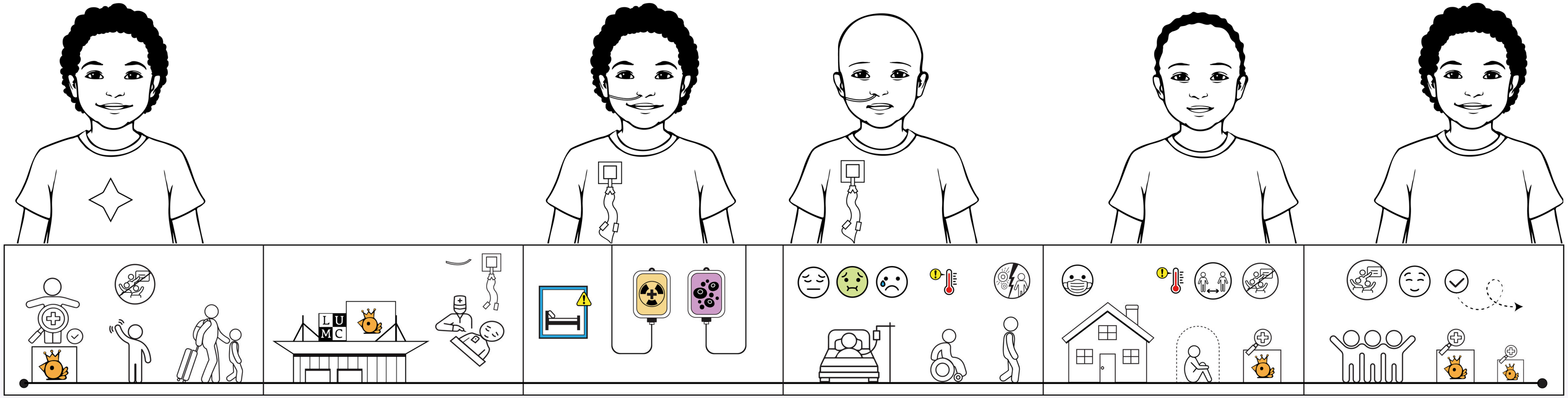

StemSense

A Tangible Toolkit for Pediatric Stem Cell Conversations

Tangible human-centred design to tell the story of complex consultation on pediatric life-altering treatments

MASTER THESIS
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A Tangible Toolkit for Pediatric Stem Cell Conversations

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EXECUTIVE SUMMARY

Shared decision-making on pediatric hematopoietic stem cell transplantation (HSCT) requires patient families to choose whether or not their child should undergo a life-altering, possibly fatal, treatment. To understand HSCT and the decision, they are informed by hours of complex consultations with healthcare professionals (HCPs). In practice, it is seen that creating understanding is difficult. HCPs struggle with fostering understanding of the content, and patient families face a range of factors that further complicate their information uptake, such as information overload, clinician-framed communication, linguistic reliance, and emotional burden. This project explores the opportunity of using human-centred design to connect HCPs and patients within conversations on life-altering treatments and presents StemSense as a design solution.

StemSense is a tangible toolkit that supports a redesigned consultation story. The product uses 3D components to represent the patient journey (treatment tiles), the impacts of treatment (main character figures), and the base medical mechanisms (cells). It makes HSCT tangible and graspable, and fosters shared understanding between healthcare professionals and the patient's family. StemSense offers:

1. **Summary** of essential consultation content into a 'big picture.'
2. **Visualization** through universal symbolism that supports understanding.
3. **Overview** of what has been discussed, for referring back to and asking questions.
4. **Structure** by design to convert treatment information into a cohesive story.
5. Opportunity for the HCP to **maintain momentum** and **gradually reveal content to avoid overwhelming.**
6. Telling the consultation from the **perspective of the patients' families:**
    a. **enabling consistency** independent of the HCP's area of expertise.
    b. **connecting** to the patient's family mental model.
    c. creating space for addressing **emotions and impact.**
7. **Tangible tools that enable interaction** between the HCP, the patient, the parent, and the consultation content beyond verbally informing.
8. **Adaptability** for explaining a range of HSCT-indicating diseases.

This project explores how we can rethink healthcare conversations and approach them through human-centred design to better connect those who tell healthcare stories with those who need to understand, consider, and undergo the care path.

Figure 1. *StemSense in use by a pediatric physician at the WAKZ*

Figure 2. *TU Delft Faculty of Industrial Design (Springstof Media, 2024)*

Figure 3. *Sophia Children's Hospital (EMC, n.d.)*

Figure 4. *Willem-Alexander Children's Hospital reception (Oliver, 2021)*

FOREWORD

This is a story about storytelling. It is the result of a project that brings together the perspectives of patients and healthcare professionals through human-centered design, approaching a complex medical challenge through a practical solution.

It was created in collaboration between the pediatric hospitals, the Sophia Children's Hospital (SKZ) and the Willem-Alexander Children's Hospital (WAKZ), and the TU Delft Faculty of Industrial Design Engineering. Within these hospitals, healthcare professionals shared the difficulties they face in the complex care pathways surrounding hematopoietic stem cell transplantation (HSCT), such as the information quantity and complexity, clinician-framed communication, reliance on verbal linguistics, and the emotional gravity of the decision that needs to be made. These challenges form the starting point of this story.

As a designer, the role is not to provide medical answers, but to explore how these experiences take shape. To zoom out and zoom in, to see the big picture while also finding the details that matter. Through conversations, observations, and research, the stem cell transplantation care pathway was explored: its characters, points of view, themes, and tensions. This project brings those elements together. It draws from a broad exploration of pediatric consultations, hematopoietic stem cell transplantation, patient groups facing communication barriers, and shared decision-making. Designers work through an iterative approach, diverging and converging through research and creation. While chronological stories are the ones that stick best, this thesis is not written as a design report. Shown in one narrative rather than separate explorations and findings, because that is how consultations are experienced: as one story unfolding over time, where informational intake, emotional processing, and decision-making cannot be separated.

Design offers a way to engage with this complexity and foster shared understanding. It allows what is broad and abstract to be visualized and made tangible. In a medical setting where complex conversations rely heavily on words, this project explores another way of sharing to support understanding, materialized in a product. This work is in itself a consultation about a new treatment option for holding consultations, so that what matters can be understood and considered.

PROLOGUE

This is Noah.
Noah is 10 years old.

He loves to play with his brothers and sisters, but he can’t play as long, can’t run as fast.

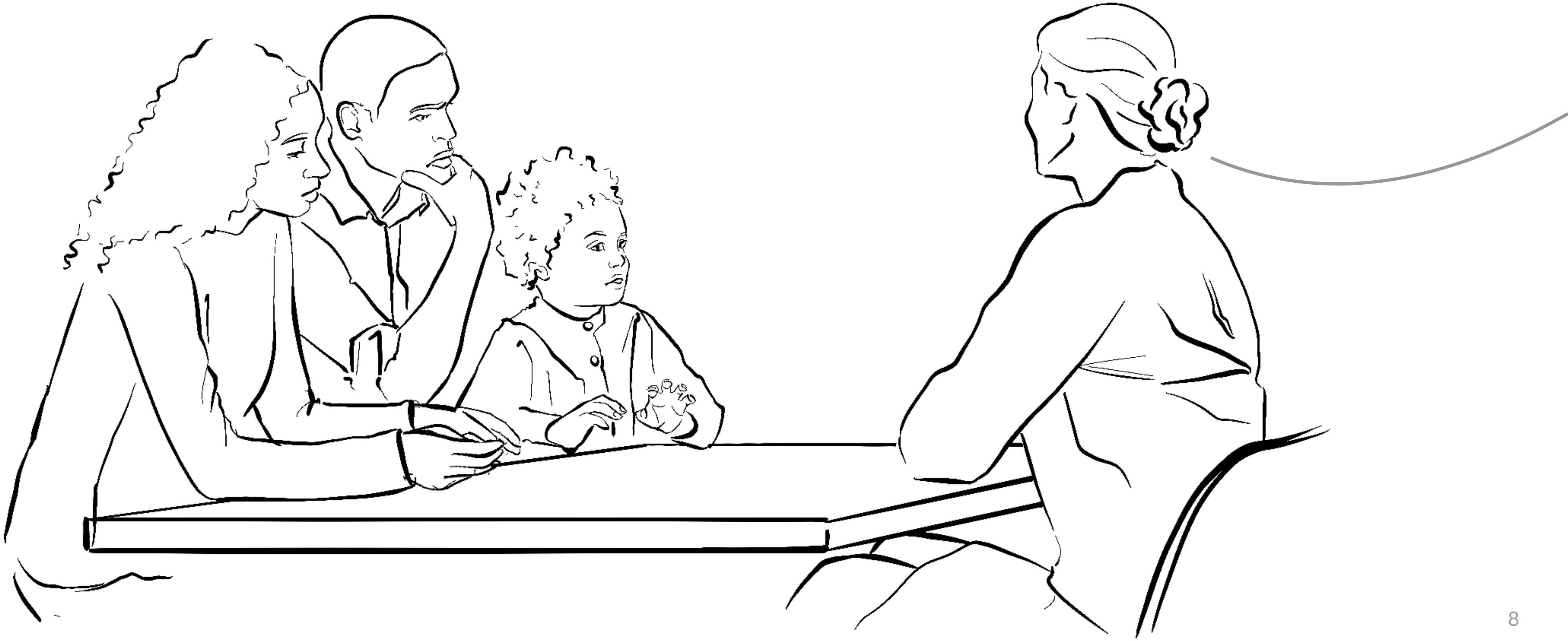
Noah is sick, always. With his sickness comes medications, many hospital visits, and sometimes terrible pain.

Noah doesn’t know what the future will be like. But he trusts that mom and dad do. They are the smartest people he knows!

They even speak a different language than they do at school or in the hospital.

Today, the hospital is different too, a new one. Mom and Dad took off from work.

They sit in a new room with a new doctor. She says there is a way Noah won't have to be sick anymore, but that it will be difficult.



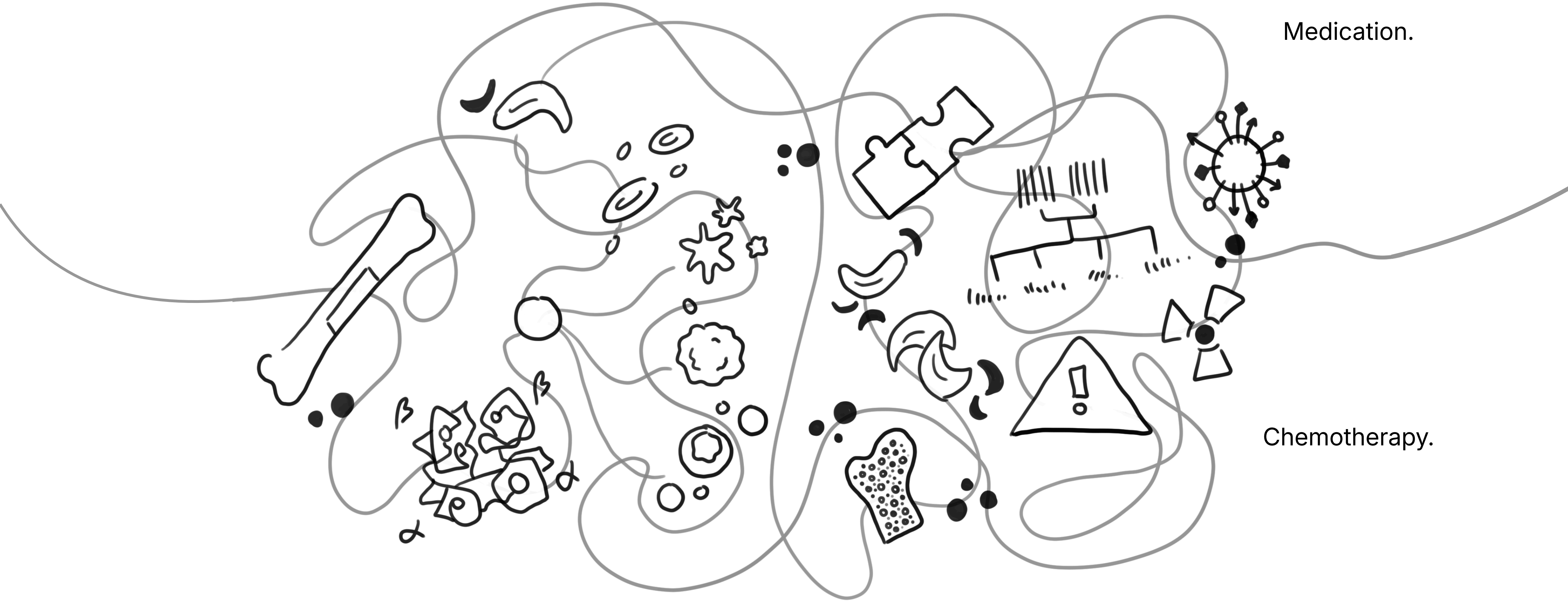
She talks of blood and cells and bones.

About his sickness and his siblings.

Transplantation.

Donors and matching.

Medication.



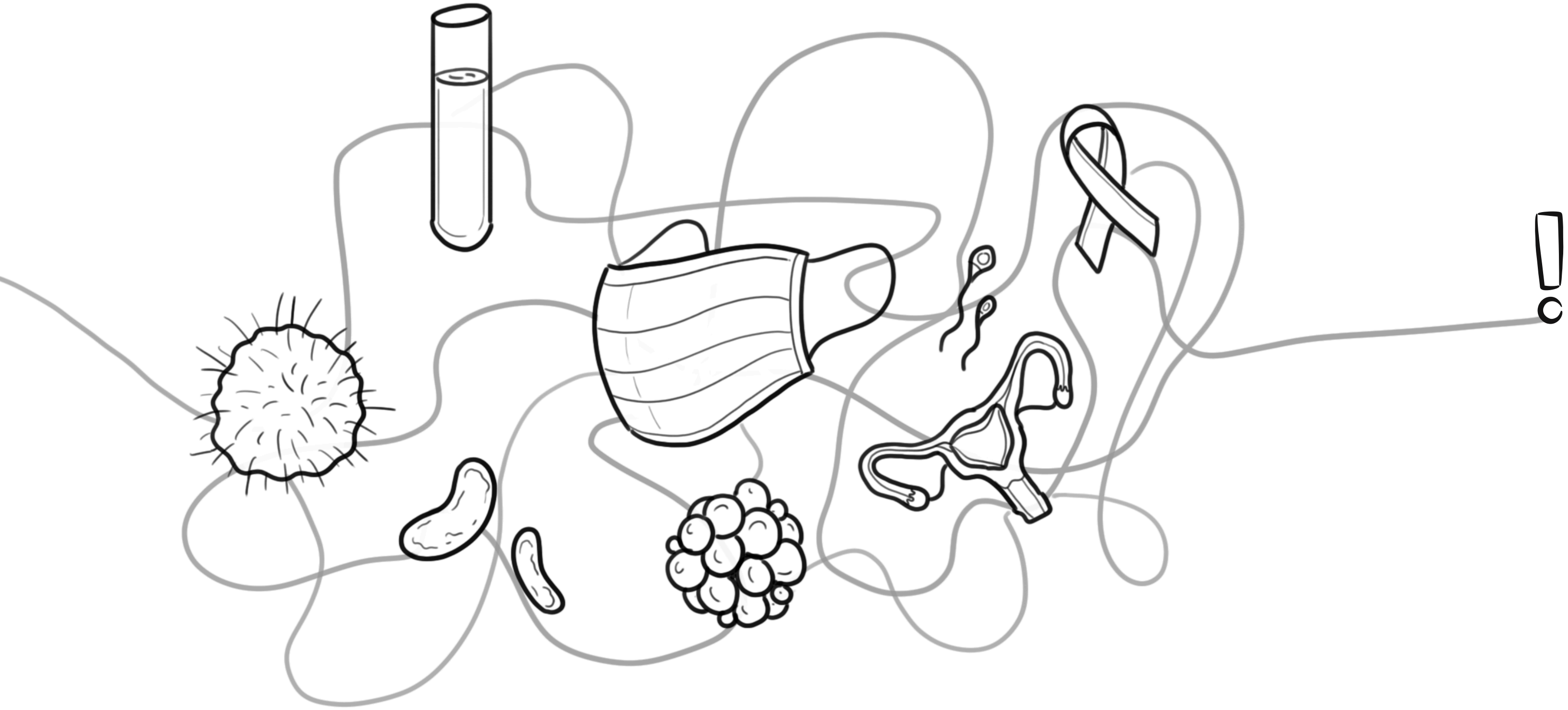
Chemotherapy.

She talks about tubes and masks.

Infections and isolation.

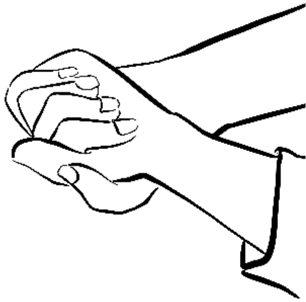
About risks…

..and **death.**



Noah has to cry. He doesn't want to die. Dad puts his arm around him.

The doctor keeps talking. She scribbles notes on a piece of paper. The drawings are upside down from Noah’s seat.



The words are hard to follow.
Mom has stopped nodding. Still, she tries to translate words for Dad.

The conversation stretches past an hour… an hour and a half…

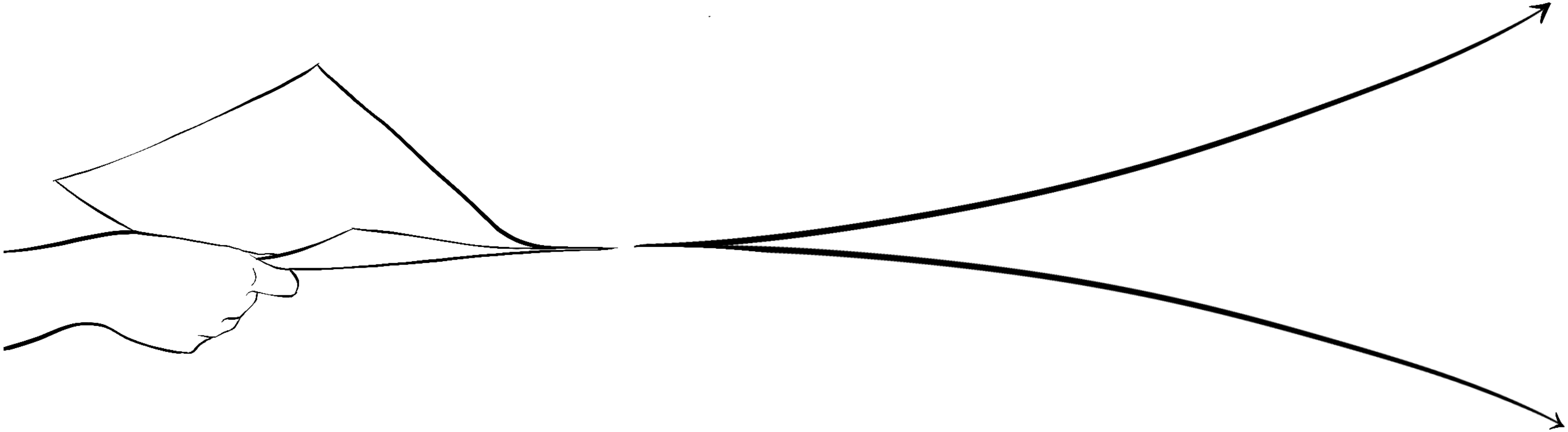
At last, the doctor asks: “Do you have any questions?”

Mom and Dad do.

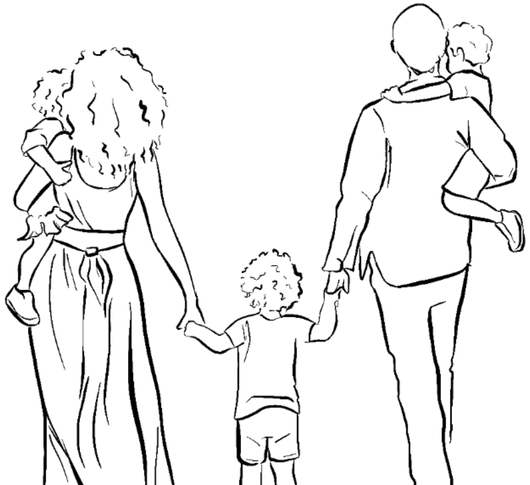
About work. About money. About Noah’s brothers and sisters. About school. About being away from home. About keeping him safe. About the risks. About his future.

But so much has been told that now they can’t find where to begin.

“Take this home,” the doctor says, giving them her drawing. “We will talk again soon. You will need to make a decision.”
It has been a long conversation, and it is only the beginning.



If this story feels overwhelming, you are not alone.



CONTENTS.

READING GUIDE.

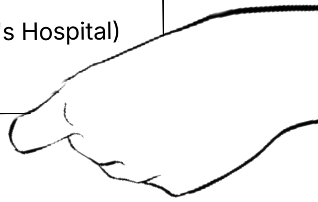
This master’s thesis is about telling treatment stories. It could have been written from an engineering perspective, packed with methods and probes, the details of each 3D model, and the precise angles to laser-cut frames. However, much like the consultations of life-altering treatments, the technical details are rarely what sticks with us. Instead, this thesis is a story about telling and listening,

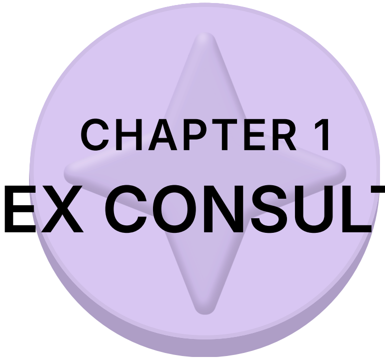
You are invited to read this story from the perspective of children and families confronted with a life-changing medical decision. Try to connect with the experience of someone who may have limited medical knowledge, yet carries an immense stake in the outcome.

It is important to note that this project developed beyond what could be fully captured within the scope of this thesis. Additional materials and documentation can be found in the Appendix, available through the TU Delft Repository.

GLOSSARY

EPR	electronic patient record
HCP	healthcare professional
HLA	human leukocyte antigen
HSCT	hematopoietic stem cell transplant
SCD	sickle cell disease
SDM	shared decision-making
WAKZ	Willem Alexander Kinder Ziekenhuis (Children's Hospital)
SKZ	Sophia Kinder Ziekenhuis (Children's Hospital)





CHAPTER 1

COMPLEX CONSULTATIONS

The stem of HSCT stories

This chapter introduces the context in which complex care conversations take place. It introduces shared decision-making for pediatric HSCT through the stakeholders, the context, and the carepath. The patient journey is explored to identify the complex consultations as an area of opportunity, and introduces the different perspectives of those who navigate pediatric HSCT shared decision-making. Together, these elements form the foundation for understanding the communication challenges that led to the development of StemSense, a tangible consultation toolkit.

INTRODUCTION.

The family in this prologue is fictional, but their situation is not. There are children and families like Noah's currently standing before a choice that may change their lives forever.

Pediatric life-altering treatments that involve serious, sometimes life-threatening risks and place a high burden on families during treatment follow a shared decision-making approach. The choice of hematopoietic stem cell transplantation (HSCT) in children is one such example. Patient families and healthcare professionals decide together whether to undergo or abstain from HSCT, taking into account their values, fears, clinical indications, and other relevant factors (Nickel & Kamani, 2018). These decisions are made with both the mind and the heart, but require a foundation of sufficient comprehension before a choice can be made.

For many patient families, achieving this understanding is difficult. And for healthcare professionals, sharing this understanding is a challenge. The Willem-Alexander Children's Hospital (WAKZ) in Leiden, which performs HSCT in children with severe blood- or immune-diseases, reports how consultations often need to be repeated and how families show misunderstandings further into the HSCT care path. The Sophia Children's Hospital (SKZ) in Rotterdam, the biggest pediatric hospital in the Netherlands, refers patients to the WAKZ for HSCT, and finds difficulties in explaining HSCT to patients and families.

Referrals that are relevant by clinical indication may be postponed or left unpursued by families due to uncertainty or misunderstanding. Understanding always takes time. In children with severe chronic illnesses, acting on time can change health outcomes. Untreated diseases may hinder development or damage organ quality. Time is health.

> "Sometimes I say to a colleague, 'Have you even spoken to this family? It is as if they heard it [HSCT information] for the first time.'"
>
> *- pediatric physician on repeat consultations.*

> "I really hope they understood, but we'll have to see next time."
>
> *- pediatric physician after a HSCT consultation.*

StemSense is a tangible toolkit developed to aid complex consultations by explaining HSCT within a cohesive story. It aligns with the patient's perspective and is designed for clinical accuracy, supported by tangible components that allow interaction from both sides of the consultation table. Before introducing the product itself, this thesis presents the people it serves, the context in which it operates, and how its form and features have been developed to address the challenges of the complex consultations within pediatric shared decision-making.

THE MAIN CHARACTERS.

Caring for families like Noah's

The story of HSCT is lived and told through its main characters: the families who face it, and the healthcare professionals who guide them. On one side of the consultation table are the familial actors: the patient, parents, siblings, and their support network.

The Child

At the center of the story is the child patient, the one who is sick. Often, they have lived with their disease for as long as they can remember. Hospitals and treatments are not unfamiliar, but this time is different. For children over twelve, the decision whether to undergo HSCT is legally theirs to consider as well (Burgerlijk Wetboek, 2023). Dependent on a child’s development and parental say, younger children, too, can be a part of that choice. They must weigh much more than just medical facts: friends, school, pain, uncertainty, and the possibility of death all press on their young shoulders.

The Parents

The parents or caregivers carry the responsibility of understanding the complex medical information. They need to ask themselves over and over: What is the right choice for my child? For some families, other factors make the decision even more complicated. Parents may stand alone or be caring for multiple children, sometimes with more than one affected by a chronic illness. Their choices affect not only their child facing HSCT but also their family as a whole (Maleki et al., 2025).

The Siblings

In the consultation room, siblings are discussed more often than they are present. A sibling from the same two parents has a 25% chance of being an HLA-identical match, the preferred stem cell donor whose cells offer the best chance for a positive treatment outcome. Even when they cannot donate, siblings become part of the HSCT story. Their lives are affected too, as the family adjusts to the long and demanding treatment process, which can stretch over months and reshape daily routines, attention, and care.

Extended family

There is the extended family. Grandparents who can look after siblings, relatives who can visit. Their presence matters in decision-making and in enduring the treatment journey.

Those who wish to help

The family bears the burden, but they are not alone. Around them are those who wish to help, from their daily lives and from patient representatives. Social networks: friends, classmates, teachers, and cultural or religious communities play a supporting role for the patient and family in getting through HSCT, if it is decided on. Patient support groups may also play a role in shaping the understanding of HSCT for the family, as they can connect them to peers and experienced HSCT stories.

Yet before that choice is made, in the consultation room itself, there are only seats for the child and their parents.

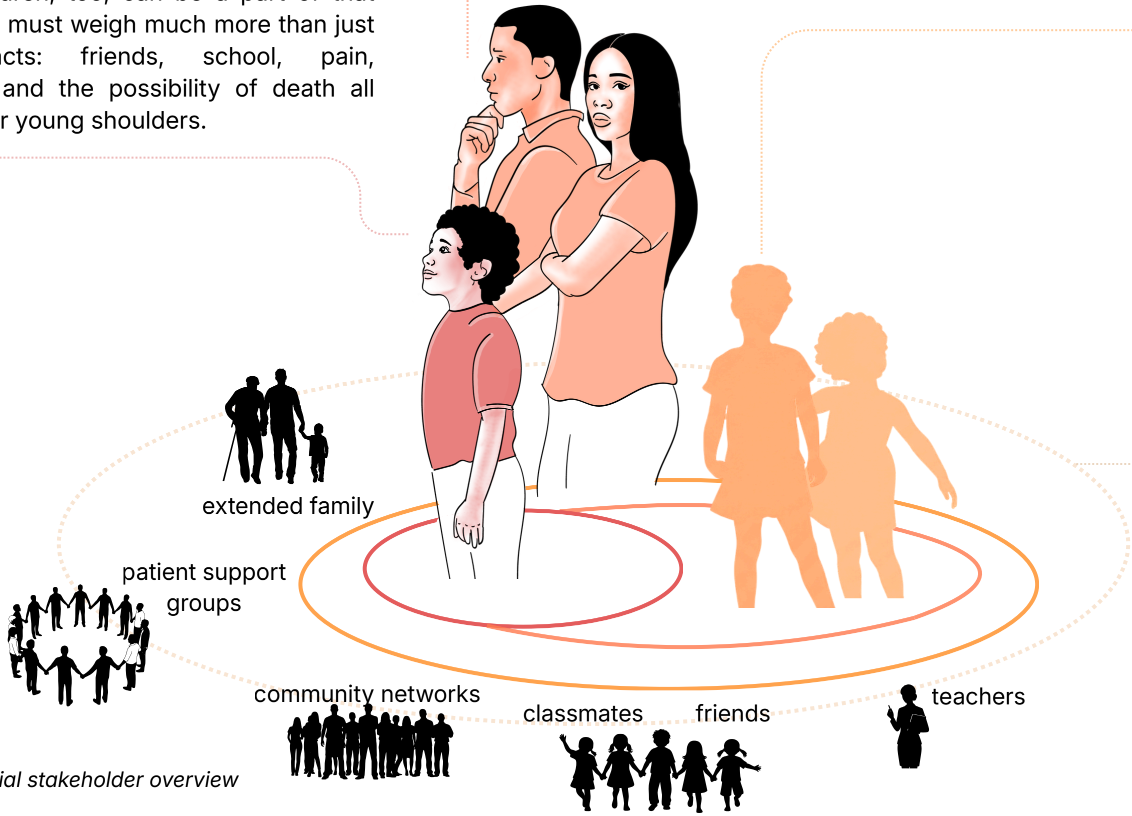


Figure 5. *familial stakeholder overview*

The Healthcare Team

HSCT is a complex treatment process involving a multidisciplinary team of healthcare professionals who shape the care pathway, from general care and the informational decision-making phase through the HSCT procedure and subsequent aftercare. Figure 7 provides an overview of the various healthcare professional roles involved in HSCT. This visual represents an estimate based on interviews; the exact composition of healthcare professionals may vary in practice or across hospitals.

The Narrator

On the other side of a consultation table is the HSCT narrator, the HCP telling the story, most often a pediatric physician: a pediatric hematologist or immunologist. They lead the informative phase of shared decision-making.

In referring hospitals, this role may also be filled by a nursing specialist, who holds a summarized pre-consultation.

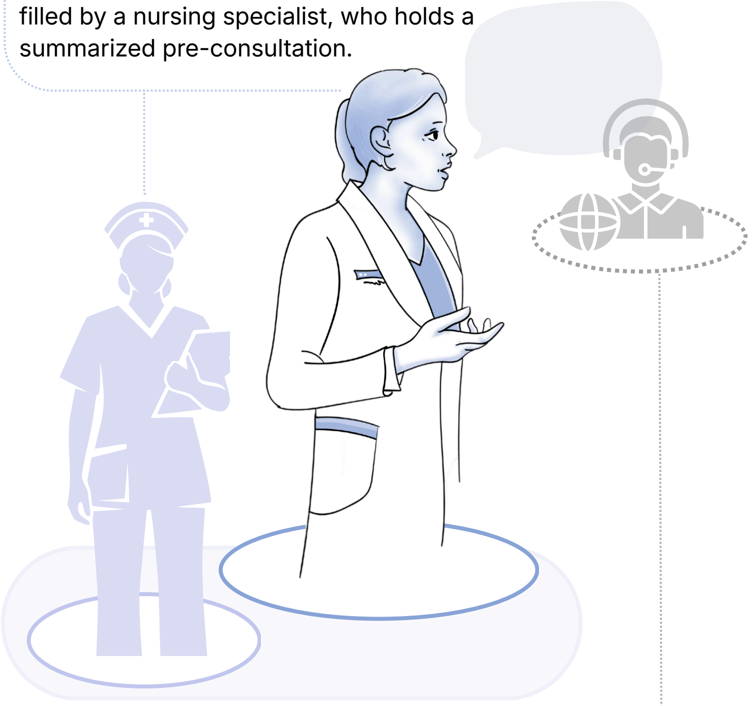


Figure 6. *Consulting HCPs*

The Translator

When patient families do not speak Dutch or English sufficiently, a medical translator supports the consultation. Often joining via telecommunication, they convey information in the family’s preferred language to support understanding.

Specialists

Responsible for diagnosis and clinical management are specialists, including pediatric hematologists, immunologists, and organ-specific specialists. They assess treatment eligibility, monitor progression, and manage complications.

Psychosocial Caregivers

Essential to HSCT is addressing emotional, psychological, and social challenges. This includes psychologists, social workers, and pediatric workers. They assess a family’s readiness for HSCT and support coping, decision-making, and mental well-being.

Direct Care

Nurses and nursing specialists support daily care during hospitalization and hold central roles in appointments, check-ups, and treatment administration. They are crucial in patient-communication.

Organisational

Professionals such as transplant coordinators and donor registries ensure the process runs smoothly across complex systems. That schooling may continue is organized by educational caregivers, who make arrangements with the school and teach the child during hospitalization.

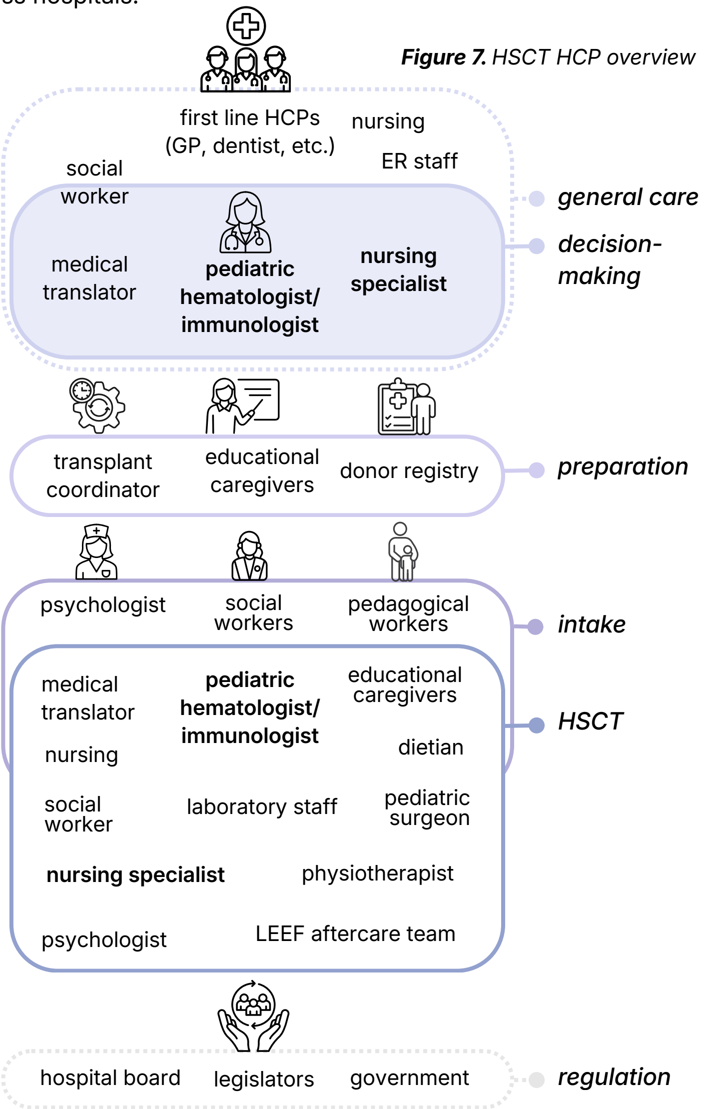


Figure 7. *HSCT HCP overview*

For the StemSense project, which focuses on the informational decision-making phase, the roles of healthcare professionals involved in patient communication and consultation on HSCT are most relevant. These primarily are the consultation narrators (Figure 6), yet are also found within the psychosocial teams, direct caregivers, and other care staff who shape the patient's understanding before and during HSCT. These HCPs from both the referring hospital and the treatment hospital were involved in the research and development of StemSense.

THE SETTING

Understanding the settings in which HSCT takes place provides context to the environment surrounding the treatment, which needs to become graspable, and the consultation spaces in which HSCT understanding is shaped. These places are part of the HSCT story and shape the frame around the StemSense design.

The places of HSCT

Across different contexts and diseases, the consultation for HSCT is similar. Differences are found in how the disease could progress, how the cells are affected, the clinical indication, and the associated risks, but the overall plot stays consistent. The treatment principles remain the same.

At the WAKZ, children with a range of conditions are considered for stem cell transplantation, among which are haemoglobinopathies, bone marrow disorders, immune system disorders, and severe autoimmune disease (Willem-Alexander Kinderziekenhuis | LUMC, n.d.). For some children with cancer or a metabolic disorder, a stem cell transplant is also a suitable treatment. For these children, in the Netherlands, this is carried out at the Princess Máxima Centre for Paediatric Oncology.

The exact purpose of HSCT consultations differs. For some, it is to decide whether to undergo the treatment. For others, it is to prepare them for a transplantation that must take place. In all cases, the consultation is meant to inform and help patient families understand what the treatment means. While HSCT consultations are held across different contexts, care centers, and patients, this story focuses on the setting in which this project was founded: the Willem-Alexander Children's Hospital and the Sophia Children's Hospital, observing non-acute non-oncological HSCT.

Stem cell treatment, from its informational phase to the completion of treatment, happens across many places within and outside of the hospital. The most notable setting of transplantation is the isolation room, in which the patient spends weeks to months, separated from the outside world. While Figure 9 shows the interior of a pediatric room at the WAKZ, in isolation, children are not allowed to sleep or touch their stuffed animals. Isolation requirements are in place even within the room, with an antechamber (Figure 8) and a plastic curtain dividing them, and the child's treasures from home are to be enjoyed only from a safe distance.

Figure 8. *doctor working in an isolation anti-room at the WAKZ (Studio Oliver, 2021)*

Figure 9. *pediatric room WAKZ (Studio Oliver, 2021)*

The consultation takes place long, sometimes years, before HSCT, in a small and private clinic room. Here, patients, parents, and the physician sit on opposite sides. This is done so that eye contact is possible, which is valuable for the HCP to assess parental understanding and for both to communicate through body language. Cognitive indications, emotional reactions, and non-verbal behavioural signals are all needed to recognize and avoid deterioration in physician-parent communication (Ferretti et al., 2023).

In both the SKZ (Figure 10) and WAKZ (Figure 11), the doctor's side also holds multiple screens, on which the electronic health record (EHR) of the patient is shown, so the HCP can prepare and align with the patient-specific context. These contextual factors, where the physician looks, who the objects on the table are facing, and the seating arrangement, all impact the dynamic of the conversation between patient, parents, and the HCP.

The seating arrangement is built in by design in the consultation rooms of the WAKZ and the SKZ. Translated into metaphors, this set-up reflects the aim of the patient, family, and HCP 'seeing eye to eye': that they arrive at an agreement through a shared understanding. What they are not is 'side by side', looking through the same lens and going through the same experience.

Figure 10. *consultation room SKZ (EMC, 2026)*

Figure 11. *consultation room WAKZ (Studio Oliver, 2021)*

Figure 12. *hallway and waiting area at the WAKZ (Studio Oliver, 2021)*

Figure 13. *parents and child at the WAKZ (Studio Oliver, 2021)*

Beyond this consultation space, there are the hospital hallways, sometimes new for the patient and family who have been referred from elsewhere. They navigate them, sit and wait, sit and listen. And then they take the consultation story home. There, the weight of the decision stays with them, while the information itself becomes reliant on how well they remember it, and how able they are to navigate and reproduce it themselves. When sharing it with others in their family, they hold mini consultations of their own, with their version of the consultation story.

THE CAREPATH.

We now know the who and the where, but why is there a need to design for HSCT understanding beyond what is currently done in practice? Pediatric HSCT requires shared decision-making (SDM), where the treatment choice is made by the patient's family, informed and guided by the healthcare team. SDM is used for several benefits, such as increased patient and physician satisfaction, increased patient knowledge, and reduced decisional regret (Stacey et al., 2017). But what does 'shared' mean in practice, and how is it experienced at the start of a care path that still needs to be decided on? Here, the SDM care path is presented as a journey of choices, which enabled the identification of the consultation phase as the area of most opportunity to improve understanding. The challenges within this journey will be explored later, in connection with the design of StemSense.

Shared Decision-making

There is a difference in decision-making needs based on clinical indication. In critical HSCT, where children are so ill they are unlikely to survive without a transplant, families rely in the healthcare team to guide and advise them with clear clinical direction (Passweg et al., 2019). There is trust and the choice is made, but families still need to understand what lies ahead. For other conditions, such as sickle cell disease, transplantation is considered preemptively; these are the cases in which SDM is actively applied (Mekelenkamp, 2024). The disease is chronic, with a significant impact on quality of life and life expectancy (Badawy et al., 2017), but the disease course is uncertain: a child may experience severe complications early in life, or live into adulthood before the disease takes its toll. The trajectory is unclear, but the outcome is known: ongoing pain, limitations, and a shortened life. The stem cell transplant presents an almost opposite structure. The process itself is relatively well-defined, but its outcome is uncertain, expressed in statistics of chance that are difficult to fully grasp and do not align with the emotional weight of the possibilities. A child may be cured and healthier than ever before. They may face serious complications or not survive the treatment (Nickel et al., 2014). It is this contrast that makes the decision so difficult and why it needs to be shared with both healthcare professionals and parents. Yet within that shared space, the roles and knowledge are not equal. HCPs bring expertise, experience, and clinical understanding. Parents bring their child, their values, and the weight of the decision. In preemptive HSCT, the parents hold the final say and, with that, the responsibility of choosing. Responsibility is the ability to respond, yet in practice, parents often do not feel or show themselves to be able to. The SDM carepath consists of activities aimed to enable parents to make this choice, in which HCPs need to share parts of their role with the patient's family: knowledge, agency, and a frame of reference. It is in this sharing that disconnection takes place, as these parts do not fully, or not effectively, reach through to the patient's family. This project aims to reconnect within SDM through design.

A Journey of Choices

When listening closely to those involved before HSCT begins and studying their care path, you find that the decision isn't made with one choice. Neither is it a straight path towards an answer. Figure 14 shows the patient journey of the shared decision-making process for HSCT for pediatric sickle cell disease. This colorful map shows the many people who influence the HSCT decision, as well as the challenges, sources of information, and emotions that shape the path. It shows the tensions from both the parental and the HCP point of view. There are 5 key choices, 'checkpoints' that are made by both parties before HSCT has been initiated to a point of no return. To understand the development of SDM, it should be seen as a journey of choices.

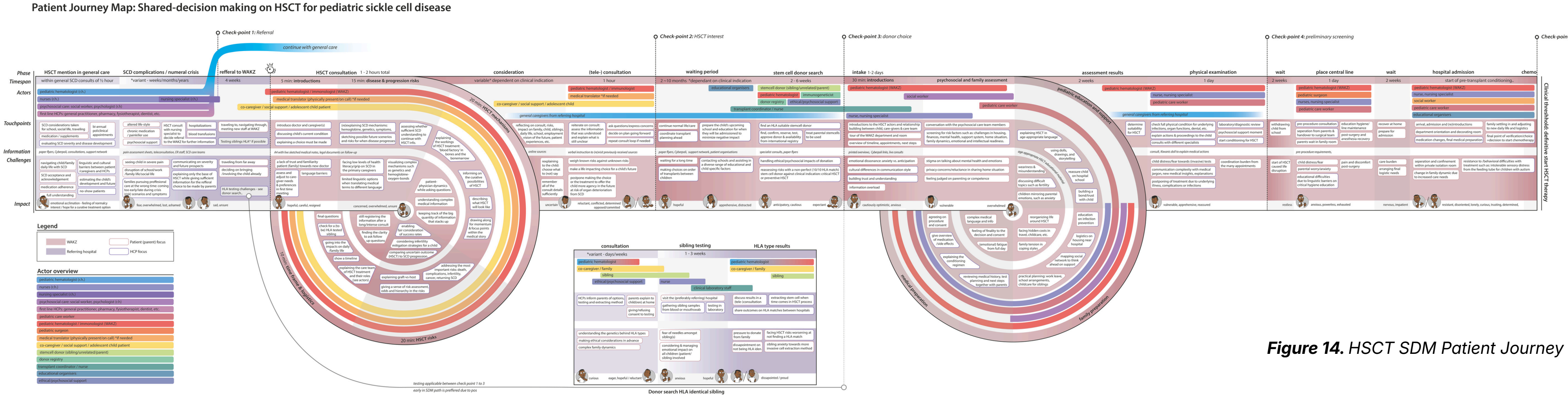


Figure 14. *HSCT SDM Patient Journey Map*

Checkpoint 1: Referral

The first decision is the choice of referral. Stem cell transplantation is introduced as a curative possibility, and a first informational conversation can be held at the referring hospital. Guided by clinical indications and patient circumstances, the physician may recommend referral, but it is the parents who decide whether to continue. Choosing to proceed often means entering unfamiliar territory. Families travel to a new hospital, meet a new care team, and step into a different phase of the decision-making process.

Around this moment, the search for a suitable donor begins. When possible, siblings are tested early, as the presence of a compatible donor shapes both the risks and the potential outcomes of treatment.

Checkpoint 2: HSCT Interest

After referral, the choice becomes whether to show interest in HSCT. This phase is centered around understanding. It is here that the informative consultations take place. How long this phase lasts is dependent on the clinical indication and on the reception of the information by the parents. The challenges for understanding, such as the cultural and linguistic barriers, may require the consultation to be repeated numerous times, though in each, the same verbal approach continues to be used. This part of the journey could be a loop, one where informational conversations are frequently repeated, or where patient families move back to the pre-referral phase to postpone or abstain from the decision. Even this choice carries its own uncertainty, as waiting may allow the disease to progress. Once parents feel they understand the treatment well enough, they may decide to take the next step by expressing interest and continuing along the decision-making path.

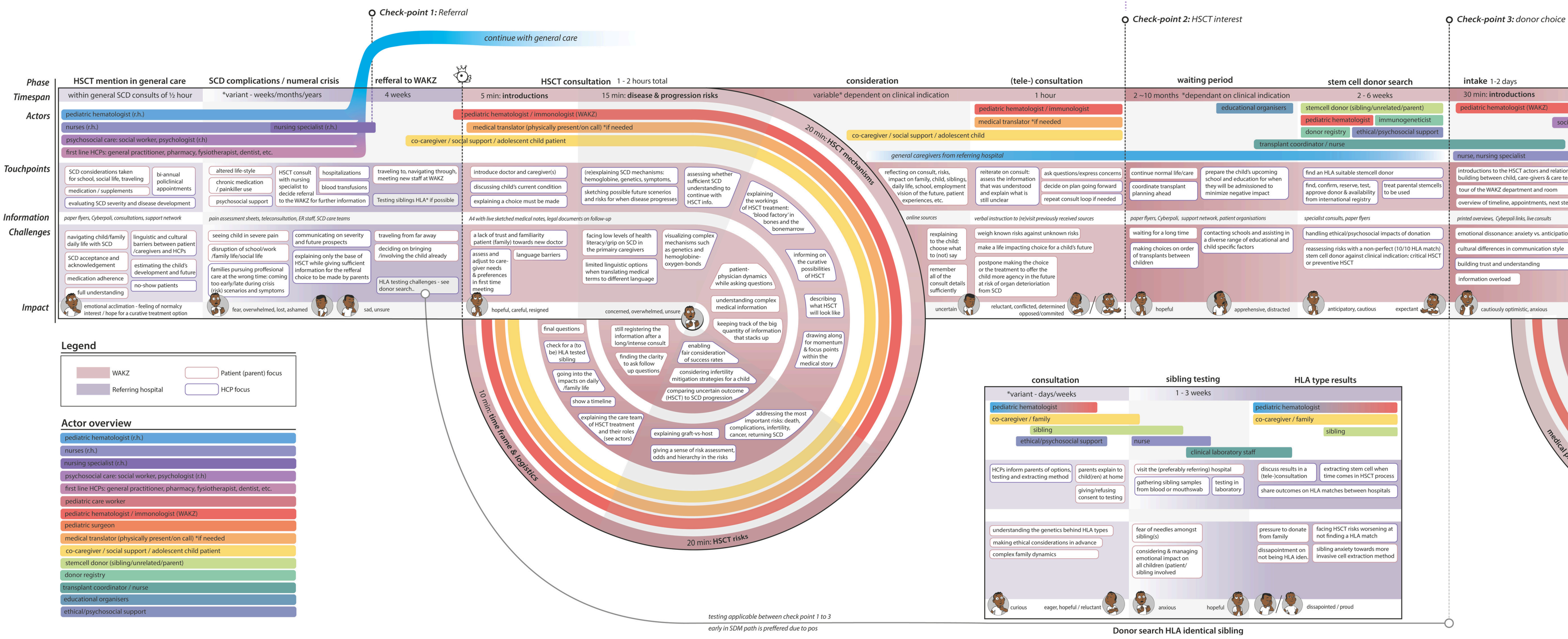


Figure 15. *HSCT SDM Patient Journey Map - checkpoint 1 to 3*

Checkpoint 3: Donor Choice

The third checkpoint centers on finding a suitable donor. Once families choose to move forward, the process shifts into a waiting period of one year on average. General care for the patient continues while the hospital searches for a suitable donor. If an HLA-matched sibling can be a donor, this period may be shorter. Without that identical option, the international stem cell donor registry is checked. Potential donors from all around the world are assessed for compatibility. A close match is important, as mismatches can lead to serious complications, such as the body rejecting the transplant or the donor cells attacking the patient. Graft vs. host can be fatal. Donor availability plays an important role in HSCT decision-making. The outcome of this search shapes the path ahead. The presence of a suitable donor can bring the treatment closer. Its absence may lead families to reconsider whether to continue.

During this period, the hospital also starts preparing for the HSCT process and patient admission. The educational caregivers coordinate with the child's school to make arrangements for continuing the child's education during treatment. They aim to minimize educational disruption caused by the months of absence due to hospitalization and recovery. In practice, negative effects are inevitable. Schooling is an important part of daily life for children and families and is necessary for a sense of normalcy in the difficult times ahead. Psychosocial care is available for families during this time.

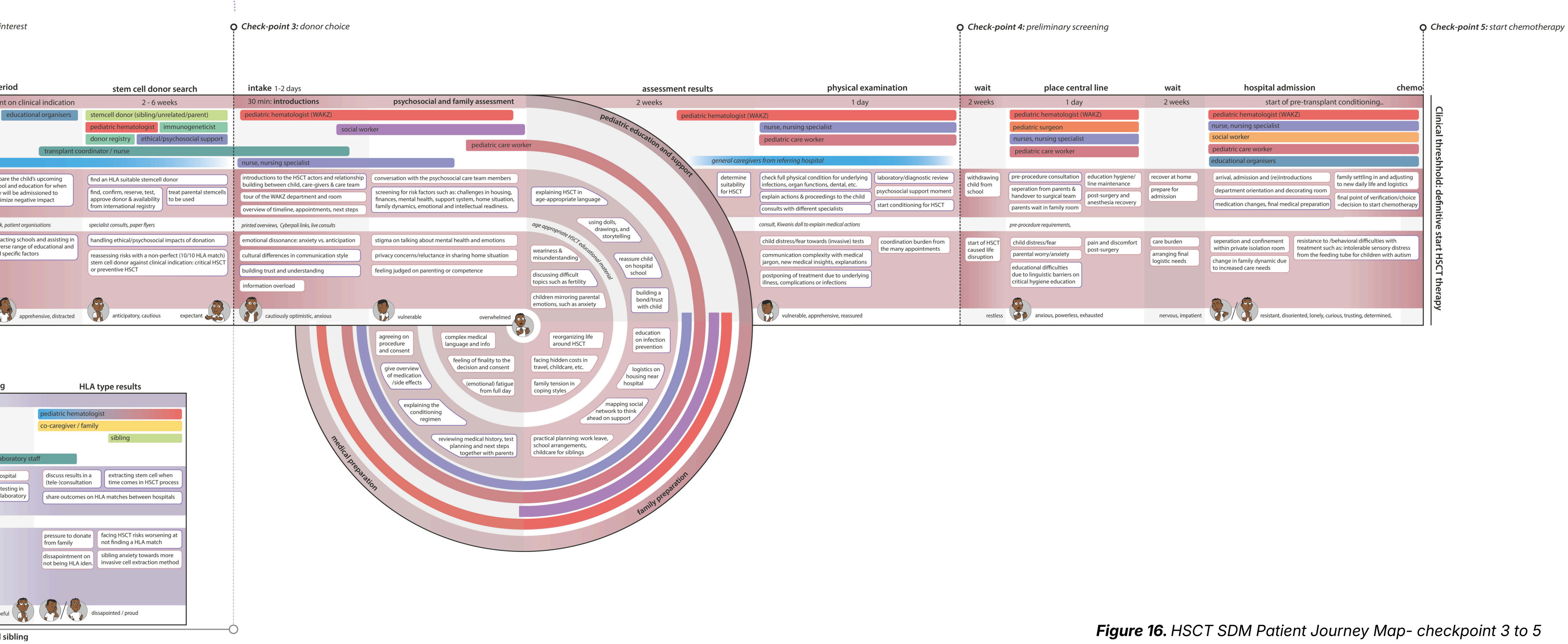
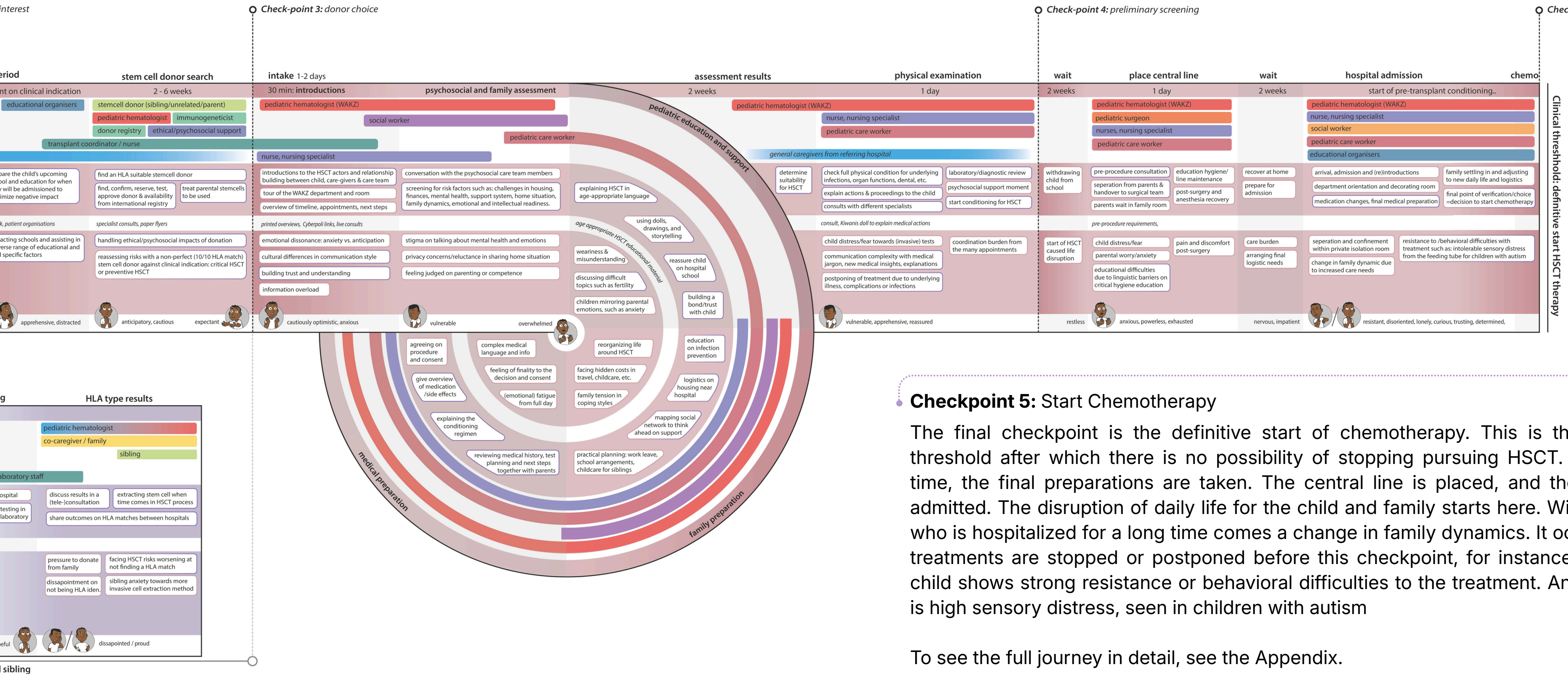


Figure 16. *HSCT SDM Patient Journey Map- checkpoint 3 to 5*

Checkpoint 4: Preliminary Screening

Once a donor is secured and hospital capacity allows, the process moves into preliminary screening. This phase assesses not only the child's medical readiness, but also whether the family can sustain the intensive treatment period ahead. Practical arrangements, such as work, care for other children, housing, and finances, must be in place, as one parent will always be present with the child during hospitalization. At the same time, families need a clear understanding of the periods of isolation, both in the hospital and later at home. The family must understand the why and the how. Misunderstandings and mistakes around a child with a compromised immune system can be deadly. It is here that the need for good consultation and mutual understanding has full effect.

Screening takes place through an intake process. The child is medically assessed for factors such as infections, dental health, and organ condition, while psychosocial professionals evaluate the home environment and emotional readiness. Complex or unstable family situations may lead to postponement. During this phase, the child is also prepared for what lies ahead in an age-appropriate way. Based on these combined insights, the care team determines whether the family is ready to proceed. If not, treatment is not declined, but delayed, with support provided to address the identified challenges.



Checkpoint 5: Start Chemotherapy

The final checkpoint is the definitive start of chemotherapy. This is the clinical threshold after which there is no possibility of stopping pursuing HSCT. Until this time, the final preparations are taken. The central line is placed, and the child is admitted. The disruption of daily life for the child and family starts here. With a child who is hospitalized for a long time comes a change in family dynamics. It occurs that treatments are stopped or postponed before this checkpoint, for instance, when a child shows strong resistance or behavioral difficulties to the treatment. An example is high sensory distress, seen in children with autism

To see the full journey in detail, see the Appendix.

Different mental models within consultations

The SDM journey of choices shows the base knowledge that drives the care path is founded by the HCPs explaining HSCT through consultations: face-to-face conversations between the HCP and the patient's family. These interactions shape the course of the decision-making process in momentum and direction. Families can decline continuing in the carepath, can be driven on by their interest in HSCT, or can remain in the consultation phase for a long time, as they are repeated when the information does not reach through or no conclusion has been made. Continuing towards HSCT without this information leads to misunderstandings and distress further into the SDM or even the HSCT carepath (Vrijmoet-Wiersma et al., 2009).
Consultations are also the main touchpoints throughout the SDM journey, where HCPs and the patient's family can interact. They are the only touchpoints within the treatment hospital before the preliminary screening takes place, at which most decision-making checkpoints have already been decided on from the patient's perspective. When designing to aid shared decision-making, the consultation space is where improvement can have the most continuous impact on its added value, and where it can reach both sides of the consultation table: patients, parents and HCPs.

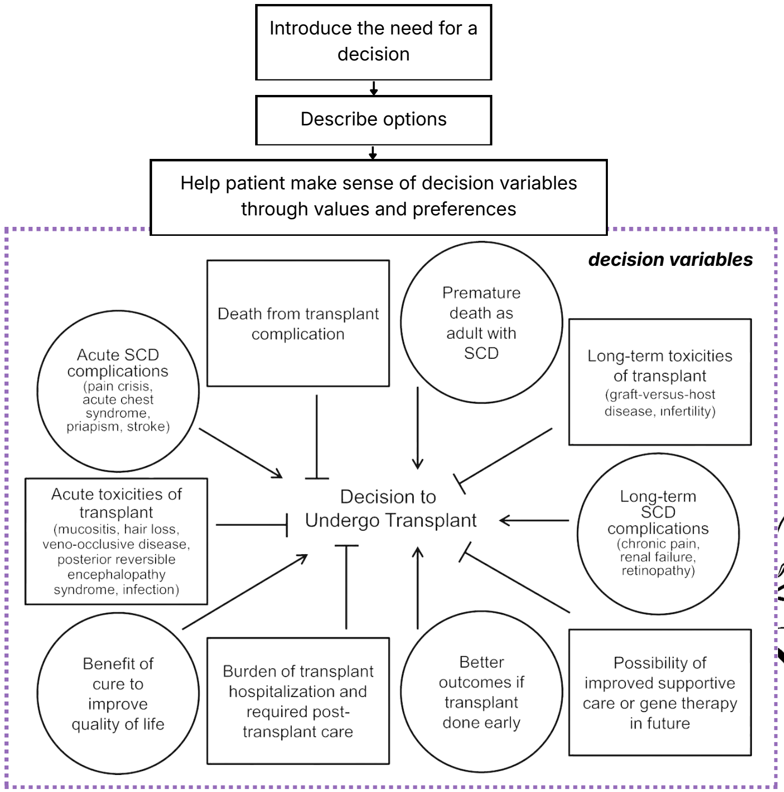


Figure 17. *HCP mental model on the HSCT decision*

Within a conversation that lasts over 1 to 2 hours, the HCP informs the families as much as they are able on the key themes of HSCT: the child's disease, the disease progression, stem cells, finding a donor, HSCT treatment, and the risks of HSCT. The order in which these are told, and the extent of the information, is dependent on the consulting HCP and how they assess the family's level of understanding.

The consultation is held for the patient, but shaped by the clinician, actors who hold different perspectives on the content and the information uptake. HCPs follow their clinical expertise and guidelines. Figure 17 shows these in an HCP-based mental model, based on the model of shared decision-making (Thériault et al., 2020), and the decision variables that make up the decision calculus for the disease of the patient, such as for sickle cell disease (Nickel & Kamani, 2018): clinical, linear, and rational.

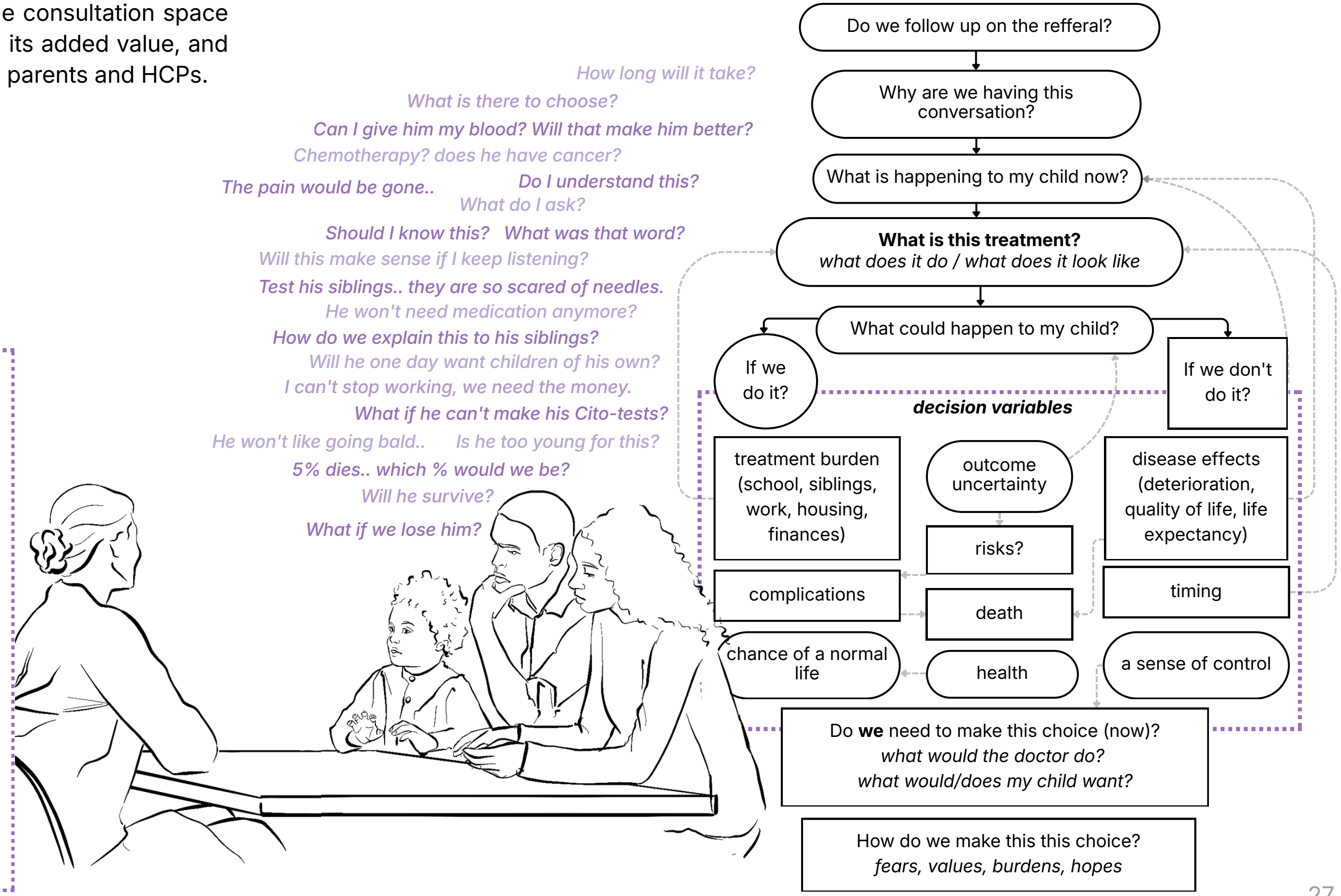


Figure 18. *Parental mental model on the HSCT decision*

As the doctor says

HCPs see shared decision making (SDM) not as convincing the patient to follow their recommendation, nor is it about leaving patients to decide on their own (Grad et al., 2017). Shared decision-making follows a three-step model of introducing the choice, describing the options, and helping patients make sense of this information. In practice, the interpretation of how these steps are taken and how such a decision is shared is dependent on the clinician. From research, observations, and the journey of choices, key themes* for HCPs were found:

- Patient/parent/physician dynamics
- Evaluating parental context
- Transferring their knowledge
- Supporting the best-fitting decision

As the patient listens

The patient's family listens from a different perspective. Their processing of information is not based on the medical context, but on how the information fits into their daily lives and personal experiences (Ferretti et al., 2023). While they are listening to the HCP, countless questions cross their minds, of which they ask only a fraction. Though the HCP may guide them through a clinical explanation, there is no guarantee they are able to comprehend and retain this information. In their mental model (Figure 18), there is no ‘big picture’ of HSCT as the HCP has it; they experience the consultation as complex, personal, and through their emotions. The decision variables on which the shared decision-making for HSCT is grounded are reached only when the treatment itself and the need for it have been established clearly. The heaviest topics, such as death from transplant complications, are so severe that they disrupt the conversation, and topics that are addressed after it are not registered fully.

Their personal contexts of patient families require acknowledgement and support, especially for patients with complex circumstances, such as a refugee background, adopted children, or families with lower health literacy. For the patient’s family, several key themes* shape how they receive and interpret information:

- Short- and long-term needs of the child
- Stability of the family
- Agency and a sense of control
- Retention and comprehension of information
- Accessibility and overview of information

**All key themes are explained in further detail in relation to the redesigned consultation and toolkit.*

THE PROBLEM.

Pediatric HSCT shared decision-making, especially for hemoglobinopathy patients, is a complex process. It is already difficult for health care professionals to decide whether and when it should be offered (Mekelenkamp et al., 2021). For parents, this decision is even more complex, lacking a frame of reference and confidence in handling the information. Besides understanding the treatment principles and the medical foundation, the decision involves potential risks, benefits, and further variables that the parents need to consider, but are only able to process if a base understanding is reached.

Parents need to be able and feel able to respond to the decision. Within the consultation, they are not equals to the explaining healthcare professional, not in knowledge, not in position, not in how they can contribute to the conversation. They often come from chronic care paths in which they already have a dynamic with healthcare professionals, one where HCPs lead. The professionals direct and inform on the care path, and the parents follow. In the decision-making for preemptive HSCT, these roles change, while the dynamic remains in place.

Parents are shifted from the passenger seat beside the doctor into the driver's seat, suddenly having to steer their child's care path (Figure 19). For many, this is unfamiliar, difficult, and daunting. Some parents even try to decline the responsibility, postponing the decision or trying to return it to the HCP. These questions aren't answered, or rather, handled as neutrally as possible:

> "But what would you do, doctor?"
>
> *- parent considering HSCT for their child, during observations*

> "I would never say, as a doctor, you would ask me, what would you advise me. It's not important what I think, but it's important what you think, and your child would think, and the reasons for which you decide whether you want something or not."
>
> *- pediatric hematologist (Mekelenkamp, 2024)*

This shift in roles, the navigation of a new dynamic, and the weight of a life-altering decision come together in an extensive consultation, which was already inherently complex. Several factors complicate the conversation:

- **Clinician-framed communication**

Consultations are driven by clinician-specific expertise, at risk of misaligning the story that they tell with the story that parents need and can process.

- **Information overload**

The density, pace, and cumulative structure of HSCT information make it difficult for families to grasp, retain, and identify gaps in understanding.

- **Linguistic reliance**

In a solely verbal consultation, translation, cultural differences, and varying health literacy levels disrupt communication, limiting clarity and shared understanding.

- **Emotional burden**

What is intended as medically neutral information is interpreted by the family through fear, hope, and personal values, influencing what they hear, understand, and remember.

The key themes identified in this chapter are further elaborated in Chapter 3, where they are examined in relation to underlying product values and design principles.

StemSense is a human-centered design solution that aims to support shared decision-making in life-altering treatments by improving communication, addressing consultation complexity, and fostering connection between patients, families, and healthcare professionals, so that consultation may become stories that can be understood, remembered, and shared.

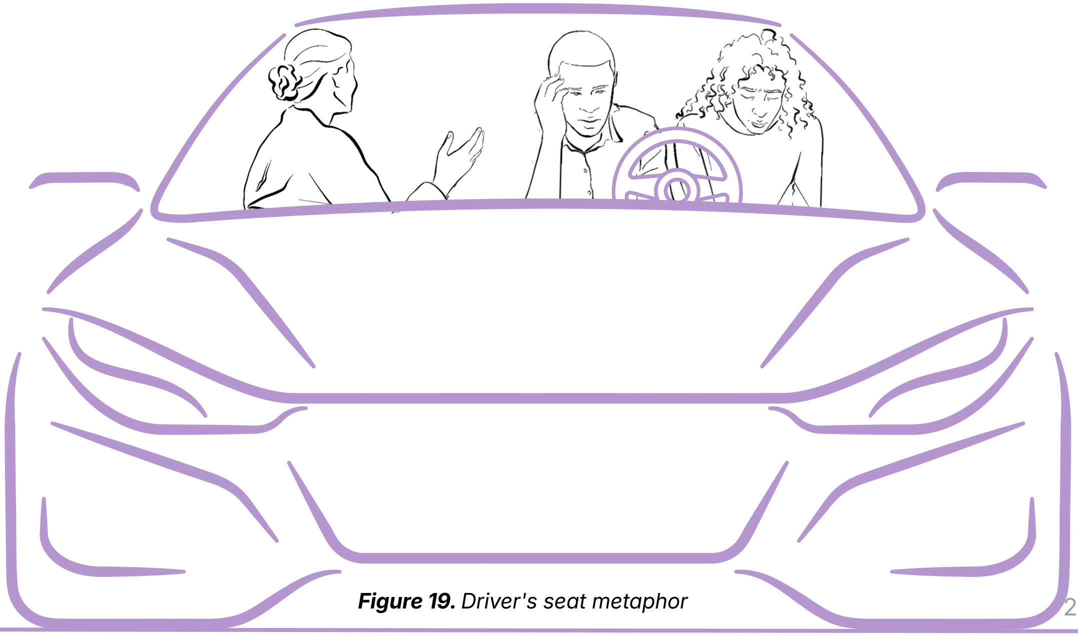
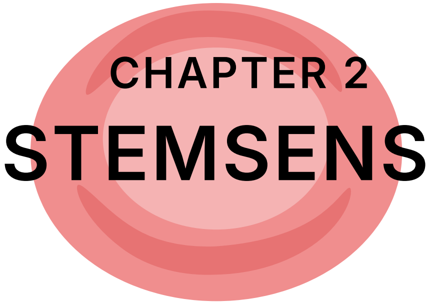


Figure 19. *Driver's seat metaphor*



CHAPTER 2

STEMSENSE

A human centred design solution

To inform patients truthfully and ethically, the content must remain. Design does not and shouldn't change its medical facts and factors. Instead, it reshapes how the story is told to support the challenges it faces. It highlights the qualities HCPs work hard to uphold and structures the story in a way that aligns with how patients listen.

StemSense lets stem cell consultations make sense. It does this by rewriting the consultations using storytelling principles that create a cohesive story patients can hold on to, and supports this beyond language through a set of tools that can be held, interacted with, and referred back to. The toolkit offers adaptable anchor points within the conversation and visually represents the human, medical and treatment parts of the story. This chapter shows the StemSense concept, its use, and its place within the consultation room.

A STORY TO HOLD ON TO.

Narrative by Design

Storytelling by design is used to facilitate health communication where the narrator 'storifies' the message to increase uptake. It is a part of human nature to tell and listen to stories, both to ourselves and to others (Harari, 2016). We create and share stories to make sense of life. Stories are the way we pass and exchange knowledge in a comprehensive way that shares both its meaning and the context. Narratives come at a wide range of scales and impacts. They can be grand drivers of culture, such as the stories shaping religions. Or they can be small and personal, like the imagined worlds through which a child makes sense of reality.

Stories are also found, perhaps especially, within healthcare. In observations of HSCT consultation stories at the WAKZ, one physician used the phrase:

"Let's imagine you have 20 of your [child's name]. A full, happy house of them. If they all had this treatment. You would lose one, as they will pass away due to complications."

Instead of stating

'There is a 5% mortality rate.'

The message was personalized to their name, visualized within a familial context, and communicated in a way that conveys the emotional weight of the information. Whether this narrative approach is used is dependent on the HCP, their communication style, and their experience in holding HSCT conversations. How consultation training was a part of their education also differs between different types and cohorts of care professionals (Zota et al., 2023). In practice, they fill in the consultations with their own interpretation of how they are able to tell it, with the chance of inconsistencies within the story and between HCPs. What is missing is a supporting storifying structure that all can follow.

Stories are built from four principles, underlined by a narrative (Bronwen, 2016). Narratives hold the additional purpose of a story (Gray, 2009). In HSCT consultations, this is to inform on the treatment and elicit decision-making.

The principles that make a story are:

- a **chronological timespan**
- **identifiable characters** to follow throughout the timeline
- the **events** that the character experiences
- the **settings** in which these events take place.

These principles are already present in some of the components of HSCT consultation: there is a beginning and an end to treatment, there are the actors involved, there are treatment steps to undergo, and different places that are visited during treatment. How these components are told, however, is dependent on the physician's communication style and is often interwoven with medical information that holds little to no narrative foothold. The risk in relying on medical jargon as the thread to weave the consultation story together is losing its narrative connection, and with it, the patient's understanding.

When choosing to storify the conversation, HCPs should be aware of whom the story is meant for. How stories are interpreted is a social process, dependent on cultural background (Westerhof & Voestermans, 1995). To allow for connection with those facing the greatest understanding barriers, including young patients and culturally or linguistically diverse parents, the story should focus on the global lines of HSCT treatment, with anchor points to complicated topics such as graft vs. host, without confusing the big picture.

To understand anything is to be able to fit various parts into a system which is an integrated whole, so that they 'make sense' (Bruner, 1987).

The Redesigned Story

The consultation design solution is both a toolkit and a story. StemSense shapes the HSCT story through the following features:

Foundation: the explanation of complex medical mechanisms is supported by visual tools.

Sequence: the consultation story is told chronologically, through key events.
Setting: the key events are placed within the main locations of treatment.

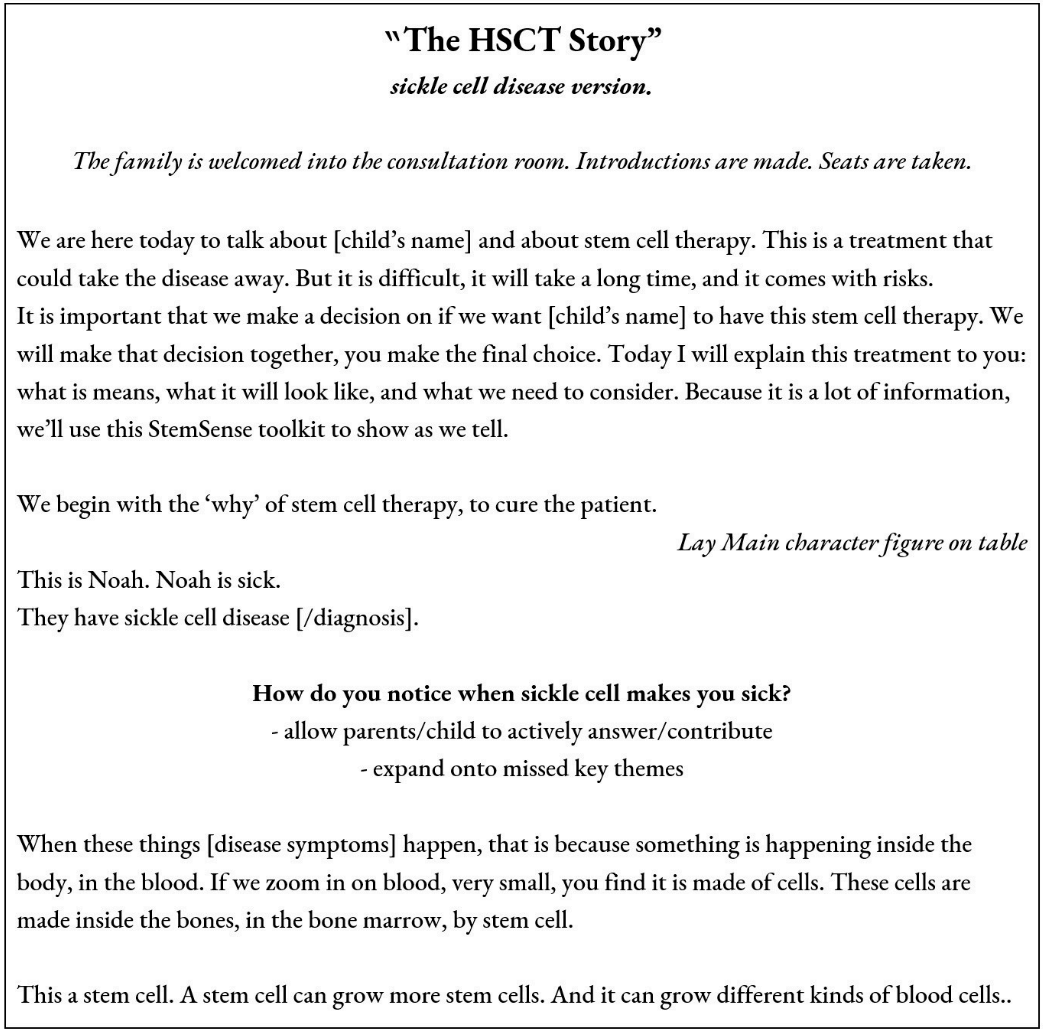
Resonance: the treatment events are explained through the patient's perspective.

Body: the physical impacts of the treatment are visualized.

Face: the patient's experience of treatment is visualized by expressions.

Because the story is broken up into event sequences, and these are represented by physical tools that need to be placed down, there are natural spaces for questions by the parents between event placements, where they can refer back to the parts already placed.

The script shows a preview of the HSCT consultation story, rewritten by narrative principles, of which the frameworks are found in the Appendix. In words alone, this story is not yet whole. It comes with a set of tools to guide and make tangible. First, get to know the components before they’re used as one.



“The HSCT Story”

sickle cell disease version.

The family is welcomed into the consultation room. Introductions are made. Seats are taken.

We are here today to talk about [child’s name] and about stem cell therapy. This is a treatment that could take the disease away. But it is difficult, it will take a long time, and it comes with risks.
It is important that we make a decision on if we want [child’s name] to have this stem cell therapy. We will make that decision together, you make the final choice. Today I will explain this treatment to you: what is means, what it will look like, and what we need to consider. Because it is a lot of information, we’ll use this StemSense toolkit to show as we tell.

We begin with the ‘why’ of stem cell therapy, to cure the patient.

Lay Main character figure on table

This is Noah. Noah is sick.
They have sickle cell disease [/diagnosis].

How do you notice when sickle cell makes you sick?
- allow parents/child to actively answer/contribute
- expand onto missed key themes

When these things [disease symptoms] happen, that is because something is happening inside the body, in the blood. If we zoom in on blood, very small, you find it is made of cells. These cells are made inside the bones, in the bone marrow, by stem cell.

This a stem cell. A stem cell can grow more stem cells. And it can grow different kinds of blood cells..

Figure 20. *preview of HSCT story script for SCD*

A TOOLKIT TO HOLD.

2D narrative visualizations already play a role in communicating medical stories (Meuschke et al., 2021), yet the role of interactive 3D models remains largely unexplored. Tangible props are considered more engaging and enable interaction (Krone et al., 2017). It is through interaction that understanding is shaped, and stories can become shared (van Boeijen et al., 2025).

StemSense makes the consultation graspable, literally. The story of stem cell transplantation is placed on the table, where it can be built, followed, and returned to throughout the conversation. Instead of relying solely on verbal explanation, the consultation unfolds through physical elements that visualize complex concepts, give structure to the narrative, and make space for the patient’s perspective.

Through this shared interaction, the HCP and family move step by step through the treatment story. The tools provide a clear overview while allowing moments to pause, revisit, and elaborate. In this way, the consultation becomes not just an exchange of information, but a story that can be constructed and understood together. It is not a restrictive script; it is a flexible set of tools that can be used by the HCP in their style, as an addition to their consulting abilities, while upholding the narrative structure.
StemSense consists of three elements:

- **The main character** who represents the patient
- **The cells** that show the essential disease and treatment mechanisms
- **The treatment tiles** that lay out the events across time

Together, these components shape the narrative of HSCT from the patient's perspective.

Figure 22. *StemSense Toolkit*

Figure 21. *StemSense in use*

MAIN CHARACTER.

The main character is the protagonist who drives the HSCT story. They represent the child patient to allow empathy without intensifying the consultation by using the child's real name and addressing them directly. This enables the discussion of heavy topics such as risk and mortality with emotion and a measure of distance.

The human figures depicting the character are used as a narrative anchor, on which the treatment applications which the patient will experience for a long time are shown: a feeding tube, for when the effects of chemotherapy make eating difficult, the central line, through which blood is drawn and chemotherapy, new stem cells, and blood transfusions are given. The impacts of treatment too are shown on the character, such as hair loss, heavy emotions, and a gradual recovery.

The main character comes as laser-cut plywood figures. Their thin, tactile quality allows them to be picked up, exchanged, and passed between physician and family as the story unfolds. The 2D versions of the illustrations, too, are applicable within the care path, yet in the consultation room come best to their value in a 3D form.

Figure 23. *pediatric patient at the WAKZ (LUMC, n.d.)*

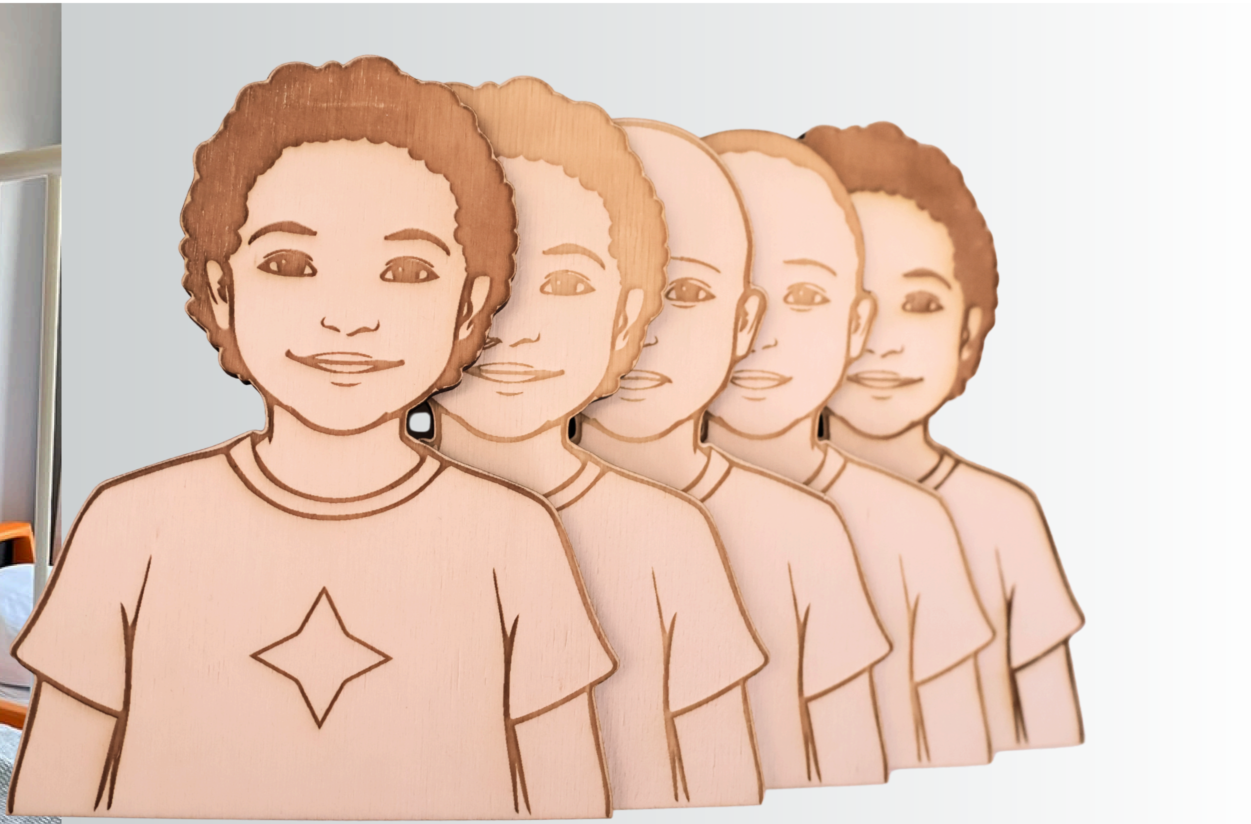
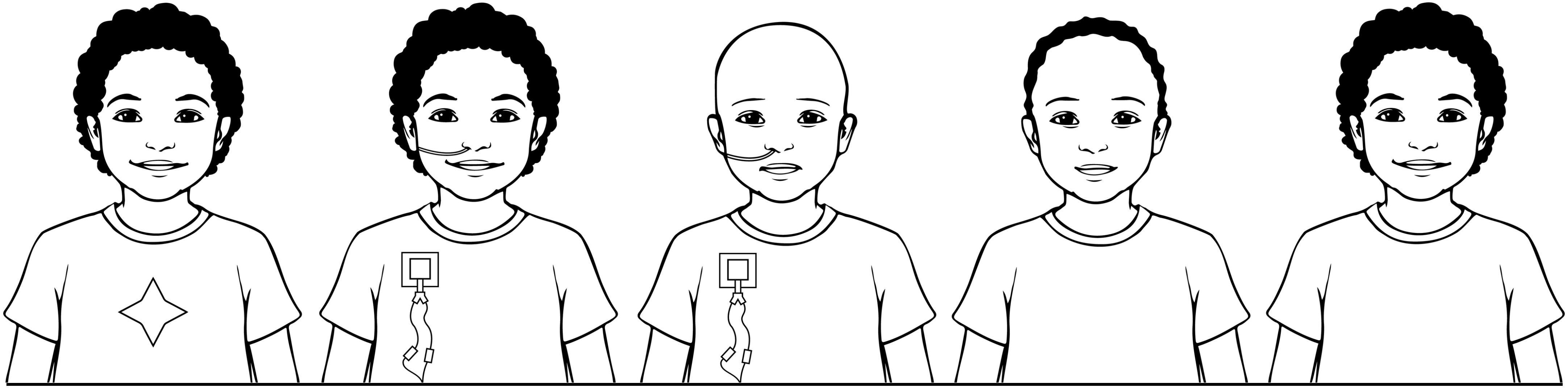


Figure 24. *StemSense main character figures*

Form

The main character is a stack of human figures depicting a child of ambiguous gender, race, and age. Each figure shows the effects of a treatment through a set of 5 (see Figure X):

Figure 25. *Protagonist progression across treatment*



Happy with HLA star
A child with a bright smile, open eyes, and a full set of curls.

The star on their shirt serves as their HLA type, to explain donor matching.

Getting ready
The happy child with a central line & feeding tube.

Chemotherapy
A saddened child with tired eyes, thin eyebrows, full hair loss, a central line, and a feeding tube.

Recovering
Freshly regrowing hair, tired but with a hopeful expression.

Happy and healthy
A repetition of the child with a bright smile, open eyes, and a full set of curls.

CELLS.

A StemSense consultation begins not with the treatment, but with what lies beneath it: the cells that the transplantation wishes to replace. The cells connect the knowledge parents are most likely to be familiar with and confident in: that of the disease, its symptoms, and its mechanisms, to the story of HSCT.

The HCP introduces the cells one by one, placing them either on the table on the patient's side, or in their hands to hold. Which cells are found in the blood? What roles do they play in the patient’s health? What is a stem cell? What can it become? The focus is set on the patient as their disease is explored through the 3D cells they can see, hold, and share. What is the difference between sick cells and healthy cells? How can stem cell transplantation change the blood? As the cells are explored, the story finds its basis. A complex, and for some, abstract concept of cells becomes tangible.

The cells are designed to be clearly identifiable, simplified in shape, and distinguishable from each other. They are kept within two cell-shaped containers that represent the stem cells. One holds the patient’s system, containing the diseased variation. The other represents the donor, filled with healthy cells. Compared side by side, they show the difference between what is and what could be, the replacement principle of transplantation.

As the consultation story continuous cells can be rearranged, removed, and reintroduced. Their removal shows the effects of chemotherapy, while their absence is connected to the phases of HSCT. One by one, corresponding to treatment progression, the cells are returned to the patient, at which the HCP can expand on what experiences come along with the regrowth of said cells. The red blood cells return energy. Wounds will heal again when the platelets regrow, etc. This is especially valuable for explaining the importance of isolation due to the absence of white blood cells, and the different types of isolation needed for the different moments of regrowth of the G-cell (granulocyte) and the L-cell (lymphocyte).

Figure 26. *Stem cell containers with the 5 healthy cell types*

Figure 27. *Spare cell storage in the StemSense toolkit*

Figure 28. *Overview of all StemSense cells*

The consultation toolkit comes with a different set of diseased cells, made to look different from the healthy cells by a variant appearance. Before the consultation begins, the HCP can assemble the contents of the patient's stem cell container with a cell combination that best represents their specific disease. The consultation zoomed in at the smallest scale of cells, held and shared. They are side characters to the story. After they are introduced, they move alongside the main character. For a full overview of all cells available in a StemSense toolkit, see the Appendix.

Form

The cells are 3D printed components. The use of 3D models in doctor-patient communication is an underexplored topic still in its infancy (Traynor et al., 2022), applied in niche studies that show positive outcomes (see Figure 29). Their form is based on existing visualizations used in education on cells, adjusted to be simplified and distinctive from one another. Its color-coding system allows for a clear overview and easy identification during the consultation. Purple is used for stem cells, red for red blood cells, white for white blood cells (including lymphocytes and granulocytes), and orange for platelets. Diseased cells are modeled differently to visually distinguish them from healthy cells. This can include smaller size, altered shapes, and/or the use of transparent material, allowing patients and families to immediately recognize the difference between healthy and affected cells.

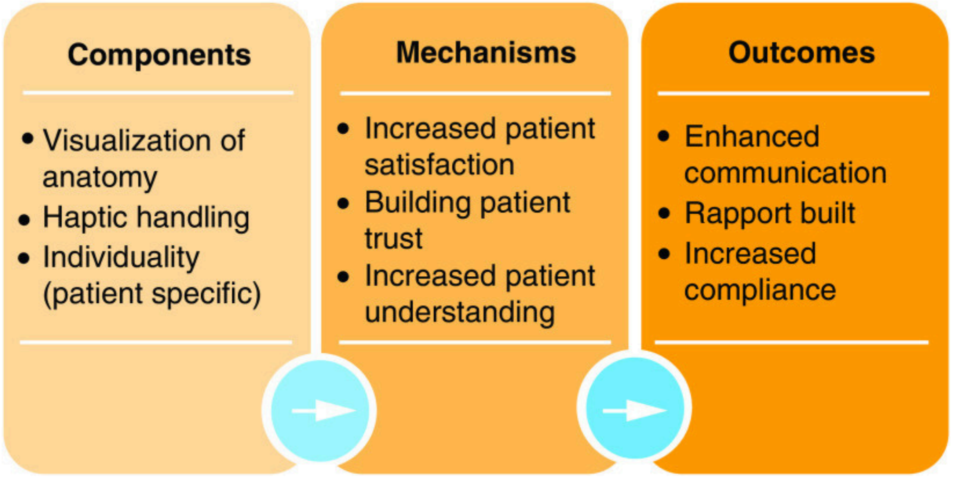


Figure 29. *Logic model for the use of 3D models for communication in medicine (Traynor et al., 2022)*

TREATMENT TILES

The treatment tiles are the ones that make up the story. The chronological sequence of events of the HSCT care path, is illustrated in six phases, each with their own implications for the patient. The tiles translate the practical HSCT information into the perspective of a patient and their family, answering not just the question of what happens, but what does that mean for their daily lives. Consulting while using the tiles compels the consulting HCP to tell the story chronologically and as a whole. Key themes the tiles illustrate are:

- What will happen during HSCT?
- Where will the HSCT steps take place?
- What do the treatment steps mean for the patient's daily life?

The treatment tiles illustration can be compared to the current HSCT onepager with timeline that is available to patients online at the WAKZ website (Figure 30). The StemSense toolkit consciously abstains from using language or numbers to make it a sole visual product and make is applicable to different patient contexts.

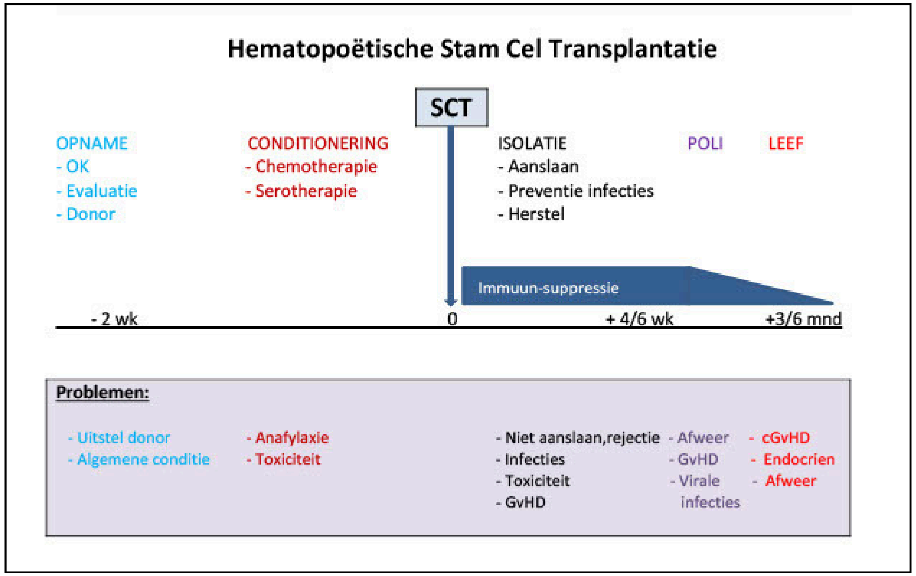
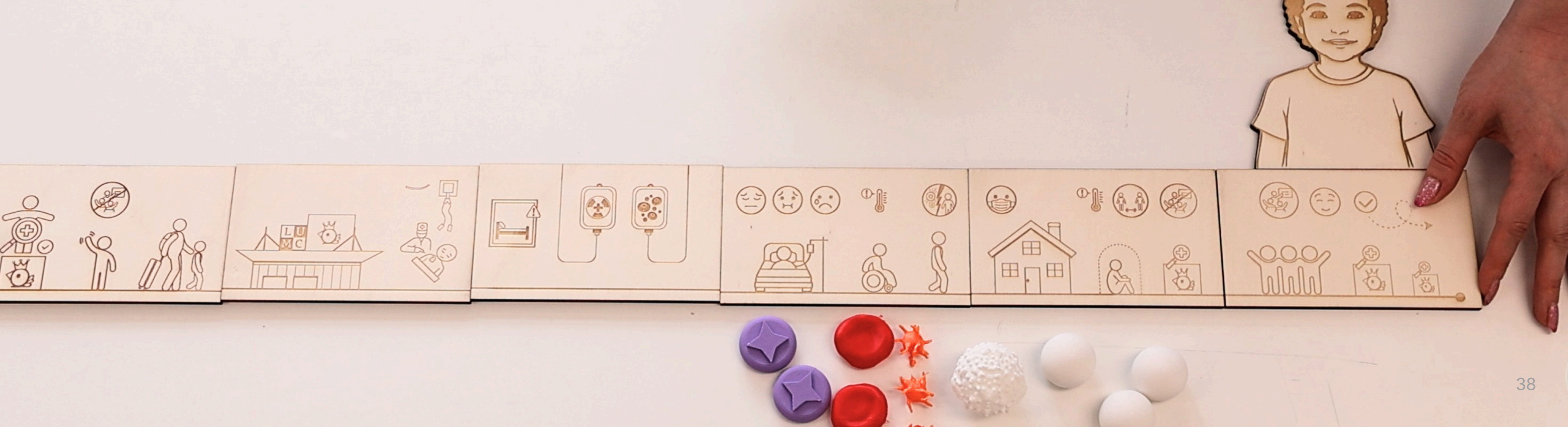
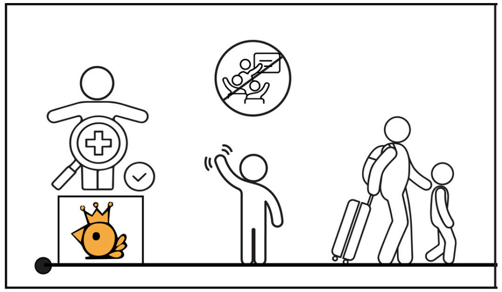


Figure 30. *HSCT event visualization currently used for patient understanding*

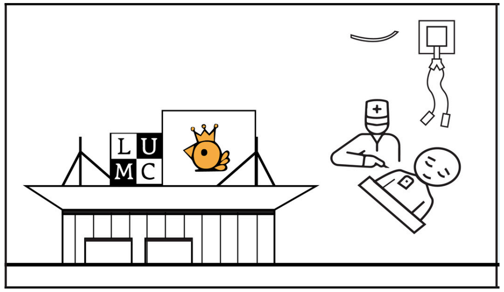
Figure 31. *Treatment tiles in use*





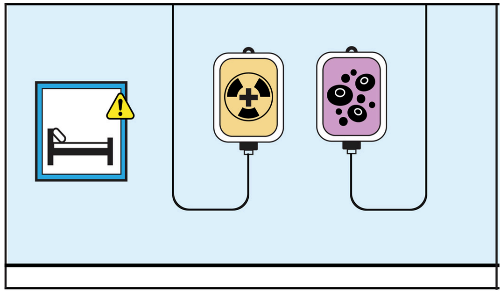
Tile 1:

- A full screening of the patient's health is done at the hospital.
- The patient says goodbye to their friends, and they stop physically going to school.
- The patient and a parent pack their bags to get ready for a long stay at the WAKZ. A parent may stay with the child at all times.



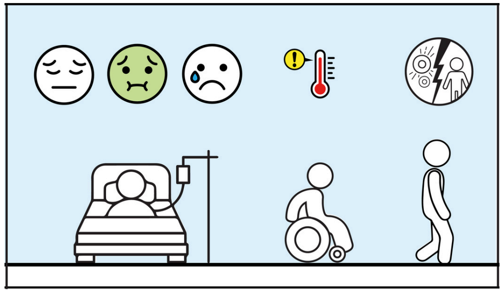
Tile 2:

- The patient travels to the hospital and moves into their own room at the WAKZ.
- Through a small operation, the central line is placed.
- The patient is given a feeding tube to prepare for when eating might become difficult.



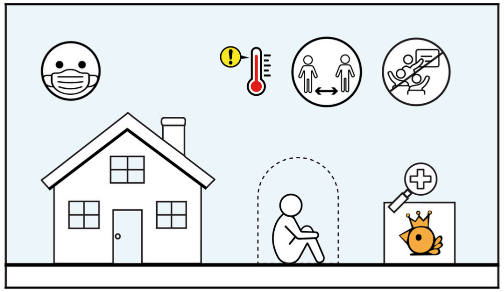
Tile 3:

- Isolation starts, and the patient has their own isolation room. It is protected through an anti-chamber, a plastic curtain, and strict hygiene regulations.
- The patient is given chemotherapy, which will stop the body from making its own stem cells and blood. It is given through the central line. The patient's own cells disappear as no new blood is produced.
- When the patient's own cells are gone, they are given the donor stem cells. These come in an IV bag. The cells will need time to grow.



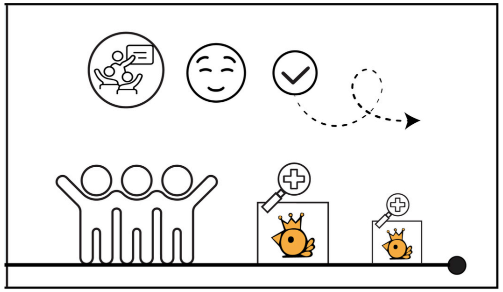
Tile 4:

- A few weeks after chemotherapy, when the new cells are already in the body but haven't grown yet, the patient will feel very sick. They will have no energy, may be nauseous as they struggle with eating, and can be sad.
- A close eye is kept on the recovery of the patient, as the cells return, first the red blood cells, then the platelets, they will start to feel better. Because the immune system isn't working, we have to watch out for fever and infections.
- When the G-cells, which protect against bacteria, grow back, the patient feels better, good enough to go home. They aren't fully healed yet, because the L-cell, which protects against viruses, isn't back yet. At this time, something dangerous can happen. L-cells scan for what belongs to the body and what doesn't. There is a chance that the L-cells that come from the donor grow in the patient's body but start to attack the body of the patient from within: this is called graft vs. host. Patients can get so sick from this that they pass away. The doctors watch closely in the blood to see if these cells are active, if needed they give something to calm down the L-cells so they can get used to being in a different body.



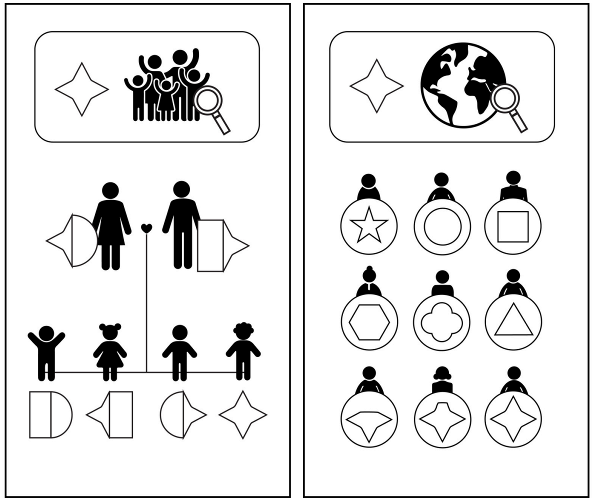
Tile 5:

- The patient is well enough to go home, but doesn't have working L-cells yet. They go home, where they will be in home-isolation: quarantine, just like during corona. They will have to wear a face mask and stay at home and at a distance from others. No friends can visit yet, and they can't go to school.
- Being isolated at home can be lonely and take a long time.
- During this time, we'll need to be careful with infections, as without the L-cells, the patient is still vulnerable to viruses.
- Frequent check-ups of the blood will be done at the hospital to see if the cells have all grown back.



Tile 6:

- If all goes successfully and the cells grow back without complications, the transplantation has worked, and the patient is no longer sick.
- After a while, they can also stop with their medication and live a normal life.
- They can see their friends and family again and return to school and their daily lives.
- At the hospital, they still keep an eye on the patient to make sure the disease stays away, and all cells have been changed. This will become less and less as time passes.



Donor tiles - family:

- Searching for a stem cell donor is first done within the family.
- Every person has their own HLA 'code' that marks their cells are theirs. You got half your code from each parent.
- There is a ¼ chance a sibling has the same code, making them a suitable stem cell donor.

Donor tiles - international registry:

- If no donor is found in the family a worldwide donor registry is checked for a match.
- There are many different types of HLA 'codes', for transplantation there's a search for as close a match as possible.
- If no identical 10/10 match is found, there is a search for 9/10, 8/10, etc.

- If no match was found in a sibling, nor in the donor registry, it is possible to use a parent as a donor as they have a 5/10 match.

Form

The tiles are lasercut and engraved from thin plywood, fitting the form of the main character. The tiles are separate pieces that allow the treatment to be laid down like a puzzle. This flexibility allows HCPs to adjust it to their momentum and enables a gradual reveal of the total treatment picture.

HOW STEMSENSE IS USED.

The following pages show a storyboard of a StemSense HSCT consultation in practice.

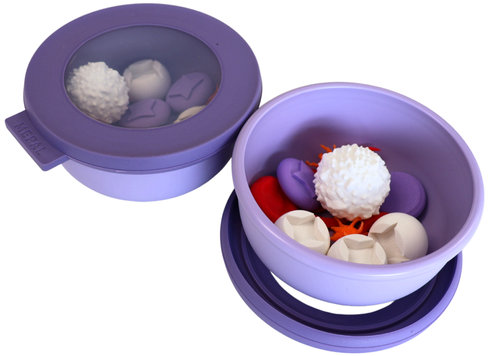
This storyboard explains the foundations and journey of HSCT through a cohesive story, guided by the physical tools from the toolkit.
The story is prepared beforehand by the consultation narrator to fit the specific patient context. The story unfolds alongside the patient's family, as the narrator lays it out on the consultation table.

This summarizing storyboard is a considerable number of pages, the condensed version of a consultation that in practice takes 1-2 hours.

Before Consultation

The narrating healthcare professional (HCP) opens the StemSense toolkit in their workspace and takes out the stem cell containers.

With the spare cell components, the HCP can adjust the contents of the stem cell container that represent the cells that the patient's stem cells can create.

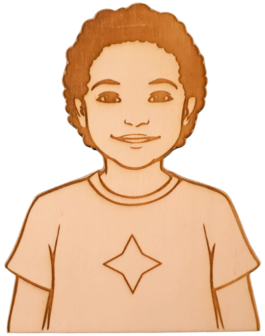


They assemble it to fit the body and the combination of cells that make up the patient's disease.

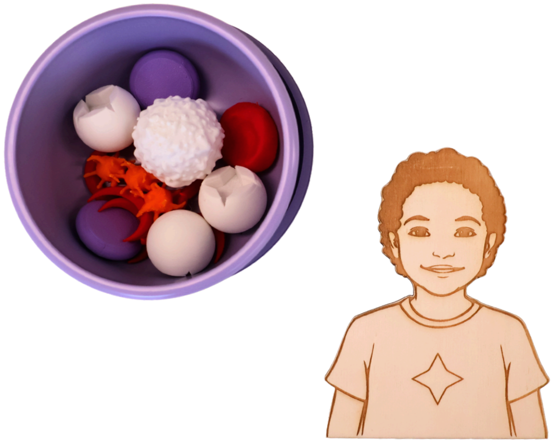
The HCP brings the StemSense case into the consultation room.

The patient and parents are welcomed. Introductions are made and seats are taken.

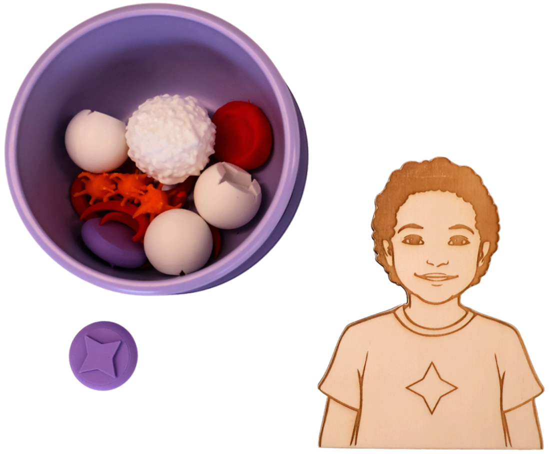
During Consultation



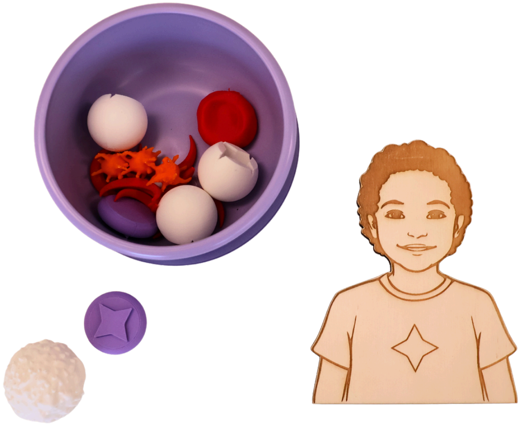
HSCT is introduced. It is told that this will be an intensive conversation and that an important choice will need to be made. StemSense is introduced, explaining that the consultation will be guided as a story. The main character is placed on the table, facing the patient and parents.



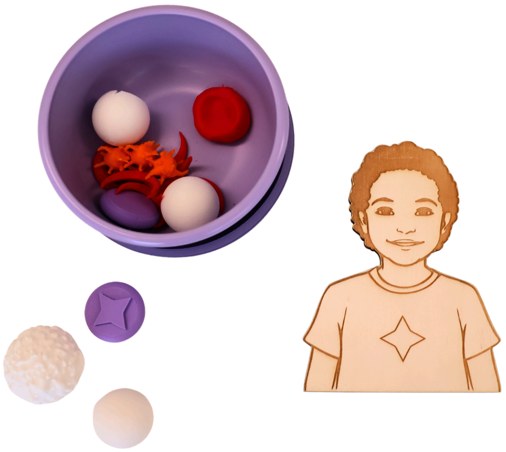
The HCP explains what a stem cell is: a cell from which other cells can grow. A blood stem cell makes blood cells. Your blood contains different types of cells, each with its own function. The patient's disease is caused by one type of cell not working properly.



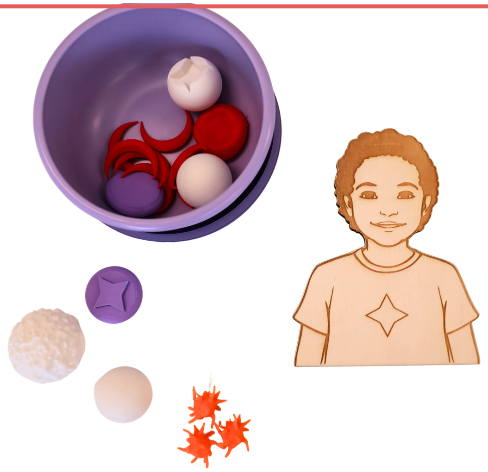
From stem cells new stem cells can grow. This way the 'blood factory' can keep running and blood continues to be made.



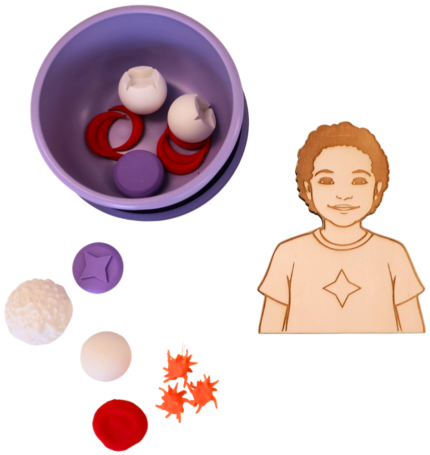
The big white blood cell: the granulocyte ("G-cell") is explained. It is part of your immune system and protects your body against bacteria.



The smaller white blood cell: the lymphocyte ("L-cell") is explained. It is also part of your immune system and protects your body against viruses.



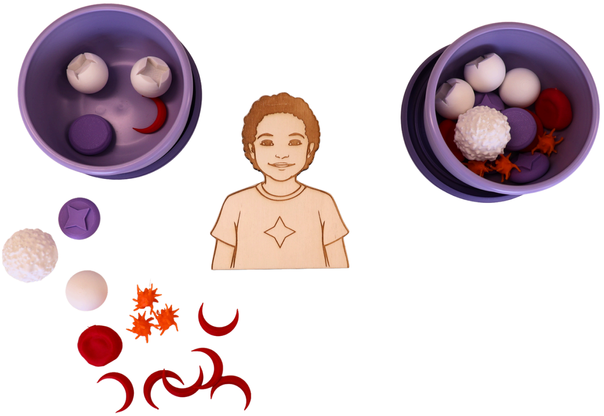
The platelets are explained. They are the glue of the blood, which can stick together and form clots to seal and heal wounds.



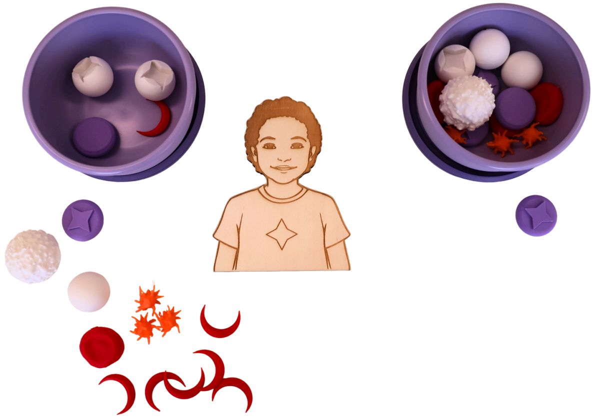
Red blood cells are explained. They carry oxygen from your lungs to the rest of your body. In your body (sickle cell disease example), some red blood cells are the round normal shape, but there are also cells that are different: under certain conditions, like fever, dehydration or pain, they can collapse and become sickle-shaped.

This half moon sickle shape causes problems because these cells can carry less oxygen, can hook into other sickle cells, and block arteries as they clump together. This causes pain and damage, and crises.

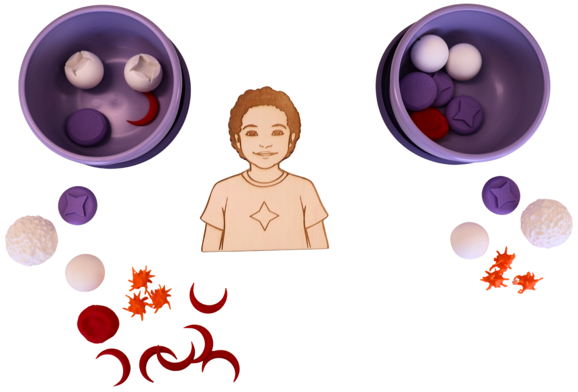
The HCP explores what the patient and parents already know about the disease. They ask about the symptoms and experiencse and connect these to how their cells work. The mechanisms of sickle cell disease are demonstrated using the 3D cell model. Here the disease progression, and possible futures without HSCT are discussed.



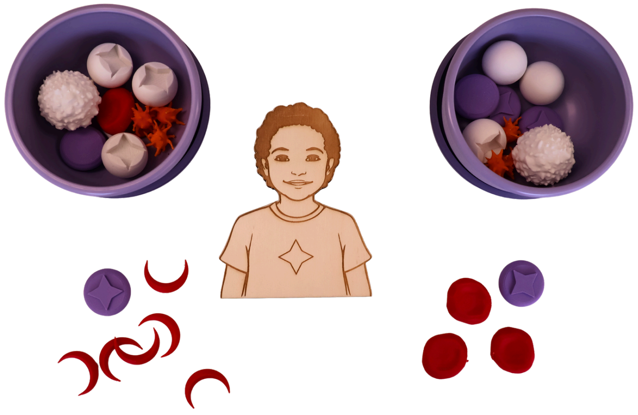
With a stem cell transplantation, the goal is to replace the stem cells that make unhealthy cells with stem cells that make healthy ones. If your stem cells are healthy, your body can produce healthy blood cells, and you will no longer be sick.



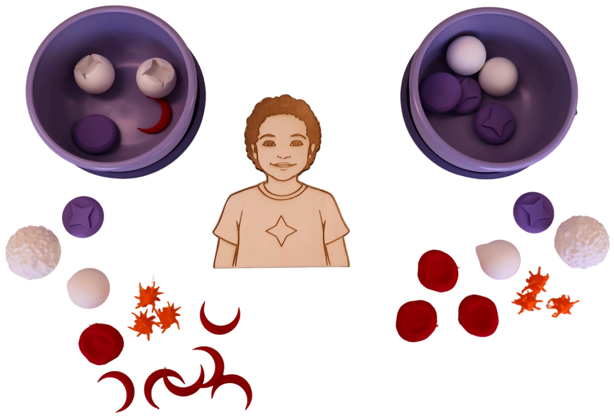
If we can replace sick stem cell with healthy stem cells, the healthy stem cells will grow more healthy stem cells, from which only healthy cells will grow.



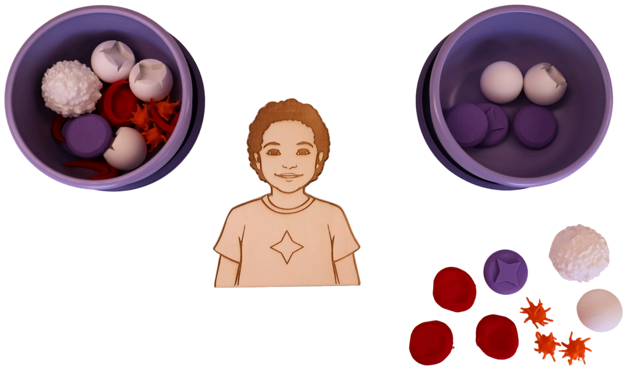
Most of the cells this healthy stem cell makes are the same as yours. That is becomes most of your blood cells are healthy. The sickle cell disease is only in the red bloodcell.



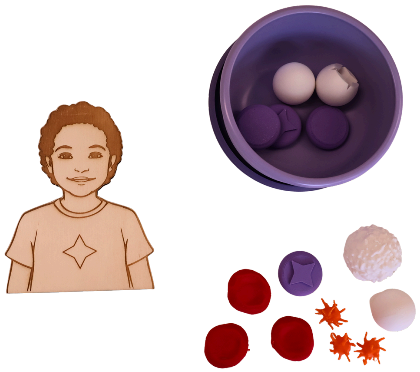
The healthy red blood cells look different. They are round and flexible and can carry more oxygen. Having healthy cells will give you more energy and stop the painful crises of sickle cell disease and the damage it does to the body.



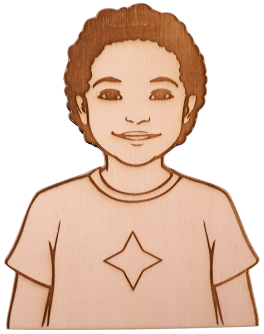
Because the stem cell creates all of the blood cells, to change the red blood cell, we'll need to replace the stem cell with one that won't make sickle cells. This is done through stem cell transplantation.



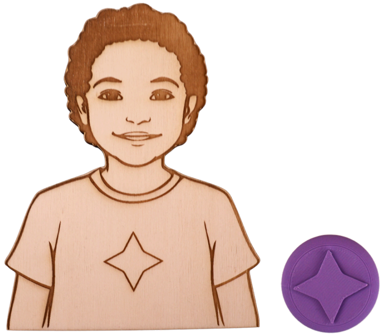
In a stem cell transplantation we use stem cells from a healthy donor: someone who does not have a disease. This will give you all of their blood cells, healthy ones.



To replace your stem cells with donor stem cells, your own stem cells first need to be removed. This happens during the transplantation process. At the end of transplantation you will only have health cells that have grown from the ones from the donor.

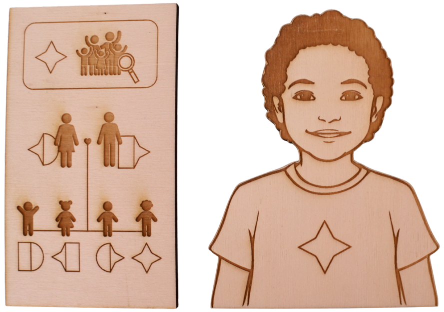


For the transplantation to work, it is important that the cells of the donor look as much like yours as possible. Each person has their own 'code' on their cells, we call this your HLA type. Let's say this star is your personal code.

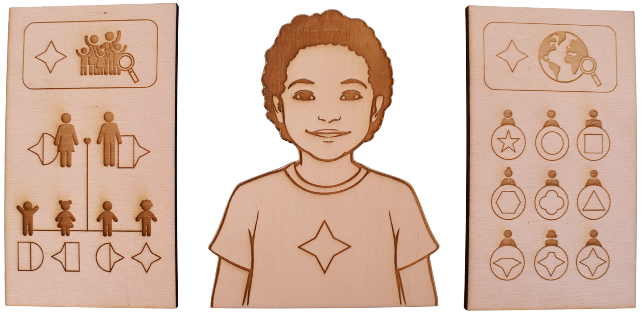


The star is on your cells, and there to let your body know that the cells belong to you.

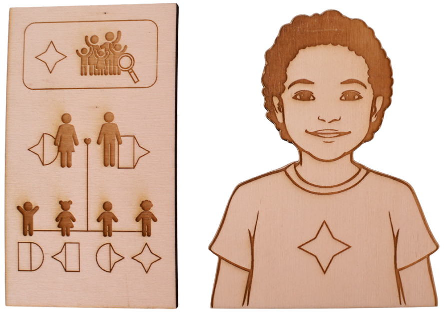
The white blood L-cells protect the body against threats from outside. They scan cells constantly to check if they belong to your body. If they do not match they attack. Because you get the immune system, the white blood cells, of the donor, we don't want those new cells to attack you once inside your body. We call this Graft versus Host. It can be dangerous. We need to look for someone who also has a star as a code, or one that looks as much alike as we can find.



You got your code from your parents. They each gave you a half, and together it made your star. There is a one-in-four chance that a sibling, a full-blood brother or sister, has the same code as yours. There are different combinations possible. We can test your siblings to see if there's a match. This would be a good donor.



If there is no sibling with your code, we can look in a donor registry with people from all over the world. They have a database full of codes, in which we look for yours. We'll first look for a perfect match, but if we can't find a 10/10 match, we'll look again for 9/10, and after that for 8/10, and so on.



If no matches are found in the donor registry, we can also use the stem cells of one of the parents. These automatically match for 5/10 in the code. For this, the cells will need to be treated first.

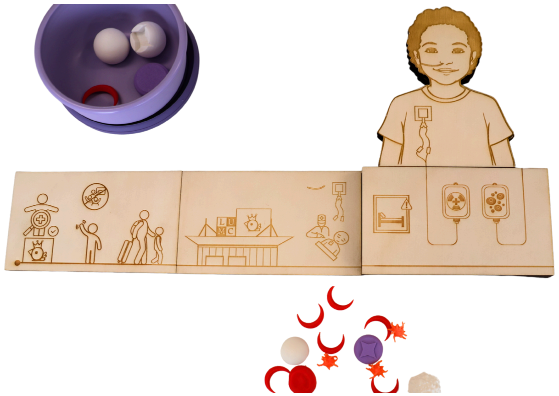
When a donor with a good match has been found, stem cell transplantation can start.

The treatment begins with a full-body check at the hospital. This includes tests for infections, blood tests, and visits to specialists such as the dentist. We also check how things are at home and what needs the family has for undergoing the treatment, this could be with the work of the parents, or with arranging support for caring for other children, or perhaps the elderly within the family.

You have your disease and sick cells, but if no other underlying complications are found, and the family is ready, it is time to prepare. You say goodbye to school and friends, pack your bags with a parent, and get ready for a long stay in the hospital.

You go to the hospital and there you are given your own room. A parents may always be with you and sleep over.

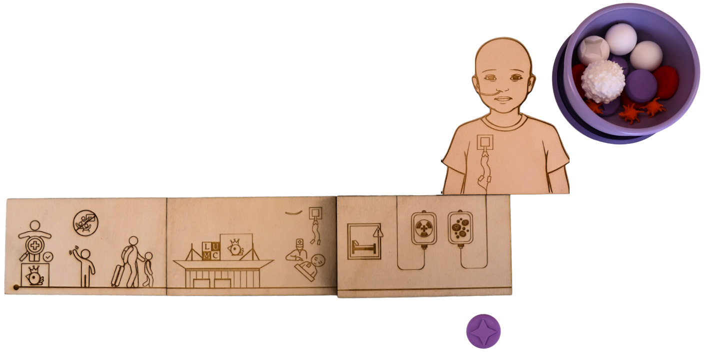
The first thing that happens in the hospital is that a central line is placed. This is a type of IV on your chest through which medication can be given, and blood can be taken without repeated needle pricks. This is placed through a small operation. A feeding tube is placed to help when eating becomes difficult later.



When everything is prepared, you move to an isolation room, where extra hygiene measures are taken to protect you from infections. When we continue with the treatment, you'll become vulnerable to them.

To make space for the new stem cells, your own stem cells are removed using chemotherapy. This is given through the central line. Chemotherapy has strong side effects, including hair loss.

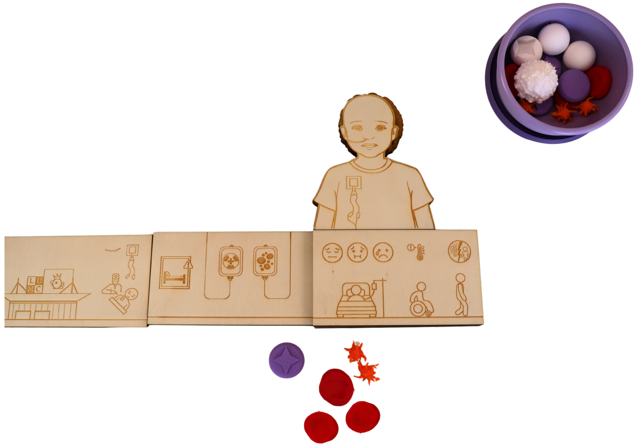
It takes some time for the chemotherapy to have its effects, usually a few weeks, and for the existing cells in your body to disappear as the product has stopped.



When your own cells are gone, the donor stem cells are given through the central line, from an IV bag. These new stem cells travel through your blood to your bone marrow.

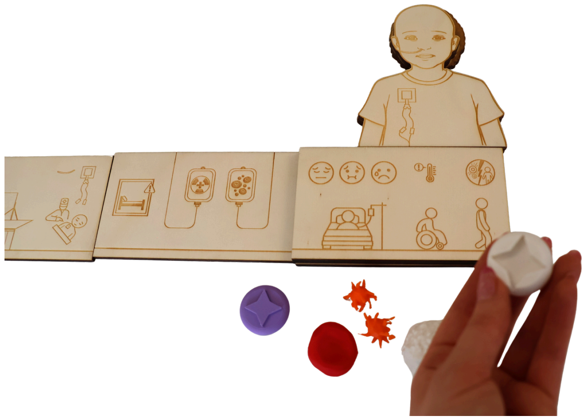
The new cells need time to grow. During this time, your blood cell levels are very low. This can be a difficult period, you may feel tired, nauseous, and emotionally low.

The first cells to recover are red blood cells. These will be healthy and no longer sickle-shaped. As they return, you will start to feel more energy.



Next, platelets recover. Wounds will begin to heal more easily, including possible sores in your mouth, making eating easier again.

After that, the G-cells (granulocytes) return. These help protect you against bacteria. You will continue to feel stronger and better able to digest food.



However, the transplantation is not yet complete. The L-cells (lymphocytes) still need to recover. These protect against viruses but also check whether cells belong in your body.

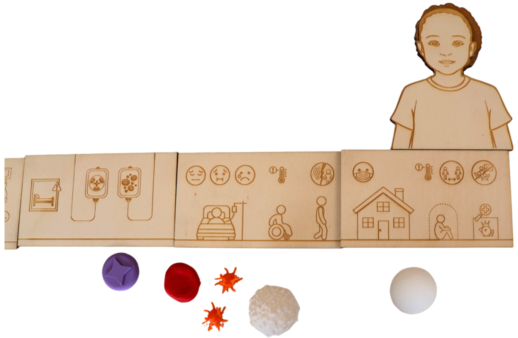
There is a risk that these donor L-cells may attack your body. This is called graft-versus-host disease. Medication (immunosuppression) can help control this, but complications can still occur. This can be life-threatening, some patients do not survive this. This is why finding a well-matched donor is so important.

Even though your L-cells are still recovering, you may be allowed to go home. Your immune system is still weak, so you will need to be very careful. At home, you will live in a form of isolation, similar to quarantine during COVID:

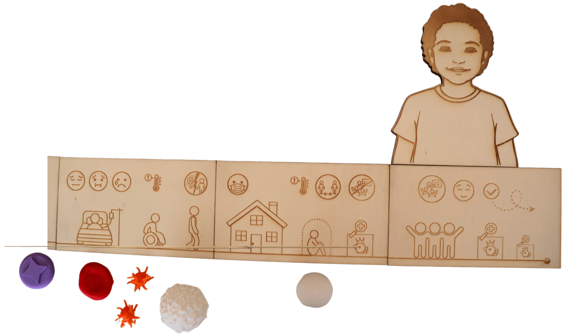
- Wearing a face mask
- Staying home
- No visitors, family, or friends over
- Not returning to school yet

This period can be long and difficult. You may feel lonely, as you are back home but not yet able to fully take part in daily life. You will be closely monitored for signs of infection, such as fever, and will have frequent hospital check-ups to track your recovery.

When the L-cells recover, your blood system is complete again. Your hair will start to grow back, and you will feel stronger. Because your immune system is new, you will need to receive vaccinations again.

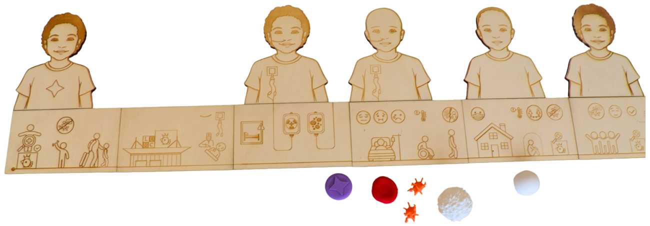


Your body has new stem cells and is no longer producing sick cells. Hospital tests confirm that the transplantation was successful.



You can gradually return to normal life. You can see your friends again, go back to school, and take part in activities without feeling sick.

Over time, you may no longer need medication. Hospital visits will become less frequent, though occasional check-ups will remain important to ensure your health stays stable.



This is the full basic treatment story. After explaining this, the risks and possible complications can be discussed in more detail. Strategies to reduce these risks can be connected to different moments in the treatment process.

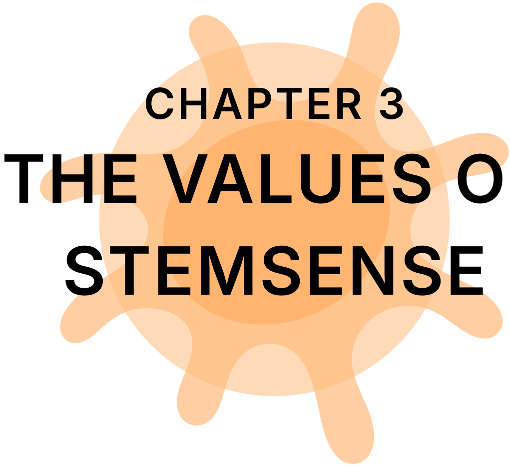
The depth of these topics within one consultation depends on how ready patient and parents are, and on their health literacy and understanding.

PLACEMENT WITHIN THE CONSULTATION ROOM.

The consultation takes place across a table, with people facing one another. It unfolds by the HCP's hand but faces the patient and parents. This position allows for eye contact, for the healthcare professional to read the reactions of parents and adjust the story to the assessed level of their understanding. Eye contact is an important consultation principle for making families feel seen and heard when addressing the HCP (Hart, 2017).

For use within the consultation room, the toolkit follows the requirements of the clinical context. It is hygienic, with the surfaces treated to be cleaned by alcohol wipes and safely handled without sharp edges or splintering. The tools avoid choking hazards of small elements by following toy industry sizing guidelines. At the same time, it remains coherent and practical in use. The components fit together, are easily stored and transported within a toolkit case. The cells can be assembled quickly by the HCP by interchanging components from spare parts. Its simplicity allows it to adapt to different consultations and for intuitive use within the consultation room.

Figure 32. *StemSense in use by WAKZ physician*



CHAPTER 3

THE VALUES OF STEMSENSE

Binding the challenges of HSCT consultation

The StemSense toolkit was developed to translate abstract interactions and qualities into tangible tools that support complex consultations and help clinicians uphold these qualities in practice. This chapter elaborates on the key challenges addressed, along with the features through which StemSense responds to them. It presents the design from both healthcare professionals and patient-family perspectives, and concludes with a summary of its added values.

WHEN WORDS FALL SHORT

Answering the challenges of complex consultation

Clinician-framed visualization

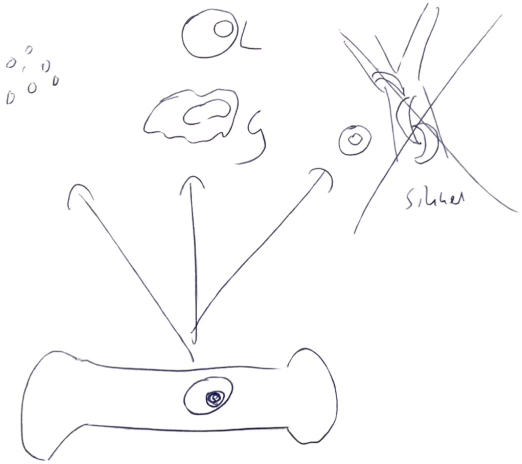
Consultations are held verbally. In practice, it is seen that some HCPs try to sketch alongside their words (Figure 33), as much for the patient as for themselves, to find their momentum. During the conversation, this paper often remains on the HCPs' side of the table, facing their direction. Some HCPs might attempt sketching upside down, which is seldom beneficial for the visual clarity of their drawing.

This HCP initiative for visualization shows their need for anchor points in their consultation story, both to maintain momentum and as a point of reference for what has and hasn't yet been discussed. HCPs also recognize patients' families' need for support alongside verbal information when discussing concepts, such as cell mechanisms, that are abstract to those unfamiliar.

The challenges observed in the current visualizations are:

- They are drawn quickly and depend on the HCPs' sketching abilities for clarity.
- They are made from the HCPs' perspective:
    - Literally, the sketches often face the HCP or remain on their side of the consultation table.
    - Figuratively, as the HCP draws on their own expertise and sketches highly complex concepts, which are not essential to their story and may further complicate it for patients, such as how hemoglobin binds to oxygen on a molecular level in different shapes of red blood cells, as seen in observations.

Figure 33. *Consultation sketch explaining cell production - drawn by a pediatric hematologist*



Patient-centered design

StemSense answers the visualization needs and challenges through a defined set of visual components. The HCP no longer needs to sketch themselves and can instead use the provided tools in a way that structures the content and enables their momentum. During consultation, the components face the direction of the patient's family, and can be clearly seen and interacted with by both. These visualizations bring consistency in quality, quantity, and complexity independent of different HCPs and consultations. The components were designed with a balance of complexity and necessity: only the parts essential to the base HSCT story were kept.

Visuals that were frequently seen to cause misunderstandings were left out, such as the images of bones in which stem cells produce blood. Patients, especially those with language barriers and low health literacy, often made the incorrect assumption that during HSCT, the bones need to be physically opened to change stem cells within. This implied the need for heavy operations and distorts the view of the treatment and influences the decision-making process. StemSense instead uses stem cells as the focus of blood production, designed to be clearly identifiable in purple so they can be easily referred back to (Figure 34). Its visualizations are made for how the patient will interpret them, assisting the HCP to connect to their perspective

Figure 34. *Cell production and functions explained through StemSense at the WAKZ*

Clinician-framed communication

The current consultation follows a global story that meets key themes of HSCT:

1. The child's disease - *why HSCT is applicable*
2. The disease progression - *what could happen without HSCT*
3. Stem cells - *what HSCT is*
4. Finding a donor - *what is needed for HSCT*
5. HSCT treatment - *what HSCT will look like*
6. The risks - *what could happen with HSCT*

How these themes are addressed, in which detail and which order, differs in narrative and structure between care professionals. For example, a pediatric hematologist may go into depth on how hemoglobinopathies affect blood cells on a molecular level. A pediatric immunologist may expand on how stem cells travel throughout the body before settling into the bones. Each healthcare professional tells the story best they can, from their expertise and specialized perspective. For them, too, it is complex to balance full transparency and completeness with accessibility during such an extensive conversation. Each parent listens and tries to grasp and remember to the best of their ability. Most parents do not look for the medical details, but foremost at what the implications are for their child and their family. Implications that, in the moment of consultation, they can't yet grasp. Patients need information about a transplant that is practical, contextual, and structured around their values and lived experience (Rodenbach et al., 2024).

Patient-centered storytelling

Together with the cohesive visualizations, StemSense comes with a redesigned consultation story that is designed for and around the patient. It takes the themes that are essential and already present within the consultation and restructures them using storytelling principles, enabling improved information uptake and retention. The components allow for flexibility by the HCP in pace and momentum, but centre the story around the patient, both visually with the main character and through connecting each part of the HSCT story to this character (Figure 35). The key themes are told through the patient context. This is found, for instance, in the adaptability of the cells to represent the patient's disease and the possibility to connect these to the patient's experience, and in the key events of treatment being told through the implications they would have on the patient's daily life, such as mentioning school and friends, and a timeline that also shows the carepath phases outside of hospitalization.

All key themes, except the risks of HSCT, are built into the tools. These risks are deliberately left out of StemSense because of the sensitivity and potential disruption of that information. The risks are in part dependent on the patient's condition and case, but due to chemotherapy, they can include an increased chance of cancer, infertility, and organ damage. Because of graft vs. host disease (GvHD), a risk is that the child will not survive treatment. Such topics require careful communication with the compassion and experience of the HCP that can't be distilled directly into symbolism. The StemSense components do offer points that risks can be connected to, such as for GvHD in the 4th tile in combination with the lymphocyte and stem cells (Figure 36). The HCP may divulge on these risks as they consider suitable to the family.


Figure 35. *Main character as consultation centerpiece*


Figure 36. *StemSense opportunity to discuss GvHD*

Information overload

HSCT consultations are, by nature, complex. They are educational conversations that require medical understanding, sustained focus, and cognitive stamina. Even families with high health literacy can struggle to retain the volume of information shared over the course of a long consultation. Research shows that most patients would prefer multiple shorter consultations over one extensive one, and be given the chance to register and process information in between (Herrmann et al., 2021). The reason why these extensive consultations are held is that the topics build on one another. Understanding what a stem cell is forms the basis for understanding how cells regrow. Knowing the roles of different immune cells is necessary to grasp why different forms of isolation are required. If consultations are held in parts, a patient's family could have a wrong or incomplete idea of HSCT while already starting to consider their decision, which could lead to premature decisions that do not align with the one they would have made, or increased anxiety due to uncertainty. During consultation, when parts of this building's foundation of information are misunderstood or missed entirely, families often do not interrupt the conversation, but continue listening with the intention of making sense of it later. Over time, these gaps can distort the overall story.

Although some healthcare professionals pause between topics to invite questions, responding is not straightforward. It can be difficult for families to identify what they do not fully understand, especially when information feels incomplete or unclear. While it is part of the professional role of the HCP to assess understanding, the density and pace of information in a single consultation make it challenging to recognize where misunderstandings occur, particularly before they begin to build on one another.

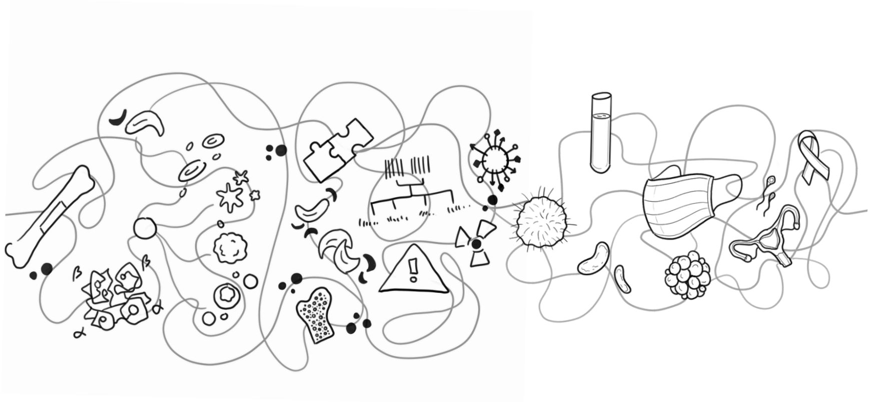


Figure 37. *Overwhelming consultation content illustration*

Big picture

The StemSense story is told through the most essential parts and components needed for a foundational understanding of HSCT. It focuses on the big picture of HSCT and creates this picture on the consultation table. The core medical basis is explained through the cells, the treatment steps through the tiles, and the implications and experience through the main character. The components create the story in its essential form while allowing the HCP to elaborate on and detail the content based on their assessment of a patient's family’s health literacy. This elaboration can also take place between consultations, with the initial informing consultation focused on the essential big picture and expanded upon once the family has had time to process that information. Offering information in this more manageable way may also improve the confidence and experience of the family when navigating the consultation content.

Because the big picture is laid out part by part, the story does not overwhelm all at once and allows the HCP to create momentum and emphasis within the narrative. At the same time, the components that have been used remain on the table and give the patient’s family an overview of what has already been discussed. This also allows them to better assess what they have not understood and to ask their questions more effectively. This improved assessment of understanding and the encouragement of questions works both ways: with the piece-by-piece approach, the consultation content is divided into parts and provides the HCP with natural moments to pause, assess how the information has been received, and discuss this with the family. Misunderstandings and areas of complexity can be more easily identified and given the necessary attention and clarification.

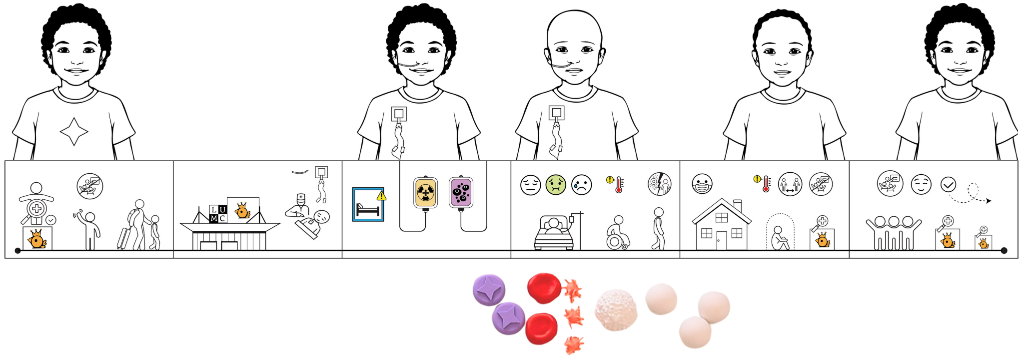


Figure 38. *StemSense complete overview*

Linguistic reliance

As consultations are verbal stories, there is a sole reliance on language-based information that is dependent on words, vocabulary, and semantic context. Research shows there is a significant and positive impact of visual healthcare communication, but a need for more research and development of visual communication tools that can be used in practice (Jensen et al., 2019). The consultations in which understanding becomes most complex are those where language barriers add to the already demanding nature of the HSCT story. Some of these barriers are visible. At the WAKZ and SKZ, when neither Dutch nor English is spoken by the patient's family, a medical translator is involved, often through telecommunication. These conversations can take up to twice the time of a regular consultation, or leave insufficient space to address all themes in full (Mekelenkamp, 2024). The flow of the story changes. It becomes dependent on translation, on pauses, on interpretation. Its effectiveness relies not only on what is said, but on how well it can be translated, on whether the language holds the right words for Western medical concepts.

> "The parents kept thinking it was an operation. That we'd cut into their child and open their bones. We found out only later that the Arabic word for operation and medical treatment was the same."
> - *pediatric physician*

عملية

operation/procedure/what will be done medically

Cases such as Sickle Cell Disease make these challenges particularly visible. As a genetic blood disorder more prevalent among people with ancestry to malaria-endemic regions, namely in Africa, consultations often involve families from non-Western backgrounds. Here, language differences are intertwined with cultural differences. Culture shapes how people communicate, how they interpret information, and how they express understanding or uncertainty. These differences can make it more difficult for healthcare professionals to assess what families have understood, further complicating an already complex consultation.

Some barriers to understanding consultation are hidden. For more than one in three people in the Netherlands, the healthcare system is too complex (Pharos, 2024). Understanding, evaluating, and applying medical information is not self-evident. Low health literacy often goes unnoticed and is not limited to any patient group, background, or language. It quietly shapes how medical information is received and considered, and how confidently patients and families engage in conversation.

When a pedagogical worker explains a treatment to a young child, in the one-on-one child-focused consultations that take place before the treatment begins, they often turn to tangible tools, a doll or object, to make a part of their story visible. For instance, to show the physical treatment component of a feeding tube, as is done at the WAKZ with a Kiwanis doll (Figure 40). For adults, the Dutch healthcare system remains verbal. The story is told in words and is expected to be understood in words. There is a sole reliance on language, when words can fall short.

Figure 39. *Sickle cell patients at the SKZ (Sinterniklaas, 2022)*

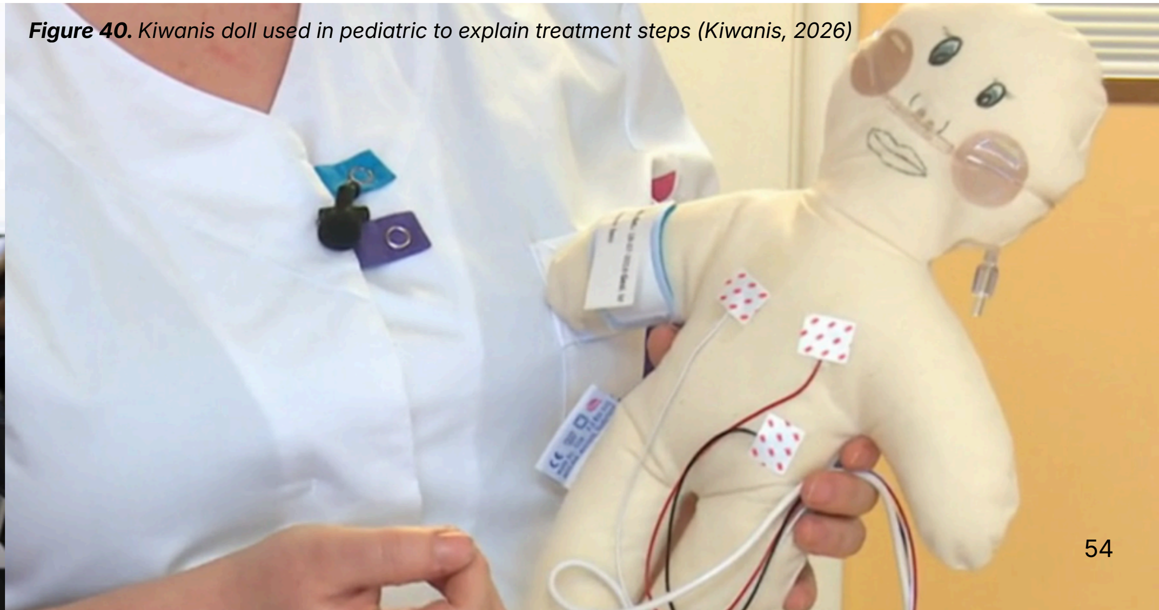


Figure 40. *Kiwanis doll used in pediatric to explain treatment steps (Kiwanis, 2026)*

Tangible, inclusive, interactive

StemSense intends not to replace verbal consultations, but to support them. In the design of the toolkit, no words or numbers are used. This allows the content to be adapted to the patient context and translation. The symbolism and illustrations were developed with considerations of cultural sensitivity, as is needed when designing for effective universal visual communication (Cassedy and Zender, 2014).

The visualizations aim to avoid misunderstandings by depicting treatment steps, tools, and impacts as accurately as possible. Examples include the central line depiction on the main character and the alignment it creates with the IV bags of chemotherapy and donor stem cells on the third treatment tile (Figure 41). The design was iterated on with specialists, nurses, and patient representatives to identify common misunderstandings and clarify them visually.

Besides offering visual support in understanding, StemSense is tangible. All components are 3D and designed to be picked up, shuffled, and exchanged during consultation. This allows for physical interaction with the content, both for the HCP and the patient's family. It is interaction behaviours from HCPs, where the patient is actively involved and encouraged to engage with the medical content, that improve patient participation and communication within healthcare conversations (Mai et al., 2024). The components face the family and can also be held and studied more closely. An example is letting the family hold the cells that their child would have during treatment, so they can closely experience the shift, disappearance, and regrowth that occur during HSCT. The HLA matching can also be explored interactively through the matching designs on the stem cell and the lymphocyte, which can click together (Figure 42).

Figure 41. *Treatment tile and main character alignment showing chemotherapy*

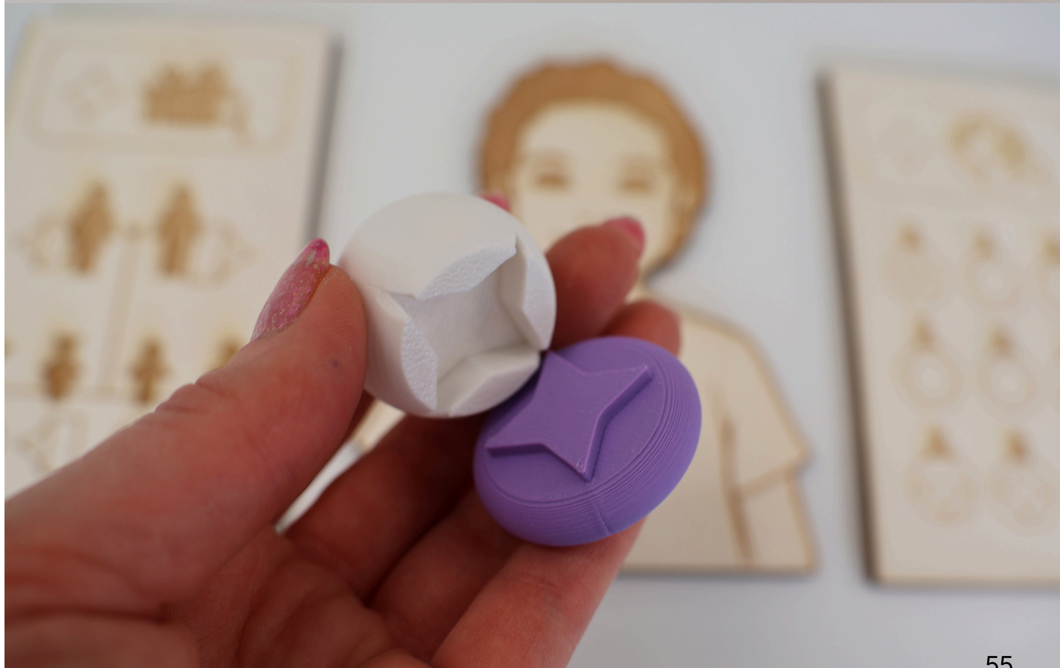


Figure 42. *Stem cell with lymphocyte 'HLA match' interaction*

Emotional Burden

The consultation is primarily framed from a medical perspective, reflecting the role of HCPs, often specialized physicians, in conveying treatment information. The more emotional and personal aspects of care are typically distributed across other members of the team, such as psychologists and social workers. Information about HSCT is communicated as honestly and neutrally as possible, particularly when transplantation is considered preemptively rather than in response to an acute clinical indication. The intention is not to steer families toward a decision. Yet presenting information in an objective manner does not reduce the emotional weight it carries. This is a conversation about a child's life, involving risk, uncertainty, and the possibility of death.

> **"Why does it make you cry?" "I didn't know that I could die."**
> *– pediatric physician & pediatric patient during an HSCT consultation*

Families do not receive this information as neutral recipients; they interpret it through their values, fears, and hopes. Even when HCPs attempt to limit emotional framing, families still experience the consultation as emotionally charged. They consider not only the medical implications but also the emotional consequences of treatment, and they empathize with what it might feel like for their child and family to undergo HSCT. The way the consultation is experienced emotionally shapes what families hear and remember. How they feel when deciding, how they imagine they will feel during treatment, and how they hope to feel afterward all become important to their choice. Conversations with patients and families undergoing HSCT consistently indicate that emotion plays a vital role in the final decision.

> **"In the end, I decided [on HSCT] with my heart. It's what felt right."**
> *- parent of a pediatric HSCT patient*

Figure 43. *emotional expression during consultation as seen in observations*

Space to acknowledge and express

StemSense incorporates space for emotion and lived experience throughout the tool. Several components represent the effects of treatment through both character figures and dedicated treatment tiles (Figure 44). By making visible key physical impacts alongside emotional expressions, the tool helps set expectations for the treatment journey.

The depiction of the child figure during illness is intentionally confronting, not to alarm, but to honestly reflect the effects of chemotherapy and contrasts with the 'happy and healthy' child figure. The low point in HSCT is presented as an inherent part of the process and an important aspect of treatment burden that informs decision-making. Alongside this, the representation of chemotherapy effects, the isolation of at-home recovery, and the gradual return toward health create structured moments where these experiences can be acknowledged and discussed. These moments were designed with input from both HCPs who specialize in the HSCT care path, as well as patients and families who have undergone HSCT.

The central child figure anchors the narrative in the patient's perspective, ensuring that each medical element is consistently tied back to what it means for the child. This supports HCPs in framing the consultation in a way families naturally engage with: through the lived implications of HSCT. It also allows space for empathy to sit alongside clinical information.

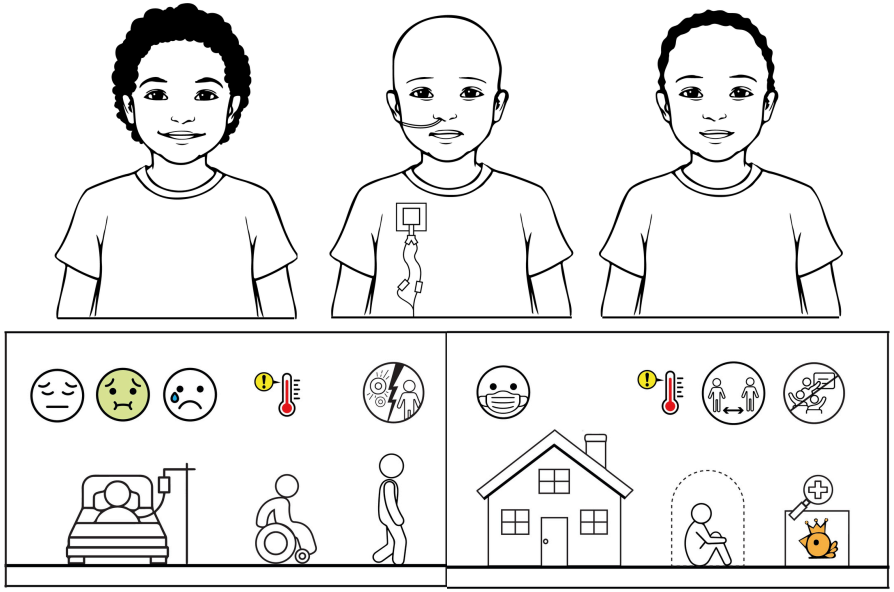


Figure 44. *StemSense components addressing emotional state and impact*

ANSWERING KEY THEMES.

StemSense was designed for both the health care professionals and patient families. The exploration of their experience in the care path of HSCT shared decision-making was structured within the journey of choices and allowed for the key themes of each perspective to be defined. Here these key themes are explained and connected to the design of the StemSense toolkit and story.

As the doctor says - HCP Themes

Patient/parent/physician dynamics

Each consultation is shaped by the relationship between HCPs and the patient's family. In HSCT decision-making, this dynamic is often newly formed, as families are referred to a different hospital. Establishing trust and rapport is therefore an early and necessary step, creating a foundation for sharing personal values, concerns, and uncertainties. Families who lack familiarity or trust with their HCP may be less inclined to express questions or concerns openly. At the same time, HCPs actively work to build this relationship while informing, in order to better understand the family's needs.

StemSense supports the development of this dynamic through its interactive qualities. By offering a shared focus during the consultation, the tool helps bring families closer to the story. Its use encourages a more inviting and collaborative interaction, for instance, by letting the family keep hold of the cells during the treatment explanation and put away or return cells at appropriate treatment moments. This interactive approach can improve the 'shared' experience, and, in turn, strengthen the relationship between families and HCPs. By enabling more active participation, it contributes to building a more open and responsive exchange.

Evaluating family context

Understanding how families interpret information and form their decisions requires ongoing assessment of their context. This begins during intake (e.g., checkpoint 4, focusing on psychosocial factors) and continues throughout the consultation. HCPs continuously gauge how information is received, adjusting their explanations and pacing to align with the family's level of understanding. This iterative process allows the consultation to remain responsive to the needs of those involved.

By using the overview and the natural pause opportunities StemSense offers, the HCP can more frequently and effectively refer back with the family to how information is being understood. This creates moments to reflect together, allowing the HCP to adjust their explanation to the family's level of health literacy without losing the flow of the consultation. In this way, evaluation and iteration on facilitating understanding is enabled without disrupting the big picture of consultation.

Transferring their knowledge

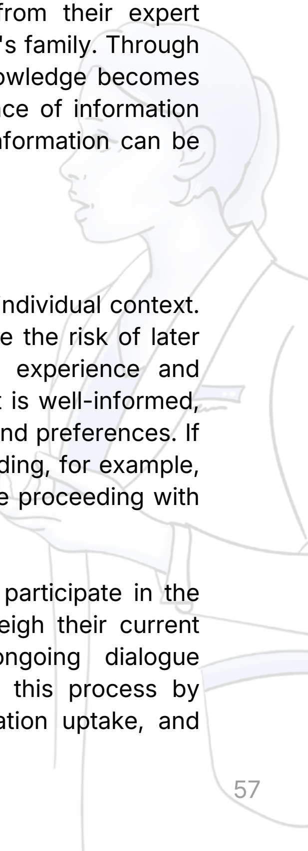
Within shared decision-making, physicians typically take the lead in providing medical information and guiding the decision process, while nurse practitioners often play a more supportive role in discussing HSCT with families (Mekelenkamp et al., 2021). The timing and depth of information are shaped by the physician's clinical perspective and experience. In primarily informational consultations, explanations are often grounded in the physician's area of expertise, with the aim of conveying treatment details as accurately and comprehensively as possible.

The summarizing, patient-centred approach is the core of the StemSense product. It guides the HCP, especially physicians, to tell the story not from their expert perspective, but through a narrative that connects with the patient's family. Through structuring, condensing, and visualizing information, complex knowledge becomes more accessible, improving both the efficiency and the experience of information transfer. In this way, StemSense demonstrates that healthcare information can be both accurate and concise.

Supporting the best-fitting decision

HCPs aim to support families in reaching a decision that fits their individual context. While many emphasize neutrality to protect autonomy and reduce the risk of later regret, some offer more explicit guidance based on clinical experience and perceived disease burden. A 'good' decision on HSCT is one that is well-informed, understood, and aligned with the family's personal values, goals, and preferences. If a parental decision appears to be based on insufficient understanding, for example, if key aspects of HSCT are not fully grasped, HCPs may postpone proceeding with transplantation until a more informed choice can be made.

HCPs can facilitate decision-making by encouraging patients to participate in the conversation, inviting them to reflect on the information and weigh their current feelings against previously held values, and supporting ongoing dialogue (Rodenbach et al., 2024). The design of StemSense supports this process by encouraging participation through interaction, improving information uptake, and creating space for discussion of questions, emotions, and values.



As the patient listens - patient family themes

Short- and long-term needs of the child

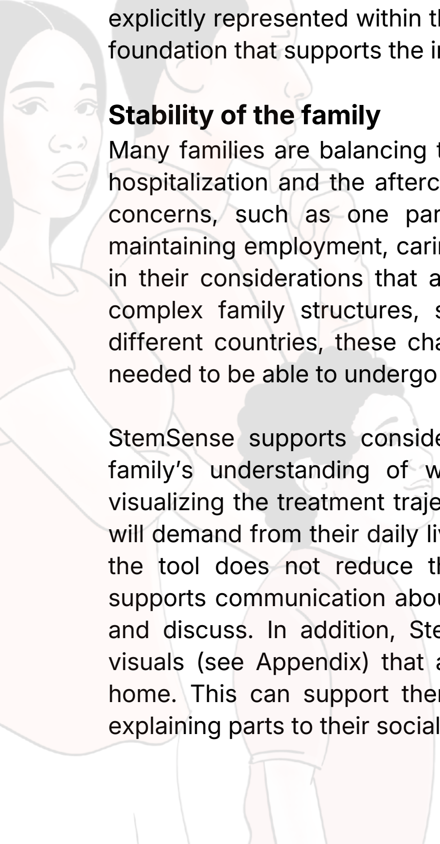
Families have intimate knowledge of how the child feels in the present and how symptoms have evolved over time. They continuously weigh the potential impacts and consequences of treatment decisions. Their considerations range from immediate concerns, such as how the child might experience visible side effects like hair loss, to long-term implications, including fertility and the child’s future life. Parents face high emotional burdens when making decisions for their child's future, while balancing the short-term impacts.

StemSense supports this focus on the child’s short- and long-term needs by creating space within the consultation to address both impacts and emotions. Its components make the effects of treatment more tangible, helping families to better grasp what different stages may mean for their child’s experience. By visually and narratively highlighting moments such as physical side effects, isolation, and recovery, the tool enables more grounded discussions about immediate and evolving needs. Although topics such as long-term complications, like infertility, are not explicitly represented within the product, StemSense provides a clear and structured foundation that supports the introduction of these more complex considerations.

Stability of the family

Many families are balancing the needs of multiple children. The demands of HSCT hospitalization and the aftercare period will put strain on their household. Practical concerns, such as one parent needing to remain with the hospitalized child, maintaining employment, caring for siblings, and managing the home, play a big role in their considerations that are not a direct topic within the consultation. In more complex family structures, such as separated parents or families living across different countries, these challenges are further intensified. A sense of stability is needed to be able to undergo HSCT.

StemSense supports considerations around family stability by strengthening the family’s understanding of what HSCT requires in practice. By structuring and visualizing the treatment trajectory, it helps families better assess what the process will demand from their daily lives, including periods such as at-home isolation. While the tool does not reduce the practical and emotional burdens of treatment, it supports communication about them, making these implications easier to anticipate and discuss. In addition, StemSense visuals can be made available as printable visuals (see Appendix) that allow families to revisit and share the consultation at home. This can support them in retelling the treatment story themselves and in explaining parts to their social network or to siblings.



Agency and sense of control

Parents differ in how actively they wish to engage in medical decision-making. However, within HSCT decisions, a sense of agency is essential for arriving at a grounded and sustainable choice. Parents need to understand that they carry the responsibility for the decision, while also feeling capable, informed, and supported in acting on that responsibility. When information is overwhelming or insufficiently understood, parents may feel a loss of control, leading to distress, hesitation, or attempts to defer the decision to healthcare professionals. Without a sufficient sense of agency, there is an increased risk of decisional conflict and potential long-term regret.

StemSense supports a sense of agency by enabling parents to engage more actively with the consultation content and make it their own. Its interactive elements invite participation, allowing parents to pause, ask questions, and identify specific topics they want to explore further when something is unclear. Rather than passively receiving information, they are positioned as contributors within the conversation. This is reinforced by the narrative perspective of the tool, which is oriented toward the family and visually faces their way. Moments of interaction, such as exchanging cells or linking explanations of disease mechanisms to the child’s experienced symptoms, create opportunities for parents to connect medical information to their own knowledge of their child. In this way, the consultation becomes more shared, both in how the story is told and how it is shaped in the room, supporting a stronger sense of involvement and agency in the decision-making process.

Accessibility, comprehension, and retention of information

Parents listen to the best of their ability, but not all information is retained or understood. Their experienced understanding is important to their decision-making ability and the decision outcome. Some parents will look to sources of information beyond the hospital context to engage with the information in a way that is accessible to them, or seek additional support from their communities or patient organizations to make sense of what they have heard. Hearing the lived experiences of others who have undergone HSCT is particularly valuable, as it provides insight into emotional and practical realities beyond clinical explanations. Parents also consider how they will communicate this information to their child, their other children, the extended family, the school, classmates, and in their own workplaces. They listen not only to understand, but also with the awareness that they will need to translate and share this information within their own social context.

Accessibility lies not only in the complexity of the information itself, but in how it is communicated, how it connects to a larger picture, and whether that overview is available for families to process. The design of StemSense aims to improve shared decision-making by supporting this early phase of shaping understanding. While hearing lived experiences and engaging with patient representatives remains important, and is often clearly recognized as storytelling, StemSense also frames the informational role of the HCP in a narrative form, drawing on the benefits of storytelling for cohesion, accessibility, and retention.

By structuring information as a coherent story that relates to the care pathway, StemSense brings complex content closer to families in a way that is easier to grasp and hold onto. This supports them not only in understanding HSCT itself, but also in engaging with it over time, during the decision, and in communicating on it to others with greater confidence, direction, and understanding.

THE VALUES OF STEMSENSE

- **Summary** of essential consultation content into a 'big picture.'
- **Visualization** through universal symbolism that supports understanding.
- **Overview** of what has been discussed, for referring back to and asking questions.
- **Structure** by design to convert treatment information into a cohesive story.
- Opportunity for the HCP to maintain **momentum** and **gradually reveal content** to avoid overwhelming.
- Telling the consultation from the **perspective of the patients' families:**
    - enabling **consistency** independent of the HCP's area of expertise.
    - **connecting** to the patient's family mental model
    - creating space for **addressing emotions and impact**
- Tangible tools that enable **interaction** between the HCP, the patient, the parent, and the consultation content beyond verbally informing.
- **Adaptability** for explaining a range of HSCT-indicating diseases.

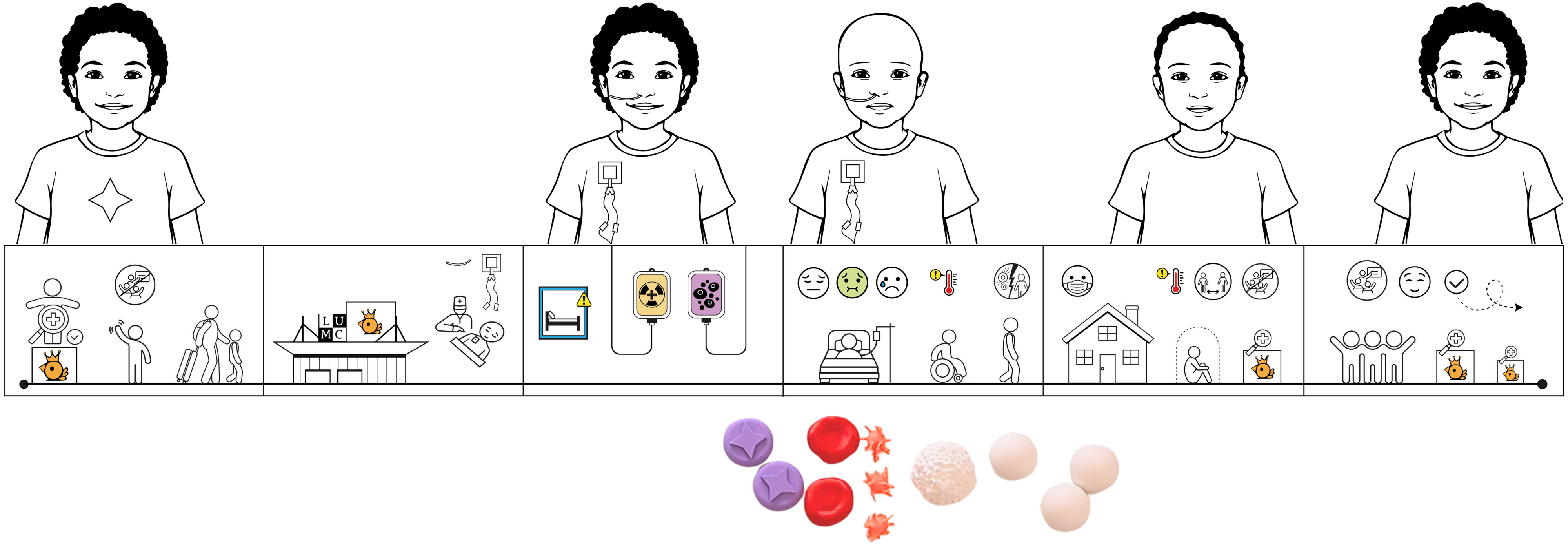
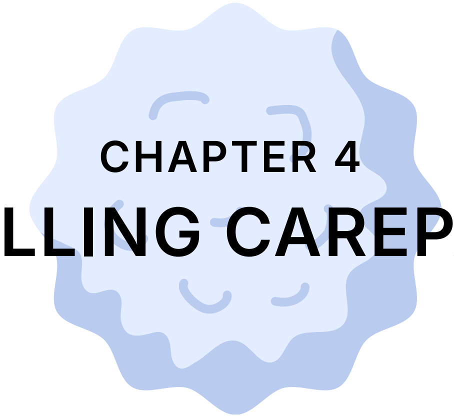


Figure 45. *StemSense full visualization*



CHAPTER 4

RETELLING CAREPATHS

Designing for care conversations

The values of StemSense can be applied beyond the HSCT-specific design. This chapter explores how a similar approach can be used to redesign consultations for other treatments and care paths. It outlines the developmental steps through which care path consultations can be rethought and supporting tools can be created. It describes a process of translating clinical pathways into narratives, and these narratives into tangible forms that support understanding in practice.

RETHINKING CARE CONVERSATIONS.

Redesigning healthcare conversations requires a change in perspective. Rather than focusing only on what information is given, attention turns to how that information is heard, experienced, and understood. In the context of shared decision-making, this means moving from consultation as explanation toward consultation as a shared conversation. Design thinking in healthcare can be used to connect the needs of both patients and HCPs and develop interventions (Altman et al., 2018). Rethinking care conversations is best initiated from within the healthcare system by HCPs addressing communication challenges, yet the design should be connected to the patient to create a holistic solution.

StemSense is an example of a design solution that supports consultations to be accessible and comprehensive through physical tools and a structured story. This product was created specifically for HSCT, but its principles and the challenges faced apply across many more complex treatment conversations found in healthcare. Similar products can be developed for other care paths. The core of this approach is the idea of translating treatment explanations into a story.

Translating care paths to visual stories

Translating care paths into visual stories requires a structured approach that bridges medical complexity and patient understanding. The following steps show how treatment information can be reframed into a narrative, including supporting tools that is both accurate and accessible.

CARE PATH TRANSLATION STEPS

Step 1: Identify the essential medical components

What are the most fundamental elements of the disease mechanism?
These form the foundation of the medical narrative. They can be used to explain the disease in comparison to a healthy situation, as well as to relate disease progression to treatment outcomes. Focus on the core of these components and visualize them using simple, easily recognizable shapes or drawings. Additional complexity can be introduced verbally when recipients have higher levels of health literacy.

Example: bones, blood, cells (Figure 46).

Step 2: Identify the leading character

Who is the story about? Who is it told to? Who is it for?
In treatment consultations, this is most often the patient (Figure 48). In other care paths, it may be a supporting actor who needs help understanding the healthcare journey. When a non-patient actor is central, the story should be told from their perspective and connected to the situations and experiences they may encounter.

Example: patient, parents, siblings, classmates (Figure 47).

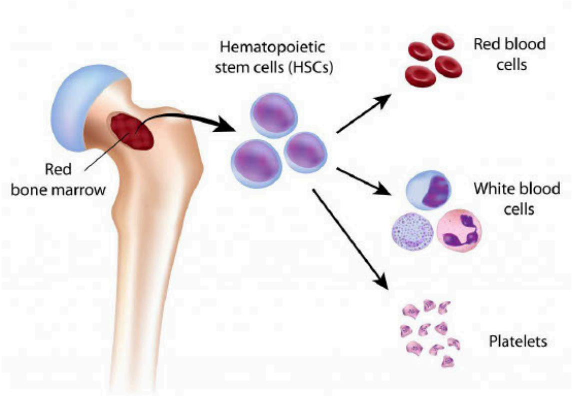


Figure 46. *Essential medical HSCT components (LUMC, n.d.)*

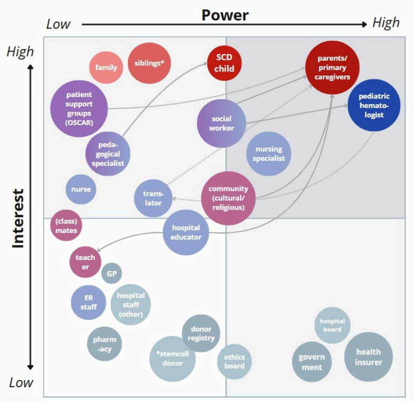


Figure 47. *stakeholder mapping*

Figure 48. *WAKZ motto 'Child is King' (LUMC, n.d.)*

3. Map the care path

What are the key events? Where do they take place? What is their impact on the leading character?

The care path is structured as a chronological sequence of key events. Each event is linked to a location and its implications for the patient's life. Distinguishing between what happens inside and outside the hospital helps present the care path as more than a series of clinical actions. It also includes preparation, recovery, and everyday life. Write this path as a story: a sequence of events connected to the experiences that accompany them.

Example: physical screening (hospital), saying goodbye to friends (school), packing a suitcase (home), placement of a central line (hospital).

4. Visualization and prototyping

How can we show what we tell?

Translating the consultation into visuals and physical elements enables interaction and shared understanding. Early prototypes help explore how form, scale, and representation influence the flow of the conversation and how HCPs and patients engage with the material.

Example: treatment materials that are applied to a human figure, icons for treatment steps, and emoticons expressing emotional impact (Figure 49).

5. Iterate with HCPs to ensure clinical accuracy

What works? What is missing? What is too much? What is medically (in)correct?

Simplifying a complex medical process requires careful balance. Information must remain accurate while becoming accessible and coherent for those without a medical background. Iterating with healthcare professionals ensures clinical validity and helps identify where complexity should be reduced or emphasized.

Example: explaining hereditary HLA matching in detail may be too complex for initial consultations and can distract from the treatment narrative. Visualizing temperature measurement should reflect appropriate clinical practice for immunocompromised patients to avoid misinformation.

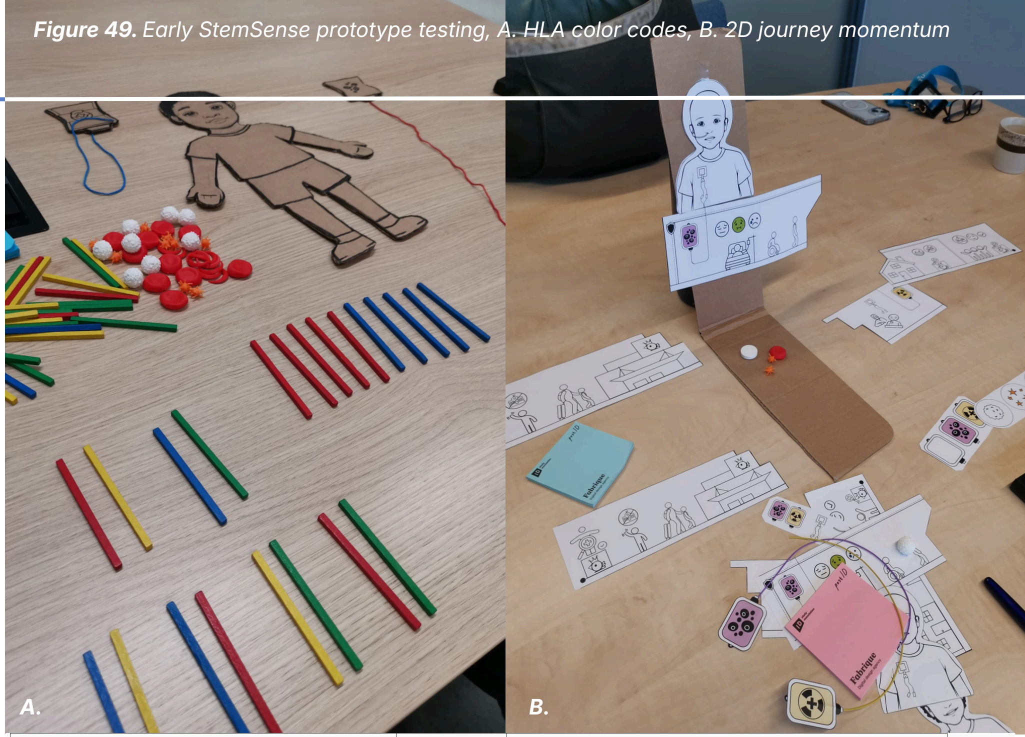


Figure 49. *Early StemSense prototype testing, A. HLA color codes, B. 2D journey momentum*


Figure 50. *care path iterations developed through HCP input*

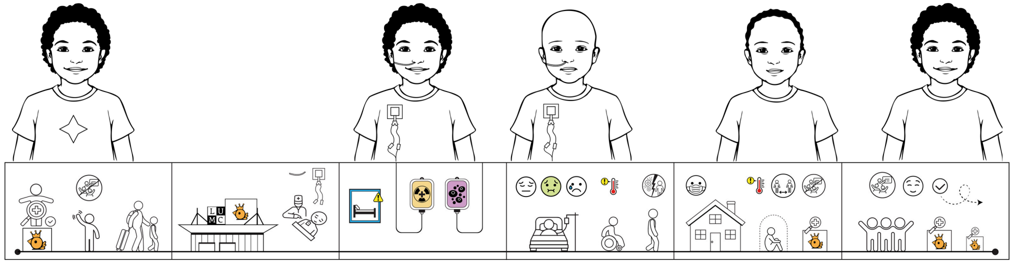


Figure 51. *final journey overview*

6. Iterate with patients to represent lived experience

How is the story understood and experienced? What feels relevant or missing?

Engaging patients and families ensures that the narrative reflects real experiences, concerns, and interpretations. Their input helps ground the story beyond clinical logic, shaping how daily life, emotions, and uncertainties are represented.

Example: the home-isolation phase of HSCT was experienced as heavy and lonely by patients. The recovery period should be shown in several gradual stages.

7. Validate within context

How does the solution function in practice?

The redesigned story and tools need validation place within the real clinical environment, where the interaction between the healthcare professional, patient, and design can be observed. This step ensures that the narrative, its pacing, and its form support the consultation. During development, this can be done in consultation simulations with experts of the context, such as healthcare professionals.

Example: a tile-based form best upkept conversational momentum.

Figure 52. *Gathering patient perspective at the HSCT patient day with project stand*

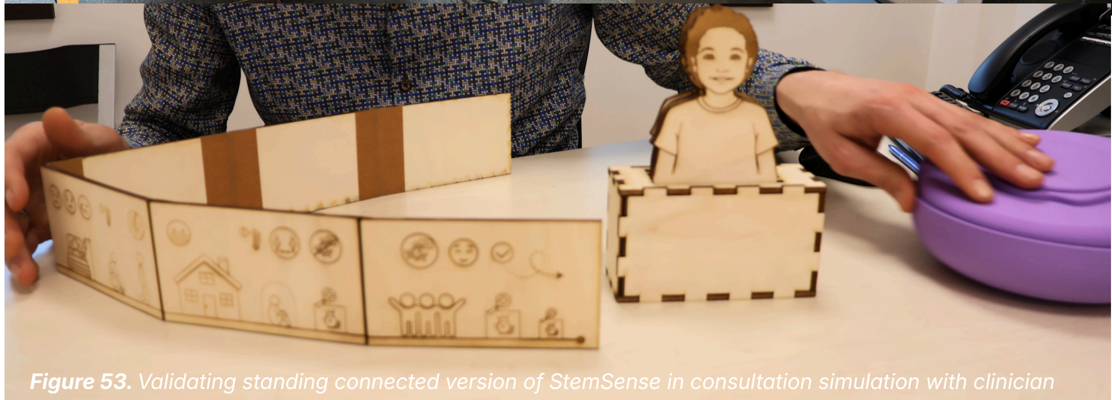


Figure 53. *Validating standing connected version of StemSense in consultation simulation with clinician*

Figure 54. *Validating tile based StemSense concepts in consultation simulation with clinician*

DETAILS MATTER.

What to consider in consultation design

As storytelling toolkits are content-driven and care path-specific, they need to be developed with an eye on the details. Small design decisions impact interpretation, effectiveness and impact. Important details to consider during development are:

Scale

When telling of disease mechanisms, different levels within the body are addressed. From the molecular level of DNA, to cells, to organs, to the body as a whole. When speaking of these levels and translating them to 2D or 3D tools, one needs to be aware of what scales are used. For those unfamiliar with the concepts, scale differences and comparisons with other tools can be confusing. Scales need to be consciously decided on to align with the intended interaction and the component's role in the full story and in comparison to the full set of tools.

Realism

This awareness too should be kept for realism. In pursuit of medical accuracy, especially when working with HCPs, there is a preference for optimizing the realism when representing medical components. In efficient educative simulation, the key is to align the type and level of fidelity with the specific learning objectives and the learners' needs (Hamstra et al., 2014). The goal is not to make specialists of the patient and parents, but to inform them about the medical components so they understand the implications and the basics in relation to the treatment. Distinguishability and associability are key features that the medical components should be designed with.

Conversational momentum

The storytelling approach gives the consultation a built-in sequence when told. Tools should be supportive of this without diverting the momentum. This means tools should be laid down piece by piece, not to expose too much information all at once and distract the listener from the story or overwhelm them. A gradual exposure lets the story 'flow' so emphasize can be put deliberately by the storyteller.

Complexity hotspots

A large part of development lies in establishing the right balance between minimal storytelling and sufficient information. This is done by identifying complexity hotspots and considering these critically from both the patient and HCP perspectives. Components need to be selected consciously to fit into the whole of the story. Highly complex parts can be left out initially, with the intention to be involved further along in the informing period or by the HCP's discretion at the right time, rather than disrupt the introduction of the main story.

The right match

Remain aware of the demands of a product within a clinical setting. It needs to be a match with consultations held in practice. Practical considerations are found in technical details such as avoiding choking hazards when working with small components, and storability to align with the workflow of a doctor moving between different clinic rooms. Materials should be suitable for healthcare environments, and components should be adaptable to different patients and contexts. This includes representing diverse patient groups and allowing flexibility in how the tools are assembled and used during consultations.

PRODUCTION

Consultation toolkit costs

StemSense is developed as a low-fidelity toolkit, produced in small quantities, around one to five per department, to fit the specific context of a care path. Its production is most effectively carried out on a small scale and can be done independently by the designer leading the treatment redesign project

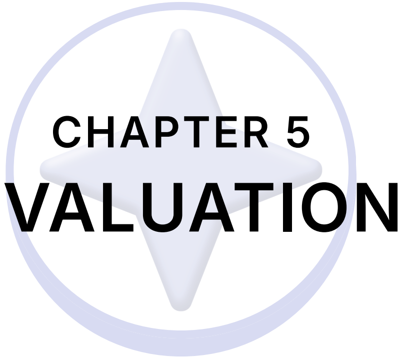
The visual elements can be produced in both physical and digital formats. Printed or digital versions offer low-cost and widely accessible means of distribution, while physical toolkits enable interaction within the consultation.

For tangible components, techniques such as laser cutting and engraving allow for precise yet accessible production. Laser-cut elements cost approximately €30 in material and machine use, while 3D printing averages around €20, with an additional €10 for finishing and assembly. To ensure suitability for clinical environments, components are coated with a non-toxic, water-based polyurethane, allowing them to be cleaned with alcohol wipes. Protective casing adds roughly €30, resulting in a relatively low-cost product even at small production volumes and with a high level of detail.

The primary investment lies not in manufacturing, but in development. Research, iteration, and validation require significant time to ensure both clinical accuracy and alignment with patient experience. This process can be supported through collaboration with design institutions such as the TU Delft Faculty of Industrial Design Engineering or product design agencies.

A collaborative workflow can further distribute this effort. Healthcare professionals may initiate the process by outlining the medical foundation, defining key components and the care path, after which designers translate these into visual and interactive forms, incorporating patient perspectives and iterating toward a coherent consultation tool.

Figure 55. *StemSense toolbox storing components*



CHAPTER 5

EVALUATION

Implementation and implications of StemSense

StemSense is a complete concept, technically ready for implementation. Before it can find its place in practice, it must be evaluated with those who would use it: healthcare professionals and patient families. This chapter follows the first steps of that process. It reflects on initial user testing, what the product reveals in use, and where it still falls short. From there, it looks ahead to the steps needed to further develop StemSense, and its role in supporting complex conversations that can use a hand.

EVALUATION IN PRACTICE.

The StemSense concept was evaluated in qualitative sessions with HCPs of both the referring and the HSCT treating hospital: a nursing specialist and a pediatric physician. These sessions simulated full HSCT consultations in which HCPs were invited to use StemSense first without initial instruction, then with a product explanation beforehand. This was done to evaluate the intuitive usability and adaptability to narration styles.

Nursing specialist - referring hospital narrator

Visual alignment

In testing, the HCP effectively aligned the visual components with their intended topics without initial guidance. The visualizations were considered universal and coherent. Only the graft-vs-host symbol required further explanation. The HCP confirmed the need for visualization that they see frequently in their practice, and how StemSense could replace the images that HCP currently sketch or scavenge for on the internet.

> **"Especially for the families with a need for translation, this is incredible."**

Persistence of familiar metaphors

HCPs have built their own styles of holding HSCT consultations, often using recurring metaphors. When consulting, they return to these metaphors as the foundation of their story and as a way to guide their explanation. Not all of these metaphors align with the StemSense components. For instance, the idea of the "blood factory in the bones" was replaced by a stem cell–focused system. Bones were intentionally left out of the toolkit, as patients often misunderstand this metaphor, thinking their bones will be emptied during stem cell removal or that this requires an operation.

When these familiar metaphors persist during a StemSense consultation, they can derail the intended narrative or lead to unintended use of the components. For example, one HCP emptied a stem cell container after chemotherapy and refilled it alongside the tiles, using it as a substitute for a bone to continue their metaphor (Figure 56). The implementation of StemSense requires a training guide or session, so that its use becomes more intuitive and instinctive for HCPs, and better aligns with the intended narrative.

Figure 56. *Empty bone metaphor used in consultation simulation with nursing specialist*

Exposition

Without having been given previous instructions on the product, the HCP intuitively followed the momentum of StemSense and restructured the story around it. The details of use, however, did not all initially go as intended. For instance, the main characters' figures were left along the treatment tiles after their introduction, leaving them in view rather than being replaced to keep solely one protagonist during the story (Figure 57). While this provides a clear overview, this exposition is best left to the end of the consultation. The use of a single main character binds the narrative to become a story that is centred around the patient experience within a treatment phase.

Multitasking momentum

During the consultation, the three sets of components (cells, main character, treatment tiles) move at the same time. This requires a certain agility in timing and some experience with what will come next in the story. While not distracting from the big picture, and often quickly corrected when the HCP finds a component, such as a cell that is missing, for what they'll explain next, it would improve the HCP's experience to explore the use of the toolkit to adopt it into their consultation style, before they use it in practice. This too could be done through HCP training sessions.

"Can we also make one for standard sickle cell care? For what happens before this journey starts."

Adaptability

The HCP was exceptionally positive about the product and the possibility of implementing it into their practice. Already imagining how this could be done, several questions arose, such as: could this be applied beyond HSCT? And how could healthcare staff initiate such development? Especially for patient groups with diverse backgrounds, there is an opportunity for improving communication. This evaluation shows both the alignment and enthusiasm for tangible consultation tools, and some of the considerations that need to be made for the next steps of the product. These are practical in implementation, as well as conceptual, like separate development for young child-focused tools, or adaptability to developing treatments.

"It makes me wonder why we don't have something like this yet."

Figure 57. *Stemsense evaluation at the SKZ*

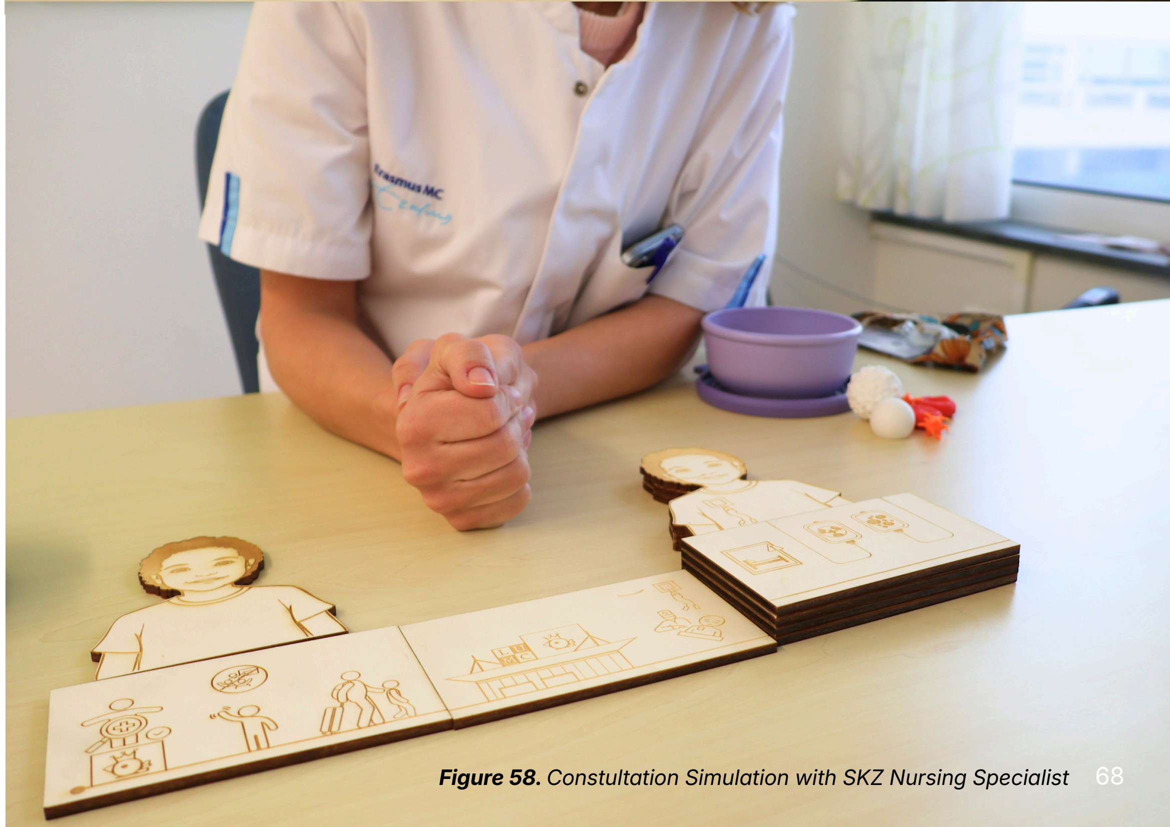


Figure 58. *Constultation Simulation with SKZ Nursing Specialist*

Figure 59. *Consultation Simulation with pediatric physician*

Figure 60. *Stemsense evaluation at the WAKZ*

pediatric physician - HSCT treating hospital narrator

Shuffle and flow

The current StemSense main characters and treatment tiles are started with as stacks, which are gradually taken apart and laid out on the consultation table. The physician in evaluation could manage this shuffling approach; however, after several iterations with consultation simulations, they changed this method. Instead, they kept the stacks beside them, a little out of view, and laid out the parts one by one. This does not change the story that is told and can be equally effective in conveying the values of the tools. The design allows for a degree of flexibility to the HCPs' preferred communication style, without causing the consultation to become clinician-framed in its narrative. This adaptability to the ‘shuffle and flow’ of the tools can also be used to explore different forms of the components, for example, a version with a fold-out mechanism, a magnetic version to click onto a wallboard, or upright figures that take a further 'theatric’ storytelling approach.

Sharing the table

When all tools have been laid out, a large part of the consultation tables (both at the WAKZ and the SKZ) have been used. Needing to stack the cells, treatment tiles, and main character accordingly, while still holding space for the stem cell containers, the HCP automatically lays the components close to the patient's side. This affirms the 'sharing' intention of the product, bringing the content close to the patient, where it is easy to see, explore, and interact with.

“I could already use this in my practice.”

Isolation-appropriate material

The HCP considered the current product ready for implementation and suited to their practice. Considering how its values could be applied further across the SDM and the HSCT care path, different phases would bring different design requirements with them. An optimal design would be suited and safe to use across the full care path. To comply with the requirements of isolation, this would mean a change in the product material of the treatment tiles and the main character. The wood of the current product has been treated with toy-safe coating, and is cleanable by alcoholic wipe, complying to the hygiene standards of a consultation room. Isolation standards, however, would require optimal disinfection, excluding the use of this material. Further versions with plastic-based tiles and characters could be explored.

“I imagine showing it in the consultation and bringing it along again during HSCT so we can explain what is happening in that moment.”

EVALUATION IN CONVERSATION

Patient perspective

To gather the patient perspective on the current version of the StemSense, it was evaluated by a patient representative who has both experience being a young family member of a pediatric HSCT patient, as well as a patient themselves in the pre-HSCT informational stage. The components and the consultation of StemSense were demonstrated and discussed in conversation. Here is a summary of this patient's feedback.

Medical base

The patient representative expressed a preference for keeping the cells on their side of the table, with a designated place for them. This could include visual reminders of each cell’s role, a “legend” for the cells. For instance, a white blood cell could be represented with a fighter icon. If this feature is further developed, careful consideration should be given to how the cells are positioned along the treatment timeline. This feedback also highlights that core medical information may be unfamiliar to patients. Key medical concepts, such as cell functions, should be continuously revisited throughout the consultation. This could also be done narratively by repeatedly integrating the role of the cells into the story.

Home-isolation period

It was found that the home-isolation period deserves more emphasis. This is something previously seen in patient evaluation (and taken along in product iterations), as this period is experienced as emotionally challenging and can last the longest of all treatment events, often many months. The patient considered the representation of the main character and the treatment tiles symbolism sufficient, yet felt the central line, and IV should be added to the recovering main character, as some patients keep this until the very end of this phase.

Connection to existing modules

Before HSCT the patient receives a stack of informational documents from the hospital, including a detailed explanation of the treatment and lifestyle requirements. The patient was eager of the opportunity to connect the StemSense concept to these modules. They believe the visual components could help with understanding what it is both said and written.

“The hospital gave us a stack of 60 pages of information beforehand. I'd love something like this to give us an overview.”

Placement further into the HSCT journey

Beyond the decision-making pre-treatment phase, there is still space for information, perhaps even more so as patients actively search for answers and expectations while in treatment. The StemSense concept could be used during treatment to explain at what stage and key events the patient currently is, or which cells have, or have not, grown back. As discussed in the evaluation with the physician, this calls for a needed reconsideration of the StemSense materials. The laser-cut wooden figures would have to be replaced with an isolation-appropriate material, such as plastic. This could also create a further cohesive feel to the toolkit, as the materials align. The implementation of the tools further along the HSCT carepath also brings an opportunity to enable the patient to continue to interact with the content during treatment. Patients showed interest in receiving the cells to keep during their isolation phase, so they may keep track of the regrowth of their cells. This could be comparable to the ‘beads of courage’, where children facing serious illnesses receive colorful beads to represent milestones and procedures in their treatment journey (Beads of Courage, 2026). This could also be done through a collaboration, where StemSense cells become beads.

“I would like to keep the cells during the treatment, to gather them while they grow back.”

Emotional impact

The patient considers the emotional impact something that can still remain overlooked in conversations about HSCT. It is left to the psychosocial team and put seperate of the consultations and material in which patients learn of HSCT, while for patients, both the cognitive and the emotional understanding go side by side. The representation of the patient's well-being in the main character figures was received positively. Due to varying experiences among patients, this representation could be researched further.

BARRIERS THAT REMAIN.

Limitations

While StemSense proposes a new approach to supporting healthcare conversations, it does not resolve all challenges within this space. The following barriers emerged through evaluations, feedback sessions, and testing throughout the project. They reflect both the early stage development of the concept and the complexity of the healthcare context in which it is applied.

Experimental design

StemSense introduces a new approach: connecting visualizations, storytelling, and interaction through design to consultations in a way that has not been explored before in research on medical consultation. It is an experimental addition to healthcare communication. While it has been developed and iterated alongside both care professionals and patient families, its impact must be evaluated in practice. This requires a research study in which consultations supported by StemSense are compared to those held without it. The added value, in terms of comprehension, information retention, and patient experience, needs to be measured and understood.

Context specific

This version of StemSense was designed specifically for the WAKZ and SKZ, fitting within the care pathway of non-oncological HSCT in the Netherlands. It includes hospital-specific visualizations, such as the recognizable WAKZ building and logo. These elements could be excluded or adapted to fit a broader range of hospitals and care centres. Yet, as complex and life-altering treatments are often shaped by local practices and contexts, this specificity can also be of value. Rather than moving toward a fully neutral design, the strength of the concept may lie in these details, allowing different versions of the product to reflect their own setting.

Updatability

The design of the treatment tools is closely tied to the current care path. As treatments evolve, or new options such as gene therapy are introduced (Thompson et al., 2018), the product will need to evolve with them. In a physical toolkit, this means developing new components based on the same narrative principles. This requires revisualization and new production, and therefore remains dependent on design input.

Reliance on a designer

A related barrier lies in this dependence. When updates are needed, visual changes rely on the involvement of a designer. Ideally, a StemSense-like approach would include a system of tools and visual elements that healthcare professionals can use more independently, allowing them to shape and adapt care narratives in a human-centred way alongside patients.

Continuous complexity

The challenges of life-altering treatment consultations and shared decision-making extend beyond what can be addressed in a single project. The complexity of the content and of the decisions themselves remains. Patients are asked not only to understand information, but to weigh values, fears, and possible futures. Supporting this process requires more than explanation alone.

Acknowledging patient diversity

While StemSense supports the understanding of complex verbal consultations, it does not complete the need for continued awareness of how communication takes place in healthcare. Patient groups such as those with sickle cell disease highlight the linguistic and cultural diversity within the patient population. In a multicultural society, this diversity needs to be acknowledged and accommodated, as accessibility is a key part of good and fair healthcare

FUTURE STEPS.

Recommendations

The StemSense concept was developed within 100 days. Looking ahead, there are many possibilities to help the product, and similar approaches to care conversations, grow and evolve, so they may be established into real healthcare practice.

Comparative study

Before implementation, a comparative study with patients and parents actively engaged in the shared decision-making phase is needed. This will evaluate and demonstrate the added value of StemSense in a real clinical context in how it affects comprehension, the retention of information and the patient experience.

HCP narrative training

Changing how HCPs work, by altering the consultation stories they've told for years, sometimes decades, won't be done instantly by the introduction of a product. It will require them to experience the toolkit and new approach several times to find their right momentum. Instinctive use is important during long, complex consultations. HCPs need dedicated introduction sessions to explore the toolkit and its approach, allowing them to integrate it naturally into long, complex consultations.

Exploring different forms of the components

The physical components, especially the treatment tiles, can take many forms. A more theatrical or spatial presentation could be explored by connecting tiles within a frame or experimenting with how the story unfolds across the consultation space. Iteration and experimentation will reveal how this alters the interaction, placement, and flow of the story, and how it influences the consultation experience.

Creating toolkits for other treatments

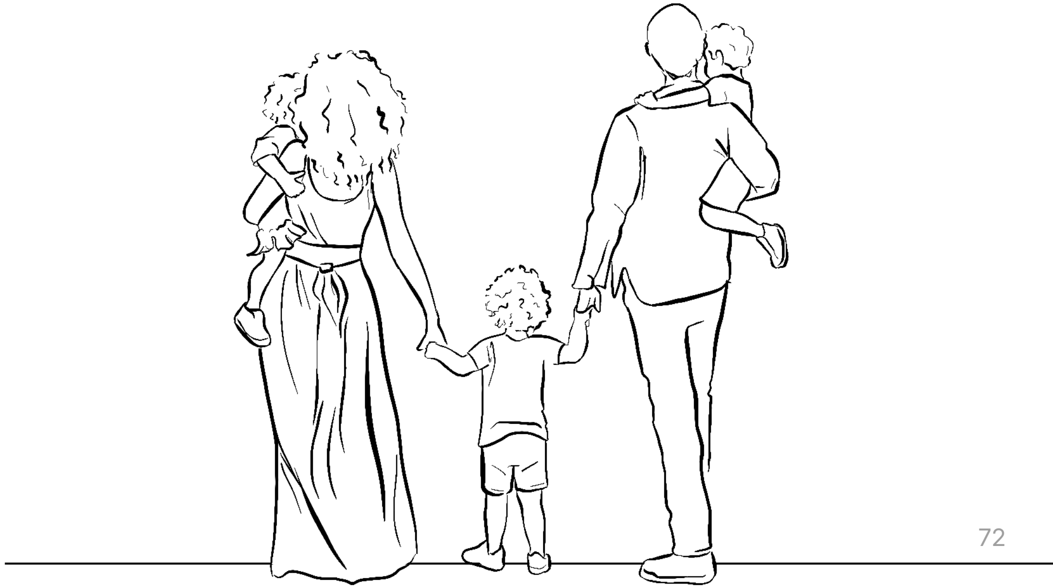
The narrative principles behind StemSense could be translated beyond HSCT to other care paths. This could include other shared decision-making journeys, care paths with frequent language barriers, or simpler child-centered care paths where visual support may strengthen understanding. Creating new storytelling consultations is a potential project for future care providers and designers to take on.

Research and development for shared decision-making

The complexity of shared decision-making in high-stakes care remains an area that deserves ongoing research and development. Solutions could include decision aids, supporting products, digital tools, or new ways to structure conversations. It is important that patient representatives continue to be actively involved in these projects to ensure solutions meet real needs.

Conversations about care conversations

Finally, it is important to create visibility and start the conversation on how we communicate between care professionals and patients: how healthcare stories are told. Who are receiving these stories, to whom do they need to be passed on, and how? This includes siblings at home, classmates at school, and others who play a role in the patient's life, who are still often overlooked in stories of care. Healthcare does not happen solely within hospital rooms. It is the stories we share and pass on between those who matter to us, about what matters.



CONCLUSION.

Implications of the project

Care conversations are all around us. Though thankfully most people won’t need to deliberate on HSCT for children, it is inevitable that at some point in our lives we will find ourselves in a difficult conversation with a healthcare provider. For ourselves, a child, an elderly parent, or another loved one, navigating the healthcare system is complex and requires connection with medical knowledge and with a broad range of healthcare staff. StemSense introduces a simple, low-cost, tangible design solution through which healthcare conversations can be approached with human-centred care, equality, and clarity, supporting both patients and caregivers in finding shared understanding.

Connecting healthcare

HCPs work hard to inform and guide patients to the best of their abilities, drawing on training, experience, and expertise. This forms a frame of reference that is essential in medical care, but one that does not always match what reaches the patient. Across different specialties, conversations, and hospitals, tangible, visual conversation aids can improve consistency and help patients connect to both the content and to their HCPs. In the creation of StemSense, over 25 HCPs and 30 patient representatives were involved through co-creation, feedback sessions, interviews, observations, and testing. Projects like StemSense also connect perspectives by gathering different lived experiences of patients and different points of view among healthcare providers. The psychological team, for example, brings a different perspective than the medical specialist, and even within care teams, interpretations can vary. When creating a tangible toolkit, these often abstract differences can be explored, and the qualities and interactions that align between the stakeholders can be defined and made concrete within the product.

Inclusive design

This project originated in designing to improve information intake for pediatric sickle cell patients and their families. Because of this, inclusivity and sensitivity to representation were key considerations in their development of the project. Designing with this perspective revealed how self-evident it can seem to those of a culturally dominant group that the systems, including the healthcare system, around us align with us, while there are people who come from diverse backgrounds who do not experience this the same. People who need to search for band-aids in their skin color or navigate words that do not exist in their native vocabulary. Even something as seemingly simple as visualisation through symbols is culture-dependent. For the patient journey, emoticon skin colour needed to be adapted to better represent the patient group. In human figures, both big and small, hairstyles were recreated to allow for curls and buns rather than smooth, light pigtails. Beyond the visual, this was also reflected in language-dependent misconceptions and in the cultural diversity HCPs see in patient values and beliefs. By making healthcare information concrete and defining it within a narrative, such as can be done through projects like StemSense, these differences become visible and explored to be better understood and acknowledged.

Designed from within

What makes StemSense closely connected to its context and stakeholders is that it was designed from within. A designer led and created the project, but the question, content, and form emerged from the input of HCPs and patients. Tangible consultation toolkits are not innovations imposed by outside opinion onto practice, but are made to be supportive, adaptive, and accessible within the everyday healthcare context. The simplicity of the product allows it to fit into the practice of the HCP and the circumstances of the patient. These kinds of projects may further inspire HCPs to take initiative in approaching the challenges they see in their practice through collaboration that enables the creation of practical solutions.

Zooming in and out

Rather than approaching healthcare innovation through big direct scopes such as ‘improve shared decision-making’, real value can be found by zooming in. By locating specific points of complexity and identifying creative opportunities within them. This project started as a sickle cell–focused intervention and resulted in a product applicable across all pediatric non-oncological HSCT. It is especially in human-centred design that qualitative findings taken from real lived experiences can drive development and distinction of what is important to the people and the context. In the same way, StemSense was developed specifically for the HSCT in the WAKZ, the only non-oncological pediatric HSCT care centre in the Netherlands. However, its approach and values can extend further, as adaptations are made to fit different narratives, treatments, hospitals, or countries. This approach identifies the details that matter, allowing them to be scaled into a product and extended across care paths.

Looking at the big picture

Healthcare in the Netherlands faces several challenges now and in its future. There is a shortage of care staff, increasing demand due to ageing and chronic illness, and with it, rising pressure on accessibility for patients and workloads for HCPs (Buijsen, 2025). These challenges are often approached through innovation by redesigning systems, digitalisation, advancing equipment, and enhancing efficiency, developments driven by technology. Consultations, especially those as complex and sensitive as pediatric HSCT, remain moments of human interaction, but do not have to be exempt from innovation. The importance of empathy and human connection is not hindered but can be strengthened through design solutions. By supporting patients in understanding complex information, consultation toolkits improve information uptake and enable patients to participate more actively in their care. This contributes to patient empowerment and health literacy, allowing patients and caregivers to better understand their situation and engage in decision-making. In turn, this can lead to more effective care conversations, better-aligned expectations, and improved care outcomes. At the same time, clearer and more balanced interactions could reduce pressure on HCPs, reduce workload due to consultation repetition, and increase satisfaction for both patients and healthcare professionals.

The care path of the HSCT patient group that StemSense was designed for stretches from far before to long after information consultations take place. The current toolkit was developed specifically to support informational consultations in the decision-making phase, but its values can be widely applied. The cells, for example, could support explanations of diagnosis, crisis, and the importance of care adherence. Visualising genetic disease inheritance can also play a role in testing pathways and in fertility care for patients post-HSCT.

This approach is not limited to HSCT. Many care paths, such as other pediatric treatments or those of elderly patients, also involve complex, layered information that can be difficult to understand and communicate. Care paths for which storifying, visualizing, and tangible tool creation could make a difference. This project has explored how patient journeys, human-centred design, and generative prototyping can be used to address complex communication challenges. It proposes an accessible toolkit for HCPs to make consultation stories more understandable for their patients, a concept that invites further exploration, as healthcare is filled with complex stories that deserve to be understood, shared, and carefully told.

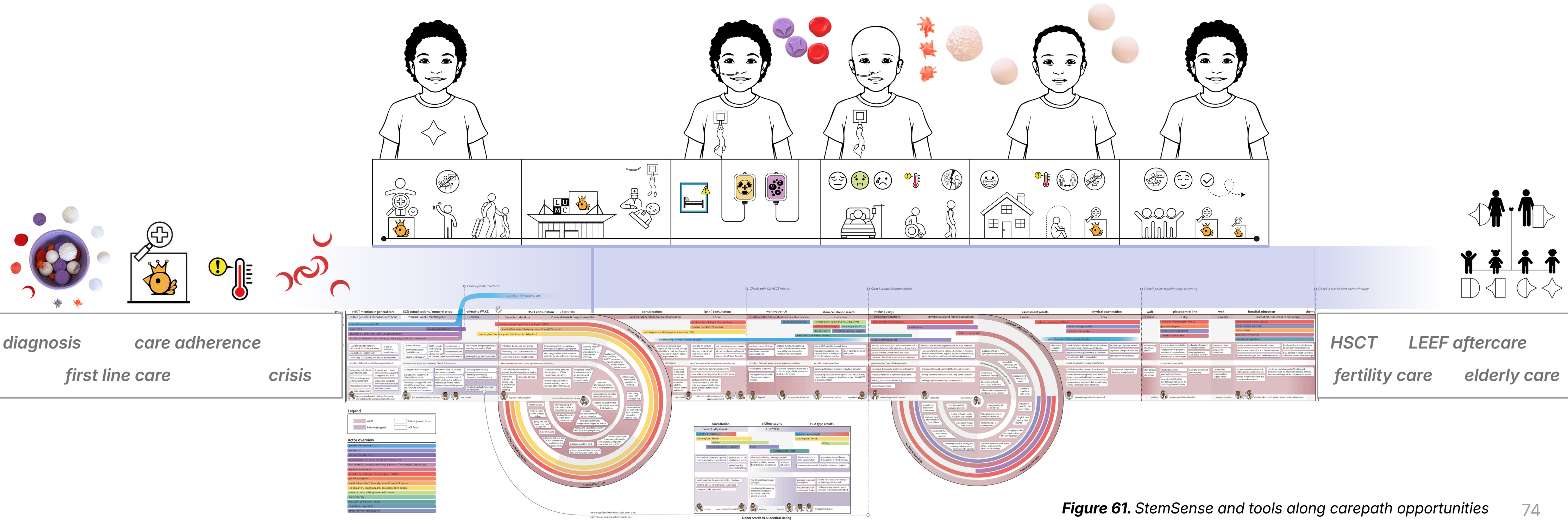


Figure 61. *StemSense and tools along carepath opportunities*

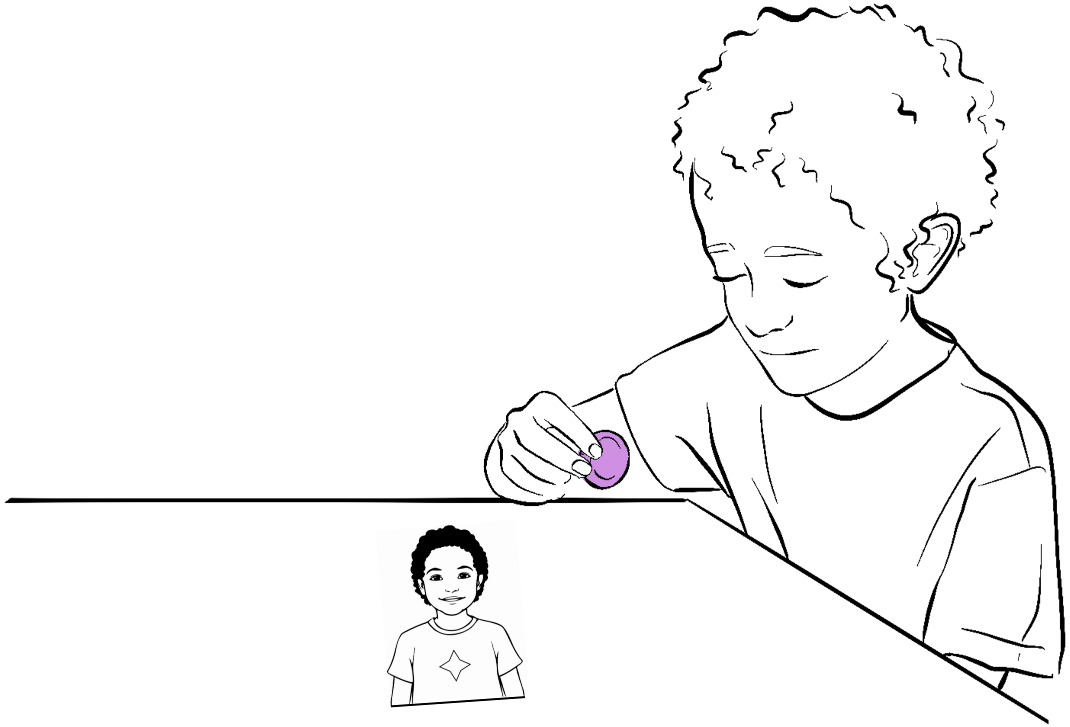
EPILOGUE

Noah comes home from the hospital conversation.
A special one, in which he got to hold cells like his own,
and see what might make him better as if it were a puzzle.

The doctor has given them a booklet of papers,
with pictures of all that she showed them before.
Mom and Dad are talking softly and thinking quietly.
There is so much to consider; now they know what there is to consider.

Mom puts the booklet on the kitchen table. They go through the pages, lay them apart.
Noah cuts out the cells, so he can put them in his hands again.
He wants to show grandma, his brothers and sisters, and his friends at school.
It is not an easy story, but he wants to tell it.

This is Noah.
He may not know what will happen in his future.
But he remembers a story about how it could go.
And he knows how to tell that story, now he has something to hold onto,
In his hands and in his head.



ACKNOWLEDGEMENTS

Thank you for taking the time to read this. This thesis, and these final pages, mark the end of my studies at Industrial Design Engineering in Delft, though perhaps not the end of this human-centred design story. It is with both relief and hope that this chapter comes to a close.

When I first began this project, its scale and ambiguity raised eyebrows, even among the healthcare professionals I spoke to. People around me questioned my choice to pursue "improving shared decision-making on stem cell transplantation for sickle cell disease" over an alternative assignment that offered clearer direction, technical certainty, and financial compensation. I am deeply grateful that I followed my intuition. It gave me the opportunity to work with a unique patient population and care teams with remarkable openness and heart, and to create something new that feels closely connected to them, to the collaborating children's hospitals, and to myself.

This project would not have been possible without the contributions of many. I would like to sincerely thank everyone who was involved in one way or another for sharing your stories and for listening to mine.

There are a few people I would like to thank in particular, starting with my supervisors at TU Delft: Armagan and Wim. How lucky I am to have had you as my supervisors.

Armagan, it is through your teachings and enthusiasm that I have found my way to Medisign. Years ago, I remember applying for your assistant position, for which I barely had the qualifications but plenty of passion. You have shown me the wonders of applying an engineering perspective to understanding healthcare experiences, the reality, and the intricacies of medical design. In this field of regulations, pressures, and complexities, there is such opportunity, inspiration, and gratitude to be found through designing innovations. Besides your expertise, your empathy and insight made our meetings a space of inspiration, encouragement, and warmth. Ones in which, even in the difficult moments of this project, I could always be open, and that I looked forward to.

Wim, as a designer, an engineer, and an artist, you were a true driver in exploring the interactions and creativity of this design. Though I had to find the balance between how striking and sensational we could make this product, and how to take our healthcare clients along, your unique perspective kept encouraging me to keep an open mind and to be critical, to keep considering what truly mattered. Not just zooming out, but standing up, taking on, and feeling the different sides of the story. You taught me that true exploration happens beyond what is directly conscious and cognitive, and that grasping new stories happens within the experiences that shape it. You show how even in seemingly tightly defined spaces, an open mind can translate abstract explorations into concrete solutions.

Gertjan, thank you for the many, many meetings we shared. It is a privilege to have had a collaborating physician who could make so much time to be actively involved in the design project. Whether it was the quick sketches you thought up on your way to work or the hours-long sessions of co-creation and consultation simulations, together we went through 11 versions of this product! If I came to Leiden double-packed with prototypes, you always made the time, and it shows in the clinical accuracy, the qualities, and the alignment to the context this product has now.

I am sincerely grateful to Marjon for connecting me to such a special group of patients and this unique design opportunity. The passion you have for those you care for, and for improving their care paths and lives, is inspiring. This project wouldn't have been possible without your initiative, openness, and commitment.

To the staff of the Willem-Alexander Children's Hospital and Sophia Children's Hospital, thank you for welcoming me into your environments and allowing me to explore these care pathways from so many different perspectives. Your openness and willingness to share your experiences were invaluable. I would also like to thank the people of OSCAR Netherlands for granting me their patient perspectives. A heartfelt thank you goes to all patients and families who shared their stories with me. Your time, honesty, and trust give this project and this product their true meaning and heart. I would also like to thank the PMB staff at the IDE faculty for enabling the many rounds of generative prototyping that shaped this project.

On a more personal note, I am grateful to my dear friend Emma for her help with the illustrations. She was the very first friend I made at IDE, and we have gone through it all together. Special thanks to my roommate, Faye, for lending me your 3D printer, for the hundred bloody cells that I have gone through in this project. Finally, to my friends and family: thank you for listening to my endless rambles, for your patience, and for your support throughout this process.

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