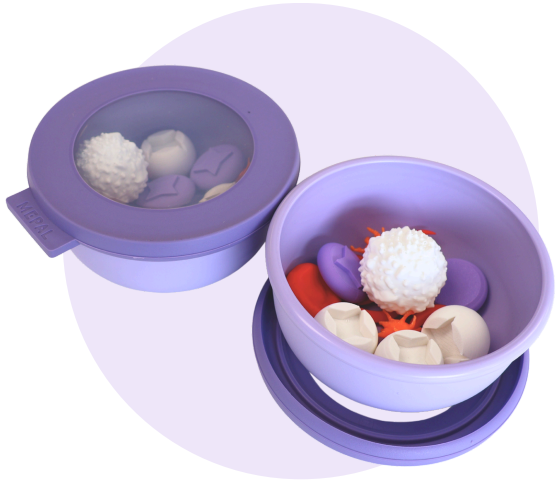
APPENDIX

to master thesis



# StemSense

## A Tangible Toolkit for Pediatric Stem Cell Conversations

Charlotte van Kats - May 2026

# CONTENTS.

# APPENDIX A - **PROJECT BRIEF**

DESIGN FOR our future

TU Delft

## IDE Master Graduation Project

**Project team, procedural checks and Personal Project Brief**

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

- Student defines the team, what the student is going to do/deliver and how that will come about
- Chair of the supervisory team signs, to formally approve the project's setup / Project brief
- SSC E&SA (Shared Service Centre, Education & Student Affairs) report on the student's registration and study progress
- IDE's Board of Examiners confirms the proposed supervisory team on their eligibility, and whether the student is allowed to start the Graduation Project

### STUDENT DATA & MASTER PROGRAMME

Complete all fields and indicate which master(s) you are in

| | |
|---|---|
| Family name | van Kats |
| Initials | C.H. |
| Given name | Charlotte |
| Student number | 5062454 |

| | | | | |
|---|---|---|---|---|
| IDE master(s) | IPD | ✓ | DfI | SPD |
| 2nd non-IDE master | | | | |
| Individual programme *(date of approval)* | | | | |
| Medisign | ✓ | | | |
| HPM | | | | |

### SUPERVISORY TEAM

Fill in he required information of supervisory team members. If applicable, company mentor is added as 2nd mentor

| | | | |
|---|---|---|---|
| Chair | Armagan Albayrak | dept./section | Human factors (HCD) |
| mentor | Wim Schermer | dept./section | Form and Experience(HCD) |
| 2nd mentor | Dr. Marjon Cnossen | | |
| client: | Sophia Children's Hospital EMC | | |
| city: | Rotterdam | country: | the Netherlands |
| optional comments | in collaboration with the stem cell therapy team in the LUMC, Leiden (supervised by Dr. Gertjan Lugthart) | | |

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

! Chair should request the IDE Board of Examiners for approval when a non-IDE mentor is proposed. Include CV and motivation letter.

! 2nd mentor only applies when a client is involved.

### PROJECT TITLE, INTRODUCTION, PROBLEM DEFINITION and ASSIGNMENT

Complete all fields, keep information clear, specific and concise

**Project title** Designing tangible tools for shared decision-making in pediatric life-altering treatments.

*Please state the title of your graduation project (above). Keep the title compact and simple. Do not use abbreviations. The remainder of this document allows you to define and clarify your graduation project.*

**Introduction**

*Describe the context of your project here; What is the domain in which your project takes place? Who are the main stakeholders and what interests are at stake? Describe the opportunities (and limitations) in this domain to better serve the stakeholder interests. (max 250 words)*

The Sophia Children's Hospital (EMC) and Willem-Alexander Hospital (LUMC) encounter complex communication challenges within their hematology departments on treatment option consultation for pediatric sickle cell disease (SCD). Due to its link with malaria resistance, this chronic genetic disease primarily affect people of African descent. In the Dutch healthcare context, it is still often seen that these children's families come from low social economic, migrant, or refugee backgrounds. They are in vulnerable positions, with language barriers, limitied health literacy and cultural differences becoming additional burdens to communication between parents, patients and physicians. These challenges make shared decision-making difficult, especially for the conversations about life-impact treatments such as stem cell transplantation, the only curative, but intensive and high risk treatment for SCD.

This project is in the domain of pediatric healthcare, intercultural communication and complex shared decision-making. The stakeholders are: physicians, nurses, social workers, pediatric SCD patients, parents/caregivers and their families. Their interests are health equality, participation in care, positive health outcomes and support during difficult medical experiences.

While this project is focused on SCD, its challenges are relevant beyond it in a multicultral society. Families from structurally vulnerable positions are more likely to face similar barriers within the healthcare system. There is opportunity for designing tools/products that can offer support in bridging knowledge gaps, clarify risks/choices, and encourage patient families in experiencing autonomy, understanding and empathy in communication with their physician. Limitations in the domain are emotional stressors, limited consultation time, and the many different experiences. Innovative, thoughtful and inclusive design can make meaningful difference in supporting families through high stakes, life-impacting choices.

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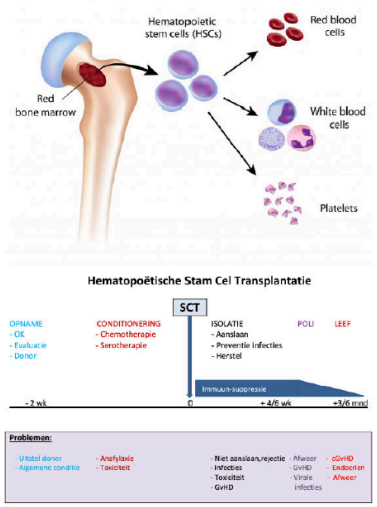


image / figure 1 Informational document currently used during consultation on stem cell therapy for pediatric SCD

image / figure 2 Erasmus MC Sickle Cell Cente providing care to sickle cell pediatric patients

DESIGN FOR our future

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## Personal Project Brief – IDE Master Graduation Project

### Problem Definition

*What problem do you want to solve in the context described in the introduction, and within the available time frame of 100 working days? (= Master Graduation Project of 30 EC). What opportunities do you see to create added value for the described stakeholders? Substantiate your choice.*
*(max 200 words)*

As families struggle to comprehend and participate fully in treatment consultations (due to language bariers, health literacy of cultural differences), this can lead to emotional distress, hesitation, confusion, and negatively influenced health-outcomes on high-impact medical decisions. Healthcare proffesionals (HCPs) face challenges of explaining complex options in limitied time (with high work pressures) while trying to build trust, a bond and understanding between them, the patient and the patient's family.

There is a lack of supportive tools that can help bridge the divide between HCPs and families from culturally diverse, or structurally vulnerable background, by shifting from a physician focus (based on medical jargon) to a holistic approach to consultation, making communication more accesible to both.

I see opportunities to explore, prototype and evaluate by bringing my users along within the project. There is opportunity to look broad and explore strategies of storytelling, narrative roles and playful design iterations. Better communication between the stakeholders can lead to clearer choices, improved experiences, stronger physician-parent-patient relationships and better health outcomes

### Assignment

*This is the most important part of the project brief because it will give a clear direction of what you are heading for. Formulate an assignment to yourself regarding what you expect to deliver as result at the end of your project. (1 sentence) As you graduate as an industrial design engineer, your assignment will start with a verb (Design/Investigate/Validate/Create), and you may use the green text format:*

*Design a prototype for bridging the linguistic and cultural barriers for shared decision-making on stem cell therapy for pediatric hematology.*

*Then explain your project approach to carrying out your graduation project and what research and design methods you plan to use to generate your design solution (max 150 words)*

The project follows an iterative, human-centered design approach, with stakeholder involvement as a core element.

Multiple co-creation sessions will be planned to explore design developments and prototypes. Methods such as context/ journey-mapping and generative techniques (probes) will be used to capture the stakeholder experiences and challenge. Generative prototyping and simulations will help make abstract interactions tangible and allow stakeholders to explore and evaluate concepts. A hands-on making approach with consistent prototyping will guide the exploration of the design space and uncover insights. Given the abstract and interaction-based nature of the challenge, iterations are best done through physical interaction with concepts.

Stakeholders I wish to involve, and have access to, include the Sophia children's hospital hematology department and the LUMC stem-cell therapy team (doctors, nurses, social workers, patient care staff). I further wish to connect to patient support groups to gather patient perspectives and evaluate concepts.

**Motivation and personal ambitions**

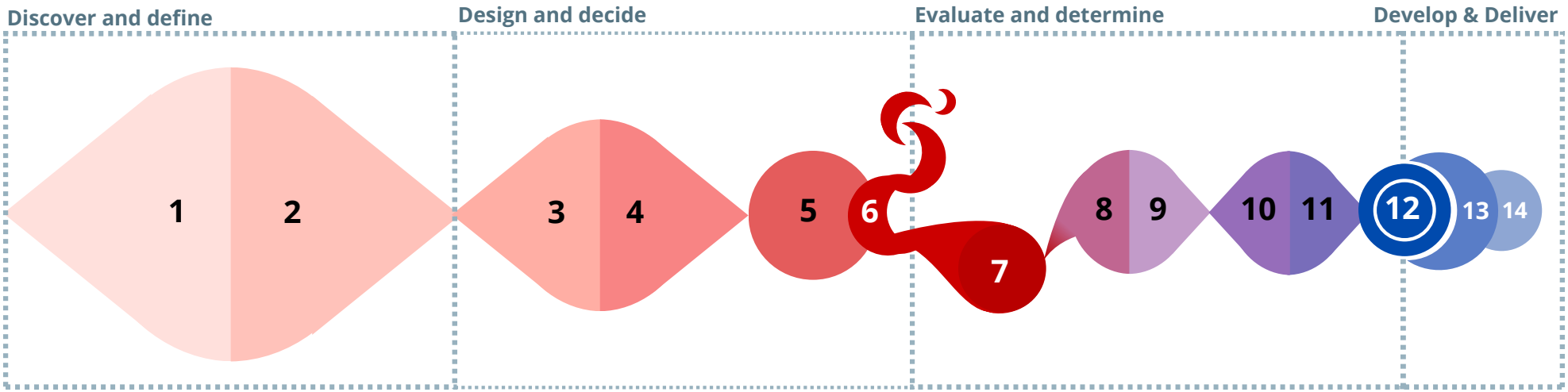
*Explain why you wish to start this project, what competencies you want to prove or develop (e.g. competencies acquired in your MSc programme, electives, extra-curricular activities or other).*

*Optionally, describe whether you have some personal learning ambitions which you explicitly want to address in this project, on top of the learning objectives of the Graduation Project itself. You might think of e.g. acquiring in depth knowledge on a specific subject, broadening your competencies or experimenting with a specific tool or methodology. Personal learning ambitions are limited to a maximum number of five.*
*(200 words max)*

I want to explore how prototyping and a product based design approach can be used for complex social challenges within healthcare. I aim to make the unknown understandable by making it tangible. In this I wish to design with empathy and sensitivity, while acknowledging the reality behind the context. I wish to finish the project with functional and use-ready prototypes that can actively be used by my client within their consultations.

My learning goals include:
- strengthening skills in generative & iterative prototyping
- developing my confidence, care and sensitivity in working with vulnerable user groups
- translating complex systemic challenges into tangible solutions
- balancing empathy, feasibility and impact

# APPENDIX B - **PROJECT APPROACH**




The project is built up from four phases. In the first phase of discovering and designing, the contextual factors surrounding pediatric SCD and HSCT were explored through a literature review, followed by investigating the current situation in practice at the SKZ and WAKZ through research, interviews, and observations (1). These findings were collected in a Patient Journey Map to visualize the decision-making process from initiation in standard care to the binding checkpoint of starting chemotherapy for HSCT. This map enabled the discovery of pain points and challenges to inspire design opportunities and directions, and select the scope of most potential (2). These challenges and opportunities were analyzed in collaboration with the relevant stakeholders: SCD and thalassemia patients/parents and pediatric hematologists from both the SKZ and the WAKZ. After narrowing the scope, the area of interest was analyzed in further detail (3). Analyzing their perspectives within the findings led to the selection of challenges and design opportunities for the area of interest in which to create design solutions (4).

The second phase of designing and deciding takes these findings as a foundation to drive ideation (5). Four potential design directions were found, on which a shared decision was made alongside stakeholders: Tools/props to clarify complex mechanisms (6). The first design solutions are realized into rapid prototypes, to allow engagement and shaping of a concept through research by design (7). This phase is completed with a concept collection to be iterated and evaluated in the third phase.

The third phase evaluates and determines. Here, the stakeholders of both HCP and patient representation are involved as the product develops. The concept undergoes two rounds of user testing (8), evaluation (10), and adjustment (9, 11) before coming to the final design (12).

The project completes in a phase of development and delivery, in which working prototypes and an implementation plan is delivered to the client for practical use. This is accompanied by a concluding list of recommendations for further projects and applications.

**Discover and define**
1. Exploration of the context of medical decision-making in pediatric HSCT by observations and literature research
2. Analysis of exploration findings
3. Investigating challenges
4. Analyzing by interviews

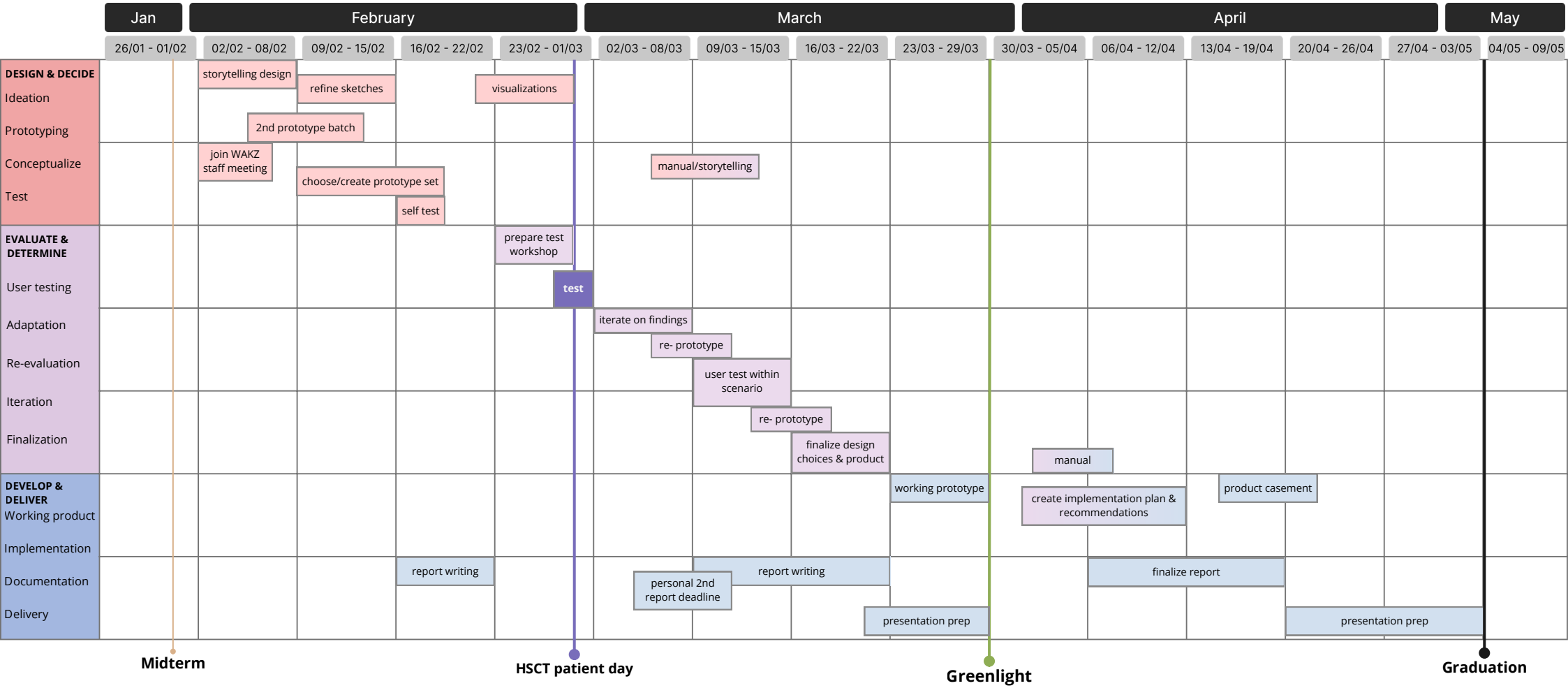
**design and decide**
5. Ideate and brainstorm
6. Decide on direction
7. Design and create a concept

**evaluate and determine**
8. Evaluate the concept with the user
9. Adapt the concept to the findings
10. Re-evalutae updated design in
11. Adjust to
12. Finalize design

**develop and deliver**
13. Develop working products to be delivered to the client
14. Deliver a list of recommendations and implementation

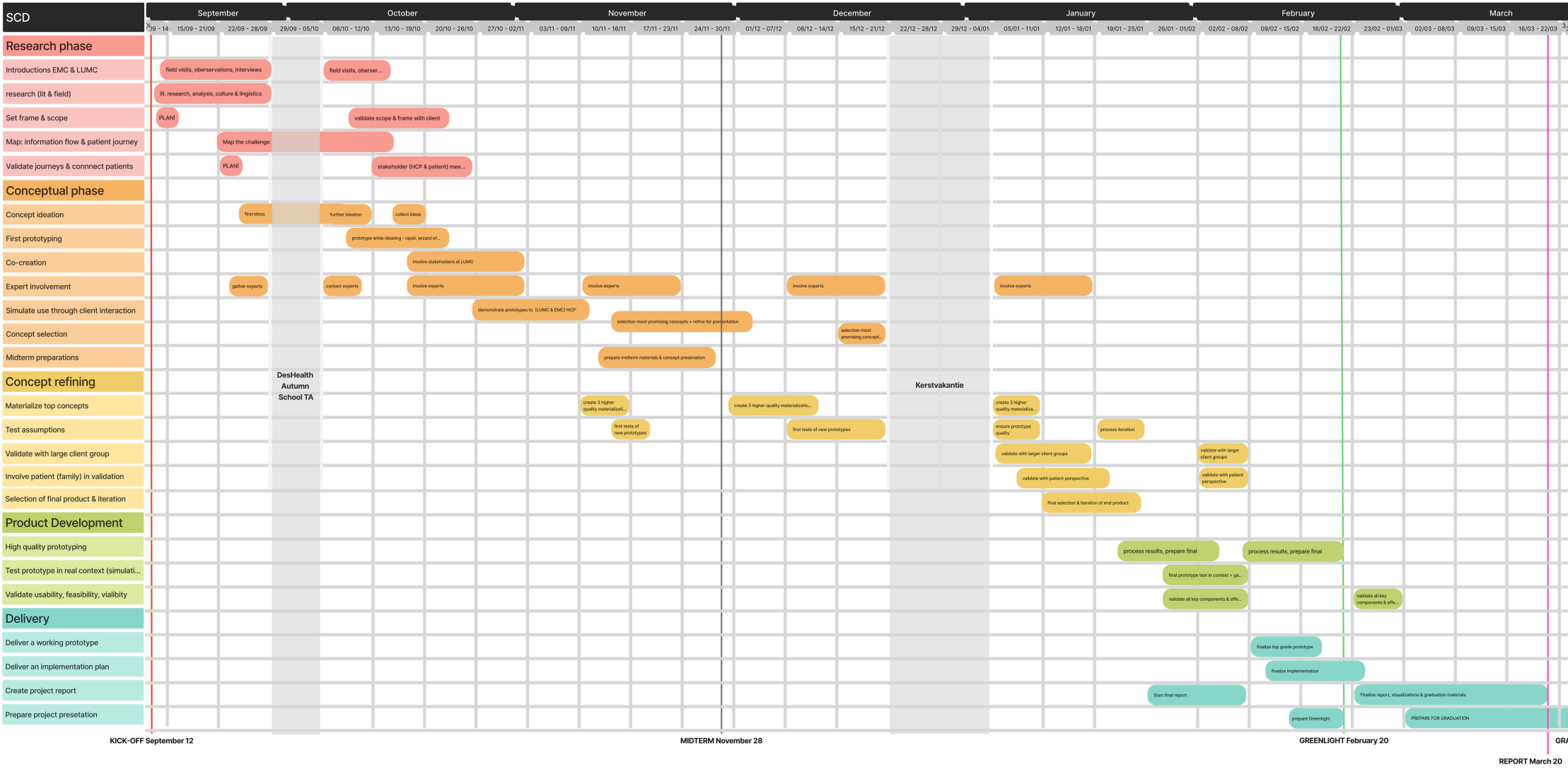
# APPENDIX C - **PROJECT PLANNING**

*PROJECT PLANNING SECOND VERSION*



# *PROJECT PLANNING FIRST VERSION*

**Graduation Planning - Gantt Diagram - Charlotte van Kats - 5062454 - "Design a working prototype to improve consultation on stem cell therapy for physicians, parents and patients in pediatric hematology."**



# APPENDIX D - **STAKEHOLDERS**

This project is in the domain of pediatric healthcare, intercultural communication, and complex shared medical decision-making. The interest power matrix maps the key stakeholders that are involved in shared decision-making for pediatric hematopoietic stem cell transplantation (HSCT) in sickle cell disease (SCD). It visualizes stakeholders' relative levels of interest in the decision-making process and their power to influence outcomes, as well as the relationships and lines of influence between them.

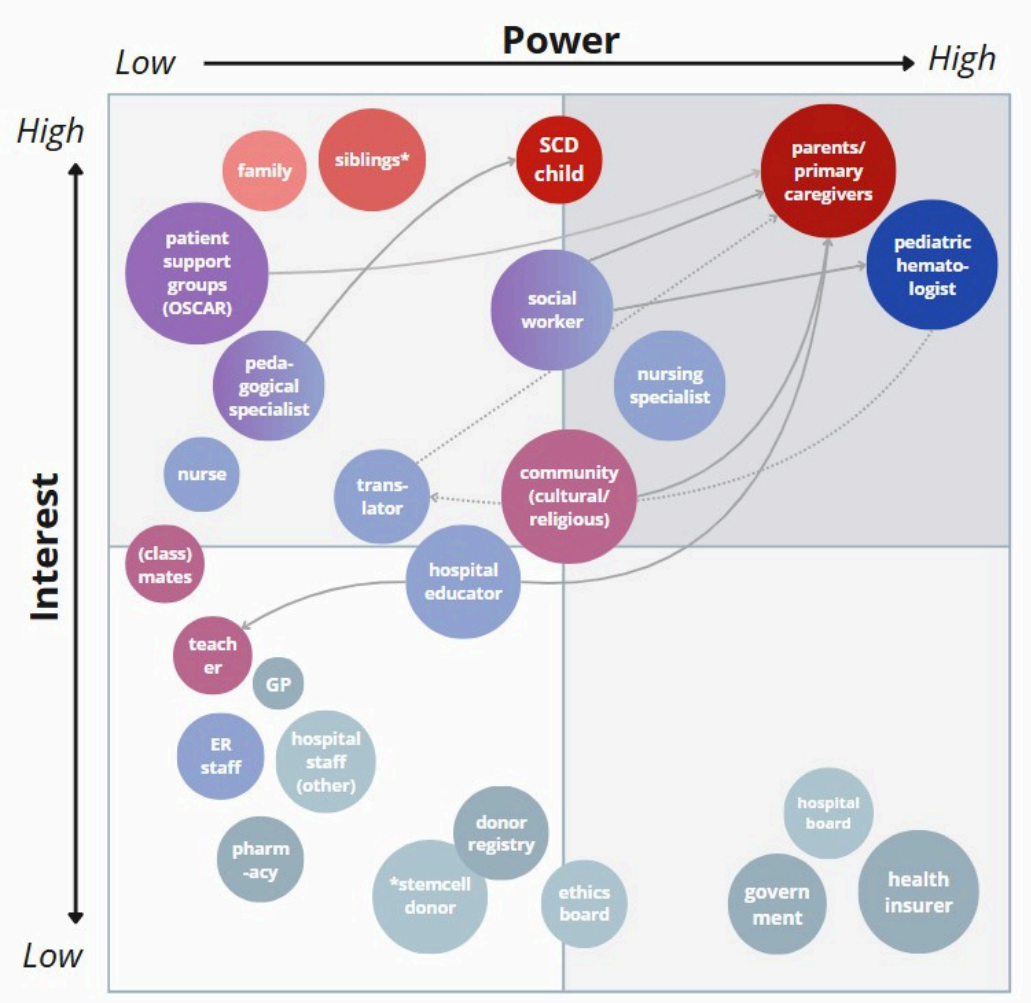
Stakeholders in the high power/high interest quadrant are closely involved in the project and play active roles in the decision-making process. The low power/high interest) Stakeholders are affected by project outcomes and will be actively consulted in the research. Other stakeholders will be informed or may benefit from the project results at a later stage. The stakeholder groups included in the matrix are:

**Familial**
- Parents / primary caregivers
- Child patient
- Siblings
- Extended family

**Supportive**
- Patient support groups (e.g., OSCAR)
- Community (cultural and/or religious)
- Classmates and friends
- Teachers

**Health Care Professionals (HCPs)**
- Pediatric hematologist / pediatric immunologist
- Nursing specialist
- Nurses
- First-line HCPs (e.g., general practitioner, physiotherapist, dentist)
- Pediatric surgeon
- Medical translator
- Emergency department staff
- Other hospital staff

**Psychosocial HCPs**
- Social worker
- Pedagogical specialist
- Psychologist
- Educational support staff
- Ethics committee / ethical board




**Organizational and Legislative**
- Government
- Donor registry
- Stem cell donor
- Transplant coordinator
- Hospital board

# APPENDIX E - INITIAL LITERATURE REVIEW

## Shared Understanding in Pediatric Sickle Cell Care: Communication, Choice, and Culture

Charlotte van Kats

June 2025

Delft University of Technology, The Netherlands

**Abstract**

This literature review explores physician-parent communication for pediatric sickle cell disease (SCD). Fourteen studies from broad range of themes on shared decision-making and multicultural healthcare experience were reviewed as a basis for a design-project on developing SCD consultation support tools. The findings are meant as starting material and considerations for concept development. The literature shows that SDM is beneficial and encouraged in theory, yet often falls short in implementation into practice, in part due to emotional states, time pressure, and unoptimal communication structures. In complex medical decisions families navigate life-altering medical outcomes within their own emotional and personal context. Trust and acknowledgment is needed for mutual understanding. Frameworks like SDM and CDM are beneficial structures for both physician and parent, and can use design solutions that make their implementation more accessible through tools that support nuance and connection, even within the complex.

**Keywords:** pediatric communication, consultation structure, multicultural healthcare, life-impacting decision-making, sickle cell disease

## 1 Introduction

In pediatric care, communication between physicians and parents is essential for shaping understanding, trust, and decision-making on a child's treatment. With life-impacting or chronic illnesses, such as sickle cell disease (SCD), and intensive therapies like stem cell transplants, the decisions to be made, and therefor the conversations and consultations, increase in weight and complexity. These moments are medically pivotal and emotionally charged, as they touch on outcomes and risks that can be life or death for the child patient. These consultations become especially complicated for both the parent and the physician when the families must navigate a divergent cultural perspective from their physician, face linguistic barriers, or encounter systemic challenges. Dutch hospitals address these consultation difficulties in pediatric SCD. This genetic hematologic disease occurs predominantly in people of African descent, and in the Netherlands, it is still frequently seen among migrant, refugee, or low SEP families.

This literature review explores the tools, theories, and strategies used in physician-parent communication in pediatric care, with a focus on the consultation in high-stakes medical contexts. The aim is to examine where these techniques face barriers in shared decision-making, in particular in addressing the needs and perspectives of families of African heritage within a Western healthcare context. This work is part of a thesis in Industrial Design Engineering and is intended to support the design and development of physical tools, prompts, or props to aid healthcare professionals and patient families in navigating complex conversations with clarity, empathy, and cultural awareness in the context of stem cell treatment for pediatric sickle cell patients.

This research was initiated after three days of field observations at the Sickle Cell Clinic of Sophia Children's Hospital in Rotterdam, the Netherlands. These included both routine biannual check-up consultations between physicians, parents, and children with sickle cell disease, and a high-stakes informational consultation for parents whose child was being considered for stem cell therapy, a potentially curative but high-risk treatment option. These observations highlighted the emotional and medical complexity of the decision-making process, and the significance of health literacy within it.

This review follows of structure of a methodology on the literature search and selection process, the organization of findings into three key thematic areas: pediatric communication, shared decision-making for pediatric sickle cell disease, and cultural, linguistic, and racial dimensions in pediatric care. The review concludes on identified gaps and opportunities relevant for designing supportive tools in medical consults.



## 2 Method

A systematic search was performed to find relevant publications and topics related to pediatric sickle cell consultation that could be of value to the later design process.

### 2.1 Research Questions

The research questions are:

**RQ1.** How does communication shape family involvement in pediatric life-limiting illness care?

**RQ2.** What influences shared decision-making in sickle cell disease treatment for children?

**RQ3.** How do culture, language, and race impact communication and care in severe pediatric illness?

### 2.2 Selection Process

The search queries were performed in the database PubMed. The following keywords drove the searches, looking only at English publications from the last 10 years. *For pediatric communication:* ("pediatric*"OR "paediatric*") AND ("clinician-parent" OR "physician-parent") AND ("communication" OR "consultation") AND ("strategies" OR "strategy" OR "tool*" OR "framework*" OR "structure*") *For sickle cell decision-making:* ("sickle cell disease" OR "sickle cell anemia") AND ("shared decision making" OR "shared decision-making") AND ("pediatric*" OR "paediatric*" OR "child" OR "adolescent") AND ("hydroxyurea" OR "transplant" OR "decision aid*" OR "toolkit*") *For cultural dimensions* ("pediatric*" OR "paediatric*") AND ("decision-making" OR "communication" OR "consultation") AND ("life-limiting" OR "oncology" OR "sickle cell") AND ("migrant" OR "refugee*" OR "minority" OR "Africa*" OR "ethnic" OR "racial") AND ("interpreter" OR "bias" OR "difference*")

*Study Selection and Inclusion Criteria* Studies were included if they:

- Focused on pediatric clinical communication involving physicians and parents (or caregivers),
- addressed chronic or life-impacting conditions (excluding palliative care),
- went beyond the clinical, medical jargoned, perspective, and
- offered insights and theory relevant to the design scope of the project.

Papers focusing solely on adult care, end-of-life decisions, or general healthcare system inequalities without communication components were excluded.

Selected papers were structured into three themes: (a) pediatric communication, (b) shared decision-making in pediatric Sickle Cell disease, and (c) cultural, linguistic, and racial dimensions in pediatric care

## 3 Review

The search resulted in a(n=17) b(n=13) c(n=30), with a total of 60 studies. After screening on the previously set inclusion criteria, this resulted in 14 studies that offer different perspectives around pediatric communication for sickle cell disease or other serious life-limiting illnesses. Figure 1 (Appendix A) gives an overview of the included studies, with their origins, keywords, and key findings. Each of the following themes gives insights for understanding the complex context behind the challenges pediatric sickle cell consultation faces.

### 3.1 Pediatric Communication

Neubauer et al. (2018) finds that when reviewing communication and decision-making in pediatric critical cardiac disease, not SCD but an illness of similar medical severity, parental preferences can be defined in three themes.

1. Information Delivery: Parents express the need for comprehensive, honest, and timely information, beyond medical facts with clear implications on options and outcomes.
2. Physician Communication Style: Parents value empathy, patience and clarity in their physician interactions. Shared-decision making was preferred over authoritative communication styles.
3. Support systems: Families rely on reinforcement from support networks, in the form of psychosocial resources, consistent members in the care team, and inclusion of both parents in shared decision-making (SDM), regardless of family structure.

When it comes to life-sustaining treatment (LST) decisions, Nageswaran et al. (2022) argues that SDM is not enough, due to the complexity of context and the impact of the caregivers expertise, position, and ethical tensions. The framework of collaborative decision-making (CDM) is proposed. The CDM model supports caregiver emotional states, beliefs, and hopes, HCP's moral concerns and clinical judgement, and the importance of aligning interprofessional communication to avoid mixed/confusing communication towards the families.

Examining the structure behind medical consultations, Manalastas et al. (2020) provides a method to

visualize pediatric communication in practice. Consultation is divided in six phases: *initiating, gathering information, summary, explanation, planning,* and *closing.* They found important phases, especially summary and closing, often omitted in practice. A dominance of the information-gathering phases suggests a physician-centred dynamic, which could limit family engagement and experience in SDM.

High-stress pediatric contexts come with risks for physician-parent communication. Ferretti et al. (2022) proposes a model for recognizing and avoiding these "communication traps". Traps arise when there is misalignment and high emotions that damages trust. The model proposes using affective (emotions), behavioural (non-verbal), and cognitive (understanding) signals within consultation. Communicating through empathy, simple language, and open-ended questions at the parent's pace can avoid deterioration of communication. While designed in neonatology, this framework is relevant for the complex SCD context.

### 3.2 Shared Decision-making in Sickle Cell Disease

From the physician perspective Bakshi et al. (2016) shows SDM exists on a spectrum. There are different physician narratives, from encouraged patient-involvement in the full decision making process, to steered advocating for a therapeutic plan. This narrative is effected by patient attributes. The level of physician involvement was influenced by the perception of patient compliance, socio-economic barriers and the severity of the patient condition. The findings of this study, while not specified to pediatric SCD, highlights the need for further awareness and education on SDM for both patients (parents) and physicians when approaching disease-modifying therapies.

From the perspective of the family, decision-making is never guided solely by clinical facts. Khemani et al. (2017) explored the patient-parent approach to hematopoietic stem cell transplant (HSCT) and found the decisions shaped by emotional state, perceived disease burden, availability of an HLA-identical sibling donor, concerns related to treatments, disease-related complications, and the hope for a normal life, not by only medical advice. Offering support to a patient, and their families, the emotional side of decision-making, for the long and intense stages of HSCT to come, may be just as important as clarifying the medical considerations.

Middleton et al. (2018) highlights the complexity of communication about SCD within families when exploring how parents communicate with their affected children. Their focus is to educate and protect their child from the effects of SCD in an age-appropriate way. Here, avoidant communication is commonly seen in parents, as they try to shield their child from difficult and emotionally charged conversations. This is related to fears and the stigma around SCD, and uncertainty on how to respond. This indirectly affects how families participate in the decision-making process. If the discussion at home is restrained, then clinical consultations on life-altering treatment may become even more cognitively challenging to fully process and communicate on.

To improve SDM for the use of hydroxyurea (HU) in pediatric SCD, the Engage HU study by Hildenbrand et al. (2022) developed a SDM toolkit and evaluated it against the usual care condition by intervention trial. The toolkit resulted in a significantly improved SDM, in perception of SDM behavior in physicians and reduced caregiver uncertainty. Though additional research is needed in context-specific factors, it suggests that integrating structure by tools into consultation can make SDM more actionable in practice. This too is seen as Echevarria et al. (2023) reviews SMD aids for chronic pediatric conditions. Most tools remain descriptive and put little emphasis on their actual implementation and effectiveness, though studies show SDM has the possibility of improving patients' health outcomes, satisfaction in the decision-making process, and treatment adherence. For sickle cell research showed that patient families are not, or only very moderately, experiencing SDM. Both patients and parents expressed their desire for it, but face challenges like time-pressure, a lack of high-quality/available information, or the emotional state within their family. To realize effective and consistently applied SDM, there is a need for evidence-based guidelines for its use.

### 3.3 Cultural Dimensions

Yazdani (2020) tells us that decision-making needs are influenced by culture. Both parental communication style, and how they perceive their physician is possibly affected by cultural norms. What makes SCD increasingly complex is that the disease is predominantly found in people of African heritage, who find themselves a cultural minority in Western medical contexts. Also in linguistics and literacy this can be a challenge for immigrant families.

Sisk et al. (2019) studied how racial and ethnic backgrounds influence the roles of parents in decision-making in pediatric oncology. Parental preference for SDM was consistent across race/ethnicity; however, in the actual decision-making, the role of the parents differed by their race/ethnicity. 25% of white parents reported having parent-led decision making, versus 37% of black (afro-american) parents. Oncologists were less able to predict the preferred parental decision style for black families, with 23% accuracy, over white families with 53%. They concluded that



minority parents tend to play a more active role and there was difficulty predicting decisional preferences for minority parents compared to parents from the dominant (white) culture, possibly due to racial biases. It suggests minority parents are at risk for inferior decision-making experiences. It should be noted that this study was done in the USA, and both black and white cultures there differ from European and African ones.

Where language and literacy is the barrier, Boylen et al. (2020) shows that professional interpreters significantly improve the health outcomes and experience for migrant and refugee families in pediatrics. In this, the use of professionally trained interpreters is inferior to translation done by family, and especially favorable in video or in-person format.

Other cultural challenge can be a underlying communication bias within pediatrics Kosoko et al. (2023). Through medical simulation with healthcare professionals they explored HCP awareness of this in pediatric SCD. They found a willingness of participants to reflect on language and assumptions, yet a need for further awareness and nuance in practice. An example is the term *sickler*, which was commonly used but can be negatively experienced by patients/families. In the dismissal of family concern there is further risk of biased language or physician demeanor damaging patient trust.

An example of an African cultural perspective in a comparable high-stakes pediatric context is seen in Kayiira et al. (2023), who in Uganda studied parents of children with cancer about decision-making on preserving fertility. This consideration too must be made for SCD when treated with stem cell therapy. Their findings show key SDM components for these parents were accurate, timely, and thoroughly explained medical explanation, active consideration of their attitude based on their religion and background, and a respect for their autonomy in their decisions and communication with their child.

## 4 Discussion

### 4.1 Understanding Consultation Context

When designing to improve pediatric consultation, one must first understand the structure and methods behind the communication. In pediatrics, communication happens between physicians, the care team, the patient, the patient's parents/caregivers, and their family. Each of these actors holds a different role, experience, and communication need. Physician-caregiver consultation is central for treatment decision-making.

The papers show that pediatric consultation between physicians and parents is not just about communicating medical content, but shaped by the context. Structure, tone, dynamics and emotions all play a role in the experience and quality of care. Models like SDM and CDM are frameworks to guide the needs of parents and physicians. Still the complexity of having to make severe life-impacting decisions for a child brings risks for the communication. There is a need for supportive tools to be available, and realized, in practice, especially in high-stakes care-paths like pediatric SCD.

### 4.2 Shared Decision-making in Sickle Cell Disease

Shared decision-making in pediatric sickle cell care means making high-stakes choices that define a child's quality of life and future. It is a weighing of current condition and future outcomes to costs, complications, patient and family burden and long term side effects. In the literature there is a pattern of endorsing SDM, yet seeing gasps in its use in practice.

The literature tells us that shared decision making for pediatric sickle cell is about more than offering choice, but asks for insight and consideration of medical timelines with family context, emotions, values, and burdens. The options given must feel accessible, understandable, tangible, and to be able to emotionally comprehend.

### 4.3 Cultural and Contextual Nuance

Yazdani (2020) tells us that decision-making needs are influenced by culture. Both parental communication style, and how they perceive their physician is possibly affected by cultural norms. What makes SCD increasingly complex is that the disease is predominantly found in people of African heritage, who find themselves a cultural minority in Western medical contexts. Also in linguistics and literacy this can be a challenge for immigrant families.

While spread across a wide range of themes, these papers give insight into considerations of culture, language, and identity that play a part in the experience of pediatric care. These dimensions are not separate from medical communication between physicians and parents, but interwoven with how families process the given consultation, interpret the treatment options, and make their decisions. Nuance and consideration are key to understanding and improving the lived experiences within pediatrics, especially in SCD, and should be considered when designing supporting tools.

### 4.4 Limitations

This selection of insights, while relevant, shows there is not an exact match between the scope of research

questions and the available sources. Much of the literature comes from medical research and is focused either on the physician or the parent, rarely looking at both within the same case. This leaves a gap for understanding how their communication is shaped as an exchange between roles, each with their own contribution to the dynamic, highly relevant when designing for shared understanding. The same goes for the underrepresentation of children's voices and impacts on these decision, which in the end are about their lives.

Research on the experience of pediatric SCD is sparse and mostly from the US. While this is a Western medical context and offers comparable medical treatment, the healthcare system, financial tensions, and cultures are different from the Dutch context of this project. The nuances of experience, such as trust, access, and identity, cannot be directly assumed as equal. There are further gaps in research due to the lack of African cultural perspectives. In western healthcare, if researched at all, there is an approach of taking African background as a singular identity defined as 'Black' or 'minority'. There needs to be acknowledgement of the nuances in language, religions, family structures, and health beliefs across the rich and wide range or African regions, ethnic groups, and communities.

Finally there is a gap in the integration of disciplines around SCD. The available knowledge comes from the fields of medicine and psychology, not from the lens of design or method development. This limits insights that can directly become actionable in design, but also shows the opportunity this project has to add value in designing tools that can actively shape and improve communication.



## 5 Conclusion

This review touches on a niche and complex subject in which many components come together. Finding relevant papers on SCD consultation experience and navigating between the medical content and qualitative observations is challenging. Because of the broad scope and short format this review does not answer the research questions in depth, but does give valuable insights for the designer perspective. In the conceptual design and generative prototyping approach this thesis project will take, the gathering of perspectives and elements to take into consideration during ideation is of more value than extensive elaboration on SDM specifications. The review helps to look beyond the clinical perspective gained in hospital observations and offers initial considerations for the exploration phase. Following activities shall be expanding on the parental perspectives through qualitative research with the patient communities in this projects specific context, the in the literature found preferences, challenges and experiences offer a basis to validate and elaborate on with this project's target users.

These insights help explore the role a designer can take within this project, not through simplifying medical content, but by connecting and supporting the human process around SCD communication. This review shows why designing tools for these consultation moments matters, and what said tools need to enable, not just for the transferring of information, but to meet meet the needs of empathy, agency and cultural identity.

## References


Bakshi, N., Sinha, C., Ross, D., Khemani, K., Loewenstein, G., & Krishnamurti, L. (2016). Shared Decision Making or Physician Advocate for a Particular Treatment Option: A Spectrum of Approaches to Decision Making about Disease Modifying Therapies in Sickle Cell Disease. *Blood*, *128*(22), 4757. https://doi.org/10.1182/blood.v128.22.4757.4757

Boylen, S., Cherian, S., Gill, F. J., Leslie, G. D., & Wilson, S. (2020). Impact of professional interpreters on outcomes for hospitalized children from migrant and refugee families with limited English proficiency: a systematic review. *JBI Evidence Synthesis*, *18*(7), 1360–1388. https://doi.org/10.11124/jbisrir-d-19-00300

Echevarria, F. M. M., McLoughlin, D. E., & Badawy, S. M. (2023). Shared Decision-Making Aids for Pediatric Chronic Hematological and Non-Hematological Conditions: An in-Depth Literature Review. *Blood*, *142*(Supplement 1), 7212. https://doi.org/10.1182/blood-2023-189361

Ferretti, E., Schoenherr, J. R., Mattiola, A., & Daboval, T. (2022). Vulnerabilities in clinician–parent exchanges and the cascade of communication traps: a review. *Archives of Disease in Childhood*, *108*(2), 86–90. https://doi.org/10.1136/archdischild-2021-323451

Hildenbrand, A. K., King, A. A., Mara, C. A., Johnson, Y., Shook, L. M., Whitacre, C., Britto, M. T., Quinn, C. T., Brinkman, W., Hackworth, R., Raphael, J. L., Tubman, V. N., Thompson, A. A., Smith-Whitley, K., Badawy, S. M., Creary, S. E., Bhasin, N., Treadwell, M., Reader, S. K., … Crosby, L. E. (2022). Optimizing Shared Decision Making about Hydroxyurea in Young Children with Sickle Cell Anemia. *Blood*, *140*(Supplement 1), 10857–10859. https://doi.org/10.1182/blood-2022-167914

Kayiira, A., Xiong, S., Zaake, D., Balagadde, J. K., Gomez-Lobo, V., Wabinga, H., & Ghebre, R. (2023). Shared Decision-Making About Future Fertility in Childhood Cancer Survivorship: Perspectives of Parents in Uganda. *Journal of Adolescent and Young Adult Oncology*, *12*(5), 718–726. https://doi.org/10.1089/jayao.2022.0127

Khemani, K., Ross, D., Sinha, C., Haight, A., Bakshi, N., & Krishnamurti, L. (2017). Experiences and Decision Making in Hematopoietic Stem Cell Transplant in Sickle Cell Disease: Patients' and Caregivers' Perspectives. *Biology of Blood and Marrow Transplantation*, *24*(5), 1041–1048. https://doi.org/10.1016/j.bbmt.2017.11.018

Kosoko, A. A., Alford, Y. R., Upplegger, K. A., & Stevens, G. S. (2023). Not Just a Pain: A Medical Simulation Case About Biased Communication and Osteomyelitis in Pediatric Sickle Cell Anemia. *MedEdPORTAL*. https://doi.org/10.15766/mep\{_}2374-8265.11335

Manalastas, G., Noble, L. M., Viney, R., & Griffin, A. E. (2020). What does the structure of a medical consultation look like? A new method for visualising doctor-patient communication. *Patient Education and Counseling*, *104*(6), 1387–1397. https://doi.org/10.1016/j.pec.2020.11.026

Middleton, J., Calam, R., & Ulph, F. (2018). Communication with children about sickle cell disease: A qualitative study of parent experience. *British Journal of Health Psychology*, *23*(3), 685–700. https://doi.org/10.1111/bjhp.12311

Nageswaran, S., Gower, W. A., Golden, S. L., & King, N. M. P. (2022). Collaborative decision-making: A framework for decision-making about life-sustaining treatments in children with medical complexity. *Pediatric Pulmonology*, *57*(12), 3094–3103. https://doi.org/10.1002/ppul.26140

Neubauer, K., Williams, E. P., Donohue, P. K., & Boss, R. D. (2018). Communication and decision-making regarding children with critical cardiac disease: a systematic review of family preferences. *Cardiology in the Young*, *28*(10), 1088–1092. https://doi.org/10.1017/s1047951118001233

Sisk, B. A., Kang, T. I., & Mack, J. W. (2019). Racial and Ethnic Differences in Parental Decision-Making Roles in Pediatric Oncology. *Journal of Palliative Medicine*, *23*(2), 192–197. https://doi.org/10.1089/jpm.2019.0178

Yazdani, N. (2020, September). Parental Decision-Making for a Child with a Life-Limiting Condition. https://doi.org/10.20381/ruor-25263

# APPENDIX F - **RESEARCH EXPLORATION**

### 1. Introductions

- What factors define the patient-parent-physician dynamics? — Charlotte
- How do contextual factors play a role? — Charlotte
- How do physicians 'win' patient-parent's trust? — Charlotte
- How can parent needs & preferences be clearly assessed? — Charlotte
- How can parent-agency be promoted since the start? — Charlotte

### 2. Sickle Cell disease & progression

- What is the very core of SCD explanation? — Charlotte
- What parts of SCD explanation are most difficult to understand/ remember? — Charlotte
- How to explain long term SCD risks, balance gravity/fears? — Charlotte
- How to add visualization and momentum to the story? — Charlotte
- What are core storytelling principles for educational purpose? — Charlotte
- How does SCD explanation best match the patient lived reality? — Charlotte

### 3. HSCT mechanisms

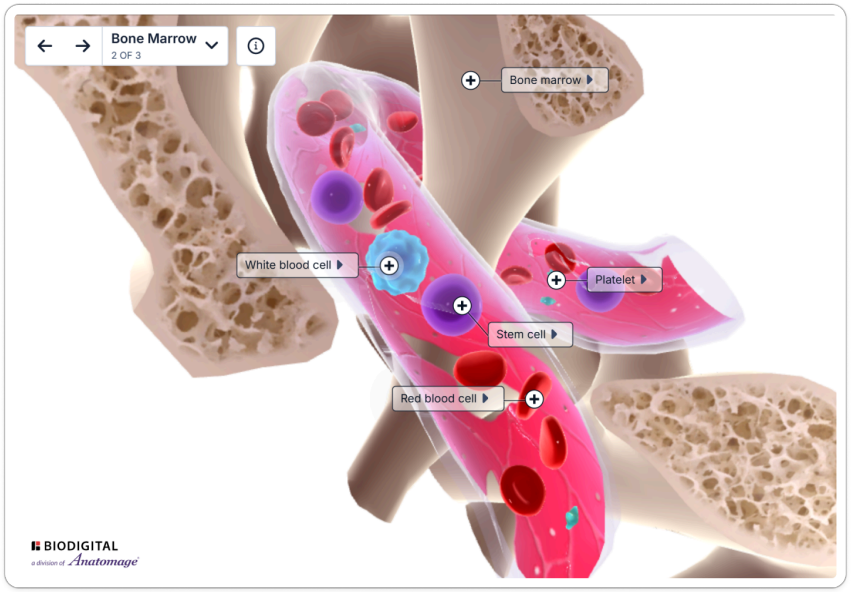
- What is the very core of HSCT explanation? — Charlotte
- What parts of HSCT explanation are most difficult to understand/ remember? — Charlotte
- What is needed to continue to the risks? — Charlotte
- How to add visualization and momentum to the story? — Charlotte
- How do patients keep track of the quick stacking of complex info? — Charlotte
- How do you enable a patient to ask questions? — Charlotte

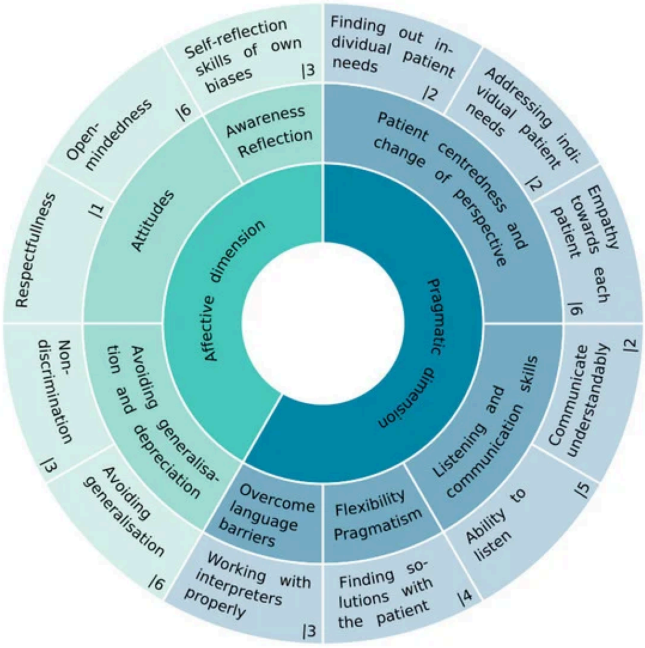
### 4. HSCT risks & risk comparison

- How do you compare known - to unknown risks? — Charlotte
- What role does fear play in decision making? — Charlotte
- How much time is needed to let information dawn to make a decision? — Charlotte
- What does the parent think about first- what is their risk hierarchy? — Charlotte
- How to explain graft-vs-host, aka risk mechanisms? — Charlotte
- What can you give the patient to help them independently make a choice? — Charlotte

### 5. Timeline & Logistics

- How do you create clear and accesible overview of the path to come? — Charlotte
- How do you best align logistical info the patient-parent experience? — Charlotte
- What is needed to continue to the risks? — Charlotte
- What role does this information play in decision-making? — Charlotte
- How do you follow-up, say goodbye in a satisfying way? — Charlotte
- Have dynamics changed by the end of the consult? — Charlotte



# *CARE PATHWAY HSCT DECISION-MAKING SICKLE CELL DISEASE - DRAFT*

**Screening**

**Hielprik**
Infanct / young child tests positive for SCD markers

**Diagnosis**

**Genetic testing**
Checking if the intial test result was correct
- Testing siblings (if not done already)

Become pediatric hematology patient

**General Care**

**Sophia's hematology policlinic**
- hematologist
- social worker
- nursing staff
- psychologist?

**Medication**
- hydroxyurea
- foliq acid
- pain killers (from paracetemol → opioids)

**Care activities**
- blood testing (& drawing)
- tranfusion*
- biyearly check up & conversation w. doctor
- emergency care with a sickle crisis

**Lifestyle**
- avoiding risk factors:
  - infection
  - fever
  - pain
  - stress
  - cold
  - dehydration
  - exhaustion
- extra care during: traveling
- energy monitoring
- missing out on playdates, school, sports, etc.

**High severity SCD**

**Inform**
- explain child's clinical condition
- explain HSCT:
  - How it works
  - Why it is needed
  - What it looks like
  - The experience
  - The risks

**Prepare**
- check siblings (if possible) on stem cell donor compatibility
- check donor database
- decide whether or not to continue with HSCT

**Refer**
- Go from Sophia's (or other hospital) to the Willem Alexander hopsital in Lieden (LUMC)

Continue with HSCT: NO

**Low life quality/expectancy**

Possible re-evaluation of options when adult/older

Increased organ degradation over time

Continue with HSCT: YES

**PREPARATION**
**Hematopoietic stem cell transplantation (HSCT)**

**Willem Alexander child hospital**
- hematologist
- social worker
- pedagogical expert
- hospital education
- nursing

**Care activities**
- Giving information
- Eliciting parent preferences
- Shared decision-making
- Deciding on fertility precautions (young female patients)

→ Start HCST & CHEMO...

**Low/moderate severity SCD**

**Stays in General care**
- Possible daily life with SCD
- monitoring continues

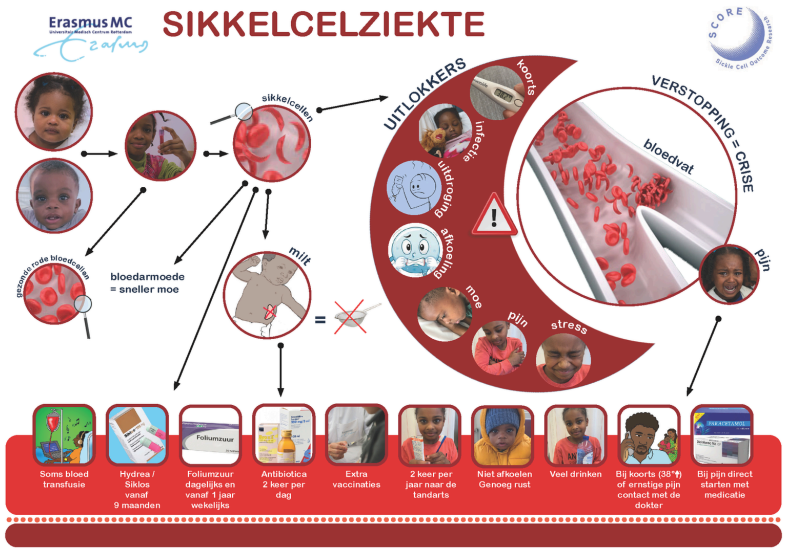
**Future**
- when 18 moves to adult EMC hematology

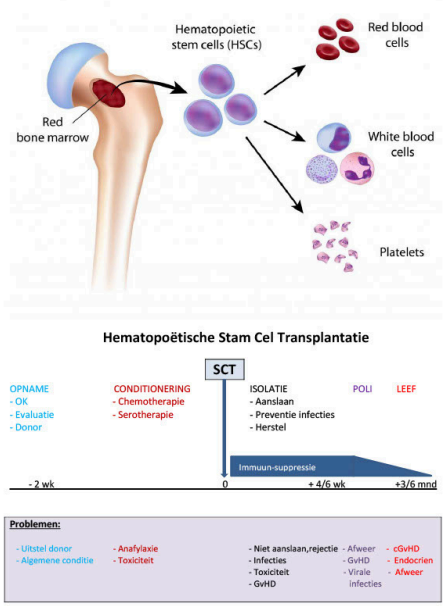
**Follow-up**

**Hoofdbehandelaar: kinderhematoloog**

Elke periode van 1 jaar herhalen

| Jaarcontrole | Halfjaarlijkse controle | (Opt.) Extra controle |
|---|---|---|
| **I Voorbespreking poli** Hemoglobinopathie-behandelteam | **I Voorbespreking poli** Hemoglobinopathie-behandelteam | **I Voorbespreking poli** Hemoglobinopathie-behandelteam |
| **II Consult** Kinderhematoloog of fellow, of VS | **II Consult** Kinderhematoloog of fellow, of VS | **II Consult** Kinderhematoloog of fellow, of VS |
| **III Consult** VC | **III (Opt.) Consult** VC | **III (Opt.) Consult** VC |
| **IV (Opt.) Vaccinatie** Kinderhematoloog, VS of VC | **IV (Opt.) Vaccinatie** Kinderhematoloog, VS of VC | **IV (Opt.) Consult** Medisch maatschappelijk werk |
| **V (Opt.) TCD** Klinische neurofysiologie Vanaf leeftijd 2 jaar, bij HbSS/HbS80 genotypen | **V (Opt.) TCD** Klinische neurofysiologie Vanaf leeftijd 2 jaar, bij HbSS/HbS80 genotypen | **V (Opt.) Bloedafname** Medewerker bloedafname |
| **VI (Opt.) Consult** Medisch maatschappelijk werk | **VI (Opt.) Consult** Medisch maatschappelijk werk | |
| **VII Bloedafname** Medewerker bloedafname | **VII (Opt.) Medicatie ophalen** ouder(s)/verzorger(s) bij de apotheek, of indien van toepassing bezorging | |
| **VIII Medicatie ophalen** ouder(s)/verzorger(s) bij de poliklinische apotheek, of indien van toepassing bezorging. | | |
| DD1 | DD2 | DD3 |



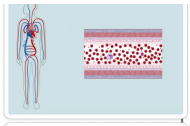



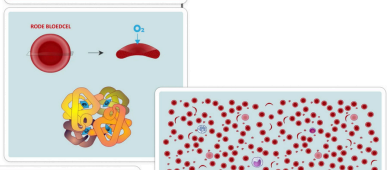
# *CONSULTATION ANALYSIS*

## Analyse van consultatie video

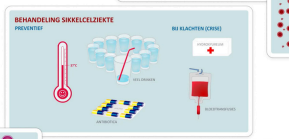
erkenning dat het veel informatie was

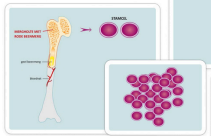
- Wat sikkelcelziekte is, wat het betekent, wat de ziekmakende momenten zijn voor SCD, wat de behandeling mogelijkheden zijn, wat HSCT betekent voor de behandeling van HSCT
- 'Samen tot een goede beslissing te komen
- Vervoeren zuurstof door de rode bloedcel (zie plaatje)
  - *drager voor zuurstof: hemoglobine
  - *4 ketens: 2 alpha, 2 beta
  - *bouwfout in ketens - aan elkaar plakken
  - oorzaak sikkelvorm
- Vastlopen sikkelcel vorige cellen in kleine bloedvaatjes, weefsel zuurstof tekort en infarct = voordurend klein beetje kapot
  - in botten = pijn, in de milt, in de longen, in elk orgaan.. hersenen
  - voorkomen sikkelen: leefregels
    - niet te koud worden.
    - genoeg drinken
    - antibiotica - infectie behoeden
    - veel crise - hydroxyhydrea / siklos
      - beta keten, babybloed behouden
    - bloed transfusies
  - Allemaal symptoom behandeling

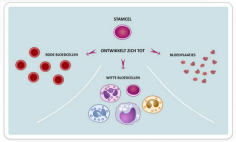






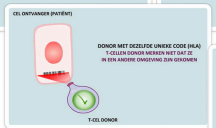





- Echte genezing = naar de bron = stamceltherapie
- bot → beenmerg → stamcellen
  - Wat zijn stamcellen? → deling voor wolk bloedcellen
- Verschillende soorten cellen die gemaakt worden
  - probleem alleen maar in de rode bloedcel, maar je moet alles vervangen
  - de 2 soorten witte bloedcellen: G-cellen (granulocyten) en L-cellen (lymfocyten) (B & T cellen)
    - zijstapje T cellen - speciale afweer cel
    - Elke cel heeft een uniek barcode voor van wie ze zijn. De T-cel de scanned of van de cellen in je lichaam
    - streepjescode = HLA helft van moeder, helft van vader.
      - Kan zijn dat je broertje of zusje precies dezelfde streepjes code heeft. = perfecte donor
        - als de code heel anders zou zijn, dan zouden de T-donor cellen de patient cellen aanvalle. HIER AL DUIDELIJK VERTELT HOE HET VERWISSELEN VAN DE CELLEN ZAL WERKEN - EERDER HSCT BASICS]
    - Graft-vs-Host
    - risico op afstoting niet 0 maar veel lager als HLA broertje of zusje
    - van de streepjes code zijn er 10 streepjes heel erg belangrijk → donor zoeken in de donot bank.
  - risico graft.vs.host beperkt en acceptable
  - Als dat niet kan → verwerken van ouder stemmen om te gebruiken, altijd 5 van de 10 streepjes

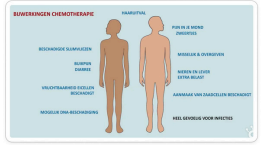


Wat zijn de stappen van stamcel transplantatie?

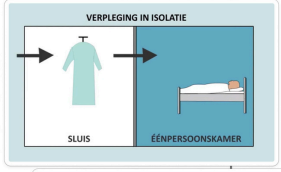
- Eerst moet er ruimte gemaakt worden in het beenmerg = chemotherapie
  - bloedfabriek opruimen
  - bekend van behandeling met kanker, kind geen kanker maar het medicijn is goed met het leeg maken van de bloedfabriek.

Welke risicos komen erbij kijken?

- Bijwerkingen:
  - tijdelijk haar uitval
  - misselijk en overgeven, dingen smaken niet meer lekker
  - beschadigde slijmvliezen
  - pijn in de mond of buik, diarree
  - hard werken voor nieren en lever
  - aantasting van de vruchtbaarheid
    - aanmaak van zaadcellen / vruchtbaarheid van eicellen
      - worden wel volledige mannen en vrouwen, maar moeilijk om laten zelf kinderen te krijgen
      - invriezen sperma
      - eierstok verwijderd en bewaard
  - Een kleine kans op later kanker (hoewel dit ook bij SCD er ook is)
  - Uitschakelen van de witte bloedcellen: de verdediging van het lichaam.
    - infecties, geen afweer systeem
    - verpleegd in afgesloten isolatie kamer, alles heel goed opletten om geen infecties te krijgen.
    - infecties:





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    - worden wel volledige mannen en vrouwen, maar moeilijk om laten zelf kinderen te krijgen
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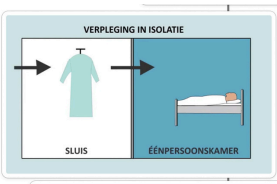
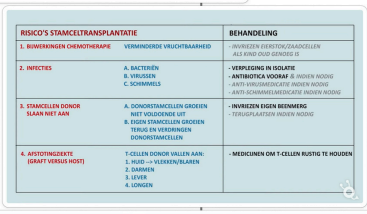
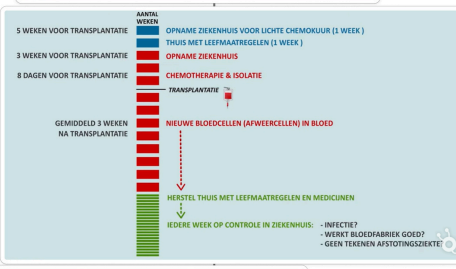
  - infecties, geen afweer systeem
  - verpleegd in afgesloten isolatie kamer, alles heel goed opletten om geen infecties te krijgen.
  - infecties:
    - bacterieel, overal bacterien = vooraf al antibiotica
    - virusen, verstoppen soms nog in het lichaam van vroeger een keer ziek zijn geweest - voordurend testen in het bloed
    - schimmelinfecties: kan in longen, lever, hersenen - testen in bloed, antischimmel pedicijn als nodig
- 3. Stamcellen slaan niet aan
  - nieuwe bloedfabriek wilt niet groeien
  - beenmerg afnemen en invriezen van tevoren als backup als hij niet goed uitgroeid
  - soms groeit een deel van het eigen bloed ook weer terug, is niet zo erg als er balans is. Maar als het eigen beenmerg te sterk word kan het het gezonde beenmerg weer weg duwen. Gynerisme. Wordt in de gaten gehouden maar kan niet zoveel aan gedaan worden.
- 4. Afstotingsziekte. Als T-cellen van donor niet de code van de patiënt accepteren. graft vs. host.
  - huiduitslag, vlekjes, blaren
  - orgaanschade
  - 'accute graft vs host'
  - heel vervelend en heel alert op. Al voor de nieuwe stamcellen al medicijnen om de T-cellen slapering en rustig te houden. Wennen aan de nieuwe omgeving, afweercellen blijven onderdrukken als nodig, maar dan infectie risico hoger
  - voordurend daarin balans zoeken.




Wat is het tijdspad van HSCT? - 3 blokken

blok 1:

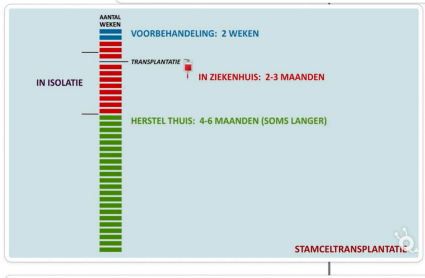
- opname ziekenhuis voor lichte chemokuur (1 week)
- thuis met leefmaatregelen (1 week)

blok 2:

- weer opgenomen (3 weken voor de nieuwe stamcellen)
- chemotherapie & isolatie (8 dagen voordat de stamcel worden toegediend)
- TRANSPLANTATIE (dag 0)
- nieuwe bloedcellen in het bloed (relatief, ongeveer 3 weken)
- wanneer sterk genoeg, niet meer in isolatie hoeft - herstel thuis

blok 3:

- thuis isolatie met leefregels
- herstellen, afweercellen moeten sterker worden, medicijnen
- elke week naar ziekenhuis voor control
  - infecties, bloedfabriek, tekenen van afstotingsziekte
- heel belangrijk om medicijnen goed te gebruiken
- Het kan wel 6 maanden duren tot je weer naar school mag
- 2 jaar lang controles, daarna om het half jaar




Levenslang onder controle, niet ziek meer

Ouders cellen gebruiken

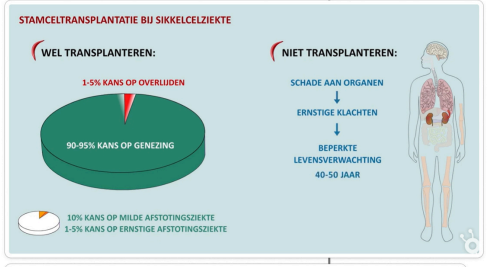
- na transplantatie een bepaald medicijn om de T-cellen daarna uit te schakelen
- effectief en veilig, hiermee voor elke patient een kans om te transplanteren

Wat is het effect?

- genezing

Risico kansen

- overlijden (1 tot 5 van de 100 kinderen)
- genezing 90-95%
- 10% patienten milde vorm van afstoting
- 1-5% op ernstige afstoting
- risico van niet transplanteren
  - schade organen → ernstige klachten → beperkte levensverwachting 40-50 jaar
  - overlijden SCD voor 18 is 4%

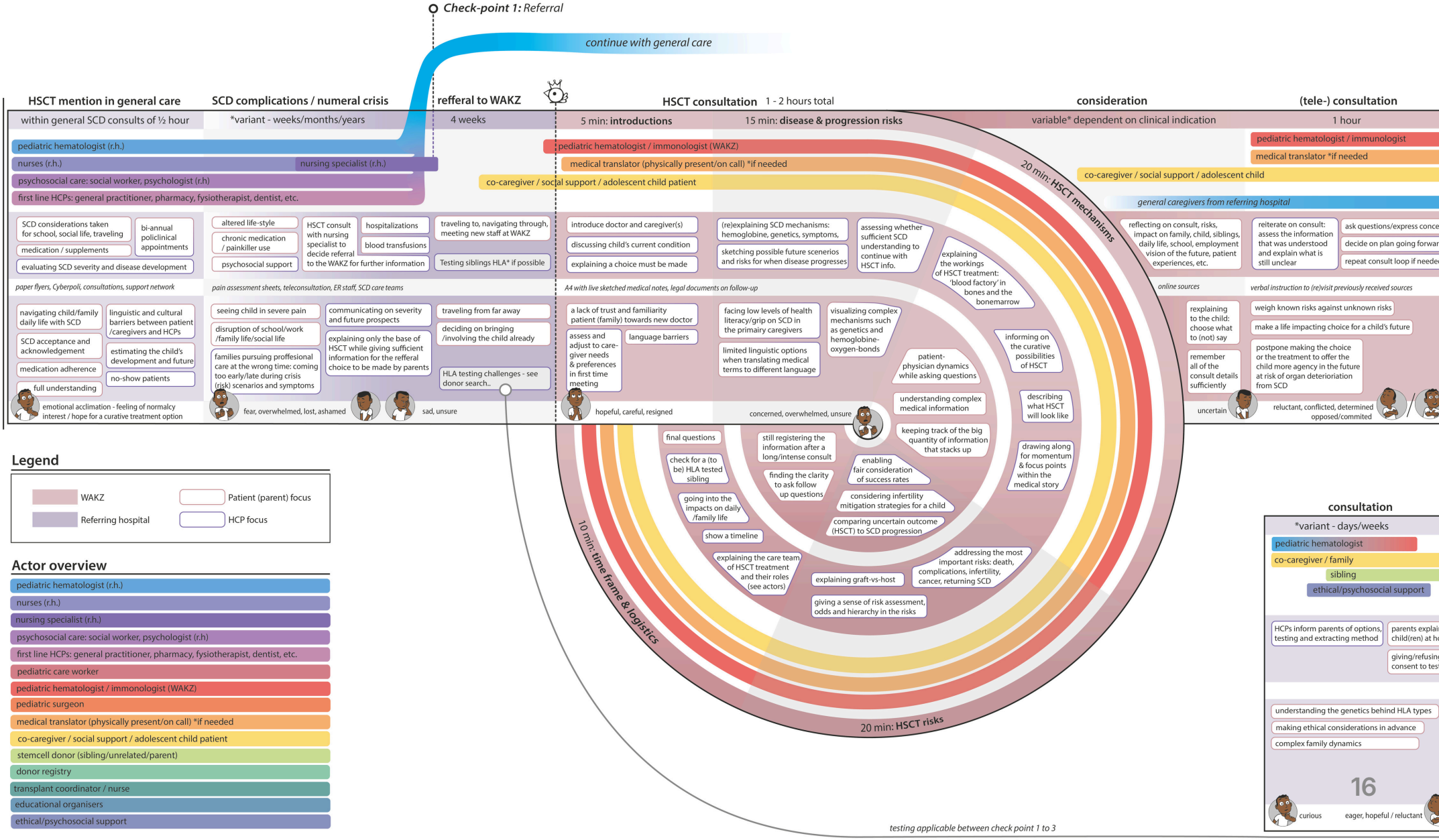




Vergelijken is een moeilijke keuze. Daar moeten we over praten en blijven praten

# APPENDIX G - **PATIENT JOURNEY MAP**

## Patient Journey Map: Shared-decision making on HSCT for pediatric sickle cell disease

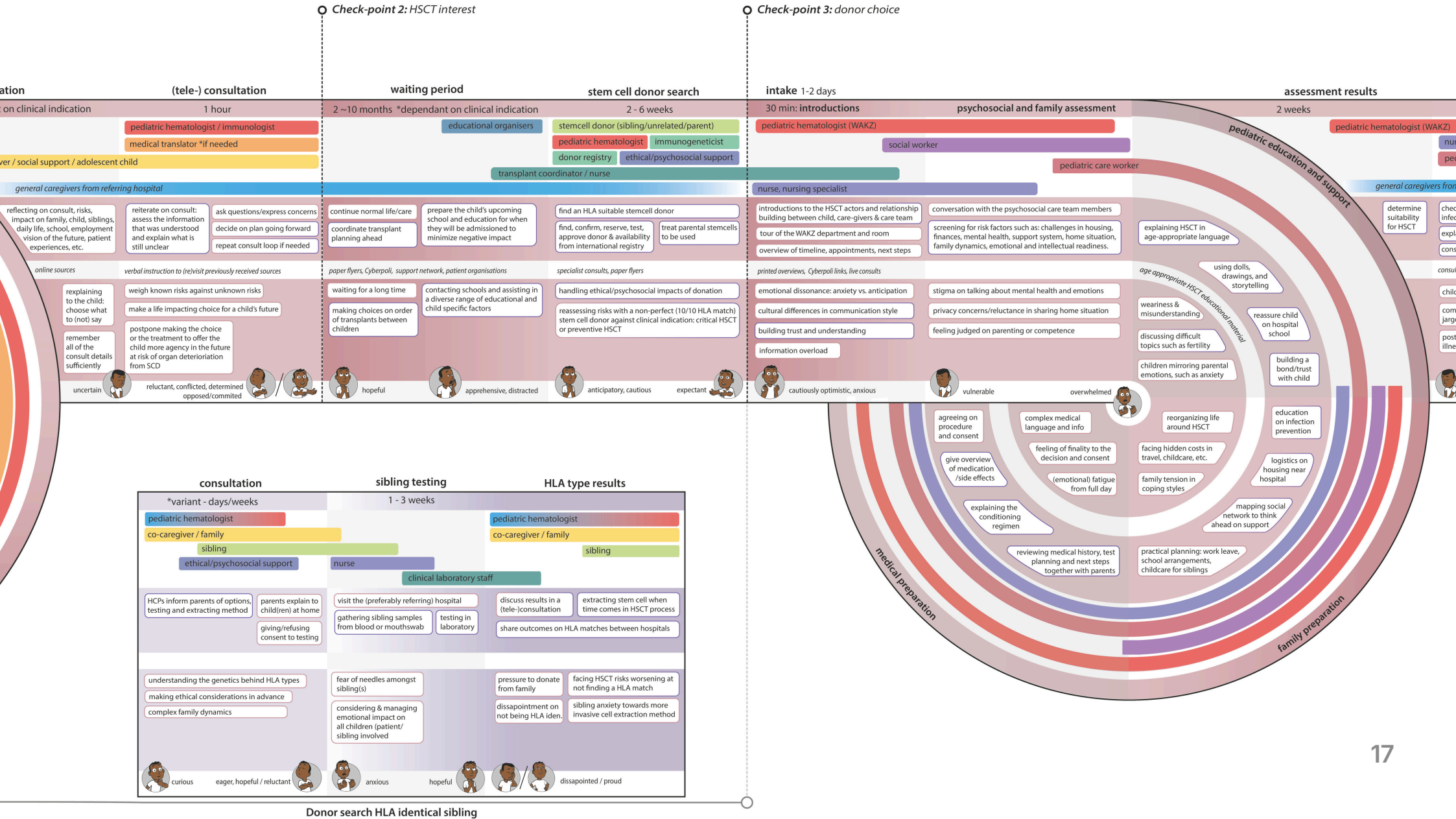


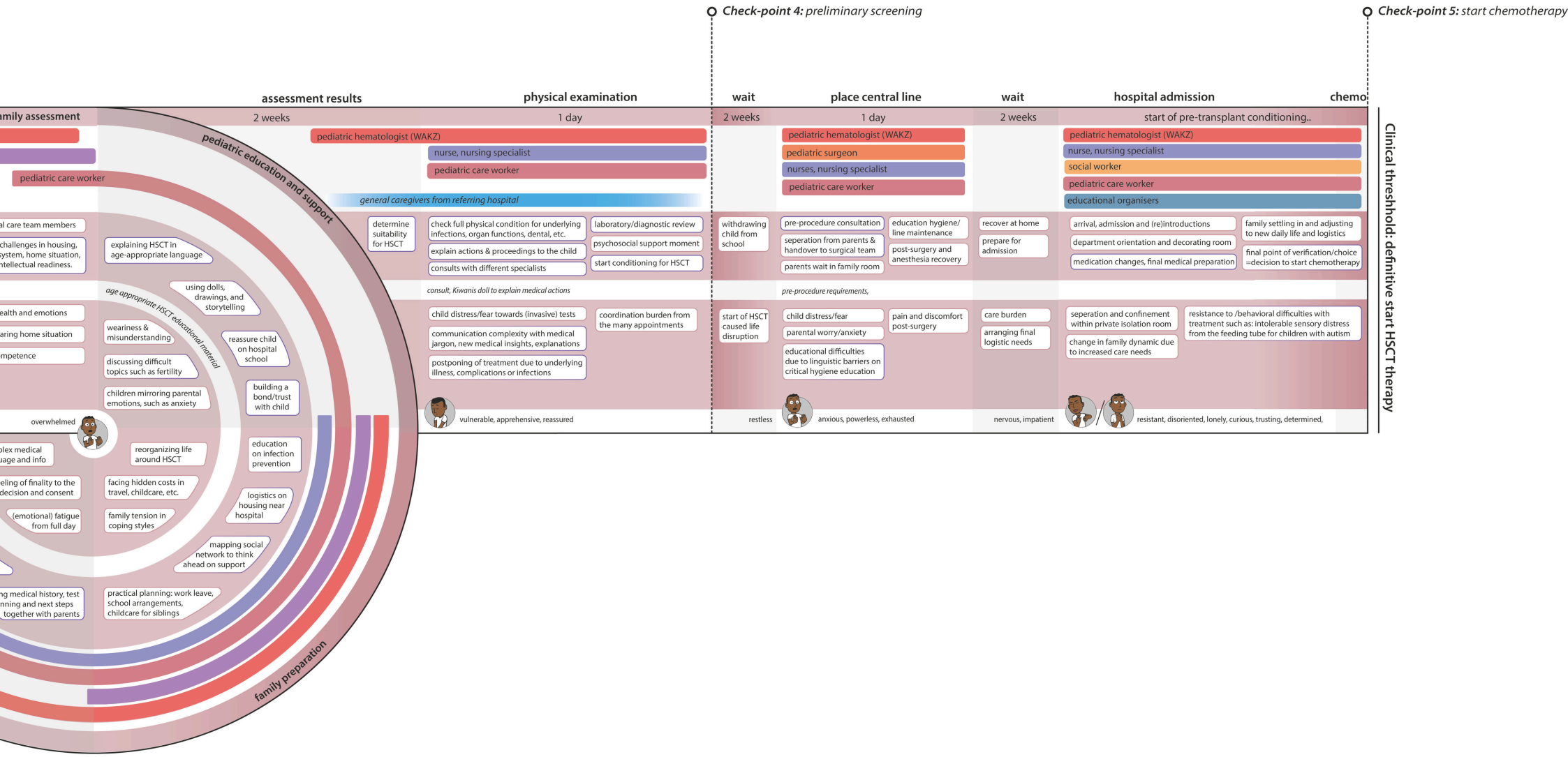

### Legend

- WAKZ
- Referring hospital
- Patient (parent) focus
- HCP focus

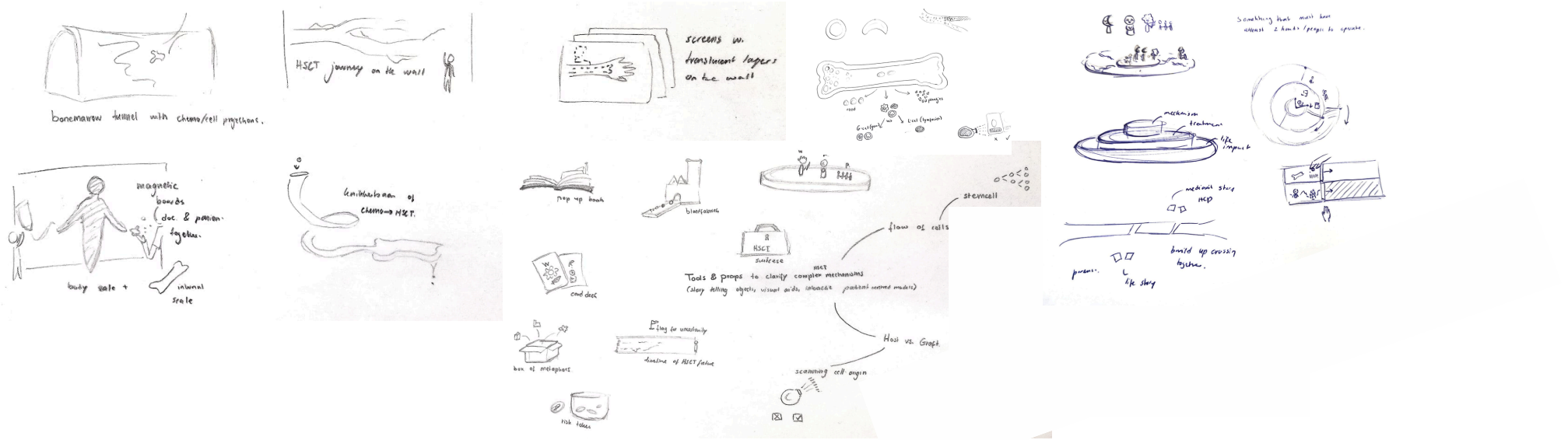
### Actor overview

- pediatric hematologist (r.h.)
- nurses (r.h.)
- nursing specialist (r.h.)
- psychosocial care: social worker, psychologist (r.h)
- first line HCPs: general practitioner, pharmacy, fysiotherapist, dentist, etc.
- pediatric care worker
- pediatric hematologist / immonologist (WAKZ)
- pediatric surgeon
- medical translator (physically present/on call) *if needed
- co-caregiver / social support / adolescent child patient
- stemcell donor (sibling/unrelated/parent)
- donor registry
- transplant coordinator / nurse
- educational organisers
- ethical/psychosocial support


Check-point 2: HSCT interest
Check-point 3: donor choice
ation
(tele-) consultation
waiting period
stem cell donor search
intake 1-2 days
assessment results
on clinical indication
1 hour
2 ~10 months *dependant on clinical indication
2 - 6 weeks
30 min: introductions
psychosocial and family assessment
2 weeks
pediatric hematologist / immunologist
medical translator *if needed
ver / social support / adolescent child
educational organisers
stemcell donor (sibling/unrelated/parent)
pediatric hematologist
immunogeneticist
donor registry
ethical/psychosocial support
transplant coordinator / nurse
pediatric hematologist (WAKZ)
social worker
pediatric care worker
nurse, nursing specialist
general caregivers from referring hospital
general caregivers fron
reflecting on consult, risks, impact on family, child, siblings, daily life, school, employment vision of the future, patient experiences, etc.
reiterate on consult: assess the information that was understood and explain what is still unclear
ask questions/express concerns
decide on plan going forward
repeat consult loop if needed
continue normal life/care
coordinate transplant planning ahead
prepare the child's upcoming school and education for when they will be admissioned to minimize negative impact
find an HLA suitable stemcell donor
find, confirm, reserve, test, approve donor & availability from international registry
treat parental stemcells to be used
introductions to the HSCT actors and relationship building between child, care-givers & care team
tour of the WAKZ department and room
overview of timeline, appointments, next steps
conversation with the psychosocial care team members
screening for risk factors such as: challenges in housing, finances, mental health, support system, home situation, family dynamics, emotional and intellectual readiness.
determine suitability for HSCT
online sources
verbal instruction to (re)visit previously received sources
paper flyers, Cyberpoli, support network, patient organisations
specialist consults, paper flyers
printed overviews, Cyberpoli links, live consults
reexplaining to the child: choose what to (not) say
weigh known risks against unknown risks
make a life impacting choice for a child's future
remember all of the consult details sufficiently
postpone making the choice or the treatment to offer the child more agency in the future at risk of organ deterioration from SCD
waiting for a long time
making choices on order of transplants between children
contacting schools and assisting in a diverse range of educational and child specific factors
handling ethical/psychosocial impacts of donation
reassessing risks with a non-perfect (10/10 HLA match) stem cell donor against clinical indication: critical HSCT or preventive HSCT
emotional dissonance: anxiety vs. anticipation
cultural differences in communication style
building trust and understanding
information overload
stigma on talking about mental health and emotions
privacy concerns/reluctance in sharing home situation
feeling judged on parenting or competence
explaining HSCT in age-appropriate language
age appropriate HSCT educational material
using dolls, drawings, and storytelling
weariness & misunderstanding
reassure child on hospital school
discussing difficult topics such as fertility
building a bond/trust with child
children mirroring parental emotions, such as anxiety
uncertain
reluctant, conflicted, determined
opposed/commited
hopeful
apprehensive, distracted
anticipatory, cautious
expectant
cautiously optimistic, anxious
vulnerable
overwhelmed
pediatric education and support
medical preparation
family preparation
agreeing on procedure and consent
complex medical language and info
reorganizing life around HSCT
education on infection prevention
feeling of finality to the decision and consent
facing hidden costs in travel, childcare, etc.
give overview of medication /side effects
(emotional) fatigue from full day
logistics on housing near hospital
family tension in coping styles
explaining the conditioning regimen
mapping social network to think ahead on support
reviewing medical history, test planning and next steps together with parents
practical planning: work leave, school arrangements, childcare for siblings
consultation
sibling testing
HLA type results
*variant - days/weeks
1 - 3 weeks
pediatric hematologist
co-caregiver / family
sibling
ethical/psychosocial support
nurse
clinical laboratory staff
HCPs inform parents of options, testing and extracting method
parents explain to child(ren) at home
giving/refusing consent to testing
visit the (preferably referring) hospital
gathering sibling samples from blood or mouthswab
testing in laboratory
discuss results in a (tele-)consultation
extracting stem cell when time comes in HSCT process
share outcomes on HLA matches between hospitals
understanding the genetics behind HLA types
making ethical considerations in advance
complex family dynamics
fear of needles amongst sibling(s)
considering & managing emotional impact on all children (patient/ sibling involved
pressure to donate from family
facing HSCT risks worsening at not finding a HLA match
dissapointment on not being HLA iden.
sibling anxiety towards more invasive cell extraction method
curious
eager, hopeful / reluctant
anxious
hopeful
dissapointed / proud
Donor search HLA identical sibling


Check-point 4: preliminary screening
Check-point 5: start chemotherapy
assessment results
physical examination
wait
place central line
wait
hospital admission
chemo
amily assessment
2 weeks
1 day
2 weeks
1 day
2 weeks
start of pre-transplant conditioning..
pediatric hematologist (WAKZ)
nurse, nursing specialist
pediatric care worker
pediatric hematologist (WAKZ)
pediatric surgeon
nurses, nursing specialist
pediatric care worker
pediatric hematologist (WAKZ)
nurse, nursing specialist
social worker
pediatric care worker
educational organisers
general caregivers from referring hospital
pediatric care worker
pediatric education and support
al care team members
challenges in housing, system, home situation, ntellectual readiness.
explaining HSCT in age-appropriate language
determine suitability for HSCT
check full physical condition for underlying infections, organ functions, dental, etc.
explain actions & proceedings to the child
consults with different specialists
laboratory/diagnostic review
psychosocial support moment
start conditioning for HSCT
withdrawing child from school
pre-procedure consultation
seperation from parents & handover to surgical team
parents wait in family room
education hygiene/ line maintenance
post-surgery and anesthesia recovery
recover at home
prepare for admission
arrival, admission and (re)introductions
department orientation and decorating room
medication changes, final medical preparation
family settling in and adjusting to new daily life and logistics
final point of verification/choice =decision to start chemotherapy
consult, Kiwanis doll to explain medical actions
pre-procedure requirements,
ealth and emotions
aring home situation
mpetence
using dolls, drawings, and storytelling
age appropriate HSCT educational material
weariness & misunderstanding
reassure child on hospital school
discussing difficult topics such as fertility
building a bond/trust with child
children mirroring parental emotions, such as anxiety
child distress/fear towards (invasive) tests
communication complexity with medical jargon, new medical insights, explanations
postponing of treatment due to underlying illness, complications or infections
coordination burden from the many appointments
start of HSCT caused life disruption
child distress/fear
parental worry/anxiety
educational difficulties due to linguistic barriers on critical hygiene education
pain and discomfort post-surgery
care burden
arranging final logistic needs
seperation and confinement within private isolation room
change in family dynamic due to increased care needs
resistance to /behavioral difficulties with treatment such as: intolerable sensory distress from the feeding tube for children with autism
overwhelmed
vulnerable, apprehensive, reassured
restless
anxious, powerless, exhausted
nervous, impatient
resistant, disoriented, lonely, curious, trusting, determined,
plex medical uage and info
reorganizing life around HSCT
education on infection prevention
eling of finality to the decision and consent
facing hidden costs in travel, childcare, etc.
logistics on housing near hospital
(emotional) fatigue from full day
family tension in coping styles
mapping social network to think ahead on support
g medical history, test nning and next steps together with parents
practical planning: work leave, school arrangements, childcare for siblings
family preparation
Clinical threshhold: definitive start HSCT therapy

# APPENDIX H - **IDEATION & ITERATIONS**




**scale & 'levels'**

- molecule (DNA)
- cells
- organs
- body (child)
- treatment items
- life impact

**context** **materials** **adaptability** **momentum**

**complexity hotspots**

- HLA matching
- genetics
- cell interactions
- graft vs. host
- isolation needs
- treatment steps

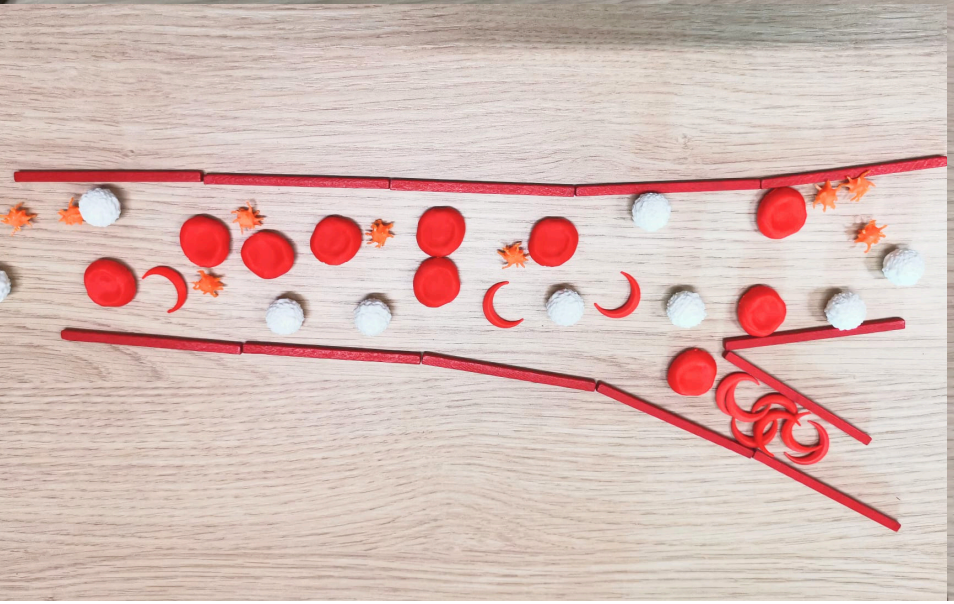
**minimal storytelling vs. sufficient information**

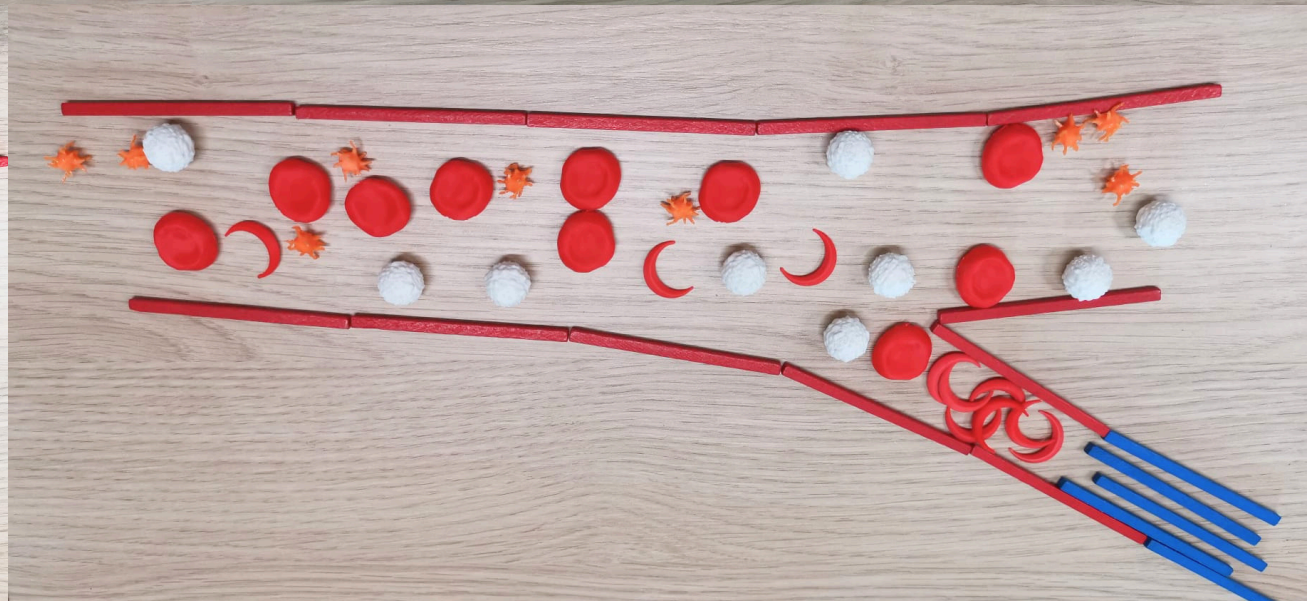
- narrative guidelines (involve (medical)storytelling expert)

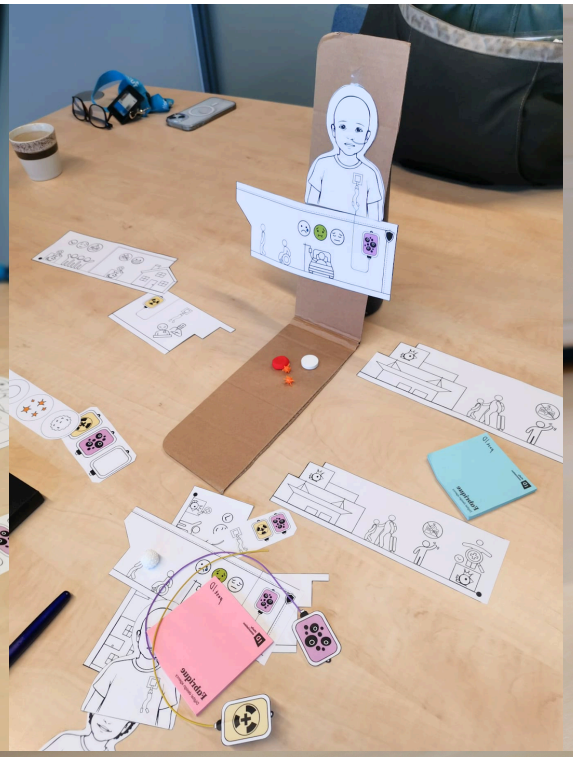
**guidelines** **toolkit** **usability**

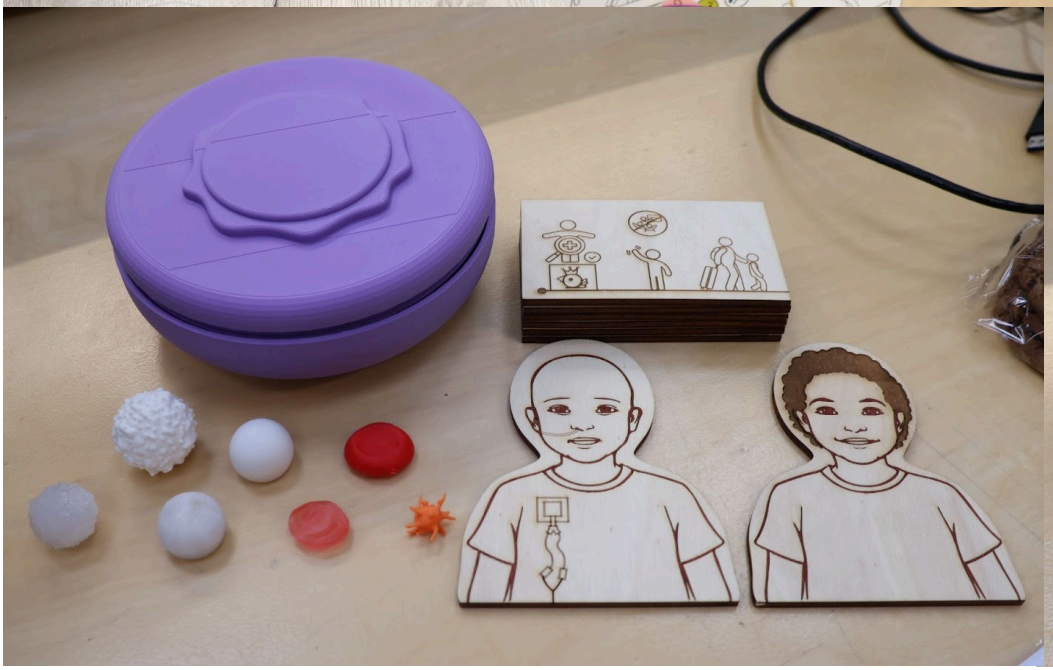
**selecting components**

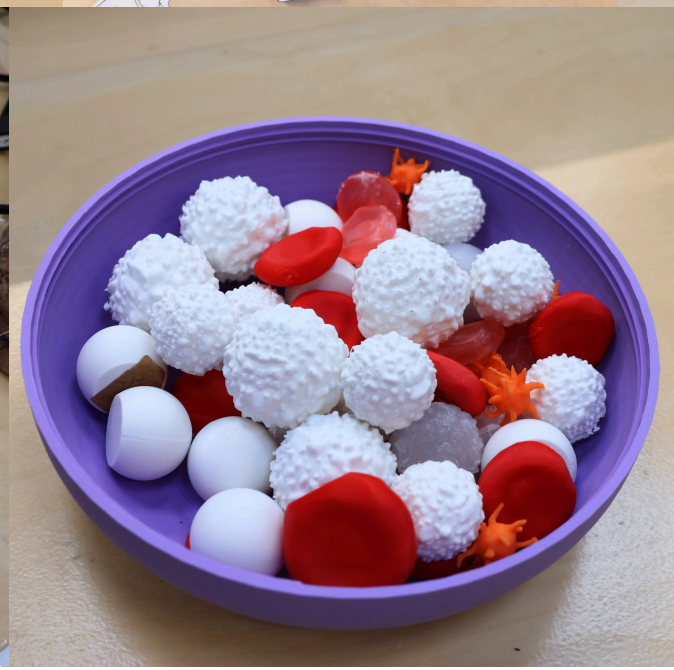
- stem cell development
- immune acceptance



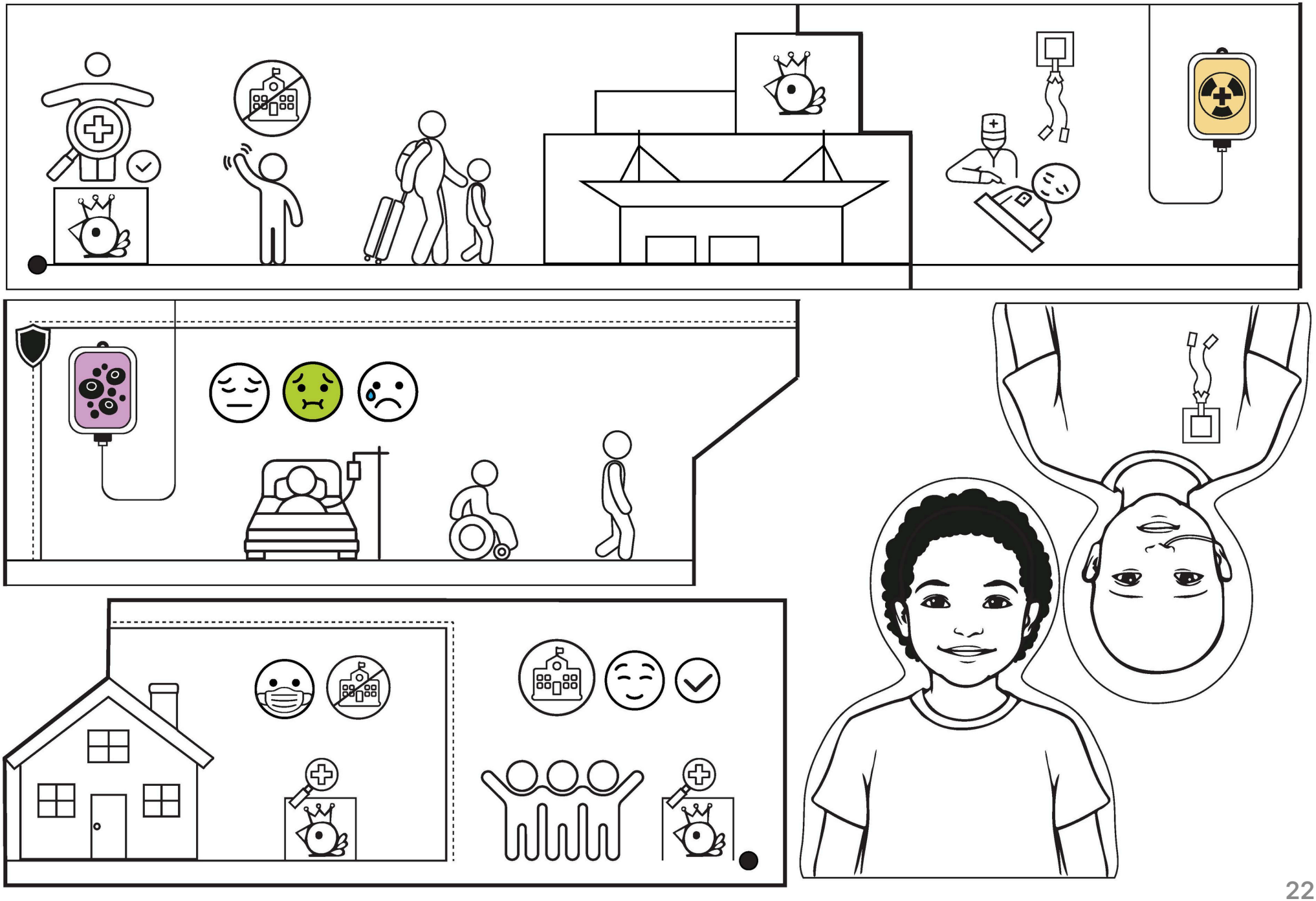




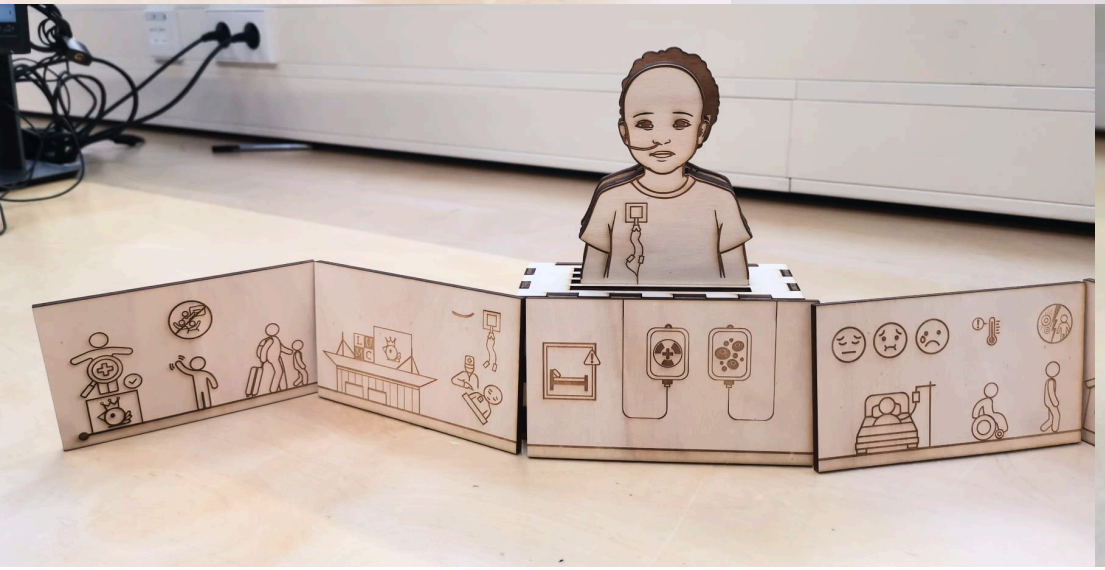


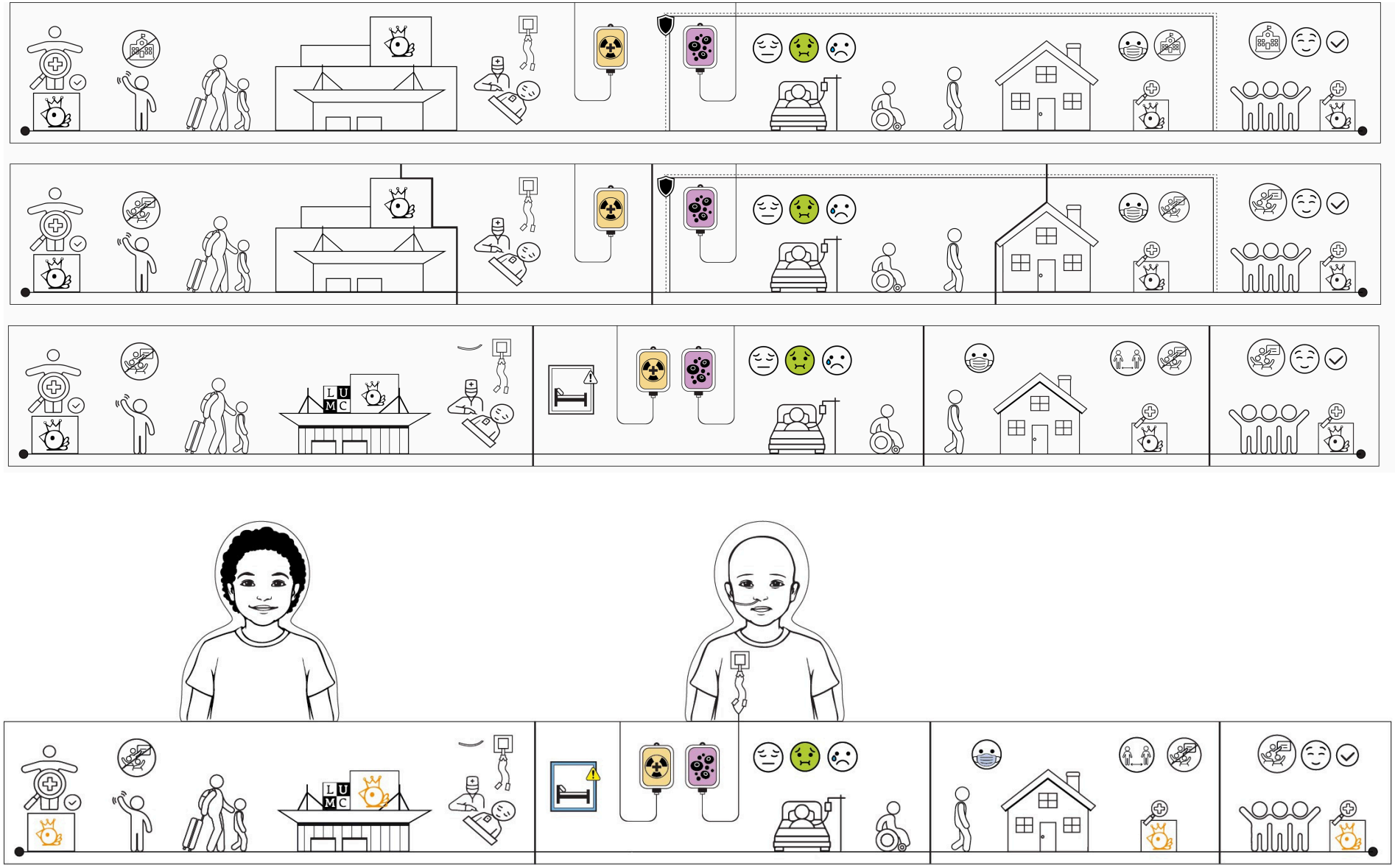



Samenwerkingsafspraken en tips voor gesprekken



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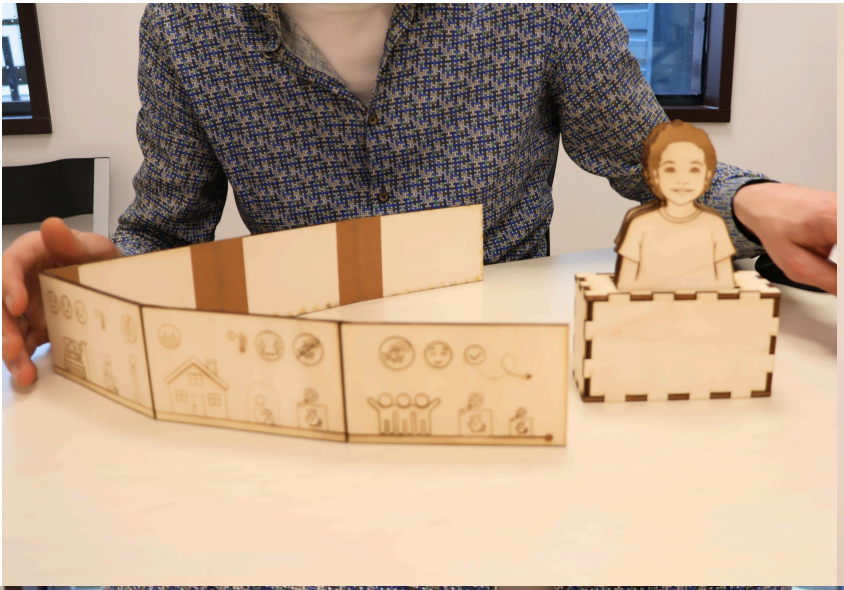
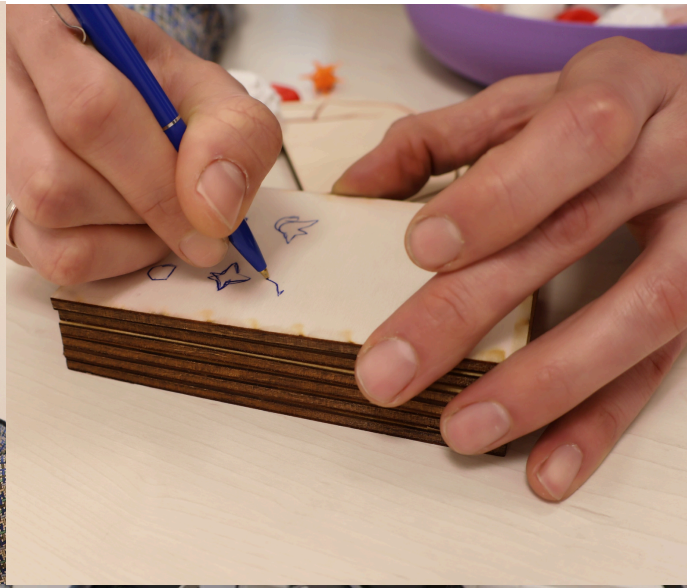
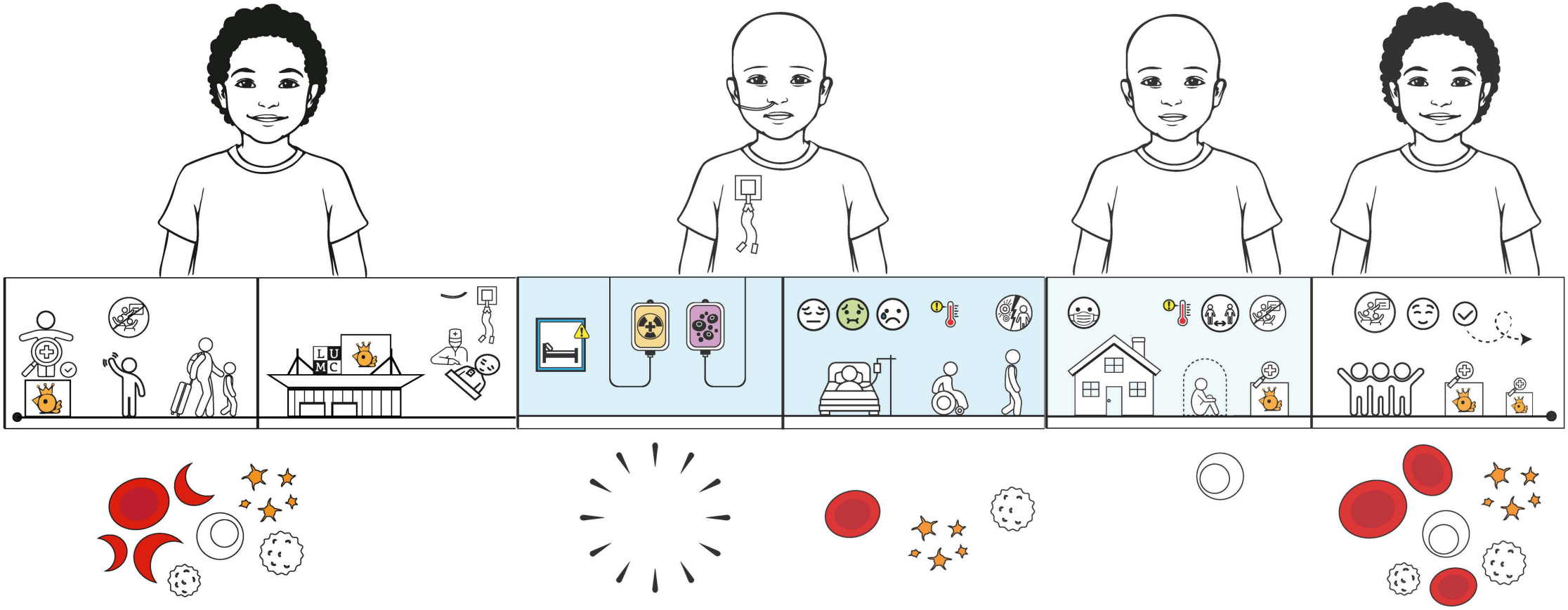
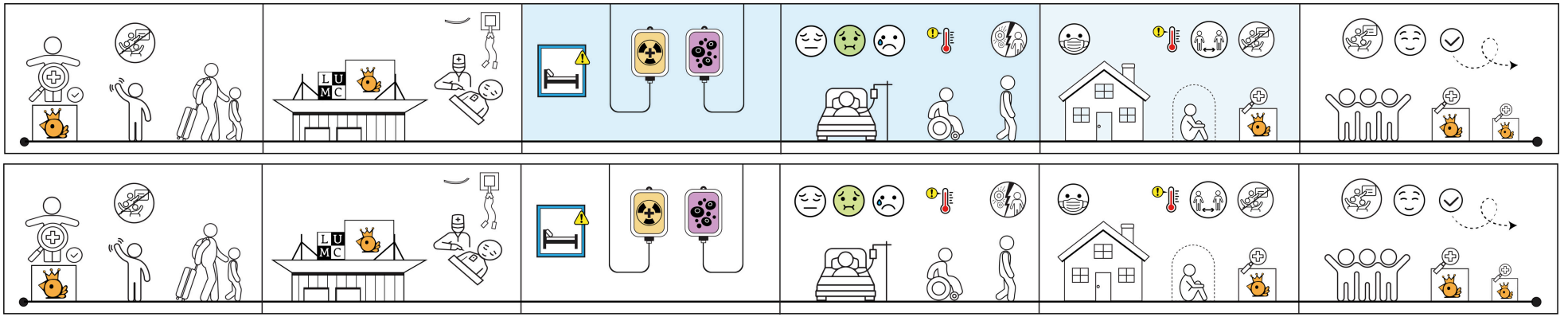




*ONE-PAGER 8TH ITERATION*

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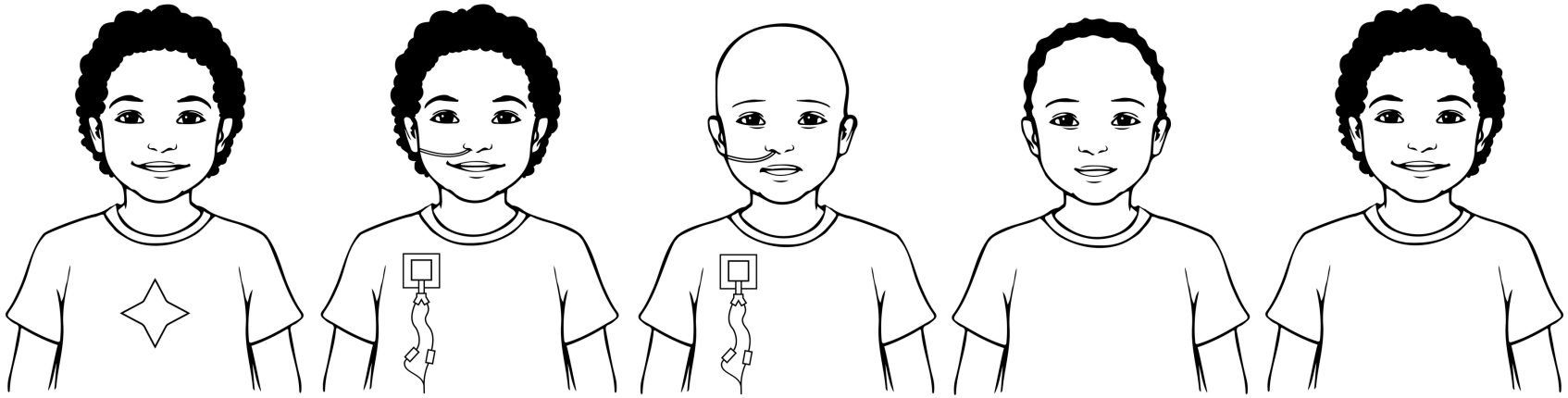
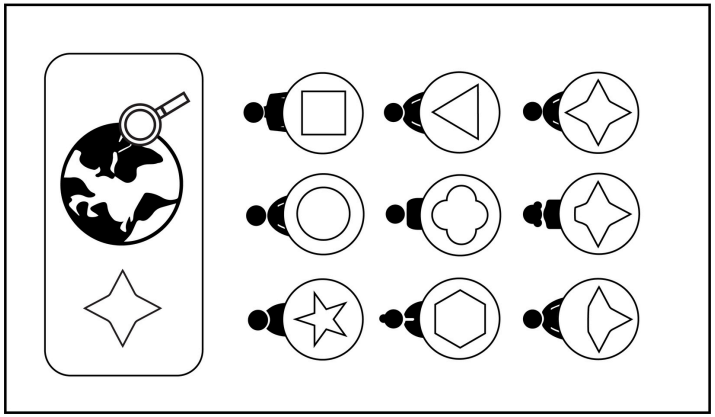
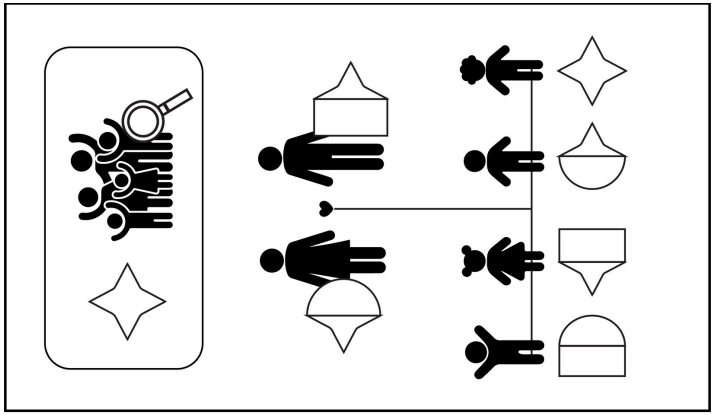






# APPENDIX I - **CELLS**

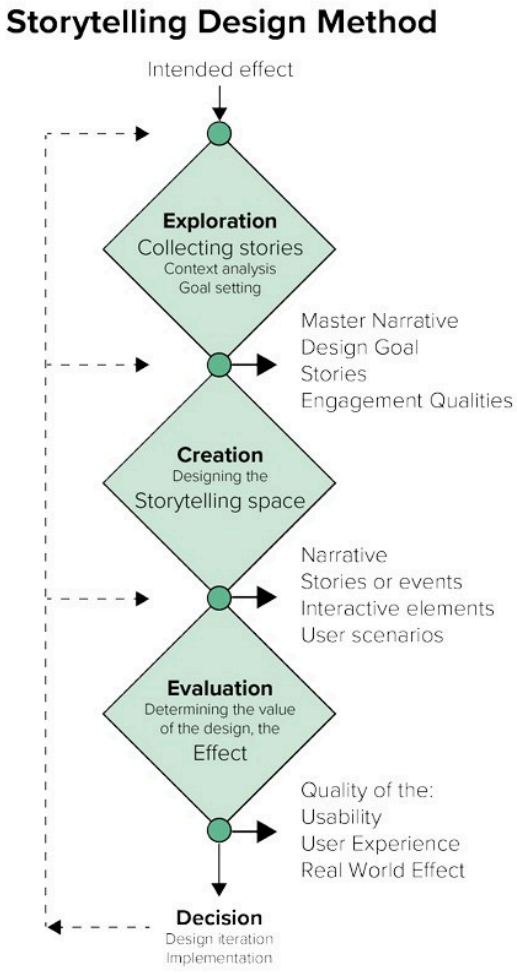
| Cell | Variations | Ct. | d(cm) | Role |
|---|---|---|---|---|
| **Stem cell** | Container (purple) | 2 | 12 | Stores the other cells that can 'come from' the stem cell. The two cell-shaped boxes separate the sick patient cells from the healthy donor cells. |
| | Small (purple) | 10 | 3 | These smaller variations show how stem cells can grow from other stem cells and how they are reintroduced after transplantation, before growing into specified blood cells.<br><br>The stem cells hold an positive star shape that matches with the lymphocyte, which represents the HLA type. |
| **Red blood cell** | Healthy (red) | 10 | 3 | The red blood cell carries oxygen and is recognizable for its colour and shape. |
| | Diseased (pink translucent) | 6 | 2.5 | The smaller, pink, translucent red blood cell differentiates from the healthy cell and represents haemoglobinopathies (diseases of the red blood cells), for example, beta-thalassaemia. |
| | Sickle cell (red) | 6 | 3 | The crescent red cell represents sickle cell disease, assisting in the explanation of decreased oxygen uptake and the clustering effect of sickle-shaped cells, resulting in blocked blood vessels. |
| **Lymphocyte** | Healthy (white) | 10 | 3 | The smooth, round white blood cell protects the body against viruses. It is the last to grow back and does so during the home-isolation phase, late into the treatment. It is also the cell that causes Graft vs. Host, a dangerous complication of HSCT. It is the cell that scans whether cells are endogenous.<br><br>The healthy lymphocyte holds a negative star shape that matches with the lymphocyte, this represents the HLA type. |
| | Diseased (transparent) | 6 | 3 | The transparent lymphocytes represent cells affected by lymphocyte disorders, such as severe combined immunodeficiency (SCID)<br><br>The unhealthy lymphocyte also holds a negative star shape that matches with the lymphocyte, this represents the HLA type. |
| **Granulocyte** | Healthy (white) | 6 | 4 | The biggest of the white blood cells protects from bacteria, the third cell to grow back during hospital isolation |
| | diseased (transparent) | 3 | 3 | The transparent granulocytes represent cells affected by granulocytopoiesis such as chronic granulomatous disease (CGD) |
| **Platelets** | Healthy (orange) | 10 | 2.5 | The blood platelets clot together as they do to create scabs when injured. They return second after HSCT. They are the smallest blood cells. |
| | Diseased (grey) | 6 | 2.5 | Grey versions of the platelets represent the (rare) transplantable diseases affecting platelets. |

# APPENDIX J - **STORYTELLING FRAMEWORKS**

## STORIES: An evidence-based framework for storytelling excellence

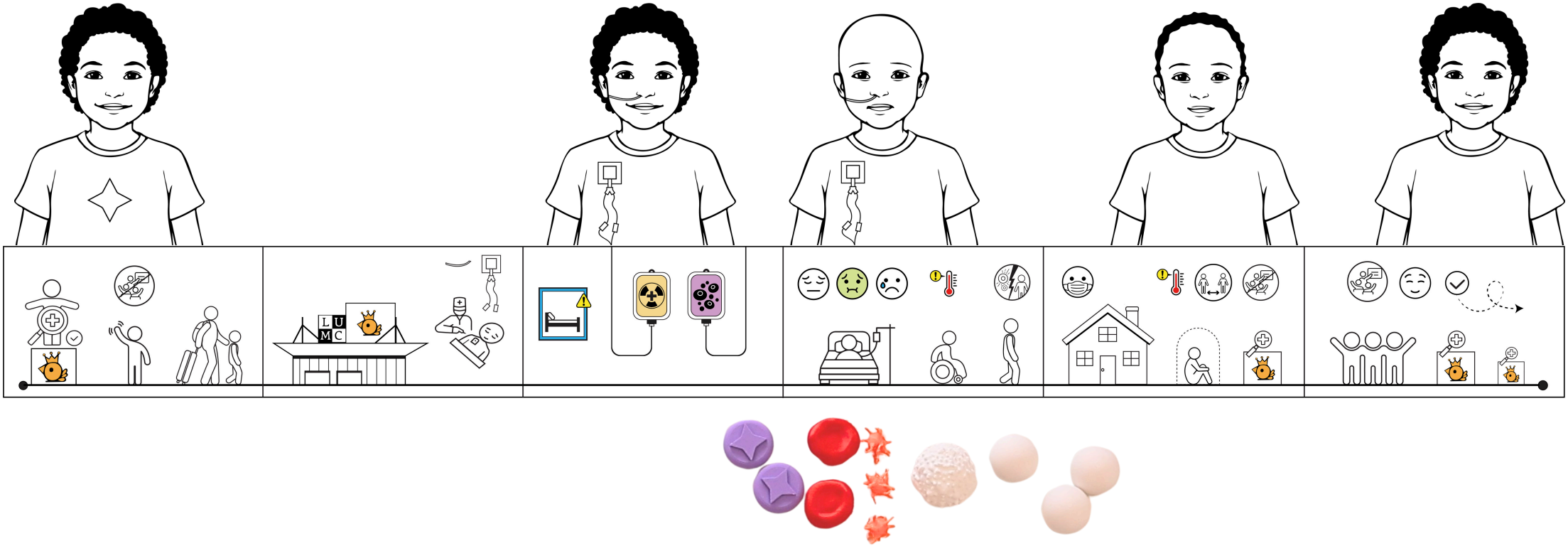
| S | T | O | R | I | E | S |
|---|---|---|---|---|---|---|
| STRUCTURE | TAILORING | ORIGINALITY | RATIONALITY | IMMEDIACY | EMOTIONALITY | SIMPLICITY |
| Maximize the use of the structural features of stories that give them their power[10-12] | Effective stories are always developed with the audience in mind[13-20] | Novelty is needed for stories to grab and keep attention, engage, and be memorable[21,22] | Standards of *narrative rationality* are key to establishing credibility[25] | Creating a sense of psychological closeness with the audience increases urgency[26-28] | Emotional content makes stories more engaging, persuasive, and memorable[7,30-33] | Distill complexity to simplicity to increase comprehension and impact[37-45] |
| • **Cause-and-effect relationships** between events create meaning, build tension, and drive momentum<br>• **Setting** (a time or place) provides context<br>• **Protagonist(s)** should be included if possible | • **Ensure relevancy** by understanding the audience (knowledge gaps, attitudes, beliefs) and tailoring the story accordingly<br>• **Leverage *identification*** (a mechanism by which recipients of a story feel they can relate to the protagonist), thereby making the story more persuasive | • **Provide a fresh perspective** on a familiar topic<br>• **Adopt a less common narrative arc**—sequence the plot differently<br>• **Provide unexpected—but relevant—details**<br>• **Include a "hook"** to pique the audience's curiosity (eg, an unanswered question) | • **Ensure *coherence*** (the extent to which the story "hangs together" and makes sense) by iterative testing and refinement<br>• **Optimize *fidelity*** (the extent to which the story resonates with the beliefs and values of the audience) via extensive research or even stakeholder co-creation | • **Adopt a first-person narrative voice** to increase the immediacy of stories<br>• **Use present tense verbs** over past tense ones, where appropriate | • **Including the experiences of individuals** (eg, patients, HCPs, researchers) can bring statistics and abstract concepts to life, promote empathy, and inspire action<br>• **The measured use of emotive language** can increase the impact of stories | • **Identify the core messages** and omit extraneous and tangential elements<br>• **Use metaphors and analogies** for understanding of complex or abstract concepts<br>• **Incorporate visual storytelling** to facilitate conceptual understanding of complex topics |

*An evidence-based framework for storytelling excellence includes seven key considerations for effective, purpose-driven stories. Note. From Storytelling: The Underappreciated Cornerstone of Evidence-Based Medical Communications, by S. Towers. (2020). Medical Affairs Professional Society.*




*Note. From Healthy Storytelling: Hoe storytelling design kan helpen om overgewicht en obesitas te verminderen, by Visch, V.T., Vegt, N.J.H., van Boeijen A.G.C. (2021), Delft: Technische Universiteit Delft – faculteit Industrieel Ontwerpen.*

# APPENDIX K - **ONE-PAGER FINAL**



# APPENDIX L - **CONSENT FORMS**

**Informed Consent – Research Sessions: HSCT Consultation Tools**

***Healthcare Professionals***

You are invited to participate in a research session as part of a Master's thesis project titled "Designing tangible tools for complex consultation on pediatric life-altering treatments." This study is conducted by Delft University of Technology (TU Delft) master's student Charlotte van Kats as thesis for the Integrated Product Design programme. The research is carried out in collaboration with clinicians from Sophia Children's Hospital in Rotterdam and Willem-Alexander Children's Hospital in Leiden.

The aim of this project is to explore how tangible tools and visual aids can support communication and information uptake during consultations about pediatric hematopoietic stem cell transplantation (HSCT). The research seeks to develop and evaluate concepts that may help patients and parents better understand the treatment pathway. The outcomes of this study will contribute to the researcher's Master's thesis and may inform future design research on clinical communication tools.

Participants in this study are healthcare professionals involved in consultations on pediatric HSCT. During the session, you will be asked to participate in a research interview and concept evaluation session lasting approximately 45 minutes. Specifically, you may be asked to:

- Share your experience with stem cell transplant consultations and conversations
- Review and interact with visualizations of the HSCT care pathway
- Reflect on design concepts intended to support consultation conversations

Your input will help evaluate and refine the proposed toolkit to align with the needs of healthcare professionals involved in HSCT consultations.

During this research session, limited personal data may be collected, such as your relation to the topic and your responses during the session. No personally identifiable information will be collected. The research sessions will not be audio- or video-recorded. Notes taken during the session will be de-identified and anonymized before analysis. Personal information will be handled confidentially and stored securely by the researcher in accordance with the data management guidelines of the TU Delft.

The collected data will be used solely for academic research purposes, including analysis, reporting within the Master's thesis, and academic dissemination, such as presentations. Data will be reported in anonymized form, ensuring that individual participants cannot be identified. Access to the research data will be restricted to the researcher and academic supervisors. Research data may be archived securely for a defined retention period of 10 years in line with TU Delft research data policies and may be deposited in the TU Delft research repository in anonymized form.

Participation in this study is voluntary. You may choose not to answer any question and may pause or withdraw from the study at any time without giving a reason. Any data related to your participation can be removed from the dataset if requested.

Some discussion topics related to stem cell transplantation and life-altering treatment decisions may be emotionally sensitive. You are free to pause or skip any question if you feel uncomfortable. No foreseeable physical or reputational risks are expected from participation.

Participants will not receive financial compensation for participation.

If you have questions about this research or would like to withdraw your data, please contact:


Corresponding Researcher: Charlotte van Kats
*Master's Student, Industrial Design Engineering*
*Delft University of Technology*
*Email: C.H.vanKats@student.tudelft.nl*

Supervisor: Armagan Albayrak
*Assistant Professor, Human Centred Design*
*Delft University of Technology*
*Email: A.Albayrak@tudelft.nl*


If you have concerns or complaints regarding this research, you may contact the responsible researcher using the details above.

By signing this consent form (or agreeing verbally before the session begins), you confirm that you have read and understood the information above and voluntarily agree to participate in this study.

| Explicit Consent Checklist | Yes | No |
|---|---|---|
| 1. I have read and understood the study information dated 11/3/2026 or it has been read to me. I have been able to ask questions about the study and my questions have been answered to my satisfaction. | ☐ | ☐ |
| 2. I consent voluntarily to be a participant in this study and understand that I can refuse to answer questions and I can withdraw from the study at any time, without having to give a reason. | ☐ | ☐ |
| 3. I understand that taking part in the study involves:<br>• Sharing your experience with stem cell transplant consultations and conversations<br>• Reviewing and interacting with visualizations of the HSCT care pathway<br>• Reflecting on design concepts intended to support consultation conversations<br>Findings are anonymized and recorded through written notes | ☐ | ☐ |
| 4. I understand that taking part in the study involves topics related to stem cell transplantation and life-altering treatment decisions that may be emotionally sensitive. I understand that these will be mitigated by being able to pause or skip a question/topic or stop the session at any time. | ☐ | ☐ |
| 5. I understand that personal information that can identify me, such as my name, where I live, my medical details, and my treatment preferences, will **not** be collected in the research.<br>The personal data that will be collected is: role in relation to HSCT conversations (patient representative/ healthcare professional) and HSCT conversation experiences. | ☐ | ☐ |
| 6. I understand that the personal data I provide will be deleted at the project end date May 2026 or passed on to supervisors for anonymized storage in the secure TU Delft Surfspot environment, where it shall be destroyed after 10 years. | ☐ | ☐ |
| 7. I agree that my responses, views or other input can be quoted anonymously in research outputs | ☐ | ☐ |
| 8. I give permission for the de-identified HSCT role and consultation experience that I provide to be archived in the TU Delft repository so it can be used for future research and learning. | ☐ | ☐ |

**Signatures**

| Name of participant | Signature | Date |
|---|---|---|
| | | |

I, as researcher, have accurately read out the information sheet to the potential participant and, to the best of my ability, ensured that the participant understands to what they are freely consenting.

| Researcher name | Signature | Date |
|---|---|---|
| | | |

Study contact details for further information: Charlotte van Kats, 06 30486777, C.H.vankats@student.tudelft.nl

## Informed Consent – Research Sessions: HSCT Consultation Tools

***Patient Representatives***

You are invited to participate in a research session as part of a Master's thesis project titled "Designing Tangible Tools for Shared Decision-Making in Pediatric Life-Altering Treatments." This study is conducted by Delft University of Technology (TU Delft) master's student Charlotte van Kats as thesis for the Integrated Product Design programme. The research is carried out in collaboration with clinicians from Sophia Children's Hospital in Rotterdam and Willem-Alexander Children's Hospital in Leiden.

The aim of this project is to explore how tangible tools and visual aids can support communication and information uptake during consultations about pediatric hematopoietic stem cell transplantation (HSCT). The research seeks to develop and evaluate concepts and prototypes that may help patients and parents better understand the treatment pathway. The outcomes of this study will contribute to the researcher's Master's thesis and may inform future design research on clinical communication tools.

Participants in this study are healthcare professionals or experts involved in HSCT consultations and pediatric care. During the session, you will be asked to participate in a research interview and prototype evaluation session lasting approximately 45 minutes. Specifically, you may be asked to:

- Share your experience with stem cell transplant consultations and conversations
- Review and interact with visualizations of the HSCT care pathway
- Reflect on design concepts intended to support consultation conversations

Your input will help evaluate and refine the proposed toolkit to align with the needs of healthcare professionals and families involved in HSCT consultations.

During this research session, limited personal data may be collected, such as your relation to the topic and your responses during the session. No personally identifiable patient information will be collected. The research sessions will not be audio- or video-recorded. Notes taken during the session will be de-identified and anonymized before analysis. Personal information will be handled confidentially and stored securely by the researcher in accordance with the data management guidelines of the TU Delft.

The collected data will be used solely for academic research purposes, including analysis, reporting within the Master's thesis, and academic dissemination, such as presentations. Data will be reported in anonymized form, ensuring that individual participants cannot be identified. Access to the research data will be restricted to the researcher and academic supervisors. Research data may be archived securely for a defined retention period of 10 years in line with TU Delft research data policies and may be deposited in the TU Delft research repository in anonymized form.

Participation in this study is voluntary. You may choose not to answer any question and may pause or withdraw from the study at any time without giving a reason. Any data related to your participation can be removed from the dataset if requested.

Some discussion topics related to stem cell transplantation and life-altering treatment decisions may be emotionally sensitive. You are free to pause or skip any question if you feel uncomfortable. No foreseeable physical or reputational risks are expected from participation.

Participants will not receive financial compensation for participation.

If you have questions about this research or would like to withdraw your data, please contact:


Corresponding Researcher: Charlotte van Kats
*Master's Student, Industrial Design Engineering*
*Delft University of Technology*
*Email: C.H.vanKats@student.tudelft.nl*

Supervisor: Armagan Albayrak
*Assistant Professor, Human Centred Design*
*Delft University of Technology*
*Email: A.Albayrak@tudelft.nl*


If you have concerns or complaints regarding this research, you may contact the responsible researcher using the details above.

By signing this consent form (or agreeing verbally before the session begins), you confirm that you have read and understood the information above and voluntarily agree to participate in this study.

| Explicit Consent Checklist | Yes | No |
|---|---|---|
| 1. I have read and understood the study information dated 11/3/2026 or it has been read to me. I have been able to ask questions about the study and my questions have been answered to my satisfaction. | ☐ | ☐ |
| 2. I consent voluntarily to be a participant in this study and understand that I can refuse to answer questions and I can withdraw from the study at any time, without having to give a reason. | ☐ | ☐ |
| 3. I understand that taking part in the study involves:<br>• Sharing your experience with stem cell transplant consultations and conversations<br>• Reviewing and interacting with visualizations of the HSCT care pathway<br>• Reflecting on design concepts intended to support consultation conversations<br>Findings are anonymized and recorded through written notes | ☐ | ☐ |
| 4. I understand that taking part in the study involves topics related to stem cell transplantation and life-altering treatment decisions that may be emotionally sensitive. I understand that these will be mitigated by being able to pause or skip a question/topic or stop the session at any time. | ☐ | ☐ |
| 5. I understand that personal information that can identify me, such as my name, where I live, my medical details, and my treatment preferences, will **not** be collected in the research.<br>The personal data that will be collected is: role in relation to HSCT conversations (patient representative/ healthcare professional) and HSCT conversation experiences. | ☐ | ☐ |
| 6. I understand that the personal data I provide will be deleted at the project end date May 2026 or passed on to supervisors for anonymized storage in the secure TU Delft Surfspot environment, where it shall be destroyed after 10 years. | ☐ | ☐ |
| 7. I agree that my responses, views or other input can be quoted anonymously in research outputs | ☐ | ☐ |
| 8. I give permission for the de-identified HSCT role and consultation experience that I provide to be archived in the TU Delft repository so it can be used for future research and learning. | ☐ | ☐ |

**Signatures**

| Name of participant | Signature | Date |
|---|---|---|
| | | |

I, as researcher, have accurately read out the information sheet to the potential participant and, to the best of my ability, ensured that the participant understands to what they are freely consenting.

| Researcher name | Signature | Date |
|---|---|---|
| | | |

Study contact details for further information: Charlotte van Kats, 06 30486777, C.H.vankats@student.tudelft.nl

# APPENDIX M - **USERTESTING**





# APPENDIX N - **FINAL PRODUCT**