical and emotional issues.

Communication and collaboration is crucial
HCPs must collaborate to give diagnosis and information on hemophilia. Nurses build trust with parents through verbal information and reassurance. This gives parents education and support. Hemophilia treatment in children requires a trained and compassionate healthcare team working with parents. Clear communication, adaptability, and easy access to HCPs comfort parents and give the best care for their child.

The need for more clear and structured periodic consultations
Parents must have clear and structured periodic consultations, especially for mild patients, when it might be a moment of awareness. It also underlines the importance of transparent communication regarding the substance of the consultations and who will be involved for parents to be properly informed and prepared. It guarantees that the child's health and well-being remain key to the treatment plan, and that periodic check-ups are an important element of caring for children with hemophilia.

The need for an overview of all topics that can be discussed
The interview data raises several frequently asked questions. When these questions are asked, there appears to be information about it, but it needs to be clarified that it can be discussed. An overview of these subjects would help understand parents' concerns and what information and support they would like to receive. It also emphasizes the necessity of providing parents of children with hemophilia with clear and accessible information to better prepare for and feel supported in their child's care.

The need for a standardized format to pass down information
Parents desire a common story to explain hemophilia and its consequences to their child's social environment. They specifically mentioned teachers from schools and daycares. This request was created so parents could share a simple story without giving unnecessary medical details. A clear story would help parents incorporate hemophilia care into their daily lives. It would also help teachers and counselors understand the child's condition and medical treatment. If a situation requiring medical assistance arises, the school's instructors and personnel must respond immediately and appropriately. Understanding can help establish a more inclusive and supportive environment for the child, which benefits their well-being and self-esteem. Parents of children with hemophilia highly value communicating their medical care to others clearly and easily. A clear story with illustrations could be beneficial.

The need for psychosocial support besides the medical care
Parents need time to digest the situation, especially at first. It also illustrates the need for empathetic and clear communication from HCPs during diagnosis. HCPs serve as psychologists in addition to their medical roles. They recognize that parents have anxieties and emotions and that a good balance of reassurance and openness from the HCP is critical in assisting parents in coping with hemophilia's challenges. A safety net of information provision can help parents cope with the emotional impact and information overload of receiving a diagnosis. It ensures that parents are well informed and supported during this critical period. Moreover, it emphasizes the importance of balancing protection and encouraging the child to develop.

The need for more tailored information and care
HCPS must understand the unique needs of children with hemophilia and provide them with the care and treatment required to ensure their health and well-being. This insight emphasizes the importance of tailoring care to the individual child's needs and characteristics and providing support to manage fears during medical treatment.

The need for encouragement and guidance in case of (possible) bleeding
The emotional and practical difficulties parents of hemophiliac children face when dealing with acute events are highlighted. Despite knowing what to do, feelings of guilt and a lack of understanding about serious and non-serious cases of bleeding can prevent them from acting fast. When in doubt, parents should be encouraged to call HCPs immediately so that their child can receive appropriate medical care.

The need for a vacation checklist
Prior to the holiday, having clear and reliable information is essential for enjoying a carefree holiday and acting appropriately in an emergency.

The importance of having the option between physical and digital
Providing physical and digital information options for parents of children with hemophilia can be beneficial. As a result, parents can select the best form for them and have easy access to relevant information to provide their child with the best possible care.

The necessity of good working digital tools
The technological issues mentioned on the Vaste Prik app demonstrate the necessity of user-friendly and well-functioning digital tools in healthcare. Clear explanations and support from HCPs can assist parents in making the most of these apps and, as a result, enhance care for their child with hemophilia.

DEFINE

03

8.0 Defining the Direction

Within this chapter, the knowledge acquired from the interviews serves as a compass for constructing an information flow framework. This framework systematically delineates the pain points encountered. Next, the problem definition will be described. Lastly, the design direction is established by crafting a specific design goal to steer the following design process.

8.1 INFORMATION FLOW FRAMEWORK

Answering research question

8 What are the pain points, and improvement opportunities within the information provision for caregivers of patients with hemophilia?

Drawing upon the insights garnered from interviews with both HCPs and caregivers of patients, a thorough understanding has been gained regarding the dynamics of information transmission from HTCs to patients and their caregivers and within the broader social sphere. A comprehensive framework has been crafted to capture this complex web of information flow (Figure 26). See Appendix C1 for the co creation session that was held to do so. This framework serves as a visual representation of how information travels through two distinct domains:

1. Internal HTC Information Provision: This serves as the input domain, illustrating how information is shared within the HTC environment.
2. External Patient-Caregiver-Social Context Information Dissemination: This is the output domain, depicting how information radiates into the social context of patients and their caregivers.

Within the confines of this framework, areas of concern and opportunities for enhancement, which surfaced from the interview data and were highlighted in the information journey map and conclusions, are depicted by exclamation marks. This systematic representation highlights the specific points where improvements can be implemented to streamline and enhance the information flow.

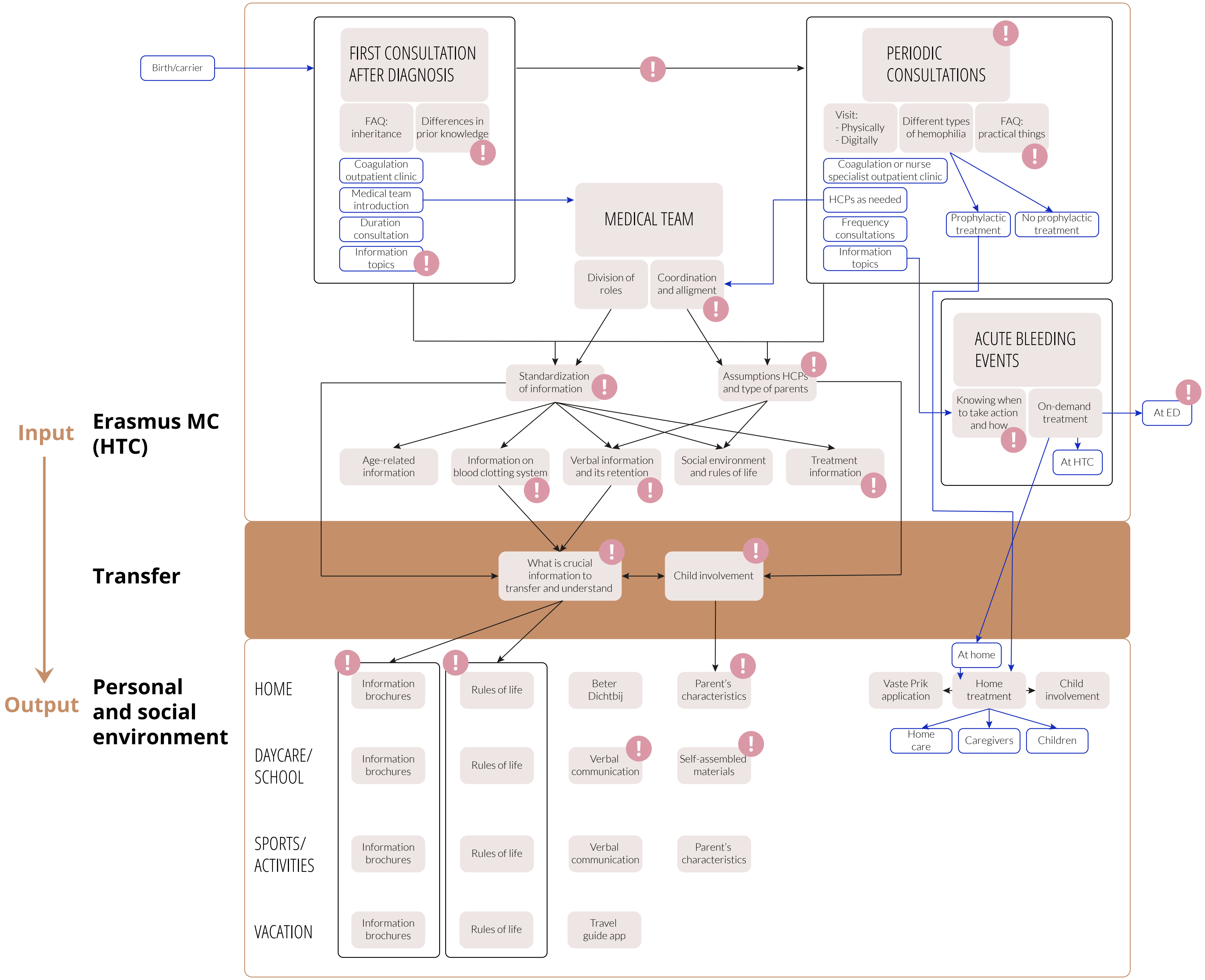


Figure 26: Information flow framework

8.2 PROBLEM STATEMENT

The identified pain points and areas for improvement within the information flow highlight two crucial overarching problems that must be addressed.

Firstly, there is an issue within the input phase where enhancements are necessary to deliver and convey information to parents during outpatient appointments effectively. This is crucial to ensure that parents understand the nature of the disease, know the appropriate actions to take, and recognize when they should reach out for assistance. The problem arises primarily because the required information is provided verbally within a limited time frame of just 20 minutes per outpatient clinic visit. Given the significance of these 20 minutes, which occur merely once a year for some parents, optimizing this process is essential.

Secondly, a challenge exists within the output phase, where there is room for improvement in providing avenues to process the provided information more effectively. While there is a wealth of information available at present, it is spread across various locations, both online and offline. This discourages parents as they encounter obstacles in locating pertinent information. What is needed is a clear and unified source of information that parents can easily access, thereby addressing this challenge.

8.3 DESIGN DIRECTION

Establishing a clear objective is paramount before entering the design phase. As indicated in the problem statement, two significant areas require improvement. As outlined in the project assignment, the primary aim of this project is to enhance information provision in the short-term through the development of a tool. This subsequently enables the development of a strategy for refining this tool in the long term to enhance information delivery. Considering that the initial issue is situated within the input phase during outpatient clinic visits, designing a tool with the potential for short-term impact on this phase is appropriate. Conversely, the second-mentioned issue necessitates a longer-term solution. Thus, the proposed solution will be integrated into a broader strategy for enhancing information dissemination beyond outpatient conversations at the hemophilia treatment center.

8.4 DESIGN GOAL

A design goal there is formulated for the tool and one for the strategy.

Tool

Design an **interactive communication tool** to **enhance the information transfer** between **healthcare professionals and caregivers** during outpatient clinic visits by providing **structure and clarity**.

Strategy

Design a **strategy** to **improve the information provision** for **hemophilia patients** by developing an **implementation roadmap** to gradually build and expand a **central information platform**.

8.5 REQUIREMENTS

The interactive information tool must:

- Provide structure of the information given during the outpatient clinic visit
- Integrate all topics that can be discussed
- Enhance the information transfer between HCPs and caregivers
- Supports information recall
- Facilitate room and support parents to ask questions
- Enable better comprehension of complex medical information
- Feasible to implement in the short term

In the strategy, the following requirements need to be addressed:

- Create accessibility to the same information for all hemophilia patients
- Provide all the relevant information in a central place
- Support health literacy
- Facilitate tailored information to a specific type of hemophilia
- Empowers patients and their parents in self-managing the condition
- Enable sharing information

DEVELOP

04

9.0 Ideation

This chapter provides a look into the ideation process, presenting the primary outcomes of a brainstorming session centered around ‘How Tos.’ Furthermore, it involves an exploration of interventions that are already in place.

9.1 IDEATION BRAINSTORM

To stimulate creative thinking, a range of "How Tos" has been devised and brainstormed, as outlined in Appendix D1. During this process, both the existing information flow framework, which had already identified pain points and areas for improvement, and distinct "How Tos" were examined. This brainstorming exercise yielded a variety of solutions, encompassing both digital (Figure 27) and non-digital approaches (Figure 28). A notable observation is that the digital solutions are less suitable for integration within the input phase of outpatient consultations, whereas the non-digital concepts align more effectively with this phase.

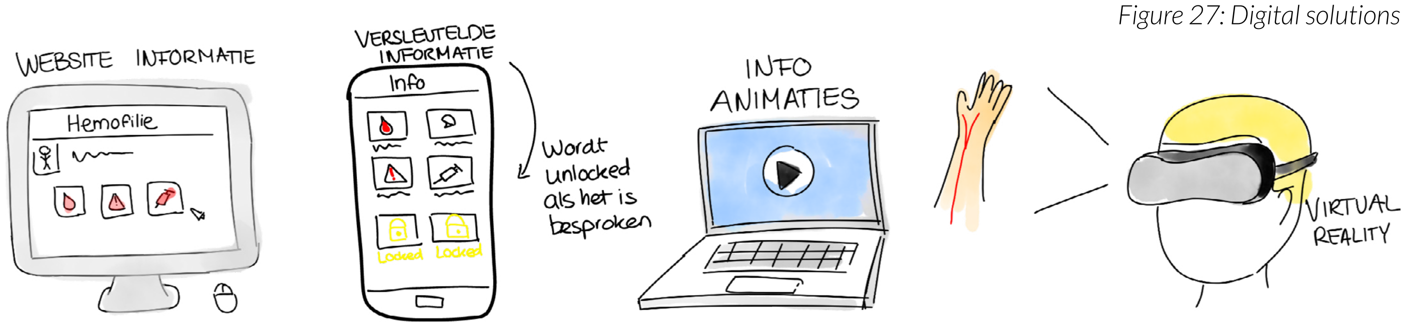


Figure 27: Digital solutions

Central website with all relevant information in a visually appealing way

Application with visual icon of topics, unlocking items when discussed with HCP

Information and eduction through animation videos

Using virual reality to for example see the blood vessels on your arm when explaining the blood clotting system

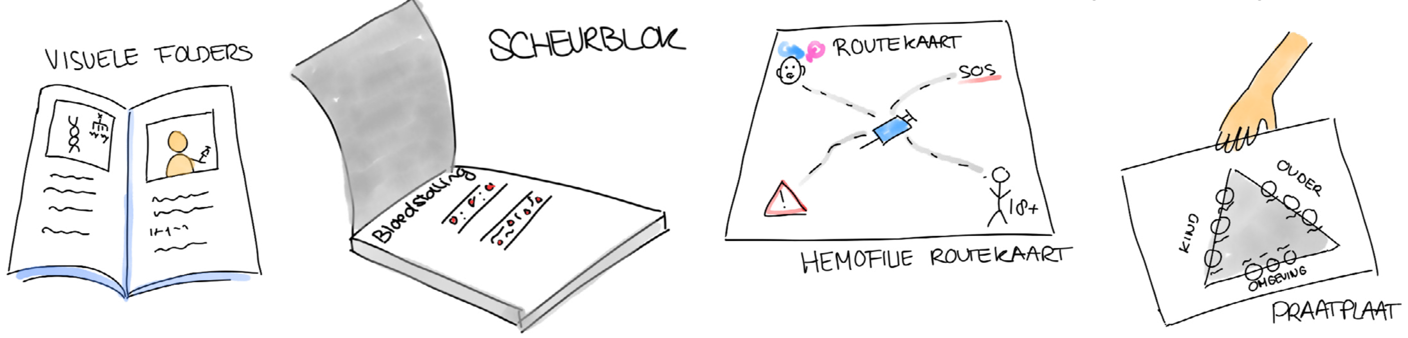


Figure 28: Non-digital solutions

Improving brochures by making them less textual and more visual for better comprehension and recall

Creating a tear block containing a page with explanatory visuals on the blood clotting systems to replace the hand drawn version and to take home

Creating a route map visualizing the pathway of a hemophilia patient by mapping out the different topics on the road

Giving an overview of all the topics than can be discussed in a hierarchical manner

10.0 Concept Development

The goal of ideation was to create a concept for developing a tool that can improve the information provision during outpatient clinic visits. This chapter introduces the concept of Samen Spraak and its implementation within the NVHP.

10.1 SAMEN SPRAAK

HCPs might sometimes overlook that a person can have limited health literacy. This can lead to them not realizing the importance of adjusting how they transmit information. Consequently, essential details like what is causing the patient's condition and the available treatment choices might not be communicated effectively. This can make it harder for the parent and patient to be actively involved in decisions and sufficiently manage their condition.

To address this, the concept of 'Samen Spraak' is introduced. This is a tool designed to tackle the issue. It offers a range of topics that can be covered during outpatient clinic visits, providing easy-to-understand information about hemophilia using text and visuals. The main aim is to help parents better understand their child's condition and be more involved in decisions about their treatment.

Samen Spraak consists of two components: the Gesprekskaart (conversation card) and the Praatkaarten (talking cards). Nurses were involved in developing this tool through a co-design process. The idea was refined and improved upon based on their input.

Gesprekskaart

The purpose of the Gesprekskaart is to serve as a consistent guide for every outpatient clinic visit. This approach aims to build familiarity and understanding by presenting an outline of all the possible discussion topics. These topics are organized into four clusters for easier reference. It is important to note that only some topics can be covered in a single consultation. This emphasizes the need for the Gesprekskaart to be used during each subsequent visit. Additionally, specific topics are relevant based on the patient's age and will not be addressed until later consultations.

This approach to outpatient clinic visits offers several benefits. It provides a systematic way to cover each topic, reducing the likelihood of important details being overlooked by HCPs. Simultaneously, it encourages parents to consider potential questions they might have. Including visual aids alongside the topic headings enhances comprehension and recall of the information for parents by simplifying the medical information.

The selection of topics for the Gesprekskaart was based on insights gained from interviews with HCPs and caregivers of patients and an analysis of the current care pathway. See Figure 29 for the concept version of the Gesprekskaart.

It is important to highlight that the Gesprekskaart is a tool rather than a substitute for effective patient-healthcare professional communication. While it can certainly enhance communication, clarity, and the efficiency of consultations, it is intended to complement the essential interaction between patients and HCPs.

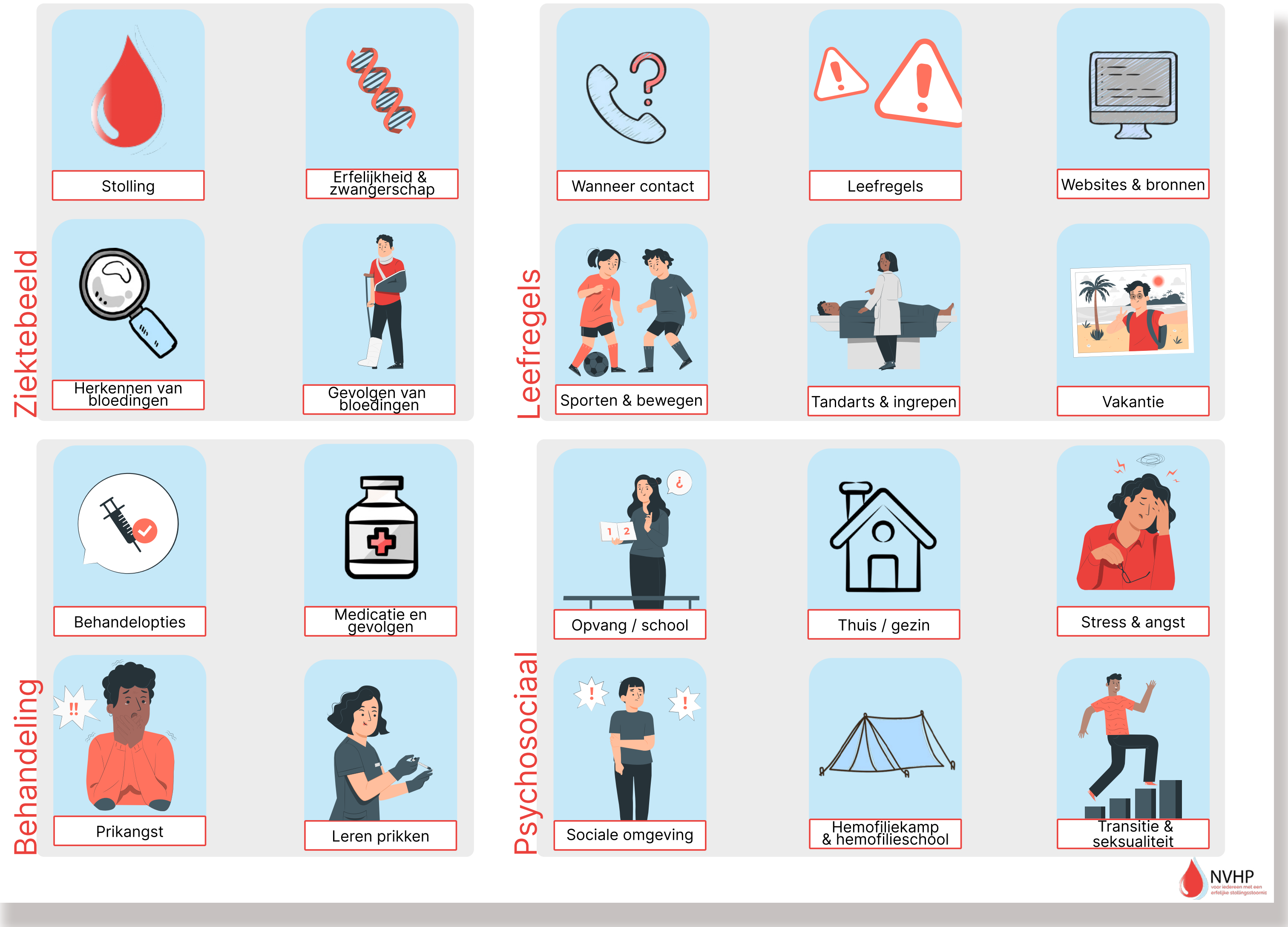
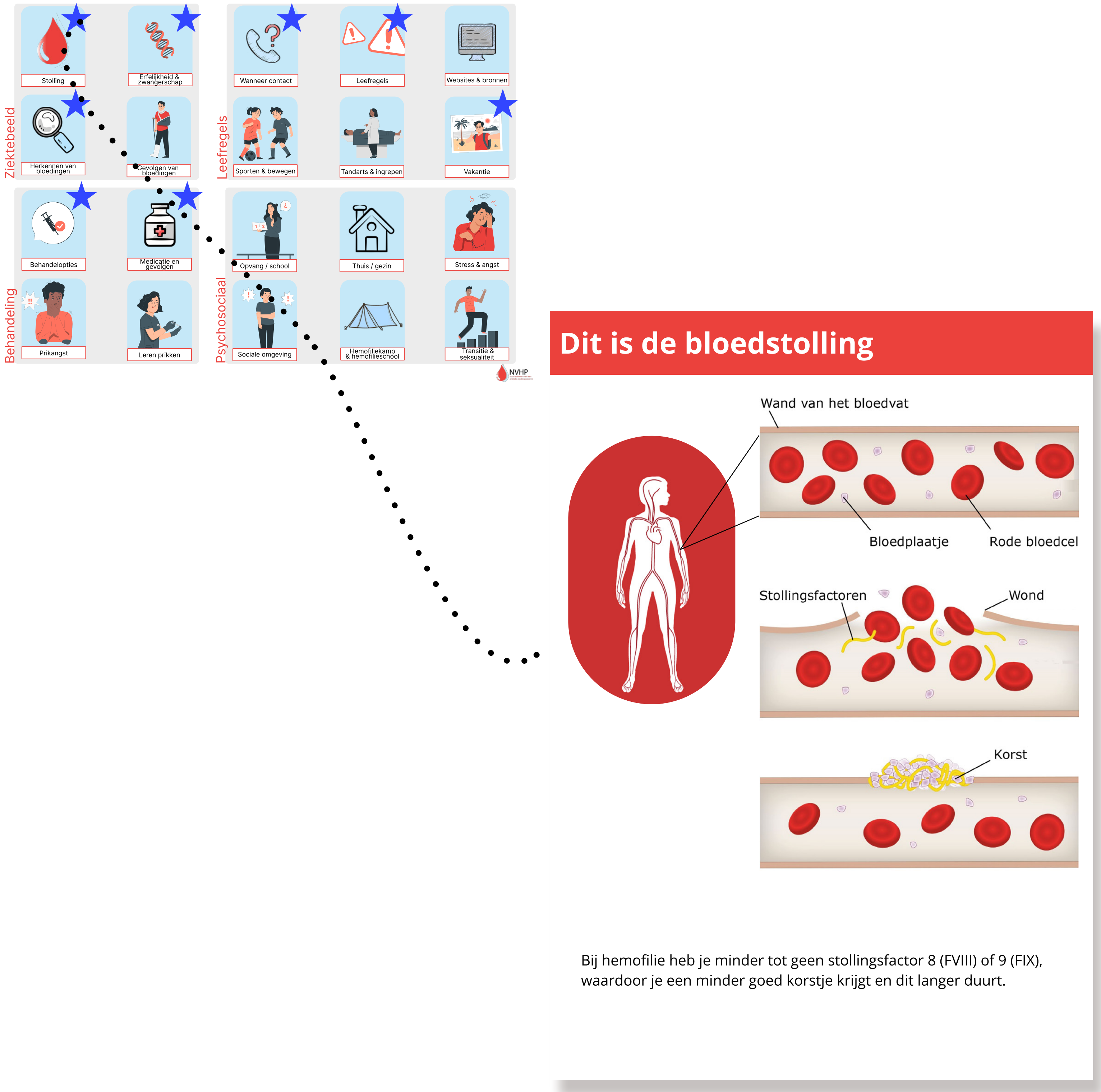


Figure 29: Concept of the Gesprekskaart

Praatkaarten

Due to the complex and medical topics of the Gesprekskaart, specific subjects have been selected to create supplementary Praatkaarten. In Figure 30, these subjects are marked with asterisks for identification. These chosen subjects were then refined in collaboration with nurses. The talking cards combine visuals and text to supplement the HCP's verbal information (Figure 31). The underlying concept involves addressing these topics using the Gesprekskaart during outpatient clinic visits. When a topic requiring additional clarification is broached and corresponds through a Praatkaart, this card provides a more comprehensible and visual explanation.

The cards also lower the bar for discussing the issues and complaints listed on the Praatkaart with the HCP. More knowledge and understanding improve self-management and shared decision-making with the HCP; the choices made are more appropriate for the patient's situation. This results in improved health outcomes.



Dit is de bloedstolling

Bij hemofilie heb je minder tot geen stollingsfactor 8 (FVIII) of 9 (FIX), waardoor je een minder goed korstje krijgt en dit langer duurt.

Figure 30: Example of the Praatkaart

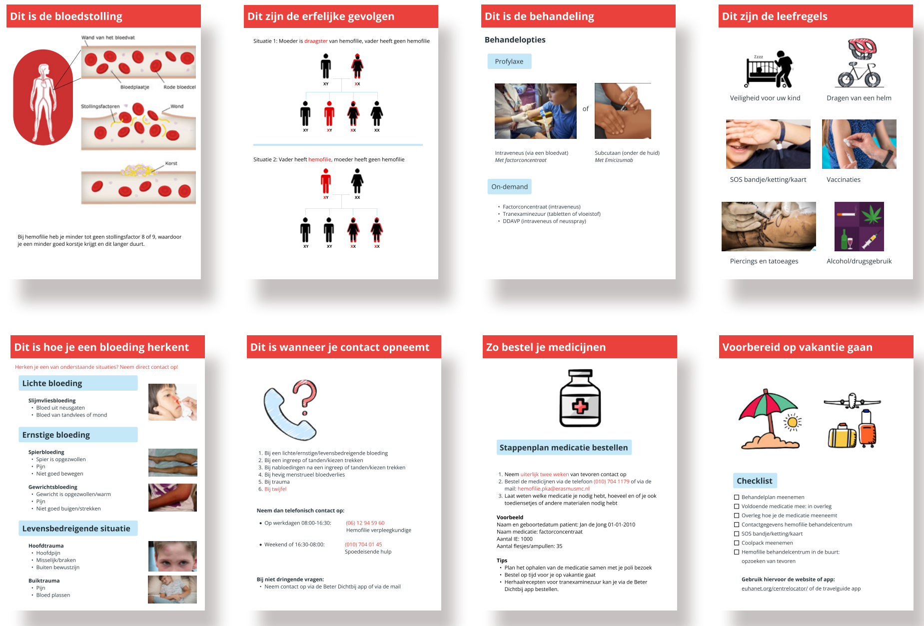


Figure 31: Overview of the Praatkaarten

10.2 IMPLEMENTATION WITH THE NVHP

After conducting the initial interview, a subsequent meeting was organized with the NVHP as part of the initial concept development stage. The purpose of this meeting was to present the concept and assess its feasibility for implementation by the NVHP. Details of the concept presented in this meeting can be found in Appendix D2.

To begin, the Gesprekskaart was introduced and demonstrated. The point was made that having this tool available during consultations could be beneficial:

"De zorgverlener ziet jou ook maar 1x per jaar, dus die moet ook maar onthouden wat er wel en niet besproken is."

"Healthcare professionals only have a yearly interaction, so they need to recall what has and has not been discussed."

Regarding the initial version of the Gesprekskaart, a discussion ensued about the inclusiveness of all topics. While the NVHP representatives found it comprehensive, they asked about 'Beter Dichtbij.' This led to the realization that some topics are linked to specific HTCs. For example, Erasmus MC employs the Beter Dichtbij app for easy communication with nurses, and Radboud UMC has an integrated chat function in their application. Therefore, the design must accommodate long-term and non-specific center usage, allowing each center to customize it according to its specific needs.

Following this, deliberations occurred about whether the NVHP could implement and deliver this concept. The NVHP representatives shared their ongoing efforts to improve HTCs in providing information independently to their patient community. Should the NVHP take charge of developing and distributing the concept, both Erasmus MC and other HTCs across the Netherlands could benefit from it. One representative expressed support but emphasized that board approval would be necessary:

"Absoluut, het allerliefst zeg ik direct akkoord tegen jou, maar dat kan ik niet alleen, dat moet even langs het bestuur. Ik heb een groot voorgevoel dat dat hartstikke akkoord is."

"I would personally love to agree right away, but I cannot make that decision alone; it needs board approval. I am very optimistic that the board will be on board with this."

Practical matters surrounding the potential implementation of this concept were addressed. The plan involves delivering the Gesprekskaart to HTCs in a durable format and making it available for download in the NVHP's media bank for easy accessibility. The next step involved presenting the concept at an upcoming board meeting, which was to take place shortly after this discussion. A preliminary version, explanation, and research description were shared with the NVHP in advance to facilitate this. Consequently, the NVHP expressed their intention to attach their emblem to the concept, making it accessible to all HTCs.

11.0 Concept Evaluation

This chapter discusses the evaluations with the different participant groups also interviewed. In addition, other stakeholders participated in the evaluations to ensure a successful implementation at the NVHP.

11.1 EVALUATION OF SAMEN SPRAAK

To evaluate the effectiveness of the concept, a series of evaluation interviews were conducted involving participants from all three participant groups, see Appendix D3 for the evaluation questions. These groups included previous interviewees. For the evaluation with caregivers, it was taken into account to interview one caregiver per treatment variety to include all perspectives. Evaluating with caregivers gave insights into the comprehensibility of the materials. The HCPs provided insights into the medical content of the materials and its accuracy, and the communication department representatives of Erasmus MC gave more insight into the understandability and guidelines fitting health literacy recommendations. Furthermore, a new stakeholder was involved in the evaluation:, a representative from the Lung Cancer Association. This stakeholder's input was particularly valuable since they had also developed their version of lung cancer talking cards. Lastly, the concept was revised by two roommates who were considered as laypersons in hemophilia and this project.

Furthermore, a comprehensive evaluation was undertaken in collaboration with the Dutch Association of Hemophilia Nurses (NVHV), representing all hemophilia nurses across the Netherlands. This step was essential to gather insights from different HTCs, each with its unique approach. The following evaluation sessions took place:

	Participants	Number of participants
1	Lungcancer association	1
2	Communication department Erasmus MC	2
3	Fellow	1
4	Pediatric hematologist	1
5	Pediatric hematologist	1
6	Caregiver of severe patient (subcutaneous prophylactic treatment)	1
7	Caregiver of mild patient and patient (on-demand treatment)	2
8	Caregiver of severe patient (intravenous prophylactic treatment)	1
9	NVHV board	4
10	Multicentral NVHV meeting	11
11	Laypersons in hemophilia and this project	2

In a subsequent development, an introductory session was held during the NVHV board meeting to present and assess the "Samen Spraak" concept with HTCs across the Netherlands. This session involved the participation of four nurses who provided their initial feedback. Subsequently, communication via email with the NVHV group was initiated to solicit an initial response, yielding three feedback responses.

Plans were made to organize an informational gathering to facilitate a more in-depth discussion. This gathering brought together several nurses from pediatric and adult departments, encompassing 11 nurses from Erasmus MC, Utrecht UMC, Amsterdam UMC, Radboud UMC, and UMC Groningen. The outcome of this meeting was unanimous: both NVHV board members and nurses from HTCs across the Netherlands expressed strong support for the implementation of the "Samen Spraak" concept.

The term "consequences" in medication and consequences sounds as if the potential side effects of inhibitor development are a standard outcome of the medication.

NVHV: "Zo lees ik het van oh, als je die medicatie neemt, dan krijg je remmers, zo is het niet, je kan het ook bijwerkingen noemen."

"That's how I read it, like, if you take that medication, you'll get inhibitors, but that's not the case; you can also call it side effects."

The image with a cast around the leg is confusing when it is about the consequences of bleeding.

The topic of 'treatment options' can also be about the new treatments in the future such as gene therapy, since there are many questions about this.

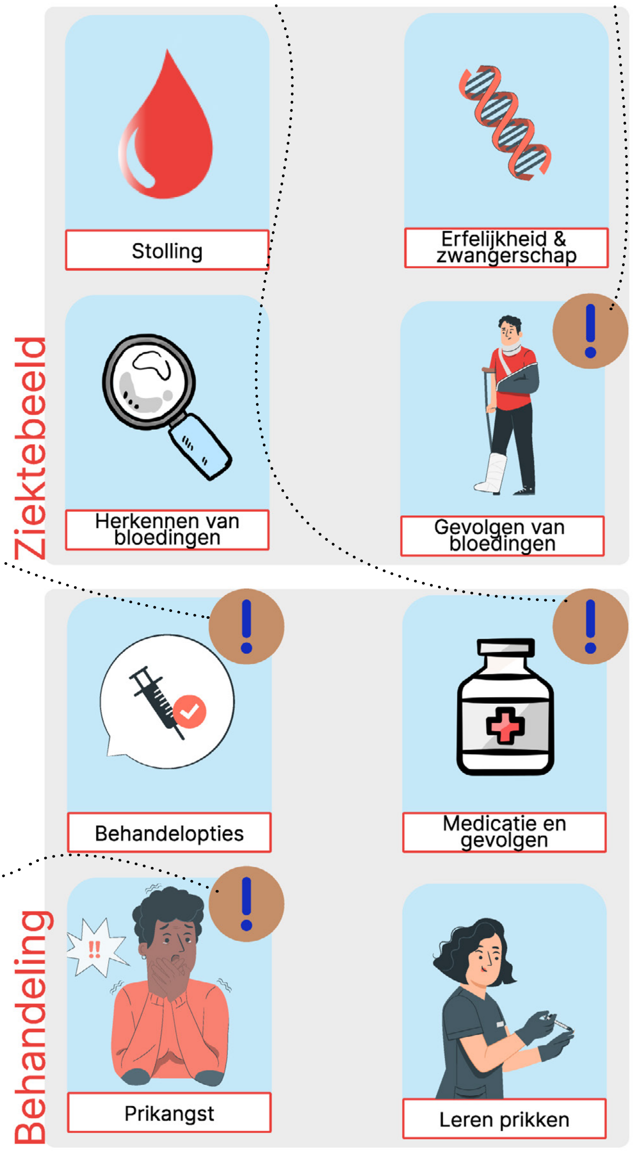
HCP: "Zou dat niet behandelopties en toekomstperspectief, ja dat je hem daaronder schaart, dan hoef je niet nog zo'n icoon te maken."

"Wouldn't that be treatment options and future prospects, yeah if you categorize it under that, then you don't need to create another icon like that."

The term "fear of needles" is now being avoided; a suitable replacement needs to be found for this.

NVHV: "Dat is natuurlijk een beetje tegendraads met hoe we nu proberen de dingen te benoemen en als je dit gaat gebruiken ook voor kinderen en voor jongeren dan is daar misschien een iets andere benaming nodig."

"That's naturally a bit contrarian to how we're currently trying to label things, and if you're going to use this for children and adolescents as well, there might be a slightly different designation needed."



"Rules of life" sounds too dramatic; they are more like recommendations provided by HCPs, and it's up to the parent whether to follow them.

NVHV: "We proberen juist een beetje te stimuleren dat je een zo normaal mogelijk leven leidt, mits je een aantal dingen in je hoofd hebt waarvan je weet dit is niet zo handig, dat kan ik beter anders doen, maar het klinkt zo ja, dit mag jij niet en dat mag je niet, terwijl je dat juist niet wilt."

"We actually try to encourage leading as normal a life as possible, as long as you have certain things in your mind that you know are not very beneficial – things you could do differently. But it sounds like, 'Yes, you can't do this, and you can't do that,' when that's actually not what we want."

"Psychosocial" is a difficult word.

To make the Gesprekskaart applicable to all hemophilia patients, including adults, more topics related to women are needed. For instance, childbirth could also be added here.

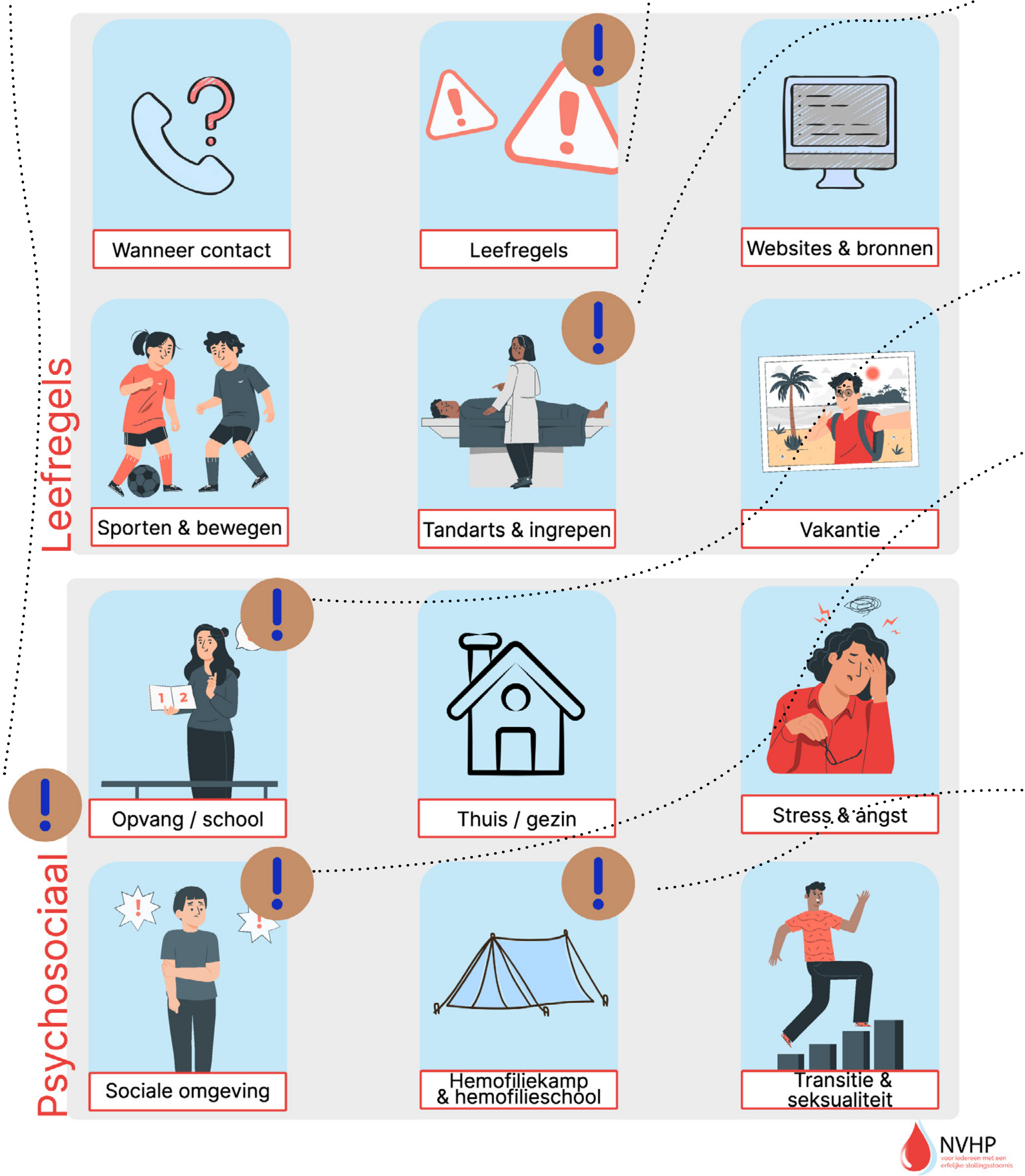
The picture for school is not clear enough for a school setting for a child.

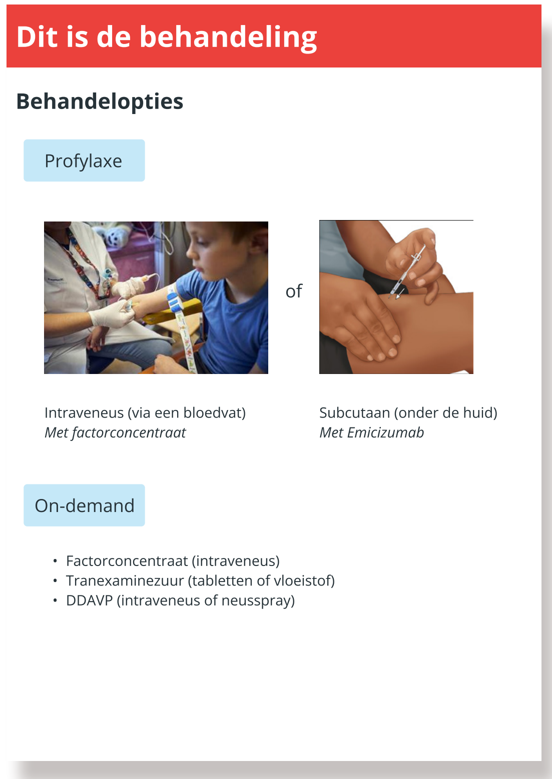
The picture for a social environment is difficult to understand for a child.

Het onderwerp hemofilie kamp en hemofilie school is centrum specifiek, vindt hier een andere titel voor zodat het aansluit bij alle centra.

HCP: "Dit is wel heel erg centrum specifiek [hemofilie kamp]. Informatiebijeenkomsten? Precies, ja zoiets zou ik het dan noemen."

"This is very center-specific [hemophilia camp]. Information sessions? Exactly, yes, something like that would be appropriate then."





Dit is de behandeling

Behandelopties

Profylaxe

of

Intraveneus (via een bloedvat)
Met factorconcentraat

Subcutaan (onder de huid)
Met Emicizumab

On-demand

- Factorconcentraat (intraveneus)
- Tranexaminezuur (tabletten of vloeistof)
- DDAVP (intraveneus of neusspray)

Figure 32: Praatkaart treatment options

In the treatment options, the option for prophylactic treatment using the port-a-cath variant was missing. This should also be added. Regarding the Praatkaart about treatment options, there was a difference of opinion between the pediatric hematologists. One suggested creating two separate cards for this, while the other didn't find it necessary.

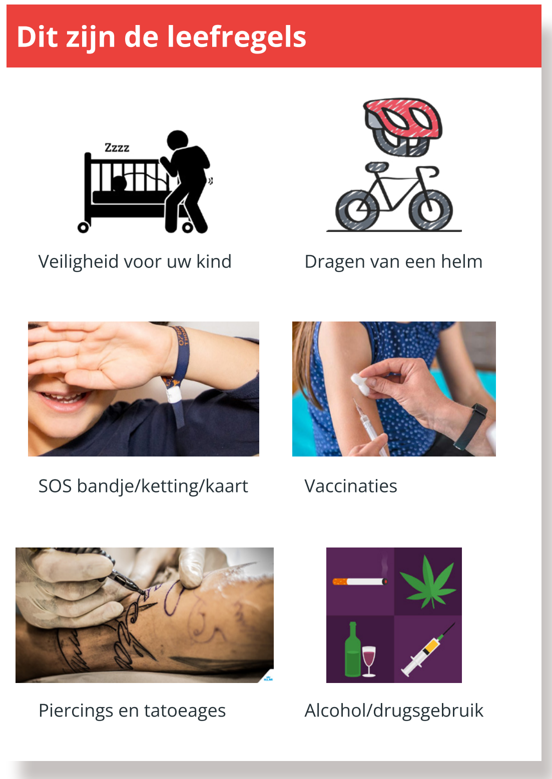
"Dit kan ook verwarrend zijn voor mensen van oh, dus het kan dat en dat maar waarom dan bij mijn kind wordt dat gekozen en waarom niet dat?"

"This could also be confusing for people like, "So, these topics are included, but why is this chosen for my child and not that, and why not this?"

"Ja, dat zou ik dus niet doen, want je legt uit: sommige kinderen moeten beschermd worden elke dag en sommige kinderen niet, en u valt in deze categorie."

"Yes, I wouldn't do that because you're explaining that some children need protection every day, while others don't, and you fall into this category."

Figure 33: Praatkaart rules of life



Dit zijn de leefregels

Veiligheid voor uw kind

Dragen van een helm

SOS bandje/ketting/kaart

Vaccinaties

Piercings en tatoeages

Alcohol/drugsgebruik

Regarding the card about life rules, the recommendation is, again, to rename it. Additionally, there was a mention that NSAIDs are missing. These refer to specific painkillers unsuitable for individuals with hemophilia due to their impact on blood clotting. Another suggestion was to adjust the hierarchy, shifting the focus away from the safety aspect for the child. The aim is to enable children to have as normal a life as possible. While this topic is crucial for parents' inquiries, it should remain accessible.

Figure 34: Praatkaart recognizing bleedings

Dit is hoe je een bloeding herkent

Herken je een van onderstaande situaties? Neem direct contact op!

Lichte bloeding

Slijmvliesbloeding
- Bloed uit neusgaten
- Bloed van tandvlees of mond

Ernstige bloeding

Spierbloeding
- Spier is opgezwollen
- Pijn
- Niet goed bewegen

Gewrichtsbloeding
- Gewricht is opgezwollen/warm
- Pijn
- Niet goed buigen/strekken

Levensbedreigende situatie

Hoofdtrauma
- Hoofdpijn
- Misselijk/braken
- Buiten bewustzijn

Buiktrauma
- Pijn
- Bloed plassen

Regarding the Praatkaart discussing how to recognize bleeding, there's a noteworthy point that the symptom of urinating blood could also be categorized as a minor bleeding issue, when it is not caused by stomach trauma. Furthermore, it's important not to overlook women's health, as heavy menstrual bleeding should be considered as severe bleeding. Likewise, rectal bleeding is a frequent occurrence and should also be classified as severe bleeding. To provide a more concise overview, the suggestion was made to combine muscle bleeding and joint bleeding, as they share similar symptoms.

"Menstruatiebloeding moet er wel nog bij ja, ik vind dat moet je er echt bij noemen. Het is wel bij meisjes dat is juist heel belangrijk"

"Menstrual bleeding has to be added yes, I think you should really mention that. It is with girls that is very important"

Conclusions

Key insights were obtained during the conversation with the Lung Cancer Association representative. One significant point was that if the concept is applied to children with hemophilia and their parents, it is vital to involve the children in testing and avoid solely focusing on the parents. Another valuable suggestion was to engage language ambassadors in the testing process to ensure the content's comprehensibility, especially for individuals with low literacy levels.

The representative also advised consulting the Pharos handbook, a center specializing in health disparities, for guidance in developing talking cards. Furthermore, she raised queries about the conciseness of the talking cards and proposed making them double-sided with explanatory content. However, after discussing the idea with HCPs for evaluation, it was not integrated. This was because the talking cards were intended to complement the verbal narratives of HCPs rather than replace them. HCPs expressed concerns that reading a textual explanation could divert attention from oral communication.

It is important to note that there was widespread enthusiasm among parents, HCPs, the NVHP, and the NVHV regarding the concept. Everyone saw the potential of using it in outpatient consultations, and all parties involved acknowledged its benefits.

Ouder: "Oh ik word hier wel enthousiast van!"

"Oh, this makes me excited!"

HCP: "Ik vind dat heel knap weet je heel vaak moet ik heel veel tekstueel verbeteren, maar jij hebt echt oog voor contact en overkoepelend en ik vind dat je het heel duidelijk compact heb je het weer gegeven. Echt knap hoor."

"I find that very impressive, you know. Often, I have to make a lot of textual corrections, but you truly have an eye for context and cohesion, and I think you've conveyed it very clearly and concisely. Really well done!"

Considering the storage of the concept within the outpatient clinic is also essential. For instance, the logistics at Erasmus MC involve multiple consultation rooms, while in other centers, nurses mentioned the absence of dedicated spaces for the coagulation outpatient clinic.

HCP: "Je raakt ze zomaar kwijt dus dat ze gewoon daar precies inpassen of zo, weet je wel? Zo'n zwart bundel ding."

"You lose them just like that, so that they fit right in there perfectly, you know? Like a black bundle thing."

Regarding the availability of the "Samen Spraak" concept, it's important to consider digital accessibility and easy retrieval, as highlighted in the interviews. While digital access is favored, it's also recognized that some individuals prefer having information in print format. Therefore, a discussion was held with the NVHP about ensuring the digital version, hosted on the website's media bank, includes the option to download it as a PDF file. This approach accommodates both digital accessibility and the preference for printed material.

HCP: "Volgens mij moet je 'm heel chique maken voor in de spreekkamer en dat je samen downloadt van nou, zo werkt het en als iemand zegt, ik ben echt helemaal niet digitaal en ik wil hem voor mijn oma hebben, dan vragen we aan de balie of ze 'm even uitprinten."

"I think you should make it very stylish for the outpatient clinic, and that you download it together like, that's how it works, and if someone says, 'I'm really not digital at all, and I want it for my grandma,' then we ask at the reception if they could print it out for them."

Guidelines

Figure 35: Guidelines of language level B1 (Eline Bakker et al., n.d.)

From the recommended Pharos handbook (Natascha Huijser van Reenen et al., 2022) and shared presentation on language levels of the communication department of the Erasmus MC (Figure 35) (Eline Bakker et al., n.d.) the following guidelines have been drawn up for the final design of Samen Spraak:

- Compose concise sentences.
- Do not use difficult words
- Avoiding the use of excessive jargon
- Refrain from utilizing abstract language

Furthermore, it is essential to consider the subsequent requirements when utilizing visuals as a means of providing support:

- The visual representation conveys a similar message to that of the written content to the greatest extent possible
- The image possesses a clear and unequivocal meaning
- Individuals possess the ability to identify and perceive their own likeness within the visual representation

All textual content must be checked with the texamen.nl tool, for which the communication department of Erasmus MC has made an account available. This is to follow the B1 level of the Dutch language as much as possible.

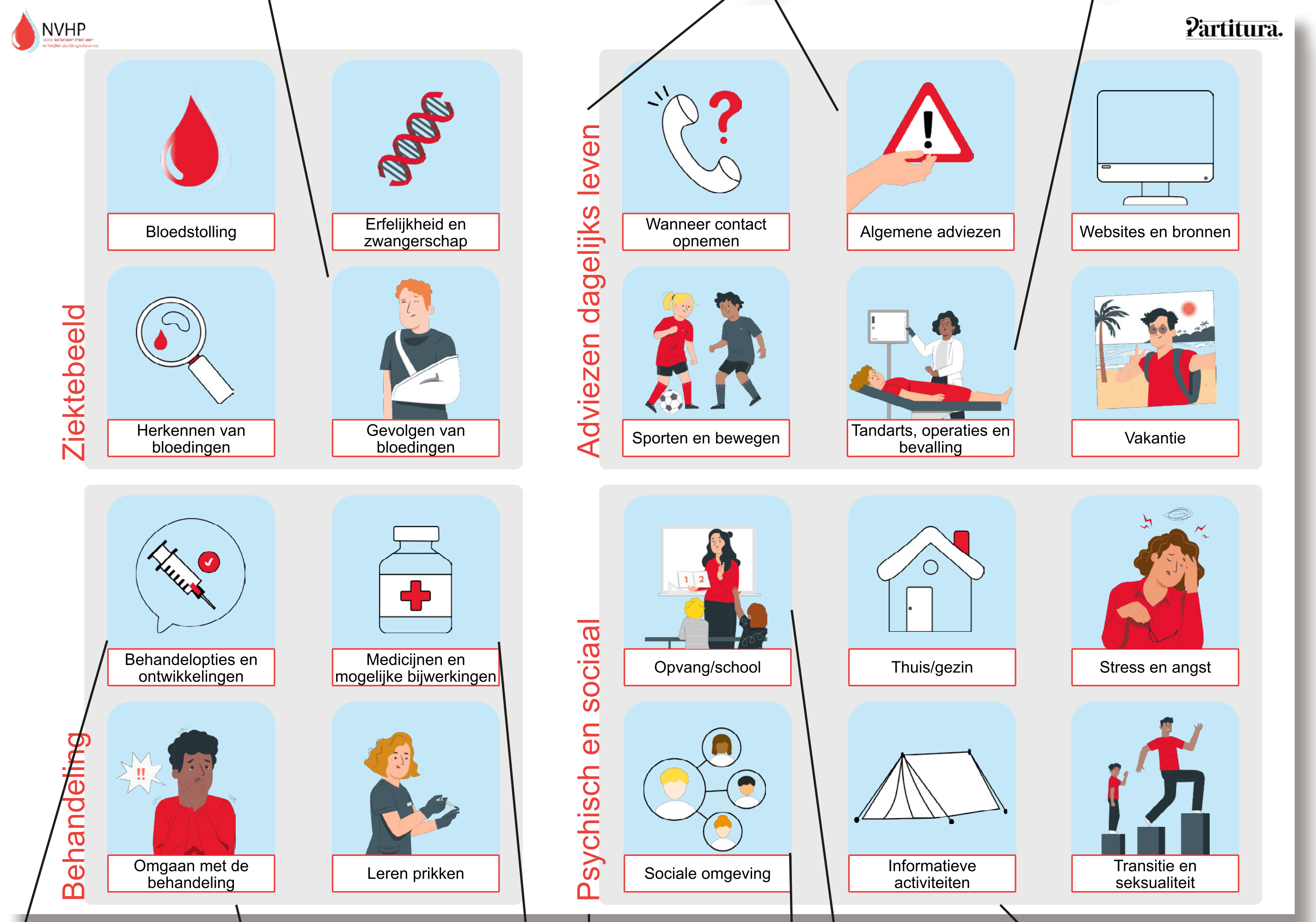
DELIVER

05

12.0 Final Design Samen Spraak

This chapter shows the iterations made after evaluating the concept to form the final design of Samen Spraak.

The outlined icons on the Gesprekskaart are custom made in Illustrator. The visualizations of persons have been modified into appropriate visuals and colors from visuals from storyset.com (Storyset, n.d.). The Partitura logo has been added in recognition of the collaboration within this group.



A more focused image of the elbow due to joint bleeding

Different wording of rules of life and various titles per cluster and subject

Addition of childbirth

New developments have been added to the subject of treatment options

Another name for fear of needles, this has been replaced by coping with the treatment and can apply to both the parents and the child themselves

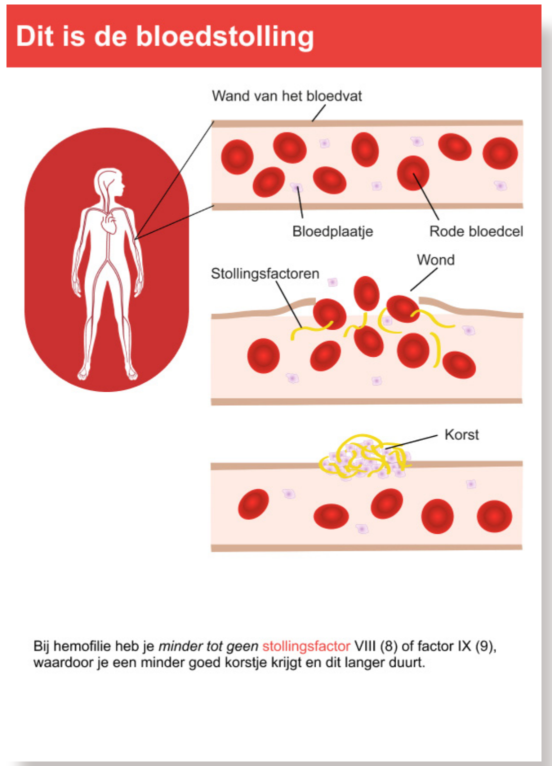
Dividing the word psychosocial for better understanding

A more extended illustration of a school setting

The Hemophilia camp and school have been replaced with information activities. Each center can give its own interpretation of this, such as information meetings and other activities

Another visual of the social environment

Another name for medicines and consequences, this has been replaced by possible side effects



Dit is de bloedstolling

Wand van het bloedvat

Bloedplaatje

Rode bloedcel

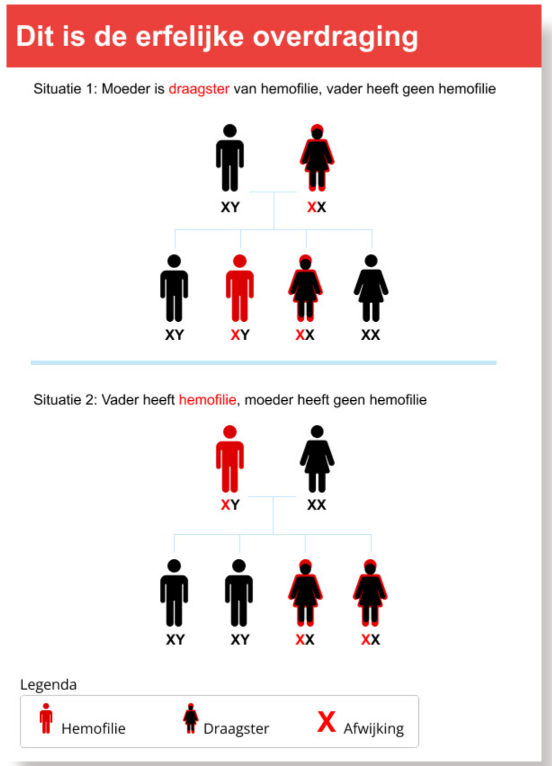
Stollingsfactoren

Wond

Korst

Bij hemofilie heb je *minder tot geen* stollingsfactor VIII (8) of factor IX (9), waardoor je een minder goed korstje krijgt en dit langer duurt.

The name of the coagulation factors has been adjusted to create recognition of the medical term.



Dit is de erfelijke overdraging

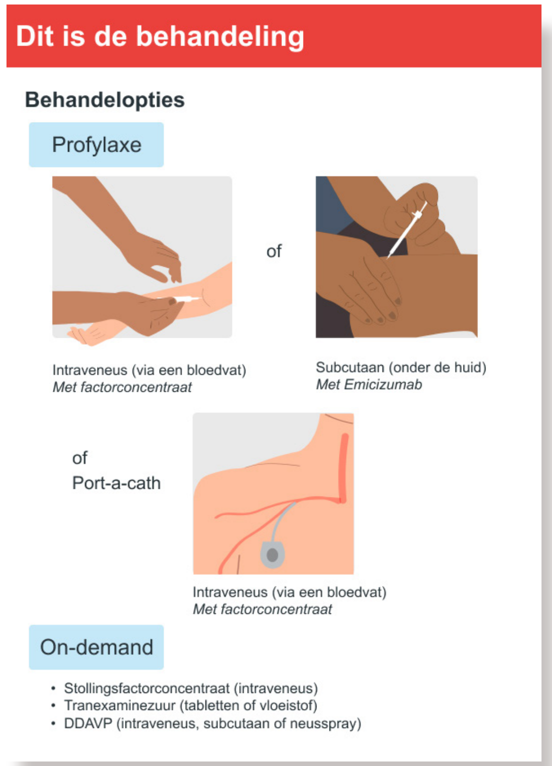
Situatie 1: Moeder is draagster van hemofilie, vader heeft geen hemofilie

Situatie 2: Vader heeft hemofilie, moeder heeft geen hemofilie

Legenda

Hemofilie Draagster X Afwijking

A legend has been added to clarify the symbols.



Dit is de behandeling

Behandelopties

Profylaxe

Intraveneus (via een bloedvat)
Met factorconcentraat

of

Subcutaan (onder de huid)
Met Emicizumab

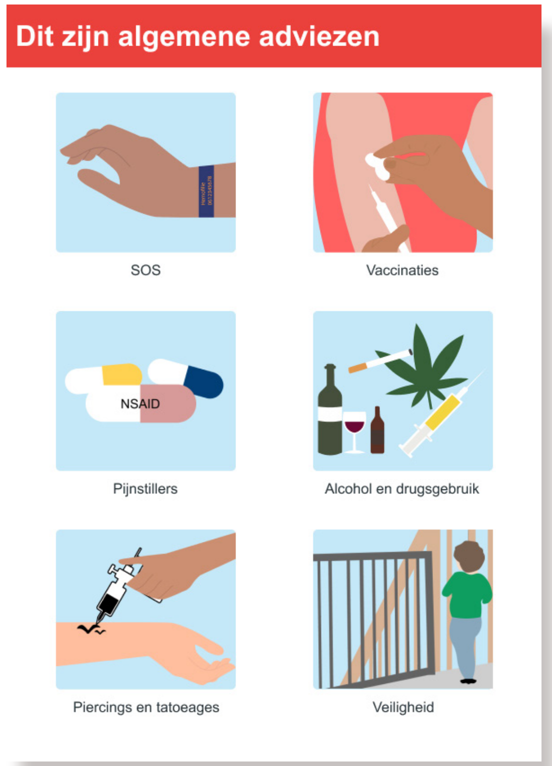
of
Port-a-cath

Intraveneus (via een bloedvat)
Met factorconcentraat

On-demand

- Stollingsfactorconcentraat (intraveneus)
- Tranexaminezuur (tabletten of vloeistof)
- DDAVP (intraveneus, subcutaan of neusspray)

Port-a-cath treatment has been added.



Dit zijn algemene adviezen

SOS

Vaccinaties

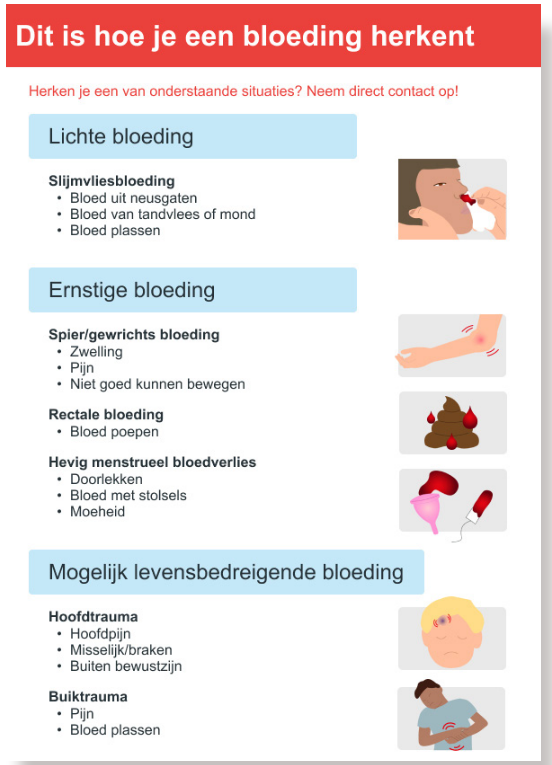
Pijnstillers

Alcohol en drugsgebruik

Piercings en tatoeages

Veiligheid

NSAIDs have been added, and a different hierarchy and visual have been created for the safety advice.



Dit is hoe je een bloeding herkent

Herken je een van onderstaande situaties? Neem direct contact op!

Lichte bloeding

Slijmvliesbloeding
- Bloed uit neusgaten
- Bloed van tandvlees of mond
- Bloed plassen

Ernstige bloeding

Spier/gewrichts bloeding
- Zwelling
- Pijn
- Niet goed kunnen bewegen

Rectale bloeding
- Bloed poepen

Hevig menstrueel bloedverlies
- Doorlekken
- Bloed met stolsels
- Moeheid

Mogelijk levensbedreigende bloeding

Hoofdtrauma
- Hoofdpijn
- Misselijk/braken
- Buiten bewustzijn

Buiktrauma
- Pijn
- Bloed plassen

Muscle and joint bleeding are combined, and rectal and heavy menstrual bleeding are added. Urinal bleeding has been added for minor bleeding, and the final title of the classification has been changed to "potentially life-threatening bleeding" to emphasize that this bleeding may be, but not necessarily, a cause of head trauma or abdominal trauma.

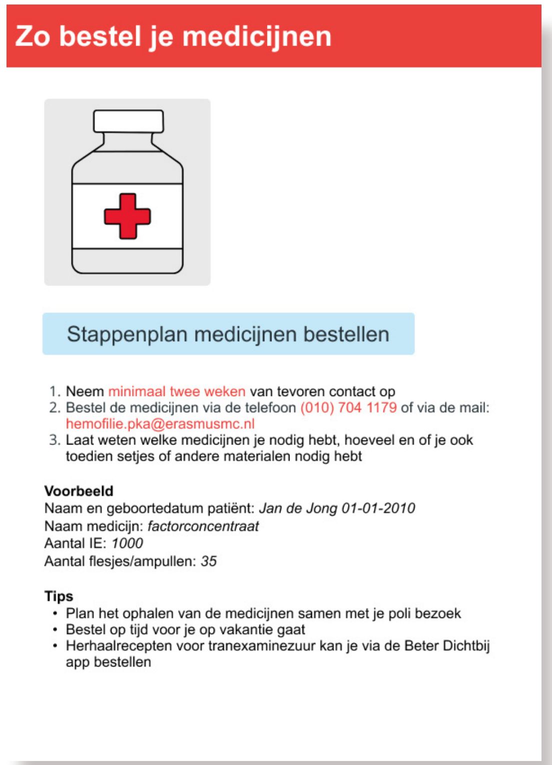
Dit is wanneer je contact opneemt

In geval van:
1. Een bloeding
2. Een operatie of tanden/kiezen trekken
3. Een nabloeding na een operatie of tanden/kiezen trekken
4. Hevig menstrueel bloedverlies
5. Trauma (ongeval)
6. Twijfel

Neem dan telefonisch contact op:
- Op werkdagen 08:00-16:30: (06) 12 94 59 60
  Hemofilie verpleegkundige
- Weekend of 16:30-08:00: (010) 704 01 45
  Spoedeisende hulp: vraag naar de kinderhematoloog

Bij niet dringende vragen:
- Neem contact op via de Beter Dichtbij app of via de mail

The classification of minor/severe/life-threatening bleeding has been removed from point 1 to prevent parents from not calling in case of other types of bleeding or doubt. It has been added to the telephone number of the emergency department that one should ask for the pediatric hematologist on duty. This map is center-specific and must be developed for each center.



Zo bestel je medicijnen

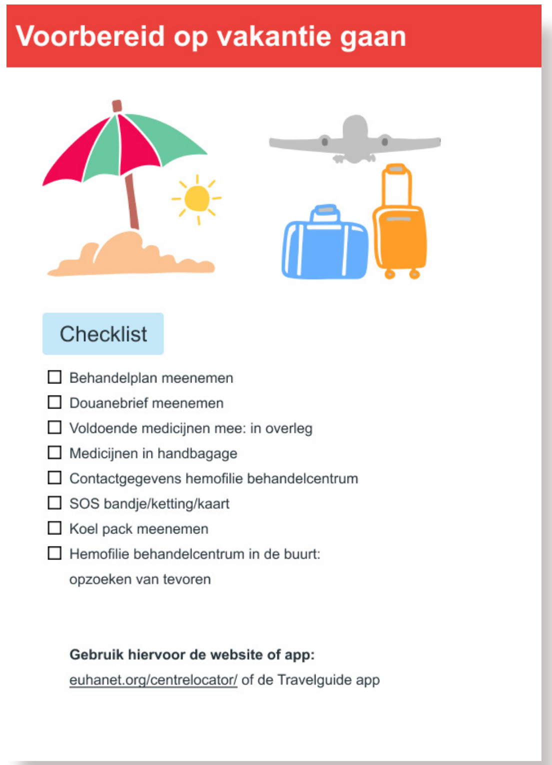
Stappenplan medicijnen bestellen

1. Neem minimaal twee weken van tevoren contact op
2. Bestel de medicijnen via de telefoon (010) 704 1179 of via de mail: hemofilie.pka@erasmusmc.nl
3. Laat weten welke medicijnen je nodig hebt, hoeveel en of je ook toedien setjes of andere materialen nodig hebt

Voorbeeld
Naam en geboortedatum patiënt: *Jan de Jong 01-01-2010*
Naam medicijn: *factorconcentraat*
Aantal IE: *1000*
Aantal flesjes/ampullen: *35*

Tips
- Plan het ophalen van de medicijnen samen met je poli bezoek
- Bestel op tijd voor je op vakantie gaat
- Herhaalrecepten voor tranexaminezuur kan je via de Beter Dichtbij app bestellen

Tricky words have been substituted. This map is again center-specific.



Voorbereid op vakantie gaan

Checklist

- ☐ Behandelplan meenemen
- ☐ Douanebrief meenemen
- ☐ Voldoende medicijnen mee: in overleg
- ☐ Medicijnen in handbagage
- ☐ Contactgegevens hemofilie behandelcentrum
- ☐ SOS bandje/ketting/kaart
- ☐ Koel pack meenemen
- ☐ Hemofilie behandelcentrum in de buurt: opzoeken van tevoren

Gebruik hiervoor de website of app:
euhanet.org/centrelocator/ of de Travelguide app

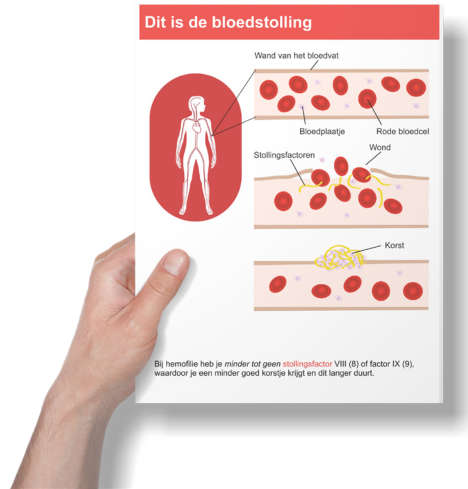
A customs letter and the advice to take medicines in your hand luggage have been added.

The final design of the talking cards incorporates self-created visuals. This decision was made to avoid any potential issues with rights during the rollout with the NVHP while ensuring a consistent visual style across all cards. The written content underwent testing using the texamen.nl tool, ensuring that the Dutch language level remains at B1 proficiency.

Moreover, the visuals on the cards have been thoughtfully crafted to align with the respective subjects and textual content. The design process also took into consideration essential principles of health literacy (Health Literacy Online | Health.Gov, n.d.). This involved selecting a sans-serif font, with Arial being the chosen typeface due to its recommended attributes. The font size has been set at a minimum of 12 to enhance readability, and a line spacing of 1.5 has been implemented.

Furthermore, the final design takes into account the insights gathered from evaluations. This iterative approach has enabled the cards to be refined and improved based on valuable feedback, resulting in a highly effective and user-friendly design.

Figure 36: Praatkaart mockup



User Scenario

As the Samen Spraak introduction outlines, the concept entails making the Gesprekskaart a standard component of every outpatient clinic visit (Figure 37). Ensuring preparedness for various subjects, which might necessitate the availability of supplementary Praatkaarten, is crucial (Figure 38). Thus, maintaining the coherence of this set is paramount. A fitting solution is proposed to achieve this: including a coordinated elastic folder to house the entire package (Figure 39). This approach ensures practical organization and accessibility, aligning with the overarching vision of Samen Spraak.


Figure 37: Gesprekskaart in context


Figure 38: Praatkaart in context

Figure 39: Elastic folders to store Samen Spraak

13.0 Implementation Roadmap

This chapter presents a detailed implementation plan based on an implementation roadmap of the designed information tool. A thorough trend analysis of developments within the healthcare sector is first presented to outline a clear vision for the future. Based on this, a roadmap is presented that charts the way to this future vision. The roadmap is built around three horizons that lead step by step to the intended future situation.

13.1 DEVELOPING THE STRATEGY

With the aim of not only optimizing the information flows within HTC but also beyond it, as shown in the information flow framework, the original design goal has been formulated to develop not only an information tool but also a strategy to further expand this tool for an improved information provision outside the outpatient clinic visits. To achieve this, the first requirement is to establish a future vision for information provision within hemophilia care.

Future Visioning

A trend analysis was executed to examine the developments in the healthcare field, considering the needs and wishes expressed in the interview findings. Two overarching trends have become apparent:

Patient- and family centered care (PFCC)

Patient- and family-centered care is a progressive healthcare approach involving patients and families as active partners in decision-making, care planning, and the overall healthcare process (Institute for patient- and family-centered care, 2012). It aims to create a collaborative alliance among healthcare providers, patients, and families to tailor care to individual needs and values. This movement recognizes that patients and families have unique viewpoints, making their involvement crucial for optimal outcomes (Everhart et al., 2019). By fostering shared responsibility, respect, and understanding, this approach empowers them to shape their healthcare journey. It prioritizes effective communication and collaborative decisions and enhances care continuity, especially in pediatric healthcare, where involving parents and caregivers is essential. This trend transforms healthcare dynamics towards inclusivity, compassion, and efficiency.

The development of personal health environments (PHE)

Patient portals and Electronic Health Records (EHRs) offer patients access to various medical records, like lab results, appointments, and medication lists. They empower patients to view, handle, and share their health information with medical professionals. A challenge arises from the existence of multiple institution-specific portals, necessitating patients to manage several accounts for various healthcare providers. To tackle this, the concept of a Personal Health Environment (PHE) has emerged. A PHE lets patients consolidate all their health data in one central location, often a website or app (Brands, Gouw, et al., 2023). Patients can even add data themselves, creating a more comprehensive health overview. PHEs also aggregate medical data from diverse institutions. Certain PHEs can integrate with digital health tools like smartwatches, granting patients more control and personalized health management. Embracing PHEs and digital tools can enhance patient healthcare experiences and communication with providers. An example of a new PHE is Digizorg, which is currently implemented at the Erasmus MC.

13.2 STRATEGIC IMPLEMENTATION ROADMAP

This chapter will discuss the proposed strategy, which will be detailed in subsequent parts corresponding to the various phases of the roadmap. The roadmap effectively and visually understandably communicates the strategy plan (Figure 40). The plan is divided into three separate horizons, each lasting three years. The primary goal of this strategy is to realize the envisioned future for the year **2032**.

This strategy prioritizes the provision of education and information to hemophilia patients. The roadmap aims to provide hemophilia patients with accurate, personalized, and easily accessible information throughout their care journey by laying a solid foundation of a digital information platform, developing educational resources, and continuously refining them based on patient feedback, improving their quality of life and enabling better treatment outcomes through accurate information, self-management skills, and a supportive community.

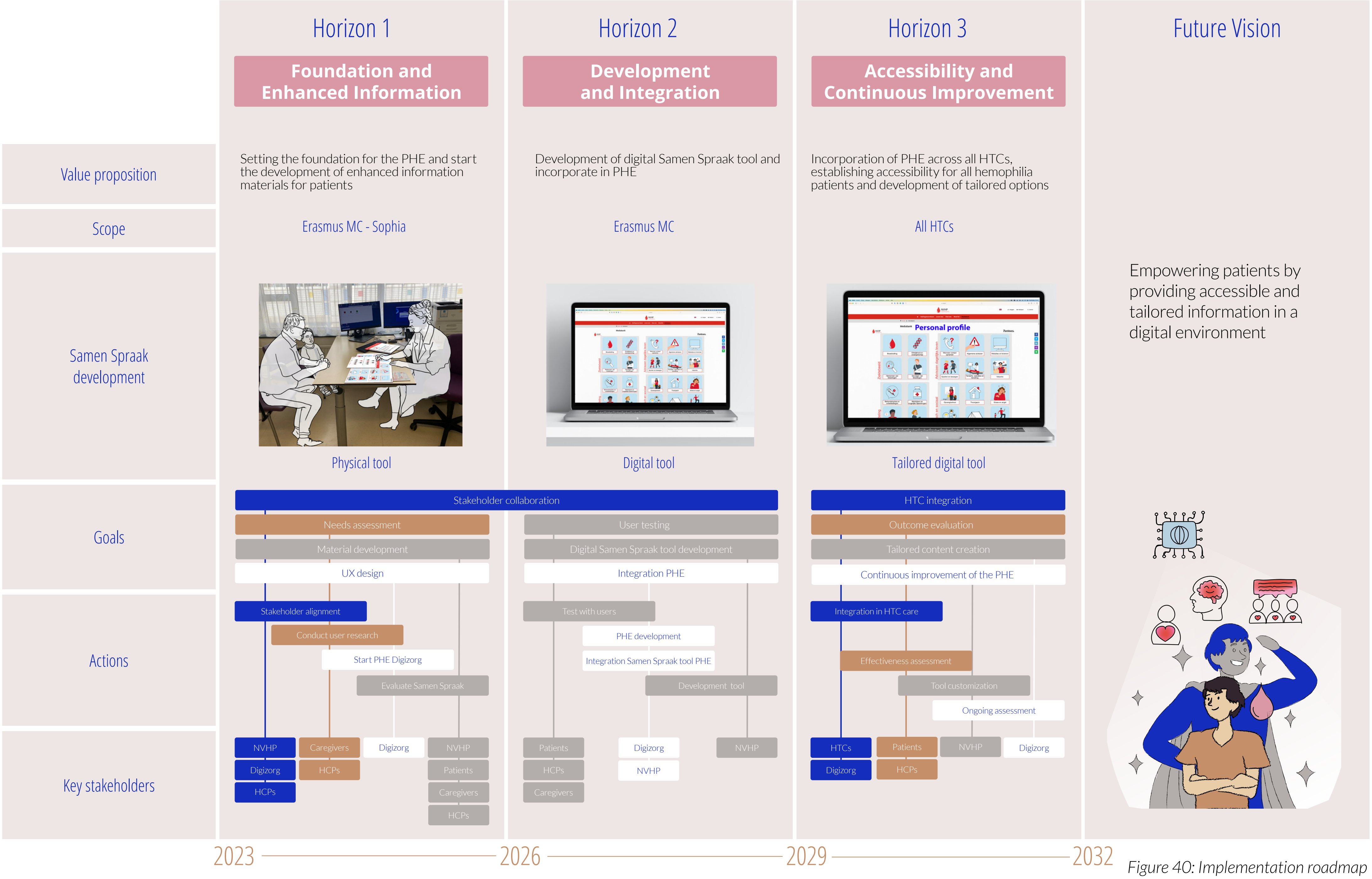


Figure 40: Implementation roadmap

Future Vision

Moving ahead, the intersecting trends of PFCC and PHE are set to merge in a transformed era of providing information to patients and their families. This envisions a healthcare landscape where patients and families actively shape their care, facilitated by easy access to personalized and transparent information. At the heart of this vision lies the seamless integration of the PHE Digizorg platform, implemented in Erasmus MC and other academic hospitals in the Netherlands.

To illustrate, individuals with hemophilia who use the PHE platform can access a central platform housing all their medical information. The platform includes the comprehensive digital tool Samen Spraak, which offers detailed guidance for living with hemophilia. This future vision aims to bridge gaps in healthcare inequalities, ensuring that all hemophilia patients can access the same information through this centralized platform.

As an extensive and tailored educational resource, the platform provides customizable information, interactive modules, and content catering to each individual's needs. Within this centralized space, patients are kept up to date with the latest advancements in research, treatment options, and support networks. This user-friendly centralized environment empowers patients to manage their condition effectively. The future also envisions the growth of a hemophilia patient community supported by an integrated forum. This enables patients to connect with others who share similar experiences, exchange insights, and provide mutual support, significantly impacting their emotional well-being and resilience.

This forward-looking perspective underscores the importance of continuous feedback loops and refinement. The PHE platform and the integrated digital version of Samen Spraak will undergo regular evaluations of patient satisfaction, engagement, and outcomes. With an eye on technological advancements, treatment choices, and patient preferences, the platform will evolve to meet changing patient needs.

Ultimately, the overarching objective is to empower hemophilia patients and enhance their quality of life. This entails improved treatment results, increased confidence in managing their condition, and heightened control over their lives. By providing accurate information, fostering self-management skills, and fostering a supportive community, patients will experience tangible benefits and improved overall well-being.

First Horizon

The initial phase, spanning **2023 to 2025**, focuses on the "**Foundation and Enhanced Information**" horizon. This phase lays the groundwork for the future of hemophilia care. Several essential steps are outlined within this horizon, serving as the project's building blocks. The primary objectives are as follows:

1. **Stakeholder Collaboration**: A pivotal aspect involves close collaboration between NVHP and Digizorg PHE. These entities collaborate as partners to establish a centralized platform. This collaboration extends to interacting with HCPs to discern patients' information requirements, aligning with the roadmap's goals.
2. **Needs Assessment:** A comprehensive evaluation is undertaken to identify gaps in providing education and information to hemophilia patients. This entails assessing existing resources, pinpointing target groups, and grasping communication preferences.
3. **Material Development:** The Samen Spraak tool requires evaluation across various HTCs. Feedback from this assessment guides its refinement. Additionally, current materials supplied by NVHP are gathered for future content updates in preparation for subsequent horizons.
4. **User Experience (UX) Design:** Establishing the foundation of a user-centric, centralized platform takes center stage. This platform serves as a hub for accurate, personalized information. Collaborations with HCPs, researchers of Digizorg, and NVHP yield valuable resources such as educational content, treatment protocols, self-care guidance, and FAQs. Partnering with external expertise, resources, and funding sources paves the way for forthcoming initiatives.

The preliminary step is completed during this graduation project, conducting interviews with HCPs from Erasmus MC - Sophia Children's Hospital and caregivers of hemophilia patients aged 0-10. Expanding this strategy necessitates conducting further interviews across various caregiver demographics and age groups. Collaboration among HCPs from different HTCs in the Netherlands is paramount for advancing this strategy's development.

In summary, the initial horizon between 2023 and 2025 concentrates on establishing a robust foundation and enhancing information dissemination in hemophilia care. The defined objectives encompass stakeholder collaboration, thorough needs assessment, material enhancement, UX design, and collaboration expansion. These initiatives collectively lay the groundwork for a holistic, patient-centric approach to hemophilia care.

Second Horizon

The second phase, spanning **2026 to 2028**, revolves around "**Development and Integration**." This phase centers on incorporating information dissemination and empowering patients to engage in their care proactively. The core objectives encompass:

1. **Ongoing Stakeholder Collaboration:** The sustained collaboration between NVHP and Digizorg PHE remains critical. Their concerted efforts are pivotal in successfully integrating the digital Samen Spraak tool within the Digizorg PHE application.
2. **Digital Samen Spraak Development:** Building on the material gathered in the first horizon, the focus shifts to implementing the digital version of the Samen Spraak tool. This digital rendition enhances user experience, featuring a clickable Gesprekskaart that leads users directly to related Praatkaart content and supplementary information. This transition replaces traditional paper brochures, ensuring consistent and accessible information delivery.
3. **User Testing:** To guarantee the usability and user-friendliness of the digital Samen Spraak tool, comprehensive evaluations and refinements are conducted through user testing. Feedback from patients, caregivers, and HCPs informs the tool's enhancement.
4. **Integration within Digizorg PHE:** The evolving Digizorg app collaborates with NVHP to seamlessly integrate the digital Samen Spraak tool into the broader Digizorg environment. This synchronization ensures a cohesive experience for users within the Digizorg ecosystem.

In conclusion, the second horizon, spanning 2026 to 2028, advances the roadmap by emphasizing development and integration. The pivotal objectives underscore the importance of ongoing collaboration, refining the digital Samen Spraak tool, conducting user testing, and seamlessly integrating the tool within the Digizorg application. This phase solidifies the foundation laid in the first horizon and paves the way for enhanced patient engagement and streamlined information dissemination in hemophilia care.

Third Horizon

The third phase, spanning from **2029 to 2031**, centers on "**Accessibility and Continuous Improvement.**" This strategic horizon is dedicated to perpetually refining, expanding, and securing the long-term viability of the initiative. The primary objectives within this phase include:

1. **HTC Integration:** To ensure equitable access for all hemophilia patients, all academic hospitals housing hemophilia treatment centers must integrate Digizorg PHE into their care. This comprehensive integration guarantees that the enriched information provision facilitated by the digital Samen Spraak tool, seamlessly embedded within Digizorg PHE, is accessible to every individual with hemophilia.
2. **Outcome Evaluation:** A foundational element is consistently evaluating the effectiveness of the digital Samen Spraak tool. This involves seeking feedback, conducting comprehensive questionnaires, and evaluating patient satisfaction. These insights are pivotal in honing and optimizing content materials and delivery methodologies. Leveraging data analysis, areas warranting enhancement are identified, refining the care delivery process.
3. **Tailored Content Creation:** A pivotal pursuit involves augmenting and diversifying the information materials available within the digital Samen Spraak tool, personalized for individuals with hemophilia. This enrichment encompasses distinct hemophilia variations, available treatment options, scientific breakthroughs, and psychosocial support. This empowerment is fortified by creating tailored profiles, allowing patients to access pertinent knowledge based on their hemophilia type and treatment approach.
4. **Continuous Improvement of PHE:** Ensuring the application's usability and comprehensibility, particularly for individuals with limited health literacy, is paramount. Ongoing assessment and refinement of the application and integrated digital Samen Spraak tool are critical to enhance information provision. Addressing potential challenges faced by individuals who struggle with comprehending e-health services is pivotal for delivering enhanced information effectively.

In summary, the third horizon spanning 2029 to 2031 encapsulates an era of heightened accessibility and unwavering refinement. The outlined objectives underscore the imperative of broad integration, consistent outcome assessment, personalized content expansion, and the continuous enhancement of the application. This phase demonstrates the roadmap's steadfast commitment to fostering a sustainable, inclusive, and patient-centric approach to hemophilia care adaptable to the evolving needs of the hemophilia community.

FINAL SECTION

06

14.0 Discussions

This Chapter discusses the research outcomes of this graduation project and end results.

The literature study has shown that only a limited part of the information provided is remembered and understood. Although the interviews and evaluations with parents did not explicitly highlight this problem, it could be because the participants in these studies may not have been a representative cross-section of the population. There was a stronger desire to gain more structure and insight into the content of the outpatient clinic visits.

Ensuring adequate information provision to patients requires several essential elements. This should take into account the specific target group and their health literacy. In addition, promoting clear communication and collaboration between healthcare professionals is crucial, as well as between healthcare professionals and patients or parents. This is not only about using the right language but also about using suitable means to transfer information. Gaining insights from the user group can help better tailor the information provision to their needs. In addition, it is very important to involve healthcare professionals to seamlessly integrate interventions into their work processes. The concept of “Samen Speech” can be of value to various healthcare departments, not only within hemophilia treatments or blood clotting disorders.

The proposed strategy outlines an optimistic outlook, in which it is considered feasible to implement the “PHE Digizorg” approach in different hemophilia treatment centers. To achieve this, two parallel processes must be followed: on the one hand, the development of the digital “Samen Speech” tool and, on the other hand, the evolution of the “PHE Digizorg” concept. In this way, it is ensured that the development of the digital “Samen Speech” tool will continue nonetheless.

14.1 LIMITATIONS

It is important to mention that the results are based on insights from healthcare professionals, patients, and parents from Erasmus MC. The number of interviews with parents may not represent the whole group.

In addition, the interview participants of the caregiver group may be biased because they are willing to participate in research and may not represent the whole group.

Although many evaluations have taken place, the concept has yet to be tested in use, so it is interactive during an outpatient visit. In addition, only three evaluations have been conducted with parents, the most important user of this concept.

The concept has been tested using the texamen.nl tool. However, for a proper evaluation of the comprehensibility to be tested, people, so-called language ambassadors, must be tested to get a good picture of the comprehensibility.

15.0 Recommendations

This chapter delves into the recommendations derived from the study’s outcomes and conclusions.

To bring about the final iteration of Samen Spraak, I propose the implementation of a testing phase. This phase could commence by introducing the current Gesprekskaart and Praatkaarten across multiple HTCs during the NVHV meeting scheduled for November. Subsequently, the Gesprekskaart en Praatkaarten can undergo testing within outpatient clinic visits during consultation hours. This will facilitate the identification of potential pain points and areas for enhancement. After this testing phase, the evaluations should be submitted and deliberated upon during the subsequent NVHV meeting, which is set to occur six months later. This would allow for a final round of iterations before producing and rolling out the definitive versions. Given their engagement and familiarity with the design, I stress the importance of the NVHP taking a leadership role and recommend that the nurses at the Erasmus MC - Sophia Children’s Hospital serve as ambassadors.

Furthermore, I advocate for language ambassadors’ assessment of the Gesprekskaart en Praatkaarten and their digital counterparts. This evaluation aims to measure the quality and comprehensibility of the textual content and informational materials, making necessary adjustments as deemed fit.

Equally essential is the testing of the concept with children. Once children reach an appropriate age, the plan is to include them in these discussions, fostering awareness and empowering them with knowledge. This approach enhances their ability to manage their medical condition independently.

To ensure the successful execution of the developed strategy, various stakeholders must establish and uphold robust collaboration. The NVHP and Digizorg must forge a close partnership to facilitate seamless integration.

BIBLIOGRAPHY

Atie Bruggeling & Tessa Govers. (2023, March 7). *Presentatie Introductiebijeenkomst nieuwe medewerkers.* Introductiebijeenkomst Thema Sophia, Rotterdam.

Brands, M. R., Gouw, S. C., & Driessens, M. H. E. (2023). Personal health records: A promising tool? *Nederlands Tijdschrift Voor Geneeskunde*, *167*, D6908.

Brands, M. R., Haverman, L., Muis, J. J., Driessens, M. H. E., van der Meer, F. J. M., Goedhart, G., Meijer, S., de Jong, M., van der Bom, J. G., Cnossen, M. H., Fijnvandraat, K., & Gouw, S. C. (2023). Patients' and health care providers' perspectives on quality of hemophilia care in the Netherlands: A questionnaire and interview study. *Research and Practice in Thrombosis and Haemostasis*, *7*(4), 100159. https://doi.org/10.1016/j.rpth.2023.100159

Chai-Adisaksopha, C., Noone, D., Curtis, R., Frick, N., Nichol, M. B., Germini, F., O'Mahony, B., Page, D., Stonebraker, J. S., Skinner, M. W., & Iorio, A. (2021). Non-severe haemophilia: Is it benign? - Insights from the PROBE study. *Haemophilia: The Official Journal of the World Federation of Hemophilia*, *27 Suppl 1*, 17–24. https://doi.org/10.1111/hae.14105

Chan, C. V., & Kaufman, D. R. (2011). A Framework for Characterizing eHealth Literacy Demands and Barriers. *Journal of Medical Internet Research*, *13*(4), e1750. https://doi.org/10.2196/jmir.1750

Cyberpoli. (n.d.-a). *Hemofilie—Hoe vaak komt hemofilie voor? | Cyberpoli*. Retrieved March 25, 2023, from https://www.cyberpoli.nl/hemofilie/medisch/voorkomenhemofilie

Cyberpoli. (n.d.-b). *Wat is de Cyberpoli?* Wat Is de Cyberpoli? Retrieved May 15, 2023, from https://www.cyberpoli.nl/info/watis

Design Council. (n.d.). *The Double Diamond—Design Council*. Retrieved May 15, 2023, from https://www.designcouncil.org.uk/our-resources/the-double-diamond/

Dingley, C., Daugherty, K., Derieg, M. K., & Persing, R. (2008). Improving Patient Safety Through Provider Communication Strategy Enhancements. In K. Henriksen, J. B. Battles, M. A. Keyes, & M. L. Grady (Eds.), *Advances in Patient Safety: New Directions and Alternative Approaches (Vol. 3: Performance and Tools)*. Agency for Healthcare Research and Quality (US). http://www.ncbi.nlm.nih.gov/books/NBK43663/

Dolan, G., Benson, G., Duffy, A., Hermans, C., Jiménez-Yuste, V., Lambert, T., Ljung, R., Morfini, M., & Zupančić Šalek, S. (2018). Haemophilia B: Where are we now and what does the future hold? *Blood Reviews*, *32*(1), 52–60. https://doi.org/10.1016/j.blre.2017.08.007

Eline Bakker, Leonie Hendriksen, & Debby van Steenderen. (n.d.). *Taalniveaus in patientenfolders*.

Erasmus MC. (n.d.-a). *Hemofiliebehandelcentrum—Erkend expertisecentrum—Erasmus MC*. Hemofiliebehandelcentrum. Retrieved May 14, 2023, from https://www.erasmusmc.nl/nl-nl/patientenzorg/centra/hemofiliebehandelcentrum#42173998-a612-4e70-99ab-30f77341898d

Erasmus MC. (n.d.-b). *Over Erasmus MC*. Retrieved July 1, 2023, from https://www.erasmusmc.nl/nl-nl/pages/over-erasmusmc#ddb83f97-d319-49c5-a3f8-80b94ea43c26

Everhart, J. L., Haskell, H., & Khan, A. (2019). Patient- and Family-Centered Care: Leveraging Best Practices to Improve the Care of Hospitalized Children. *Pediatric Clinics of North America*, *66*(4), 775–789. https://doi.org/10.1016/j.pcl.2019.03.005

Ghaddar, S. F., Valerio, M. A., Garcia, C. M., & Hansen, L. (2012). Adolescent Health Literacy: The Importance of Credible Sources for Online Health Information. *Journal of School Health*, *82*(1), 28–36. https://doi.org/10.1111/j.1746-1561.2011.00664.x

Guest, G., Namey, E., & Chen, M. (2020). A simple method to assess and report thematic saturation in qualitative research. *PLoS ONE*, *15*(5), e0232076. https://doi.org/10.1371/journal.pone.0232076

Health Literacy Online | health.gov. (n.d.). Retrieved August 24, 2023, from https://health.gov/healthliteracyonline/display/full/

Informatievoorziening. (2022). In *Wikipedia*. https://nl.wikipedia.org/w/index.php?title=Informatievoorziening&oldid=61017040

Institute for patient- and family-centered care. (2012). *What is PFCC?* https://www.ipfcc.org/about/pfcc.html

Kessels, R. P. C. (2003). Patients' Memory for Medical Information. *Journal of the Royal Society of Medicine*, *96*(5), 219–222. https://doi.org/10.1177/014107680309600504

Khaleel, I., Wimmer, B. C., Peterson, G. M., Zaidi, S. T. R., Roehrer, E., Cummings, E., & Lee, K. (2020). Health information overload among health consumers: A scoping review. *Patient Education and Counseling*, *103*(1), 15–32. https://doi.org/10.1016/j.pec.2019.08.008

Kim, H., & Xie, B. (2017). Health literacy in the eHealth era: A systematic review of the literature. *Patient Education and Counseling*, *100*(6), 1073–1082. https://doi.org/10.1016/j.pec.2017.01.015

Konkle, B. A., & Fletcher, S. N. (2022). Hemophilia A. In *GeneReviews® [Internet]*. University of Washington, Seattle. https://www.ncbi.nlm.nih.gov/sites/books/NBK1404/

Leroy, G., & Miller, T. (2010). Perils of providing visual health information overviews for consumers with low health literacy or high stress. *Journal of the American Medical Informatics Association*, *17*(2), 220–223. https://doi.org/10.1136/jamia.2009.002717

Mbanda, N., Dada, S., Bastable, K., Ingalill, G.-B., & Ralf W., S. (2021). A scoping review of the use of visual aids in health education materials for persons with low-literacy levels. *Patient Education and Counseling*, *104*(5), 998–1017. https://doi.org/10.1016/j.pec.2020.11.034

Natascha Huijser van Reenen, Majorie de Been, Hester van Bommel, Ella Visserman, Rianne van Pijkeren, & Karen Prantl. (2022). *Begrijpelijke medische informatie in woord en beeld ter ondersteuning bij het uitleggen en samen beslissen*. Pharos. https://www.pharos.nl/wp-content/uploads/2021/05/Begrijpelijke-medische-informatie-in-woord-en-beeld-methodiek-Pharos-2022.pdf

NVHP. (n.d.-a). *Behandelcentra*. Nederlandse Vereniging van Hemofilie-Patiënten. Retrieved May 13, 2023, from https://www.nvhp.nl/behandelcentra.html

NVHP. (n.d.-b). *Over ons*. Nederlandse Vereniging van Hemofilie-Patiënten. Retrieved May 13, 2023, from https://www.nvhp.nl/over-de-nvhp.html

NVHP. (2015, November 3). *Hemofilie A en B*. Nederlandse Vereniging van Hemofilie-Patiënten. https://www.nvhp.nl/hemofilie-a-en-b.html

Pipe, S. W., Leebeek, F. W. G., Recht, M., Key, N. S., Castaman, G., Miesbach, W., Lattimore, S., Peerlinck, K., Van der Valk, P., Coppens, M., Kampmann, P., Meijer, K., O'Connell, N., Pasi, K. J., Hart, D. P., Kazmi, R., Astermark, J., Hermans, C. R. J. R., Klamroth, R., … Monahan, P. E. (2023). Gene Therapy with Etranacogene Dezaparvovec for Hemophilia B. *New England Journal of Medicine*, *388*(8), 706–718. https://doi.org/10.1056/NEJMoa2211644

PublicHealth. (n.d.). *Health Literacy*. Retrieved July 3, 2023, from https://www3.erie.gov/health/health-literacy

Sørensen, K., Van Den Broucke, S., Fullam, J., Doyle, G., Pelikan, J., Slonska, Z., & Brand, H. (2012). Health literacy and public health: A systematic review and integration of definitions and models. *BMC Public Health*, *12*(1). Scopus. https://doi.org/10.1186/1471-2458-12-80

Stichting HemoNED. (n.d.-a). *Doelstellingen van HemoNED*. Stichting HemoNED. Retrieved May 15, 2023, from https://hemoned.nl/hemoned/doelstellingen/

Stichting HemoNED. (n.d.-b). *Organisatie van HemoNED*. Stichting HemoNED. Retrieved May 15, 2023, from https://hemoned.nl/hemoned/organisatie/

Symphony Consortium. (n.d.). *Home*. SYMPHONY. Retrieved March 25, 2023, from https://symphonyconsortium.nl/

van Boeijen, A., Daalhuizen, J., & Zijlstra, J. (2020). *Delft design guide: Perspectives, models, approaches, methods* (Revised edition). BIS Publishers.

Visser, L. N. C., Tollenaar, M. S., de Haes, H. C. J. M., & Smets, E. M. A. (2017). The value of physicians' affect-oriented communication for patients' recall of information. *Patient Education and Counseling*, *100*(11), 2116–2120. https://doi.org/10.1016/j.pec.2017.06.005

Wu, R. C., Lo, V., Rossos, P., Kuziemsky, C., O'Leary, K. J., Cafazzo, J. A., Reeves, S., Wong, B. M., & Morra, D. (2012). Improving hospital care and collaborative communications for the 21st century: Key recommendations for general internal medicine. *Interactive Journal of Medical Research*, *1*(2), e9. https://doi.org/10.2196/ijmr.2022